

Colleen L. Barry and Emma E. McGinty, “Stigma Reduction to Combat the Addiction Crisis,” *The New England Journal of Medicine* 382, no. 14 (April 2, 2020).

Nora D. Volkow, “Stigma and the Toll of Addiction,” *The New England Journal of Medicine* 382, no. 14 (April 2, 2020).

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Patients with Addiction Need Treatment - Not Stigma

by AMA Task Force to Reduce Opioid Abuse | December 15, 2015

Junkie. Stoner. Crackhead. We've all heard the terms, used to describe those individuals who struggle with drug addiction. These words are dismissive and disdainful; they reflect a moral judgment that is a relic of a bygone era when our understanding of addiction was limited, when many thought that addiction was some sort of moral failing and should be a source of shame. We need to change the national discussion. Put simply, individuals with substance use disorders are our patients who need treatment.

Scientific progress has helped us understand that addiction – also referred to as substance use disorder – is a chronic disease of the brain. It is a disease that can be treated – and treated successfully. No one chooses to develop this disease. Instead, a combination of genetic predisposition and environmental stimulus – analogous to other chronic diseases like diabetes and hypertension – can result in physical changes to the brain's circuitry, which lead to tolerance, cravings, and the characteristic compulsive and destructive behaviors of addiction that are such a large public health burden for our nation.

Consider that every day, 44 Americans die as a result of prescription opioid overdose, and the rate of heroin-related overdose deaths has nearly quadrupled

since 2002. In addition to these tragic figures, the nation is seeing an increase in opioid-related pediatric exposures and poisonings. There has been a distressing rise in neonatal abstinence syndrome as a result of women being exposed to opioids during pregnancy. Misuse by older adults also has become an increasing concern. The rate of opioid-related hospital admissions has increased significantly over the last two decades across all age cohorts. Because of higher rates of addiction in the current "baby boomer" cohort, illicit and nonmedical drug use among older adults is expected to increase in the future. The bottom line is that physicians must lead the nation in changing the tide of this epidemic.

ASAM and the AMA Task Force to Reduce Opioid Abuse want to ensure that America's physicians, patients and policymakers take action in three ways:

First, we must change the conversation about what it means to have addiction, and we also must increase access to evidence-based treatments. This means putting an end to stigma, increasing access to medication that can treat opioid use disorder, and supporting the expanded use of naloxone – a life-saving medication that can reverse the effects of an opioid-related overdose. People with addiction deserve to be treated like any other patient with a medical disease, and physicians are helping the nation understand how to do this. That is one reason the Task Force encourages increased education and training for MAT.

Second, we encourage physicians, dentists and other prescribers of controlled substances to register for and use prescription drug monitoring programs (PDMP) – as one tool to identify when a patient may need counseling and treatment for a substance use disorder. The trend among policymakers has been to use PDMPs to identify "doctor shoppers." This, by itself, is important, but the real work is to understand why a patient is seeking medication from multiple prescribers or dispensers – and to offer a pathway for treatment and recovery. The information in PDMPs can play a helpful role in identifying patients in need of help.

Third, consider that we must do a better job with prevention. This includes intervening early with teens who initiate alcohol and/or marijuana as well as efforts to encourage safe storage and disposal. Unused medications increase the risk of nonmedical use by adolescents who live in the home or by their friends. Unused medication also can be ingested by young children who are curious about what is inside the pill container. Implementing campaigns to educate the public on the importance of storing opioid medications locked and out of the reach of children, and properly disposing opioid medications following the end of use, can encourage these safe practices.

And this also includes recognizing that we must actively screen for and treat co-morbid psychiatric disorders in all our patients to ensure that they continue to receive the highest level of care since patients with psychiatric conditions may have even greater risk than the general population to misuse opioids. Furthermore, our patients would benefit from more active screening, brief intervention and referral to treatment (SBIRT).

There are additional issues that we must address. Pregnancy should not limit a woman's access to opioid medications for adequate pain relief. Pregnant women should not be coerced to withdrawal from opioid treatment. And punitive measures taken toward pregnant women, such as criminal prosecution and incarceration, should be eliminated. These activities have no proven benefits and, in fact, deter pregnant women who use opioids from seeking prenatal care, leading to poor child health outcomes. The threat of punitive measures also limits the disclosure by pregnant women of critical information about their drug use to their physician. A pregnant woman should have the same freedom as others to openly discuss options with her physician, choose a course of treatment, and be monitored/supported by her physician.

We also need to guard against limiting MAT services. For example, many states have enacted limits on MAT for patients in Medicaid programs, who are incarcerated, or who have "failed" a prior treatment program. Just as an evidence-based treatment policy would not discriminate against a diabetes patient for being low-income, having been arrested, or not adhering with his or her diabetes treatment program, MAT's proven success should not be limited by these approaches either.

As clinicians, we see the harsh reality faced by our patients with a substance use disorder. Stigmatizing patients helps no one. Our goal is to treat our patients and help them live as fully functional members of society. There are people in recovery at every level of government, the private sector and throughout our towns and communities. That is because treatment works.

For more resources:

Reducing the stigma of substance abuse disorder

- Barriers to Treatment (for substance use disorder) - PCSS-MAT
- CME | Stigma in Methadone and Buprenorphine Maintenance Treatment
American Society of Addiction Medicine
- Addiction, Stigma, and Discrimination: Implications for Treatment and Recovery -
PCSS-MAT

Resources on the use of medication in the treatment of addiction

- National Practice Guideline for the Use of Medications in the Treatment of
Addiction Involving Opioid Use to provide information on evidence-based
treatment of opioid use disorder.
- DATA 2000 8 Hour Waiver Qualifying Buprenorphine Training - supported by the
American Society of Addiction Medicine
-  Medication-Assisted Treatment for Opioid Addiction - Office of National Drug
Control Policy
- White House call to increase use of MAT: News release on President Obama's call
to modernize opioid addiction treatment



An investigation of stigma in individuals receiving treatment for substance abuse

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Abstract

This study examined the impact of stigma on patients in substance abuse treatment. Patients ($N=197$) from fifteen residential and outpatient substance abuse treatment facilities completed a survey focused on their experiences with stigma as well as other measures of drug use and functioning. Participants reported experiencing fairly high levels of enacted, perceived, and self-stigma. Data supported the idea that the current treatment system may actually stigmatize people in recovery in that people with more prior episodes of treatment reported a greater frequency of stigma-related rejection, even after controlling for current functioning and demographic variables. Intravenous drug users, compared to non-IV users, reported more perceived stigma as well as more often using secrecy as a method of coping. Those who were involved with the legal system reported less stigma than those without legal troubles. Higher levels of secrecy coping were associated with a number of indicators of poor functioning as well as recent employment problems. Finally, the patterns of findings supported the idea that perceived stigma, enacted stigma, and self-stigma are conceptually distinct dimensions.

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Keywords: Stigma; Substance abuse; Substance dependence; Coping

1. The role of stigma in individuals receiving treatment for substance abuse

There can be little doubt that substance abusers in recovery face stigma in its various forms, including enacted, perceived, and self-stigma (Link, Yang, Phelan, & Collins, 2004). Enacted stigma refers to

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directly experienced social discrimination such as difficulty in obtaining employment, reduced access to housing, poor support for treatment, or interpersonal rejection. Perceived stigma refers to beliefs that members of a stigmatized group have about the prevalence of stigmatizing attitudes and actions in society (cf., Link, Cullen, Streuning, Shrout, & Dohrenwend, 1989). Self-stigma refers to negative thoughts and feelings (e.g., shame, negative self-evaluative thoughts, fear) that emerge from identification with a stigmatized group and their resulting behavioral impact (e.g., avoidance of treatment, failure to seek employment, avoidance of intimate contact with others).

In general mental health areas, enacted stigma is associated with multiple negative outcomes such as unemployment (e.g., Link, 1987; Penn & Martin, 1998), housing problems (Page, 1983, 1993; Penn & Martin, 1998), and difficulty in social adjustment (e.g., Perlick et al., 2001). Self-stigma in the seriously mentally ill, many of whom also have substance use disorders, is associated with delays in treatment seeking (Kushner & Sher, 1991; Scambler, 1998; Starr, Campbell, & Herrick, 2002), diminished self-esteem/self-efficacy (Corrigan & Watson, 2002; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001; Wright, Gronfrein, & Owens, 2000), and lower quality of life (Rosenfield, 1997). Samples of substance abusing individuals self-report fear of stigma as a reason for not seeking treatment (Cunningham, Sobell, Sobell, Agrawal, & Toneatto, 1993; Hingson, Mangione, Meyers, & Scotch, 1982; Klingeman, 1991; Sobell, Sobell, & Toneatto, 1992; Tuchfeld, 1981; Tucker, Vuchinich, & Gladsjo, 1994). Because the work on stigma towards mental illness is more advanced (Corrigan, 2004; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Wahl, 1999), we drew on this work as a source of measures to adapt for use with substance abuse stigma, and as a conceptual guide in researching this area.

The present study is an initial attempt to examine the role of stigma toward substance abuse in people in recovery from substance use problems. While a number of studies have documented the existence of various forms of stigma relating to substance use (Fulton, 1999), few studies have examined the relation between stigma and treatment for substance use (Semple, Grant, & Patterson, 2005), or the relationship between substance use stigma and other outcomes of interest such as patient functioning or substance use. Now that stigma is fairly well documented as a phenomenon, it is important that research begin to examine the relationship between stigma and functional outcomes in substance abuse.

Five questions were examined. The first assessed the degree to which persons in recovery experienced stigma in its various forms. Second, we examined evidence for stigma as a multidimensional concept in the substance abuse area (Corrigan, 2004; Link et al., 2004). We assessed whether our conceptually distinct measures of stigma (self-stigma, perceived stigma, and experienced stigma) are in fact empirically distinct and associated in predictable ways with each other and with outcomes of interest. The third question was suggested by Link et al.'s (1989) modified labeling theory of stigmatization, which holds that the stigma process does not primarily begin to impact an individual until the person has entered the treatment system and has received a diagnostic label. Thus, we examined whether experienced stigma would be higher for those with more prior episodes of treatment.

The fourth question examined the impact of secrecy as a method of coping with stigma. Stigma researchers have made a distinction between concealable stigmas, such as substance abuse, and public stigmas, such as race or certain diseases (Goffman, 1963; Smart & Wegner, 1999). Little evidence exists whether it is generally helpful or hurtful to conceal substance abuse as a method of regulating stigma. The issue was examined empirically in the present study. The fifth area we examined was whether intravenous (IV) drug use or involvement with the legal system predicted higher levels of stigma. Researchers have documented that stigma toward substance abuse is usually seen in a benign or even positive light among those working in the criminal justice system (Fulton, 2001; Room, 2004), raising the possibility that drug

use may be even more actively stigmatized in people having contact with the criminal justice system. Research has also suggested that IV drug users form a distinct subculture that is more heavily stigmatized by both providers of services and other substance users (Fulton, 1999).

2. Methods

2.1. Participants

This study included 197 patients (108 men, 89 women), averaging 35 years old ($SD=10.3$, range 14–73), at 15 different substance abuse treatment sites, representing 11 different public treatment agencies in Nevada. All 15 sites provided both alcohol and drug treatment services, seven providing outpatient services, five providing residential services, and three providing both residential and outpatient services. Although we were unable to obtain exact census figures, estimates from treatment center staff suggested that our sample represented a fairly small proportion of those participating in treatment at the time of assessment, probably 20% or less. The sample was fairly evenly distributed across sites (ranging from 4 to 23 participants, $mean=13.1$, $SD=5.7$).

Participants self-identified as 8% American Indian, 3% Asian/Pacific Islander, 10% African American, 68% Caucasian, 7% other, with 6% not responding. When asked about Latino/Hispanic origin, 11% identified as Mexican, 6% as “other Hispanic”, 34% as “not Hispanic”, with 50% not responding. When asked about marital status, participants reported: 41% never married, 18% married, 11% separated, 24% divorced, 2% widowed, with 5% not responding. Participants reported participating in an average of 1.9 previous episodes of treatment ($n=195$; $SD=2.4$). On average, participants ($n=178$) reported a longest prior period of abstinence of 14.3 months ($SD=29.1$). Participants reported using a wide range of drugs, with 79% ($n=139$) reporting use of alcohol for a mean of 17 years ($SD=10.3$), 73% ($n=130$) marijuana for a mean of 13 years ($SD=8.8$), 68% ($n=121$) methamphetamines for a mean of 9.7 years ($SD=7.5$), 55% ($n=97$) cocaine for a mean of 6.7 years ($SD=7.5$), 42% ($n=74$) hallucinogens for a mean of 6.0 years ($SD=6.9$), 29% ($n=52$) amphetamines for a mean of 9.1 years ($SD=8.2$), 14% ($n=25$) heroin for a mean of 6.6 years ($SD=8.2$), 15 ($n=26$) barbiturates for a mean of 7.1 years ($SD=8.9$), 14% ($n=24$) inhalants for a mean of 4.3 years ($SD=7.4$), 14% ($n=25$) benzodiazepines for a mean of 5.5 years ($SD=7.4$), 7% ($n=12$) methadone for a mean of 5.6 years ($SD=10.1$), and 22% ($n=39$) other opioids for a mean of 6.6 years ($SD=8.0$), and 66% ($n=118$) other (mostly cigarettes) for a mean of 17 years ($SD=10.5$).

2.2. Procedure

Participants were recruited, over one summer, through postings at the fifteen substance abuse treatment facilities described above and through flyers handed out by treatment staff to patients at those facilities. Experimenters arrived on a predetermined day and assessed all interested participants in a group room at their treatment agencies. The experimenters gave a brief description of the study and emphasized that participation was completely voluntary. Experimenters reviewed the consent forms, allowed for questions, collected the signed consent forms, and gave a copy to each participant. Participants then completed questionnaire packets, typically taking about one hour. Participants anonymously placed completed questionnaires in a box and were reimbursed with \$10 gift cards to a national department store chain. Questionnaires in the packet were in the order presented in the Measures section.

2.3. Measures

2.3.1. Demographics

The first few pages of the questionnaire contained 34 face valid questions regarding personal characteristics, substance use, social functioning, education, and employment. Five yes–no questions asked if participants had experienced specific forms of enacted stigma. These were treated as individual items, not as a separate scale.

2.3.2. Quality of life

The Quality of Life Scale (QOLS; Flanagan, 1978) measures several aspects of functional status, including tasks of daily living, work, social activity, and family contact. Participants respond to this 16-item scale on a seven-point Likert scale ranging from *terrible* (1) to *delighted* (7). Higher scores reflect higher quality of life. The coefficient alpha obtained in the present study was .93.

2.3.3. Overall mental health

The General Health Questionnaire-12 (GHQ-12; Vieweg & Hedlund, 1983) available in several forms, is a widely used self-report questionnaire designed to measure general mental health and stress. The 12-item version, used in this study, asks participants to respond based on a four-point Likert scale. Higher scores indicate poorer mental health. The GHQ-12 has been shown to have high internal consistency. The current study obtained a Cronbach's alpha of .91.

2.3.4. Perceived stigma

The Substance Abuse Perceived Stigma Scale (SAPSS) is a 12 item questionnaire that assesses the construct of perceived stigma. The SAPSS was adapted for use with participants with reported substance abuse problems from a measure of perceived stigma in mental health patients (Link, 1987). The term “mental health patient” was changed to fit individuals with reported substance abuse problems, and items were scored on seven point Likert-type scale where 1=never and 7=always with agreement indicating non-stigmatizing behavior or attitudes. The scale was scored by reverse scoring each item, summing the items, and dividing by 12, thus higher scores indicate more perceived stigma. Example items include, “Most people would hire someone who has been treated for substance use to take care of their children” or “Most people do not think less of a person who has been treated for substance use.” The original mental health measure by Link (1987) showed adequate reliability (alphas=.73–.82), as did substance abuse version in the current study (obtained coefficient alpha=.89).

2.3.5. Secrecy coping

A four item scale was created based on the scales from Link et al. (1997) that attempted to measure secrecy as a method of coping with stigma. Item content was modified to focus on substance abuse. An example item is “Do you think it is a good idea to keep your history of substance use a secret?” Items were rated as yes or no. Higher scores indicate higher secrecy and total scores ranged from 0 to 4. The present study obtained a Cronbach alpha of .57.

2.3.6. Stigma-related interpersonal rejection

The Stigma-Related Rejection Scale (SRS) is a survey of mental health consumer's ongoing experiences of enacted interpersonal stigma that was originally developed by Wahl (1999). The term “mental health

consumer” was changed to fit individuals with reported substance abuse problems, and items were scored on seven point Likert-type scale where 1 = never and 7 = always with agreement indicating higher rejection. The scale includes nine statements asking about experiences such as being treated as less competent, hearing others say unfavorable things about people with substance abuse problems, and worrying that others will view one unfavorably. Reliability and validity data are not reported by Wahl (1999); the data were presented descriptively. A coefficient alpha of .79 was obtained in the current study.

2.3.7. Internalized Shame Scale (ISS)

The ISS is a highly reliable (alpha of .95) 30-item test that asks subjects to report how often they find themselves experiencing a variety of shame-related thoughts and feelings (Cook, 1987). It has 24 negatively worded “shame” items and 6 positively worded “self-esteem” items. For the original instrument, subjects rated each item on a five-point scale ranging from 0 (never) to 4 (almost always). Due to a clerical error, the present study used a seven-point scale ranging from 1 (never) to 7 (always). Estimates of internal consistency were excellent (coefficient alpha = .96).

2.3.8. Experiential avoidance and psychological flexibility

The Acceptance and Action Questionnaire (AAQ; Hayes, Bisset et al., 2004; Hayes, Strosahl et al., 2004) is a nine-item measure of the willingness to accept undesirable thoughts and feelings, while acting in a way that is congruent with values and goals. Participants respond on a seven-point Likert scale ranging from never true (1) to always true (7). Lower scores reflect greater experiential willingness and ability to act in the presence of difficult thoughts and feelings. Hayes, Bisset et al., (2004), Hayes, Strosahl et al., (2004) found that scores of 42 and 38 represented upper quartile scores on experiential avoidance in clinical and non-clinical populations. The AAQ has good convergent and discriminant validity (Hayes, Bisset et al., 2004; Hayes, Strosahl et al., 2004) but its internal consistency is just adequate (.72). A coefficient alpha of .52 was obtained in the current study.

3. Results

3.1. To what extent do people with substance problems experience stigma?

Five items from the demographic questionnaire assessed enacted stigma. The most commonly reported experience was believing they people treated them unfairly because they knew about their substance use (60%, $n=118$), 46% ($n=90$) felt that others were afraid of them when they found out about their substance use, 45% ($n=88$) felt some of their family gave up on them after they found out about their substance use, 38% ($n=75$) felt that some of their friends rejected them after finding out about their substance use, and 14% ($n=27$) felt that employers paid them a lower wage because of knowing about their substance abuse history. Approximately 39.5% ($n=75$) reported three or more of these experiences. The mean number of endorsements was 2.05 (SD=1.43); 17.4% of the sample ($n=33$) reported experiencing none of these forms of enacted stigma.

On the SRS, our measure of stigma-related rejection, the mean item score was 3.0 (SD=1.0), which corresponds to a “seldom” on the scale (Table 1). On average, across each item, 17% of respondents reported “frequently,” “almost always” or “always” experiencing the various forms of rejection listed in the scale. Participants were least likely to report that they had been advised to lower their expectations as a result of their

Table 1
Frequency of responses to items regarding experiences with stigma-related rejection

Items	Never	Very rarely	Seldom	Sometimes	Frequently	Almost always	Always	Mean	SD
1. I have worried that others will view me unfavorably because I have been in treatment for my substance use. (<i>N</i> =195)	34	30	26	66	21	7	11	3.4	1.6
2. I have been in situations where I have heard others say unfavorable or offensive things about people who have been in treatment for their substance use. (<i>N</i> =193)	24	24	20	68	36	7	14	3.8	1.6
3. I have seen or read things in the mass media (e.g., television, movies, books) about people who have been in treatment for their substance use that I find hurtful or offensive. (<i>N</i> =195)	35	27	36	59	26	8	4	3.3	1.5
4. I have avoided telling others outside my immediate family that I have been in treatment for my substance use. (<i>N</i> =194)	47	31	20	47	18	16	14	3.3	1.9
5. I have been treated as less competent by others when they learned I have been in treatment for my substance use. (<i>N</i> =193)	55	28	29	52	20	6	3	2.9	1.6
6. I have been shunned or avoided when it was revealed that I have been in treatment for my substance use. (<i>N</i> =192)	66	33	26	45	11	6	4	2.7	1.6
7. I have been advised to lower my expectations in life because I have been in treatment for my substance use. (<i>N</i> =192)	102	27	20	28	9	3	3	2.2	1.5
8. I have been treated fairly by others who know I have been in treatment for my substance use. (<i>N</i> =192)	34	42	38	46	13	4	15	3.2	1.7
9. Friends who learned I have been in treatment for my substance use have been supportive and understanding. (<i>N</i> =193)	72	41	26	35	6	6	7	2.5	1.6

Items were numbered 1–7 with 1="never" and 7="always".

drug use and that friends who learned of treatment for drug abuse were supportive and understanding (i.e., friends were not very supportive). The stigmatizing experience they were most likely to report was hearing others say unfavorable or offensive things about people who have been in treatment for substance use.

On the SAPSS, our measure of perceived stigma, participants showed a mean item score of 4.21, which is significantly above a neutral score (4) on the scale, $t(194)=3.17$, $p=.002$. Although scores varied across items, this could be interpreted to mean that the average participant believes that most people with substance abuse problems are devalued or discriminated against; 59% had a mean score over the midpoint of the scale, with 44% of individual item responses indicating a perception that most people devalue/discriminate and 30% indicating disagreement (Table 2). The most strongly endorsed forms of stigma were that most people would not trust someone who had been in treatment for substance use to teach young children (59%) or take care of young children (69%). The least strongly endorsed forms of stigma were evidenced by agreement that most employers will hire someone who has been treated for substance use if he or she is qualified for the job (49%), most people believe that a person who has been treated for

Table 2
Frequency of responses to items regarding perceived stigma

Item	(1) Very strongly disagree	(2)	(3)	(4) Neutral or don't know	(5)	(6)	(7) Very strongly agree	Mean	SD
1. Most people would willingly accept someone who has been treated for substance use as a close friend. (<i>n</i> =197)	7	14	34	63	55	8	16	4.2	1.4
2. Most people believe that a person who has been treated for substance use is just as intelligent as the average person. (<i>n</i> =197)	8	11	64	27	46	21	20	4.2	1.6
3. Most people believe that someone who has been treated for substance use is just as trustworthy as the average citizen. (<i>n</i> =197)	20	21	81	26	23	16	10	3.5	1.6
4. Most people would accept someone who has been treated for substance use as a teacher of young children in a public school. (<i>n</i> =197)	35	21	60	52	11	11	7	3.2	1.5
5. Most people feel that entering treatment for substance use is NOT a sign of personal failure. (<i>n</i> =197)	13	16	45	35	51	20	17	4.1	1.6
6. Most people would hire someone who has been treated for substance use to take care of their children. (<i>n</i> =197)	34	27	75	41	10	4	6	3.0	1.4
7. Most people do NOT think less of a person who has been in treatment for substance use. (<i>n</i> =197)	18	17	59	44	37	14	7	3.7	1.5
8. Most employers will hire someone who has been treated for substance use if he or she is qualified for the job. (<i>n</i> =197)	6	10	32	52	73	13	11	4.3	1.3
9. Most employers will NOT pass over the application of someone who has been treated for substance use in favor of another applicant (<i>n</i> =197)	15	12	64	67	26	9	4	3.6	1.3
10. Most people in the community would treat someone who has been treated for substance use just as they would treat anyone else. (<i>n</i> =195)	11	12	71	37	49	10	5	3.8	1.3
11. Most people would NOT be reluctant to date someone who has been treated for substance use. (<i>n</i> =195)	10	6	54	70	43	9	3	3.8	1.2
12. Once they know a person has been treated for substance use, most people will NOT take his or her opinions less seriously. (<i>n</i> =195)	4	10	64	58	49	8	1	3.9	1.1

Items were numbered 1–7 with 1="Very Strongly Disagree", 2="Strongly Disagree", 3="Disagree", 4="Neutral or don't know", 5="Agree", 6="Strongly agree", and 7="Very Strongly Agree". Average scores are not reverse scored, so lower scores indicate more perceived stigma.

substance use is just as intelligent as the average person (49%), and most people would willingly accept someone who has been treated for substance use as a close friend (50%).

3.2. Are measures of stigma conceptually distinct?

Generally, analyses conformed with the predicted pattern of results, suggesting that these measures are conceptually distinct. Internalized shame was moderately correlated with reports of past stigma-related rejection ($r = .503$) and to a lesser level with perceived stigma ($r = .248$). Perceived stigma was moderately correlated with experienced stigma-related rejection ($r = .423$), but less with internalized stigma (.248).

Internalized shame was moderately correlated with other variables related to psychological functioning, namely the AAQ ($r = .564$), quality of life ($r = -.487$), and global mental health ($r = -.487$), with stigma-related rejection less so ($r = .292$ with AAQ, $r = -.282$ with QOL, $r = .293$ with global mental health) and perceived stigma the least ($r = .119$ with AAQ, $r = -.290$ with QOL, $r = .152$ with global mental health). Perceived stigma had about the same level of correlation with quality of life as stigma-related rejection. Interestingly, perceived stigma was correlated with both years of education ($r = .294$) and with weeks of employment in the last year ($r = -.224$), while the other two scales were not.

3.3. Is reported stigma related to the number of previous episodes of treatment?

In order to examine the possibility that the stigma process does not primarily begin to impact an individual until the person has entered the treatment system and has received a diagnostic label (Link et al., 1989), we ran a linear regression predicting the number of previous treatment episodes from our three stigma scales (experienced rejection, perceived stigma, and shame). In order to determine which statistical controls to use, we examined the matrix of zero-order correlations between the number of previous episodes of treatment and possible correlates including gender, age, ethnicity, previous education, number of drugs of use, number of years of use of most typical drug, secrecy coping, quality of life, and overall mental health (see Table 3). Those variables with a significant zero-order correlation with number of previous episodes of treatment were included in the final regression model (Table 4).

Preliminary analyses to examine violations of regression assumptions identified two problems. The first analysis identified two outliers using the rule of thumb of those cases having standardized residuals greater than 3.3 (corresponding to an alpha of .001). These two cases were excluded from the regression analysis (the cases had standardized residuals of 3.47 and 4.03). Inspection of the data from these two subjects showed means well within 2 standard deviations of the mean on all variables except the number

Table 3
Zero-order correlations between variables used in the linear regression described in Table 4 ($n = 161$)

	# of Treat.	QOL	GHQ	Max years	# of drugs	Age	Perc. stigma	Intern. shame	Rejection
# of prev. episodes of treatment	1	-.22**	.16*	.17*	.21**	.22**	.24**	.19	.30***
Quality of Life (QOL)	-.22**	1	-.63***	-.05	-.06	-.09	-.26**	-.48***	-.31***
Overall Mental Health (GHQ)	.16*	-.63***	1	-.04	.01	.01	.14	.48***	.30***
Max years, all drugs	.17*	-.04	-.04	1	.14	.70***	-.04	.07	-.001
# of drugs in lifetime	.21**	-.01	.06	.14	1	-.11	.11	.03	.002
Age	.22**	-.08	.01	.70***	-.11	1	-.04	-.02	.02
Perceived stigma	.22**	-.26**	.14	-.14	.11	-.04	1	.23**	.48***
Internalized shame	.19*	-.48***	.48***	.07	.03	-.02	.23**	1	.53***
Stigma-related rejection	.31***	-.30***	.31***	-.001	.002	.02	.48***	.53***	1

Note: Number of previous episodes of treatment refers to the correlation between the \log_e of the number of previous episodes of treatment and other variables. This table refers does not include the two outliers removed for the purposes of the regression analysis and was created using listwise exclusion of missing variables. Low scores on the perceived stigma scale indicate greater stigma; high scores on the internalized shame, and Secrecy scales indicate greater stigma. For the well-being measures; higher scores on the QOL indicate greater well-being; low scores on the GHQ indicate better well-being.

* $p < .05$ ** $p < .01$ *** $p < .001$.

Table 4

Summary of hierarchical regression analysis for variables predicting number of previous episodes of treatment ($N=169$)

Variable	<i>B</i>	SE <i>B</i>	β
Step 1			
Quality of Life	-.005	.003	-.144
Overall Mental Health	.007	.007	.087
Max years, all drugs	.001	.006	.014
# of drugs in lifetime	.036	.014	.196*
Age	.010	.006	.195†
Step 2			
Quality of Life	-.002	.003	-.078
Overall Mental Health	.004	.007	.055
Max years, all drugs	.002	.006	.037
# of drugs in lifetime	.033	.014	.178*
Age	.010	.006	.184
Perceived stigma	.058	.048	.099
Internalized shame	-8.42E-006	.002	.000
Stigma-related rejection	.013	.006	.202*

Note: $R^2=.128$ for step 1 ($p<.001$), $\Delta R^2=.059$ for step 2 ($p=.01$). * $p<.05$, † $p=.064$.

of previous treatments for which they reported values that were approximately 9 and 10.5 SDs above the mean. The second analysis of assumption violations showed that the number of previous treatment episodes was positively skewed, so this variable was transformed using the natural log of the number of previous episodes plus one. Finally, a standard diagnostic check for multicollinearity was performed, showing an absence of high correlations between variables (all with $r<.8$) and tolerance values of more than .4 for all variables, both of which suggest an absence of multicollinearity.

A test of the full model with all predictors, compared to the model with only the control variables was statistically significant, indicating that the three stigma variables added significantly to the prediction, above and beyond the controls (Table 4). We then examined the ability of individual variables to predict episodes of previous treatment by examining the significance of individual regression coefficients. We found that the level of stigma-related rejection experiences and number of drugs used in life continued to predict number of previous treatment episodes, even after controlling for all other variables.

3.4. Is secrecy as a coping method associated with different levels of functioning?

Higher levels of secrecy coping were associated with (see Table 5) lower levels of psychological flexibility, lower quality of life, more experiences of stigma-related rejection in the past, higher internalized shame, poorer global mental health, and most strongly with perceived stigma. Secrecy coping was not correlated with weeks of employment in the past year or educational level. Those reporting problems with employment in the past 30 days also reported higher levels of secrecy coping than those without employment problems, $t(182)=2.86$, $p=.005$.

3.5. Do IV drug users experience higher levels of stigma than non-IV users?

We examined the association between IV drug use and stigma by conducting *t*-tests on the variables reported below, comparing those participants who reported having ever used IV drugs ($n=32$) and those

Table 5
Correlations between major outcome measures

	AAQ	QOL	Stigma-related rejection	Internalized shame	Perceived stigma	Global mental health	Secrecy coping
Acceptance and Action (AAQ)		-.34***	.29***	.56***	.12	.40***	.23**
Quality of Life (QOL)	-.34***		-.28***	-.49***	-.29***	-.61***	-.23*
Stigma-related rejection	.29***	-.28***		.50***	.42***	.29***	.39***
Internalized shame	.56***	-.49***	.50***		.25*	-.49***	.32***
Perceived stigma	.12	-.29***	.42***	.25*		.15*	.42***
Global mental health	.40***	-.61***	.29***	-.49***	.15*		.15*
Secrecy coping	.23	-.23*	.39***	.32***	.42***	.15*	
Weeks employed in last year	-.03	.05	-.03	-.14	-.22**	-.13	.02
Years of education	-.11	-.08	.09	-.01	.29***	.02	.14
No. of days of employment problems in last 30	-.02	-.13	.08	.08	.17*	.08	.20**
Enacted stigma item: rejection by friends	-.07	.08	.28***	.08	.28***	-.04	.19**
Enacted stigma item: family gave up	.04	.04	.23**	.05	.18*	-.06	.11
Enacted stigma item: people were afraid	-.03	.01	.20**	.02	.17*	-.11	.14
Enacted stigma item: people treated him/her unfairly	.11	-.11	.27***	.21**	.30***	.12	.23**
Enacted stigma item: employers paid lower wages	.04	-.13	.30***	.20**	.27***	.12	.23**

Note: numbers above are Pearson Correlations (with pairwise exclusion of missing data) subjected to two-tailed tests. For the stigma scales: low scores on the Perceived stigma scale indicate greater stigma; high scores on the internalized shame, and Secrecy scales indicate greater stigma. For the well-being measures: low scores on the AAQ-9 indicate higher psychological flexibility; higher scores on the QOL indicate greater well-being; low scores on the GHQ indicate better well-being.
* $p < .05$ ** $p < .01$ *** $p < .001$.

who reported no prior IV drug use ($n=165$). There were no significant differences on measures of psychological flexibility, global mental health, quality of life, number of previous treatments, internalized shame, or age. IV users more often reported using secrecy as a method of coping, $t(193)=2.07$, $p=.04$. They also reported higher levels of perceived stigma, $t(193)=2.24$, $p=.03$. The measure of stigma-related rejection approached significance, $t(189)=1.96$, $p=.051$ with IV drug users reporting more rejection.

3.6. Do people with current contact with the legal system report higher levels of stigma?

Our sample was split into two groups, those who were currently uninvolved in the legal system ($n=93$) and those who were currently on bail ($n=2$), on parole ($n=23$), probation ($n=54$), or awaiting trial ($n=11$). No information was collected about past legal involvement. Results were, if anything, the opposite of what was hypothesized. There were no between-group differences in level of perceived stigma, $t(180)=.126$, $p=.90$, secrecy as a coping method, $t(179)=.206$, $p=.84$, quality of life, $t(177)=.171$, $p=.86$, general mental health, $t(181)=1.79$, $p=.076$, or number of prior episodes of treatment, $t(144)=.29$, $p=.77$. Those with current legal problems actually reported less internalized shame, $t(178)=3.28$, $p=.001$, less stigma-related rejection, $t(176)=2.21$, $p=.028$, and higher psychological flexibility, $t(180)=3.55$, $p<.001$.

4. Discussion

4.1. Presence of stigma

Participants reported fairly frequent contact with various forms of enacted stigma and interpersonal rejection related to their substance abuse. Participants believed that stigmatizing attitudes and behaviors towards people with substance abuse were fairly common. Overall, about 60% of participants scored above the midpoint on our scale measuring perceived stigma. Averaging across individual items, about a third of the time participants agreed that most people held individual stigmatizing attitudes or behaviors. Overall, these levels of endorsement were somewhat lower than Ritsher and Phelan (2004) found in their sample of seriously mentally ill and Link et al. (1997) found in their sample of the dually diagnosed. One interpretation of these results is that our sample of substance abusing participants perceive less stigma than the seriously mentally ill participants in her sample. This interpretation is weakened by the differences in response options between our scales and theirs, with our scale including a “neutral” option and the other author’s scale not including this option, potentially reducing the rate of participants acknowledging stigma in our study. In addition, these measures were originally developed for use in seriously mentally ill population and thus some of the items may not apply particularly strongly to a substance abuse population, thus limiting our ability to make generalization about mean *levels* of stigma across populations.

4.2. Multiple dimensions of stigma

Our results supported the idea that the different measures of perceived stigma, stigma-related rejection, and internalized shame (self-stigma) are conceptually and empirically distinct (Link et al., 2004). They correlated with each other and non-stigma measures in a coherent fashion. One explanation of our pattern of results is that experiences with stigma-related rejection might produce both higher levels of perceived stigma and higher levels of internalized shame. This explanation could account for the pattern of findings in which past stigma-related rejection was moderately correlated with both perceived stigma and internalized shame, while the former two were only slightly correlated with each other. Determining whether any of these hypotheses are correct cannot occur from our cross sectional data and we thus await studies that include a longitudinal component.

This study also found that internalized shame was more highly related to measures of psychological functioning and quality of life than experienced rejection and perceived stigma. This result suggests that self-stigma might be a more appropriate target for stigma-related interventions in a substance abusing sample than perceived stigma or teaching them how to avoid rejection.

4.3. Relationship between stigma and previous treatment

Our sample demonstrated that experiences with stigma-related rejection continued to be related to number of previous episodes of treatment even after controlling for other explanatory variables. These results are supportive of the Link et al.’s (1989) modified labeling theory which holds that stigma begins to impact people with behavioral disorders once they have officially received a label from the treatment establishment. Our results are similar to those of Semple et al. (2005) who found that in their sample of methamphetamine abusers, those who had previously been in treatment reported higher levels of stigma-

related rejection than those who had never been in treatment. In general, our data are suggestive of the idea that stigma-related rejection may occur with increasing frequency with greater numbers of treatment episodes. One alternative hypothesis is that those with the most serious problems are those most likely to return to treatment and also those most likely to suffer from stigma. However, our data argue against this hypothesis in that stigma-related rejection continued to predict number of treatment episodes even after controlling for current severity. Another alternative hypothesis is that greater levels of stigma-related rejection make it more difficult to succeed in recovery, which in turn leads to a greater chance of relapse and return to treatment for those experiencing more enacted stigma. This hypothesis conforms somewhat with the results of Sirey et al. (2001), who found in their sample of 92 depressed patients that those over 65 years old who reported higher levels of perceived stigma were more likely to prematurely discontinue treatment and a second study by Sher, McGinn, Sirey, and Meyers (2005) who showed that stigma-related attitudes of primary caregivers predicted adherence to antidepressant medication. Longitudinal research is necessary to disentangle these alternative explanations.

4.4. *Secrecy coping*

Higher levels of secrecy coping were related to lower levels of psychological flexibility, lower quality of life, more experiences of stigma-related rejection in the past, higher internalized shame, and most strongly with perceived stigma. Particularly interesting was the finding that those reporting employment problems in the last 30 days reported higher levels of secrecy coping. One reasonable explanation is that these people who were engaging in a behavior (job seeking) at a rate that required fairly high levels of concealment. In our sample, secrecy coping was positively correlated with a number of negative variables. These results need to be interpreted in light of the probable limited psychometric properties of this measure of convenience which only demonstrated an alpha of .57 in this study. More research is needed to examine the adaptiveness of disclosure in relation to context. For example, in supportive environments, where one is likely to obtain help because of disclosure, perhaps disclosure would be more helpful. In other situations, such as job interviews, where one is likely to be the subject of enacted stigma for disclosure, concealment might be more adaptive. Future studies might usefully examine whether disclosure level might interact with the general level of social support, or whether context specific (e.g., workplace) disclosure might be more or less adaptive.

4.5. *IV drug users and those with legal problems*

IV drug users in our sample reported more secrecy coping, more perceived stigma, and marginally more experiences of stigma-related rejection. A factor further strengthening the idea that IV drug status may be directly related to greater experience of stigma was the finding that while the two samples did vary on some stigma variables, they did not significantly differ on variables suggestive of overall functioning (such as psychological flexibility, global mental health, or quality of life). While our results are suggestive of the idea that IV users may be more often the targets of stigma than other drug users, it is not clear what the impact of this stigma has on their functioning, because this was not also associated with lower functioning. The primary behavioral impact of greater levels of experienced stigma in this population may be greater concealment of their drug using status, an interpretation which would be consistent with our findings.

Our data were not supportive of the idea that people with current contact with the legal system encounter more stigma. In fact, in this sample, those with current legal problems actually reported less

internalized shame, higher psychological flexibility, and less stigma-related rejection. We do not have an adequate explanation for these findings. Besides the obvious interpretation that people with legal involvement do not experience more stigma, another possible interpretation is that participants with legal problems may have tended to minimize their level of distress or problems perhaps because of fear of this information being used in legal proceedings.

4.6. Measurement issues

Our results, as well as the general lack of literature on stigma in this population, demonstrate a need for several new scales related to substance abuse stigma, as well as refinement of existing scales. As a result of the lack of previous measure development work, probably the largest weakness in this study is the lack of information on the psychometrics of our measures of perceived stigma, stigma-related rejection, and secrecy coping, all previously unstudied scales. These items were taken directly from Link et al. (1989) whom also did not report psychometric properties of these items. Additionally, the AAQ, while usually demonstrating adequate alphas in most studies had a poor alpha in this study of .52, thus making questionable the unidimensional character of this scale in our study.

Our stigma scales may also suffer from problems with content validity. These measures were directly adapted from scales specifically created for use with a seriously mentally ill population. Thus, we may not have documented the existence of some forms of stigma on our scales or included some forms which, while relevant to the seriously mentally ill, might not be very relevant for those with substance abuse problems. Qualitative research could help determine what items might be usefully added or removed from our measures of perceived stigma and stigma-related rejection.

Perusal of individual items from the stigma-related rejection scale adapted from Wahl (1999) seems to suggest that this scale may not be a unidimensional measure of experiences with stigma-related rejection. For example, the scale includes items such as “I have worried that others will view me unfavorably because I have been in treatment for my substance use,” which while probably being linked to experiences with rejection, does not directly report on experiences of rejection. The scale could probably use development of new items measuring other forms of rejection and removal of items that do not clearly measure the central construct.

No measure specific to self-stigma has been created, so we were required to use a measure of internalized shame. We believe that the notion of internalized shame overlaps considerably with the construct of self-stigma, but it does not measure it exactly. The need for a direct measure of self-stigma appears strong, particularly in light of the data which show that our measure of internalized shame was highly related to outcomes of interest. Another paper examining early outcomes from an open trial of an intervention targeting self-stigma suggests that treatment can reduce self-stigma as measured by this internalized shame scale (Luoma, Kohlenberg, Hayes, Bunting, & Rye, in preparation). Also needed is a scale focused on additional forms of enacted stigma besides interpersonal rejection, such as employment-related discrimination, discrimination in social services, and housing discrimination.

An additional measurement issue brought to light in this study is the difference between reports of ongoing, regularly experienced stigmatizing events, and lifetime prevalence of these events. For example, our scale of stigma-related rejection measures ongoing rejection experiences, rather than total past experiences. It could be that these two measures could relate quite differently to outcome. For example, as a result of past stigma-related rejection, someone might now be concealing their current or past use of substances so that they do not experience further enacted stigma. This person might report having a

relatively high lifetime prevalence of enacted stigma, but report little ongoing stigma. However, the concealment that resulted from past experiences with enacted stigma may continue to have effects on the person's functioning.

A weakness of this study is the complete reliance on self-report. In the area of stigma this is particularly difficult due to the social desirability of the relevant domains. Future studies would usefully include measures of the context in which the person lives, such as attitudes of staff at the treatment centers, or perhaps measures of the attitudes of a sample of the population in the area where the person lives or their family members. Additionally, measures such as the Implicit Attitudes Test (Greenwald, Nosek, & Banaji, 2003) might be useful to get around the problems of social desirability. Finally, it is possible that because measures were not presented in a counterbalanced order, there may have been systematic, unexplained error due to participant tiredness or boredom.

4.7. Other weaknesses

Another issue is that in conducting analyses for this study, a large number of individual statistical tests were conducted, thus increasing the risk of type I error. We decided to take this risk, rather than reducing the alpha to something below .05 because at this beginning state of this area of research we would prefer to have a variety of leads to track down and eliminate as possibilities rather than make type II errors and conclude that possible relationships are not there and thus have fewer leads for future studies. Our best estimates suggested that only 20% or less of the potential population (those in treatment at the time of the study) completed our survey, leaving the possibility of a recruitment selection bias. This limits our ability to confidently generalize these results to the whole population of those in treatment.

This study presents a first, limited investigation into the experiences of stigmatization in a group of people in recovery from substance abuse. As there was no comparison group, this limits our ability to speak to which experiences of stigmatization might be at particularly high rate in this population versus other stigmatized populations (e.g., mentally ill, HIV+ individuals). Future studies would usefully include multiple stigmatized groups to allow for examination of processes of stigmatization that might be shared versus divergent across groups.

4.8. Implications for practice

While preliminary, the results of this study suggest that stigmatization is commonly perceived by people in recovery. As the primary organizational point of contact for people in recovery, it may be important for addiction treatment centers to attend to the impact of stigma on their clients. Policies and procedures could be examined for the possibility of their contributing to stigma towards clients. There may also be room for intervention with service providers, who unfortunately are not immune to stigmatizing their own clients. One study (Hayes, Bisset et al., 2004; Hayes, Strosahl et al., 2004) has even found preliminary evidence for an intervention based on Acceptance and Commitment Training that may successfully reduce stigmatizing attitudes and behavior in counselors.

This study presents a unique, but limited addition to an underexamined area of research: stigma in substance abuse. As a beginning study, it brings up more questions than answers, but it may open a pathway for other researchers to follow. We hope that others will pick up the challenge and begin to answer some of the questions brought up by this study and help us understand how generalizable these results are to other people in recovery.

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Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change.

< Prev Next >

Show details

Contents

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Views

PubReader

Print View

Cite this Page

PDF version of this file (1.3M)

In this Page

FINDINGS FROM SURVEYS OF PUBLIC KNOWLEDGE AND NORMS

FACTORS THAT INFLUENCE STIGMA

CONSEQUENCES OF STIGMA

TARGETS AND INTERVENTIONS TO ADDRESS STIGMA

Recent Activity

Turn Off Clear

Understanding Stigma of Mental and Substance Use Disorders - Ending Discriminati...

Stigma and substance use disorders: an international phenomenon

The effectiveness of interventions for reducing stigma related to substance use

See more

2 Understanding Stigma of Mental and Substance Use Disorders

The term "stigma" is used throughout this chapter and the report to represent the complex of attitudes, beliefs, behaviors, and structures that interact at different levels of society (i.e., individuals, groups, organizations, systems) and manifest in prejudicial attitudes about and discriminatory practices against people with mental and substance use disorders. Attention to stigmatizing structures of society, such as laws and regulations, enables examination of prejudice and discrimination against people with mental and substance use disorders. Discriminatory policies and practices can appear to endorse negative social norms and deepen self-stigma.

This chapter offers a brief overview of what is currently understood about stigma, including influencing factors and consequences of stigma from the level of society as a whole to the experience of people with behavioral health disorders. Targets for change and interventions for changing stigmatizing attitudes, beliefs, and behaviors are discussed in [Chapter 4](#).

FINDINGS FROM SURVEYS OF PUBLIC KNOWLEDGE AND NORMS

Go to

Public knowledge and norms about people with mental and substance use disorders have been captured through population-based surveys with components focused on the stigma of mental and substance use disorders as it is reflected in stereotypes, help- or treatment-seeking, and behavioral dispositions.

Results of an analysis of the National Comorbidity Survey-Replication that compared data from the early 1990s and early 2000s showed that stigma associated with mental health treatment decreased, and support among the general public for treatment-seeking increased (Mojtabai, 2007). A survey of states in 2007 and 2009 showed that more than 80 percent of U.S. adults agreed that mental illness treatment is effective; people living in states with higher per capita expenditures on mental health services were more likely to agree that treatment is effective and were more likely to report receiving treatment (Centers for Disease Control and Prevention et al., 2012).

The Substance Abuse and Mental Health Services Administration (2014), as detailed in [Chapter 1](#), found that some

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Committee on the Science of Changing Behavioral Health Social Norms; Board on Behavioral, Cognitive, and Sensory Sciences; Division of Behavioral and Social Sciences and Education; National Academies of Sciences, Engineering, and Medicine. *Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change*. Washington (DC): National Academies Press (US); 2016 Aug 3.

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Public knowledge and norms about people with mental and substance use disorders have been captured through population-based surveys with components focused on the stigma of mental and substance use disorders as it is reflected in stereotypes, help- or treatment-seeking, and behavioral dispositions.

Results of an analysis of the National Comorbidity Survey-Replication that compared data from the early 1990s and early 2000s showed that stigma associated with mental health treatment decreased, and support among the general public for treatment-seeking increased (Mojtabai, 2007). A survey of states in 2007 and 2009 showed that more than 80 percent of U.S. adults agreed that mental illness treatment is effective; people living in states with higher per capita expenditures on mental health services were more likely to agree that treatment is effective and were more likely to report receiving treatment (Centers for Disease Control and Prevention et al., 2012).

The Substance Abuse and Mental Health Services Administration (2014), as detailed in Chapter 1, found that some common reasons reported for not receiving behavioral health care included inability to afford the cost of care (48%), believing that the problems could be handled without treatment (26.5%), not knowing where to go for services (25%), concerns about confidentiality (10%), that it might cause neighbors or the community to have a negative opinion (10%), that it might cause a negative effect on a person's job (8%), fear of being committed (10%), inadequate or no coverage of mental health treatment (6% to 9%), and thinking that treatment would not help (9%).

Comparing results of the 1996 General Social Survey (GSS) stigma modules with those of surveys in the 1950s on U.S. attitudes about mental illness stigma showed that public knowledge about mental and substance use disorders increased, specifically as it related to the neurobiological underpinnings of these disorders. There was greater public awareness of the stigma associated with these disorders, but public stigma itself remained high (Pescosolido,

2013; Pescosolido et al., 2010). Results from the 2006 GSS found greater sophistication in the public's knowledge of disorders and treatment than in the 1996 survey administration, but stigma levels for people with mental illness did not decrease over time (Pescosolido et al., 2010).

Results of the GSS have also shown that the level of public stigma varies along a gradient of social distance. In more intimate settings, the rate of stigma reflected as social rejection was higher, for example, a depressed person to "marry into the family" (60.5% rejection rate) versus the more distant "move next door" (22.9% rejection rate). Stigma against children and adolescents was lower compared to that of adults and also varied with social distance reporting higher rates of rejection for a friend with depression (29%) than for a classmate with depression (11%). One-half of all adult respondents said that treatment would result in discrimination and long-term negative effects on a child's future (Pescosolido, 2013)

Across countries surveyed in the Stigma in Global Context Study, levels of recognition, acceptance of neurobiological causes of mental illness and substance use, and treatment endorsement were similarly high; however, a core of five prejudice items persisted. The researchers called this the "backbone of stigma": issues of trust in intimate settings such as the family, potential contact with a vulnerable group such as children, the potential for self-harm, mental illness being antithetical to power or authority, and uneasiness about how to interact with people with mental illness (Pescosolido et al., 2013).

Finally, a review of studies of public stigma of mental illness, which included studies with variables related to substance use disorders, showed that over time the proportion of Americans who endorse neuroscientific views of schizophrenia and alcohol dependence has grown (Pescosolido, 2013). Americans also have endorsed the use of physicians and prescription medication for these disorders in greater numbers and reported being more willing to discuss behavioral health difficulties with family and friends. However, the persistence of core prejudice factors help explain why increased public knowledge has not decreased public stigma. Core indicators of stigma remain higher for people with schizophrenia and substance disorders than other conditions. Further, the highly stigmatizing public perception of violence as a component of mental illness has not decreased over time.

FACTORS THAT INFLUENCE STIGMA

In this chapter and throughout the report, in discussing stigma we begin with structural stigma and work from it to public stigma and self-stigma. This ordering reflects the committee's views on the relationships among the three levels of stigma and on the importance of addressing structural stigma and its consequences as a means for also reducing public and self-stigma. Societal structures reflect public norms and values, and many of the factors that influence structural stigma are the same as those that influence public stigma. Self-stigma occurs when a person with mental or substance use disorder internalizes negative stereotypes and the public and structural stigma directed at these disorders.

Public perceptions and beliefs about mental and substance use disorders are influenced by knowledge about these disorders, the degree of contact or experience that one has had with people with mental and substance use disorders, and media portrayal of people with mental and substance use disorders, as well as media coverage of tragic events, notably gun violence and suicide (Swanson et al., 2015). Public perceptions are also strongly influenced by social norms concerning the attribution of cause, or blame, for mental and substance use disorders, and the perceived dangerousness or unpredictability of people with these disorders. Race, ethnicity, and culture are embedded in social relationships and as such play a role in shaping attitudes, beliefs, and behaviors.

Blame

A biogenic model of the origins of mental and substance use disorders has been applied in an effort to reduce blame and promote positive attitudes about the value of treatment and the possibility of recovery. People with substance use disorders are generally considered to be more responsible for their conditions than people with depression, schizophrenia, or other psychiatric disorders (Crisp et al., 2000, 2005; Lloyd, 2013; Schomerus et al., 2011). Belief that a substance misuser's illness is a result of the person's own behavior can also influence attitudes about the value and appropriateness of publicly funded alcohol and drug treatment and services (Olsen et al., 2003).

There is a lack of empirical evidence supporting the stigma-reducing benefits of a neurobiological conceptualization of psychiatric illness (Trujols, 2015). Although some research suggests that attributing mental illness to biological causes may reduce the blame placed on individuals for their behavior (Rosenfield, 1997), other research has shown that attributing behavior to a genetic cause can increase perceptions of the difference of people with the disorder, and of the persistence, seriousness, and possible transmissibility of mental illness (Phelan, 2005). Overall, promulgation of the brain disease model of addiction does not appear to have reduced public stigma about substance use disorders and may decrease perceptions of self-efficacy and ability to cope among people with behavioral health disorders (Trujols, 2015).

Stereotypes of Dangerousness and Unpredictability

Americans are more likely to believe in the dangerousness of people with mental illness than are citizens of other developed, industrialized nations (Jorm and Reavley, 2014). In a recent national survey, four in ten Americans believed that children and adolescents with depression were likely to be violent, a finding that may be related to media coverage of school shooting incidents (Pescosolido, 2013). Stereotypes of violence and unpredictability are associated with higher levels of public stigma toward people with mental illness (Martin et al., 2000, 2007; Perry, 2011; Phelan et al., 2000). People with substance use disorders are considered even more dangerous and unpredictable than those with schizophrenia or depression (Schomerus et al., 2011). In a survey conducted in the United States (Link et al., 1997), a vast majority of respondents considered it likely for a cocaine- or alcohol-dependent person to hurt others. People are less likely to endorse the stereotype of violence if they have had direct contact with people who have mental and substance use disorders and have not experienced violent acts by people with these disorders (Jorm and Reavley, 2014).

Stereotypes of dangerousness can influence public policy in terms of restricting the rights of persons with behavioral disorders (Pescosolido et al., 1999). In the current context of the increasing frequency of mass shootings in the United States (Blair and Schweit, 2013), beliefs about the dangerousness of persons with mental illness and substance use disorders have come to the forefront in public policy debates. To inform these debates, a review of epidemiological findings related to mental illness, gun violence, and suicide found that there is a greater relative risk of violence in people with mental illness than those without mental illness, but the risk is actually very small. The risk of violence is greater for people with schizophrenia, bipolar disorder, co-occurring substance use disorder, and those exposed to certain socioeconomic factors, such as poverty, crime victimization, early life trauma, and a high neighborhood crime rate (Swanson et al., 2015). People with substance use disorders and antisocial personality disorders have a higher risk of violence than people with other psychiatric disorders (Fazel et al., 2009). The risk of suicide, as another form of violence, is increased by concurrent substance use; symptoms, such as hopelessness and depression; psychotic disorders; bipolar disorder; and environmental factors, such as access to guns and media reporting of suicide (Swanson et al.,

2015). Swanson and colleagues point to the gaps in the knowledge base on the relationship between behavioral disorders, violence, suicide, and guns, as well as to the gaps in knowledge on effective policies to reduce gun violence and suicide.

Knowledge about Mental and Substance Use Disorders

Knowledge about mental and substance use disorders can positively influence public norms, yet there is evidence that reframing these disorders as brain diseases produces mixed results on people's attitudes and behavior toward people with mental and substance disorders. As noted above, public education campaigns that frame mental and substance use disorders as brain diseases can have unintended consequences, including increased perception of difference and disbelief in the likelihood of recovery (Pescosolido et al., 2010; Schomerus et al., 2012; Trujols, 2015).

People with substance use disorders, in particular, are viewed by the public as weak-willed (Schomerus et al., 2011) although evidence shows that they are as likely to adhere to treatment as people with other chronic medical conditions, such as hypertension or diabetes (McLellan et al., 2000). Unfortunately, and in spite of efforts to educate the public, this misperception has increased over time according to the findings from national surveys in 1996 and 2006 (Pescosolido et al., 2010). Media portrayals of people with untreated and symptomatic substance use disorders, rather than depictions of those on a path to recovery, may be a factor in maintaining or increasing negative stereotypes and stigmatizing attitudes and beliefs about people with substance use disorders (McGinty et al., 2015).

Among health care providers, one consequence of bias against mental illness is the misattribution of physical symptoms of illness to concurrent mental disorders (Pescosolido et al., 2008b; Sartorius et al., 2010; Thornicroft et al., 2007), as well as lower rates of referral by primary care practitioners to appropriate physical health services like mammography, cardiovascular procedures, and pain management (Corrigan and Kleinlein, 2005).

Health care practitioners outside fields of behavioral health also lack knowledge about mental illness, and there is evidence that this can lead to misdiagnosis of both mental and physical conditions, and to selection of improper and inadequate treatment regimens (Wang et al., 2002). In addition to knowledge gaps, negative attitudes toward individuals who have mental or substance use disorders are prevalent among health care providers (Meltzer et al., 2013; Van Boekel et al., 2013). For example, although high remission rates for alcohol dependence have been found in population-based studies (Bischof et al., 2005), many health professionals continue to view alcoholism as incurable. In one study, nurses' self-reported lack of knowledge related to behavioral health was associated with greater reported fear and avoidance of people with mental illness (Ross and Goldner, 2009), demonstrating the link between lack of knowledge and the holding of prejudicial beliefs. Conversely, emergency room staff who reported having skills in treating these disorders held more positive views about the possibility of recovery than those who did not report having these skills (Clarke et al., 2014).

Contact and Experience

People's immediate social networks and the extent of their contact with people with mental illness affect their understanding of and opinions about mental illness in general (Chandra and Minkovitz, 2006; Corrigan and Penn, 1999). However, increased contact with people with mental illness does not necessarily reduce stigmatizing beliefs, and some studies have found that contact with people with substance use disorders raises the level of stigma (Lloyd, 2013). Among health professionals, negative attitudes toward people with substance use disorders increased over time

during which they would have had more contact with people with those disorders (Christison and Haviland, 2003; Geller et al., 1989; Lindberg et al., 2006).

Several factors may explain why contact with people with mental and substance use disorders sometimes deepens stigma, including the affected individuals' symptom severity and stage of recovery; and, in the context of contact-based interventions, the quality of the intervention itself, the fidelity with which it was implemented, and the quality of the peer training that had been provided to the individuals offering the contact services. (Peer support services are discussed in greater detail in Chapter 4).

Medical students in Australia reported more positive attitudes about illicit drug users after they experienced contact with them in small-group settings (Silins et al., 2007). In a qualitative study of pharmacists and drug users in a needle exchange program in the United Kingdom, both groups reported a decreased sense of stigma with increasing contact and familiarity (Lloyd, 2013). A review of two similar studies found that college students for whom at least 50 percent of their friends used drugs scored lower on a measure of public stigma (Adlaf et al., 2009). In another study, people who had a family member with an alcohol use disorder reported lower levels of stigma toward alcohol users than those without a diagnosed family member (Kulesza et al., 2013). A lower level of stigma does not imply support for substance misuse; rather, it reflects more positive attitudes toward people with substance use disorders.

Importantly, despite these variations in outcomes, the bulk of available evidence suggests that there is a strong and consistent inverse relationship between contact as an intervention and the level of stigma; more contact with people with mental and substance use disorders is associated with lower levels of stigma related to these disorders. (This topic is discussed in the review of stigma change interventions in Chapter 4).

Media Portrayals

The media provide ideas about and images of behavioral health that influence public attitudes, beliefs, and behaviors toward people with mental and substance use disorders (Edney, 2004; Klin and Lemish, 2008; Nairn et al, 2011; Nawková et al., 2012). An example of the role of media comes from a study of mainstream publications from 1998 to 2008 that covered the topic of postpartum depression and other mental illnesses. The test of communication theories showed that the media's portrayals helped shape the public's opinions about postpartum depression and that when the attention given to postpartum depression and other types of mental illness was negative, public opinion tended to mirror negative perceptions (Holman, 2011).

Much of the evidence on the media's influence on stigma change is negative in direction (Pugh et al., 2015). The media play a crucial role in stoking fear and intensifying the perceived dangers of persons with substance use disorders (Lloyd, 2013). Similarly, media portrayals of people with mental illness are often violent, which promotes associations of mental illness with dangerousness and crime (Diefenbach and West, 2007; Klin and Lemish, 2008; Wahl et al., 2002). Furthermore, the media often depict treatment as unhelpful (Sartorius et al., 2010; Schulze, 2007) and portray pessimistic views of illness management and the possibility of recovery (Schulze, 2007).

There has been some positive change. An analysis of newspaper articles between 1989 and 1999 (Wahl et al., 2002) showed more coverage of issues related to stigma and mental health insurance parity in 1999 than 1989. The analysis also found that there were fewer articles that contained themes of dangerousness and negative tones in 1999 than in 1989. However, even in 1999, articles with themes of danger and negative tones were still more prevalent than positive themes in reported stories that included a focus on mental illness.

Another content analysis of a nationally representative sample of U.S. news coverage of mental health issues found that, in 39 percent of stories, an association was made between persons with mental illness and dangerousness (Corrigan et al., 2005a). Treatment was discussed in 26 percent of stories but only 16 percent of the stories included recovery as an outcome. Moreover, recent research suggests that, given the broad reach of U.S. media, the volume and intensity of negative coverage about mental and substance use disorders are increasing mental health stigma in other countries as well (Jorm and Reavley, 2014).

Studies of new social media, experimental studies, and evaluations of anti-stigma initiatives point to the potential value and capacity of the media to counter stigma. For example, in a study of tweets comparing the use of words that referred to schizophrenia and diabetes (Joseph et al., 2015), researchers found that tweets about schizophrenia were more likely to be negative, medically inappropriate, and sarcastic than tweets about diabetes. But their results also suggested that such public misinformation could also be a target for anti-stigma efforts targeted at young people.

Media reporting of suicide can be stigmatizing through selective reporting on homicides and suicides, especially celebrity suicides, but they can also be platforms for prevention by providing positive messaging about available support and resources, coping, mastering personal crises, and the value of help-seeking (Niederkröthaler et al., 2014). One study of social media reactions to an attempted suicide showed that a greater proportion of microblogs expressed caring, empathy, or calling for help (37%) than posts that were cynical or indifferent (23%) (Fu et al., 2015). More research is needed to identify effective strategies that combine media, education, and support for help-seeking (Niederkröthaler et al., 2014).

In an experimental study that compared attitudinal outcomes, researchers found that stories of recovery decreased prejudiced attitudes toward people with mental illness and drug addiction and increased belief in treatment efficacy (McGinty et al., 2015). Australia's *beyondblue* campaign, a comprehensive social marketing campaign to destigmatize depression, provides another example of the impact of positive portrayals of mental illness. The researchers assessed changes in attitudes among the general public, controlling for different levels of exposure to the campaign, and found an increase in understanding of depression, awareness of discrimination, and self-reported use of mental health treatment (Jorm et al., 2005, 2006). (The *beyondblue* campaign, along with other national-scale stigma change efforts is discussed, in greater detail in Chapter 4.)

Race, Ethnicity, and Culture

Sociodemographic characteristics have been found to affect a large number of social beliefs, but when applied to stigma, the research findings are unclear (Pescosolido, 2013). Also important, the effect of sociodemographic characteristics differs depending on whether one is looking at the stigmatizer or the stigmatized person (Manago, 2015). Research is clearer on the relationship between culture, race, and ethnicity, and the quality of care that people receive (Bink, 2015). Ethnic and racial minorities access mental health care at a lower rate than whites, and when they do, the care they receive is often suboptimal (Schraufnagel et al., 2006; Substance Abuse and Mental Health Services Administration, 1999).

Several factors influence access, quality of care, and rates of treatment for mental disorders among ethnic and racial minorities and immigrant groups (Giacco et al., 2014; Schraufnagel et al., 2006). Quality of care is compromised by language barriers and provider misunderstanding of cultural ideas about illness, health, and treatment. Although most health care professionals agree that cultural competency training is important, lack of cultural awareness remains a problem in many health care settings (Giacco et al., 2014). Provision of physical and behavioral

health services in integrated care settings has been shown to increase participation in mental health treatment for racial and ethnic minorities (Giacco et al., 2014; Schraufnagel et al., 2006).

CONSEQUENCES OF STIGMA

As defined in Chapter 1 and discussed in the introduction to this chapter, there are three distinct types of stigma: structural, public, and self. Figure 2-1 depicts these three main types of stigma and the consequences that result from each, as well as the possible targets for change and interventions that have been used to change stigmatizing attitudes, beliefs, and behaviors. This section reviews the evidence on the consequences of each type of stigma on both adults and children. However, because of the negative impacts of stigma on children and adolescents, we provide a separate discussion about young people with behavioral disorders from the perspective of the public, youth, families, and professionals.

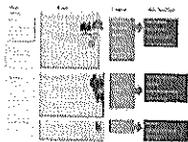


FIGURE 2-1

Stigma types, consequences, targets, and interventions.

Structural Stigma

Research on structural stigma is still in a developmental phase, and the research that has been done focuses primarily on mental illness rather than substance use disorders. While there is overlap between structural and public stigma, it is possible to define and distinguish between these phenomena. As shown in Figure 2-1, structural stigma is the societal and institutional manifestation of the attitudes, beliefs, and behaviors that create and perpetuate prejudice and discrimination. This section discusses structural stigma using examples of persistent prejudice and discrimination in public and private institutions, including government and legal systems, legislative bodies, employers, and educational institutions; health care and treatment systems; and the criminal justice system, including law enforcement, correctional institutions, and the courts.

Public and Private Institutions

One approach to operationalizing measurements of structural stigma has been through review of policies explicitly targeted at people with mental illness. A review of legislation in all 50 states found legal restrictions for people with mental illness in the following five domains: serving on a jury, voting, holding political office, parental custody rights, and marriage (Burton, 1990; Hemmens et al., 2002). A similar review of nearly 1,000 mental health-related proposed bills in 2002 found that 3 percent restricted liberties (e.g., allowed compulsory community treatment); 1 percent were discriminatory (e.g., restrictions on gun ownership, parental rights, placement of mental health facilities); and 4 percent reduced privacy (e.g., permitting disclosure of mental health information in special circumstances) (Corrigan et al., 2005b).

Although the National Alliance on Mental Illness (NAMI) described many states' mental health systems as being in disrepair, their report on state legislation in 2014 documented increased activity on mental health issues. For example, in seven states, legislation was enacted to protect the rights of individuals who are civilly committed, to clarify and improve civil commitment proceedings, and to encourage community-based court ordered treatment (National Alliance on Mental Illness, 2014).

Ironically, although much attention focuses on the dangerousness and violence of people with mental illness, numerous studies have found that they are at higher risk of victimization (Choe et

al., 2008; Desmarais et al., 2014; Khalifeh et al., 2015; Wolff et al., 2007) and of experiencing unfair treatment by authorities when they attempt to report crimes than people without mental illness (Pettitt et al., 2013). Poorer legal outcomes are also observed among plaintiffs with mental illness in employment discrimination suits in comparison with plaintiffs without mental illness (Swanson et al., 2006).

People with mental illness are more likely to experience housing and employment discrimination and homelessness than people without mental illness (Corbière et al., 2011; Corrigan and Shapiro, 2010; Corrigan et al., 2006b). Two overt and well-documented manifestations of structural stigma (Callard et al., 2012) against people with mental illness are segregated housing, some resembling psychiatric institutions (Byrne, 2000; Melnychuk et al., 2009; Metraux et al., 2007; Riley, 2011), and community-wide rejection of mental health facilities (Not-in-My-Backyard) (Piat, 2000). Some supported housing programs also have strict rules that people with mental illness must observe to maintain housing assistance, including prohibition of family or visitors, and mandatory compliance with program requirements or medication regimens (Riley, 2011; Schneider, 2010).

People with mental illness are more likely than others to be counseled to accept a job for which they are overqualified (Wahl, 1999), and they often face increased scrutiny by social workers, educators, physicians, family court administrators, and child protective services personnel (Dolman et al., 2013; Jeffery et al., 2013). On a positive note, NAMI's 2014 review of state legislation found examples of states addressing housing discrimination by enacting rules prohibiting homeless and emergency shelters from refusing services to persons with mental illness and providing funds for home ownership to families of children with disabilities. The NAMI report also documented efforts in some states to increase funding for or make other improvements to supported employment programs (National Alliance on Mental Illness, 2014).

In the arena of higher education, the Americans with Disabilities Act (ADA) and other federal disability laws prohibit discrimination against students with psychiatric disabilities and require that colleges and universities provide them with reasonable accommodations, for example, lighter course loads and extended deadlines. Unfortunately, in U.S. universities, fewer than one in four students with a mental illness will seek treatment or other supportive services (Downs and Eisenberg, 2012). A study of factors that inhibited disclosure of mental illness found these included a high level of self-stigma, fear of future discrimination, having few positive relationships, and sexual minority and Caucasian identity. Previous contact with mental health service users and belief in the effectiveness of treatment were associated with greater likelihood of disclosure and help-seeking (Downs and Eisenberg, 2012).

Another recent survey of campus experiences showed that college students with mental illness reported less social engagement and fewer relationships on campus than the general population, and felt that they were treated differently most of the time. These factors were, in turn, associated with lower graduation rates than the general student population (Salzer, 2012). Research that targets younger populations indicates that earlier experiences have already winnowed down this population, documenting reduced high school graduation rates and lower application rates to higher education (McLeod and Kaiser, 2004). Even when students with mental and/or substance use disorders do seek treatment, they often receive inadequate services, experience delays in obtaining supportive services, face segregation from other students, and receive harsher academic discipline than other students (Livingston, 2013; Losen and Welner, 2001; Skiba and Peterson, 2000; Wald and Losen, 2003).

Although much of the research discussed above referred to people with mental illness, people with substance use disorders also experience structural discrimination in many forms. A national

survey of people in recovery from alcohol and drug problems and their families (Hart Research Associates, 2001) documented barriers to treatment, such as lack of insurance and trouble obtaining insurance, the cost of treatment, and lack of access to treatment programs. They also reported fear of discrimination at work and previous experiences of being denied a job or promotion. Despite the hurdles people with substance use disorders face, the implementation of legislation such as the ADA and awarding of federal disability benefits can be more restrictive for people with substance use disorders than for those with mental illness (Join Together, 2003).

Health Care and Treatment Systems

Stigma in the U.S. health care system contributes to disparities in funding for research and treatment of mental disorders in comparison with physical disorders and to the negative attitudes, beliefs, and behaviors of health care professionals toward people with mental and substance use disorders. Structural stigma is manifested in the health care system in the low quality of care for people with mental and substance use disorders and the limited access to behavioral health treatment and other services (Institute of Medicine, 2006; Schulze, 2007; Schulze and Angermeyer, 2003); a fragmented bureaucracy for accessing behavioral health treatment; overuse of coercive approaches to care; and inadequate funding compared with that for physical care (Heflinger and Hinshaw, 2010; Institute of Medicine, 2006; Schomerus and Angermeyer, 2008; Schulze, 2007; Schulze and Angermeyer, 2003).

Parity laws for mental and substance use disorders in the United States have become a cornerstone for efforts to combat the structural inequity of behavioral health coverage versus physical health coverage and to eliminate or reduce coverage restrictions so that behavioral health benefits equate with benefits related to physical health services (Hernandez and Uggen, 2012; Sipe et al., 2015). States with behavioral health parity laws have higher utilization of services among people working for small employers and those in low-income groups (Busch and Barry, 2008). Unfortunately, increased access to care does not necessarily mean increased access to high-quality care or evidence-based treatment.

Recent efforts to address structural stigma in the health care system through parity laws have been accompanied by evolving public attitudes regarding behavioral health in the United States. A 2015 Harris Poll found that close to 90 percent of U.S. adults surveyed considered their mental health and physical health to be equally important, but 56 percent reported that physical health is treated more importantly than mental health in the current health care system, and almost 33 percent thought there were barriers to mental health care in terms of accessibility and cost. In a 2013 survey, 76 percent of adults thought that all health care plans in the United States should be required to include coverage for mental health care (Moniz et al., 2014).

Structural stigma may also be reflected in the de-prioritization and lower levels of funding for behavioral health services and research compared to general physical health services and research, despite the high prevalence of these disorders in the United States and evidence of comparable return on investment (Kelly, 2006; Mark et al., 2014). Research on mental and substance use disorders receives less scientific funding than on physical health conditions (Aoun et al., 2004; Brousseau and Hyman, 2009; Fineberg et al., 2013; Livingston, 2013; Pincus and Fine, 1992). Inadequate investment in behavioral health services research also reduces the availability of evidence-based services, especially in facilities that provide care to the safety net population (Cummings et al., 2013). Quality measurements of behavioral health care amount to only a fraction of physical health care measures, and many are narrowly focused, poorly defined, or lacking in evidence, validation, and meaningfulness (Kilbourne et al., 2010).

Low reimbursements are a factor contributing to the small percentage of psychiatrists who accept insurance (Bishop et al., 2014) and to the persistence of areas with shortages of mental health providers (Cummings et al., 2013). Even with the availability of providers and insurance coverage, insurance benefits have traditionally been more prohibitive of behavioral health services than physical health services, for example, by imposing constraints such as higher deductibles or requiring patients' mental health status to deteriorate before treatment coverage is allowed (Angermeyer et al., 2003; Corrigan et al., 2004a; Livingston, 2013; Muhlbauer, 2002).

Criminal Justice Systems

Structural stigma is apparent in several areas related to the criminal justice system. The disproportionate representation of people with mental illness with criminal justice involvement (Angermeyer et al., 2003; Corrigan et al., 2004b; James and Glaze, 2006; Livingston, 2013; Muhlbauer, 2002; Sarteschi, 2013) and their treatment within the criminal justice system may be indicators of how criminal laws are designed and enforced in such a way as to differentially target and adversely affect people with mental illness. Nationally, more than one-half of jail and prison inmates in 2005 had mental health problems (Angermeyer et al., 2003; Corrigan et al., 2004b; James and Glaze, 2006; Livingston, 2013; Muhlbauer, 2002; Sarteschi, 2013; Teplin et al., 2005). Incarcerated individuals with mental illness were more likely to have experienced multiple arrests and incarcerations, and only one in three people with mental health problems in prisons and less than one in five of those in jails accessed treatment since their imprisonment. Most U.S. states have more people with mental illness in prisons or jails than in state-operated psychiatric hospitals (Torrey et al., 2014).

To counter these trends, 11 states passed legislation in 2014 to halt the inappropriate flow of people with mental illness into the criminal justice system. Strategies included, for example, increasing training programs for law enforcement officers, examining arrests of people with mental illness and developing diversion programs, addressing court systems responses to people with mental illness, and establishing county-level mental health courts (National Alliance on Mental Illness, 2014). In 2004, Congress authorized the Justice and Mental Health Collaboration Program through the Mentally Ill Offender Treatment and Crime Reduction Act. It is a grant program to help states, local governments, and tribal organizations improve responses to people with mental illness in the criminal justice system through collaboration of efforts among the criminal justice, juvenile justice, and mental health and substance use treatment systems. Reauthorized for an additional 5 years in 2008, the act was expanded to address law enforcement responses (Council of State Governments Justice Center, 2015).

In corrections systems, whether prisons or jails, people with mental illness are more frequently abused by staff and inmates (Human Rights Watch, 2015; Wolff et al., 2007); more likely to receive sanctions like solitary confinement (Cloud et al., 2015; James and Glaze, 2006; Subramanian et al., 2015); given longer sentences; and more often denied parole (Livingston, 2013) than inmates without mental illness. While under community supervision, people with mental illness experience more intense supervision and face a higher likelihood of receiving technical violations than others under supervision even though the rate of new offenses is similar between people with and without mental illness (Eno Loudon and Skeem, 2013).

The complex relationship between substance use and criminal behavior is beyond the scope of this report. However, in terms of structural stigma, it is important to note that institutional policies that treat substance use disorders primarily as a criminal issue (e.g., the U.S. war on drugs) rather than a health concern have promoted a stigmatizing environment that excludes and marginalizes people with substance use disorders (Bluthenthal et al., 2000; Inciardi, 1986; Livingston, 2012). Anti-drug messages and harsh criminal sentences for drug use appear to label

people with these disorders as unwanted by society (Rivera et al., 2014). Thus the social processes designed to control substance misuse may actually promote its continuation by increasing shame (Livingston, 2012) and deepen the public and structural stigmatization of this population.

Public Stigma

Public stigma refers to the attitudes of the general public and also to attitudes of subgroups, such as first responders or clergy that may have norms that differ from the general public or other social groups. Public stigma persists in part because structural stigma in the form of laws, regulations and policies appears to endorse prejudice and discrimination against people with behavioral health disorders. A recent systematic review (Parsespe and Cabbassa, 2013) identified 36 articles published over the last 25 years that reported on results from population-based studies of public stigma in the United States. Many of the articles were secondary analyses of findings from national surveys, including the National Comorbidity Survey-Replication and the GSS's National Stigma Studies. These surveys examined public stigma toward people with a broad array of disorders, including adults with depression, schizophrenia, alcohol or drug dependency and children with depression, attention-deficit hyperactivity disorder, and oppositional defiant disorder.

The results of this review, confirmed by other researchers, indicate that public stigma leads to social segregation as well as diminished self-efficacy in people with mental and substance use disorders (Corrigan and Shapiro, 2010; Parcesepe and Cabassa, 2013; Pescosolido et al., 2007). Stigmatizing beliefs about the competency of people with mental illness compromise these individuals' financial autonomy, restrict opportunities, and may lead to coercive treatment, such as mandatory participation in treatment (Corrigan and Shapiro, 2010; Pescosolido et al., 2007). Despite the importance of social support for the recovery of those with substance use disorders, stigma instead contributes to social exclusion (Room, 2005). Also of importance, stigma may affect not only the substance user but his or her family members and friends as well (Corrigan et al., 2006a). Over time in both the United States and other countries, knowledge about mental and substance use disorders is increasing, but issues related to social exclusion also remain high (Pescosolido et al., 2007, 2010).

Self-Stigma

As people with mental and substance use disorders become aware of public stigma and of related discriminatory practices, they internalize the perceived stigma and apply it to themselves. The effects of self-stigma include lowered self-esteem, decreased self-efficacy, and psychologically harmful feelings of embarrassment and shame. Low self-esteem and low self-efficacy can lead to what Corrigan refers to as the "why try" effect, meaning why should a person try to live and work independently if he or she is not valued (Corrigan et al., 2009a).

Among people with mental and substance use disorders, low self-efficacy is associated with failure to pursue work or independent living; a greater degree of self-esteem is associated with goal attainment (e.g., symptom reduction, financial and academic problems), quality of life (e.g., satisfaction with work, housing, health, and finance), and help-seeking behavior (Corrigan et al., 2009b). A substantial body of research has shown that there is a negative relationship between stigma and help-seeking (Clement et al., 2015; Corrigan et al., 2014). Self-stigma can also be a barrier to recovery and community integration.

People who have disclosed their experiences report lower levels of self-stigma (Chinman et al., 2014). In a systematic review of research published between 1980 and 2011 examining associations between mental health-related stigma and help-seeking for mental health problems,

Clement and colleagues (2015) found that stigma related to fears about the consequences of disclosure was the fourth highest ranked barrier to help-seeking. Members of racial and ethnic minorities, youth, men, military service members, and health professionals were disproportionately deterred from seeking help by fears of being stigmatized. In addition, the level of public stigma shaped both reported experiences of stigma, self-stigma, and an unwillingness to use services (Evans-Lacko et al., 2012a; Mojtabai, 2010).

Stigma against children and adolescents is a serious concern because of its negative impacts, including decreased feelings of self-worth and willingness to enter treatment, and because of the deleterious long-term effects of untreated mental or substance use disorders. Compared with the adult population, stigma against children with mental disorders is less well studied. A 2010 review of studies of stigma related to childhood mental disorders concluded that stigma research lacked conceptual underpinnings and that the evidence base was quite sparse (Mukolo et al., 2010).

The National Stigma Study-Children, which was the first to include a nationally representative sample of participants to examine public stigma of childhood mental disorders specifically focused on attention-deficit/hyperactivity disorder (ADHD) and depression, comparing public attitudes and knowledge of these disorders with asthma or “daily troubles.” One set of analyses showed that 81 percent of the adult sample perceived children with depression to be dangerous to themselves or others, compared with children who had asthma or “daily troubles” (Pescosolido et al., 2007). A smaller but substantial proportion (33%) also perceived children with ADHD to be dangerous. Large proportions of the sample thought that children and adolescents with mental health problems would likely experience rejection at school (45%) and would experience stigma into adulthood (43%). Many respondents also had negative views of the benefits of medication (Pescosolido et al., 2007). The researchers concluded that some public beliefs about mental illness and treatment were based on a lack of accurate information and could present barriers for providers and for parents and others who seek treatment (Pescosolido et al., 2008a).

A growing body of research focuses on young people's subjective experiences of stigma. Interviews with 56 adolescents in a midwestern U.S. city found that 62 percent of youth experienced stigma with peers; 46 percent reported feeling stigmatized by their families; and 35 percent reported experiencing fear, dislike, avoidance, and underestimation of their abilities by school staff (Moses, 2010).

In a study of 40 adolescents taking psychiatric medication for a diagnosed mental illness, 90 percent reported experience of at least one stigma construct of secrecy, shame, and limited social interaction (Kranke et al., 2010). The study also found that adolescents' perceptions of the norms of family members and school environments can increase their experience of stigma or protect against it. Results of a large study of youth in Australia suggested that using accurate psychiatric labels reduces stigma and may assist youth by reducing perceptions of weakness (Wright et al., 2011).

The Web-based Injury Statistics Query and Reporting System (WISQARS™) shows that suicide is the second leading cause of death among young people in the United States aged 15 to 34 years (Centers for Disease Control and Prevention, 2015). There is strong evidence that stigma is an impediment to help-seeking on the part of young people and their families. Studies of family engagement in treatment have provided insight into how stigma poses barriers to care. A review of 12 qualitative studies in the United Kingdom on factors that facilitate or inhibit access and engagement in parenting programs for children with disruptive behavior problems pointed to factors directly or indirectly related to stigma (Koerting et al., 2013). Stigma was one of the factors that emerged as a prominent barrier to service from the perspective of both parents and

professionals. In these studies, stigma was manifested as shame about needing help, perceived parental failure, and fear of being labeled. Lack of information and lack of awareness about services were also major barriers to accessing care. Mainly from the professionals' perspectives, one of the main facilitators of access was effective advertisement and service promotion using media, such as leaflets or posters in locations visited by parents, promotion on the internet, local newspapers, radio stations, newsletters, and parenting forums.

TARGETS AND INTERVENTIONS TO ADDRESS STIGMA

In subsequent chapters of the report, the committee reviews the evidence on the effectiveness of stigma reduction interventions and approaches. In this section, we provide an overview of the potential targets and interventions that emerged from the committee's examination of the factors influencing each type of stigma and its consequences. Figure 2-1 illustrates the relationships among consequences of stigma at various levels and potential targets and interventions to reduce stigma at each level.

As shown in Figure 2-1, targets of structural stigma would include legislators, institutions, and policy makers of systems and organizations that fund and regulate the places and situations where discrimination, lack of opportunities, and lack of access to quality treatment persist. The interventions that would be appropriate for this level are legal, policy, advocacy, and professional education strategies. Strategies would be aimed at changing decision-making processes, policies, and regulations that support discrimination against people with mental and substance use disorders.

Targets for interventions to reduce public stigma include the general public and landlords, employers, health care providers, and groups within the criminal justice system. The corresponding interventions would be aimed at changing behaviors and interactions from discrimination, fear, neglect, and sometimes abuse to extending support, high-quality treatment, and equal opportunities for housing, employment, and personal success. Examples of such interventions include use of media for mass messaging to dispel myths regarding behavioral health disorders and treatment, education to counter the lack of knowledge about disorders and treatment, contact with people with behavioral disorders, and protest strategies against discrimination.

The general effects of self-stigma and the “why try” effect may be diminished by interventions that target individuals with behavioral disorders. As shown in Figure 2-1, such interventions would focus on promoting self-esteem and self-efficacy; empowerment through peer support, mentoring, and education to dispel myths and increase social and coping skills; and education to encourage treatment engagement (Corrigan et al., 2009a). Treatment engagement is significant because evidence-based treatments have been shown to facilitate recovery by promoting behaviors, such as symptom monitoring, continuing to take prescribed medications, and seeking out supported employment opportunities; and by encouraging family interventions, increasing skills related to illness management, and promoting entry into integrated treatment for mental and substance use disorders (Corrigan et al., 2009a, 2009b, 2014). For many individuals, disclosure may be an initial step in the process of reducing self-stigma when it can be done in a safe and strategic manner (Bos et al., 2009; Corrigan and Rao, 2012).

Chapter 4 will review the growing evidence base on the effectiveness of these types of intervention strategies as approaches to reducing stigma at each of the major levels.

Stigma and People Who Use Drugs



Stigma is defined as the experience of being “deeply discredited” or marked due to one’s “undesired differentness.” To be stigmatized is to be held in contempt, shunned or rendered socially invisible because of a socially disapproved status.¹

Stigma and Drugs

There is an extensive body of literature documenting the stigma associated with alcohol and other drug problems. No physical or psychiatric condition is more associated with social disapproval and discrimination than substance dependence.²

For people who use drugs, or are recovering from problematic drug use, stigma can be a barrier to a wide range of opportunities and rights. People who are stigmatized for their drug involvement can endure social rejection, labeling, stereotyping and discrimination, even in the absence of any negative consequences associated with their drug use. This manifests in a variety of ways, including denial of employment or housing. People with substance misuse issues are less likely to be offered help than are people with a mental illness or physical disability.³

According to research, the majority of healthcare professionals hold negative, stereotyped views of people who use illicit drugs.⁴ Stigma is a major factor preventing individuals from seeking and completing addiction treatment⁵ and from utilizing harm reduction services such as syringe access programs. In a vicious cycle, the social exclusion created by stigma can increase the need for a variety of services.

Even among people who use drugs, stigma toward other people who use drugs can be common. People who use a socially acceptable, legal drug, such as alcohol, may have negative prejudices against people who use illegal drugs, such as marijuana. People who use illegal so-called ‘soft drugs’ such as marijuana may have negative prejudices against people who use

illegal powdered or ‘hard’ drugs, such as cocaine. And people who inhale or snort their drug of choice may have prejudice against people who inject a drug.

What Can Be Done To Fight Stigma?

Know the facts. The majority of people who ever try *any* drug do not use them problematically and do not develop a physical dependence.⁶ People who struggle with drug dependence, however, should be afforded the same dignity, respect and support as a person who struggles with any difficult issue.

The public’s perception of the “deadliest” and “most addictive” drugs are often not based on scientific evidence. You can help end stigma by learning the facts about drugs, drug use and evidence-based drug treatment and sharing the information with others.

Language matters. The way we talk about drugs and the people who use them can create or uphold stigma. Words like ‘crackhead,’ ‘junkie’ and ‘pillhead’ dehumanize a person who may be struggling with addiction. Focus on the whole person, not a behavior. Instead of ‘addict’, refer to a ‘person addicted to drugs.’

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2. Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. Englewood Cliffs: Prentice-Hall

3. Corrigan, P.W., Kuwabara, S.A., & O’ Shaughnessy, J. (2009) The public stigma of mental illness and drug addiction: Findings from a stratified random sample. *Journal of Social Work*, 9(2), 139-147

4. McLaughlin, D. & Long, A. (1996) An extended literature review of health professionals perceptions of illicit drugs and their clients who use them. *Journal of Psychiatric and Mental Health Nursing*, 3(5), 283-288

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6. Comparative epidemiology of dependence on tobacco, alcohol, controlled substances, and inhalants: Basic findings from the National Comorbidity Survey By Anthony, James C.; Warner, Lynn A.; Kessler, Ronald C., Experimental and Clinical Psychopharmacology, Vol 2(3), Aug 1994, 244-268.