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CHAPTER 1

Understanding the Stigma of Substance Use Disorders

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A Social Function of Stigma

Substance use disorders (SUD) are among the most stigmatized mental health conditions (Schomerus, Lucht, et al., 2011b). A recent systematic review confirmed that the desire for social distance is particularly strong toward people with SUD, and support for structural discrimination is particularly high when compared to other mental disorders like depression or schizophrenia (Kilian, Manthey, Carr, et al., 2021). People with SUD are more likely to be held responsible for their illness and are more often considered to have a bad character or suffer from moral weakness (Kilian, Manthey, Carr, et al., 2021). Negative stereotypes toward people with alcohol use disorder are remarkably stable and have not improved over the last decades (Schomerus et al., 2014). Emotional reactions even seem to deteriorate: a time trend study of attitudes in Germany found the proportion of respondents reacting angrily toward someone with alcohol use disorder increasing from 15% in 1990 to 24% in 2011, while remaining stable at below 10% for schizophrenia and depression (Angermeyer et al., 2013).

Having an SUD provokes severe and adverse reactions from the social environment. Stigma is a severe additional burden for someone developing an SUD, and it is fundamentally unjust. In this introductory chapter, we will give a conceptual overview as to how the different facets of SUD stigma, public stigma, self-stigma, and structural stigma lead to criminalization, social exclusion, marginalization, inferior health care, and diminished life chances in people with SUD. But before we look at the harm stigma is doing, we will consider the specific social function of SUD stigma. Why are people with SUD stigmatized, and why is the stigma of SUD in many ways different from that of other mental disorders? This might appear as a detour; some theoretical musing detracting from the severe consequences that stigma has on the lives of those with SUD and their families. The stigma of SUD needs to be erased, but we believe that understanding the causes of

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SUD stigma is a prerequisite to successful strategies to combat it, particularly in a highly contested area like substance use.

How Should Substances Be Used?

To begin with, using substances is a controversial issue, and while understanding the stigma of SUD is certainly necessary to improve our dealing with substance use, establishing a consensus on what constitutes acceptable, healthy substance use is clearly beyond the scope of this book. Agreement on what constitutes acceptable substance use is constantly changing. From a medical perspective, the assessments of risks associated with substance use change. The considerable risk for cancer at various sites that is attributable to alcohol, for example, has only recently come into focus (Rehm & Shield, 2021). From a legal perspective, changing legislature with regard to taxing, advertising, or legalizing substances like nicotine, alcohol, or cannabis mirrors the constantly shifting public consensus on how we should or should not use substances for recreational purposes, and how substance use should be controlled. Moreover, there are considerable international differences on what constitutes acceptable substance use, and also subcultural differences within countries. Individual choices and preferences stand against perceived and real harm for those who use substances, their close ones, and the community. The balance between individual benefits of substance use and harm to others varies greatly. For example, while smoking cannabis can be seen as an individual choice with individual risks and benefits, it also may affect other people, for example when someone has caregiver responsibility for a child, or is driving a car (Hasin, 2018; World Health Organization, 2016). Cigarette smoking entails the risks of passive smoking (Khoramdad et al., 2020), many substances and particularly alcohol are linked to violent and dangerous behavior (Foran & O'Leary, 2008), and links between childhood abuse and neglect, and parental substance use, are well established (Walsh et al., 2003). Add the varying levels of severity of substance dependence, and balancing the preferences, health, and well-being of people who use substances with those of their social environment is becoming a truly complex and challenging task.

Stigma as a Means to Regulate Substance Use?

The stigma of substance use is right at the center of this challenge. Several aspects of substance use stigma are culturally sanctioned, like the

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criminalization of substance use, or the perpetuation of negative stereotypes about people using substances in some messages about prevention. Substance use stigma is often stigma on purpose (Corrigan et al., 2017). Phelan et al. (2008) have highlighted that stigma has a social function, and for addiction stigma, they posit that it has the inherent purpose of "keeping people in," to enforce social norms and to demarcate the boundaries of socially acceptable behavior. Other stigmata work differently: Phelan and coworkers observe that racism, for example, is rooted in exploitation or "keeping people down," while the stigma of AIDS or leprosy, as communicable diseases, can be seen as a means of "keeping people away" to avoid contraction. In the case of substance use stigma, they argue that this type of stigma may be an attempt "to make the deviant conform and rejoin the in-group" or "to clarify to other group members the boundaries of acceptable behavior … and the consequences of nonconformity" (p. 362). Discriminating against people with SUD disorders could thus be seen as a way of signaling to them and to anybody else strong disapproval of their behavior.

This social function aligns with the central position of blame in SUD stigma (Schomerus, Lucht, et al., 2011). Blame confers an expectation that people need to change their behavior. It is also mirrored in the fact that stigma toward people with alcohol use disorders differs according to national drinking cultures. Data from the European Values Survey show that stigma toward heavy drinkers is higher in countries with higher per capita alcohol consumption, a higher prevalence of heavy episodic drinking, and higher consumption of spirits (Kummetat et al., 2022). This is consistent with the role of stigma as a societal reaction to problematic drinking: the bigger the drinking problem on a country level, the more harsh is the reaction of people toward an individual with an SUD in that country. At the same time, the high stigma levels in countries with high alcohol consumption also indicate that stigma does not solve the problem of high alcohol use – if stigma were a successful strategy to control substance use, high stigma levels would have been expected to correlate with low per capita alcohol intake, but the opposite is true.

Stigma Is an Impediment to Helping People Engage in Services for SUD

The stigma of SUD is at the center of how society reacts to substance use – and, as the chapters of this book will show from several perspectives, stigma does little to solve any of the problems associated with substance

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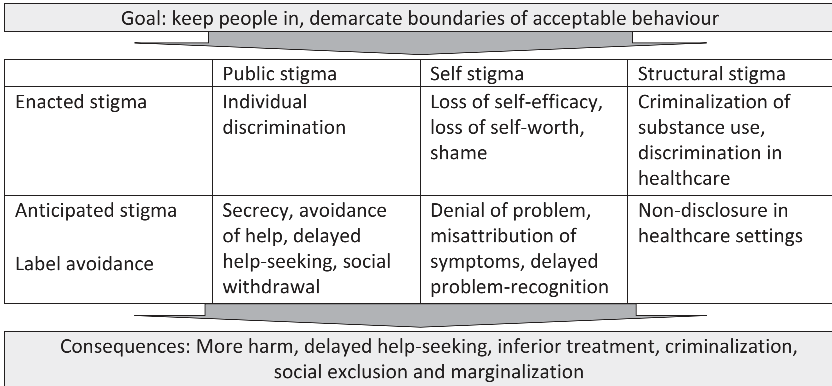

Goal: keep people in, demarcate boundaries of acceptable behaviour

	Public stigma	Self stigma	Structural stigma
Enacted stigma	Individual discrimination	Loss of self-efficacy, loss of self-worth, shame	Criminalization of substance use, discrimination in healthcare
Anticipated stigma Label avoidance	Secrecy, avoidance of help, delayed help-seeking, social withdrawal	Denial of problem, misattribution of symptoms, delayed problem-recognition	Non-disclosure in healthcare settings

Consequences: More harm, delayed help-seeking, inferior treatment, criminalization, social exclusion and marginalization

Figure 1 Stigma as a dysfunctional strategy to control substance use

use; on the contrary, it is a driver for additional harm and an impediment to recovery. Figure 1 gives an overview on how the stigma of SUD operates. Fueled by a goal to signal that certain behaviors are unwanted, it takes public stigma, self-stigma, and structural stigma, enacted and anticipated, to do harm to people with SUD and to their families (Earnshaw et al., 2019).

Public Stigma

Models describe stigma as a social cognitive process starting with *labeling* someone and thus creating an outgroup linked to this label (Link & Phelan, 2001). The abundance of derogatory terms for people who use substances, or have an SUD, seems to mirror a desire to put a sharp line between "us" and "those" who cross a boundary of socially acceptable behavior. Describing someone as a "drug addict," for example, has been shown to be associated with more stigma than describing them as "someone with opioid use disorder" (Goodyear et al., 2018). According to Link and Phelan (2001), labels trigger the stigma process by evoking negative stereotypes, leading to prejudice and negative emotional reactions, separation of "us" versus "them," and finally resulting in status loss and discrimination (Corrigan et al., 2017; Link et al., 2004). As a societal phenomenon, stigma affects individuals with SUD at several levels. *Public stigma* describes the attitudes endorsed by the general population leading to individual discrimination of someone with SUD. Discrimination experiences are frequent for people labeled as having an

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SUD, corresponding to the particularly high levels of negative attitudes associated with them (Kilian, Manthey, Carr, et al., 2021). In a study conducted in New York in the early 2000s, three out of four people who used drugs reported being rejected by their family, two out of three by their friends, and one out of four reported being denied medical care (Ahern et al., 2007). Stigma has imminent health consequences. In a qualitative study, people who injected drugs recounted how stigmatizing attitudes of healthcare providers posed a barrier in adhering to a methadone treatment regime or purchasing syringes (Paquette et al., 2018), thus interfering with vital harm-reduction measures. But the consequences of public stigma do not stop with open discrimination. There is evidence from several areas of stigma research that perceived public stigma impairs the mental and physical well-being of those stigmatized (Schmitt et al., 2014). Public attitudes form an external cultural reality that determines how we experience an SUD (Link et al., 2011). *Anticipating public stigma* leads to secrecy, avoidance of contacts in times of crisis, and even avoidance of professional help. About 70% of respondents who used drugs stated that they avoided other people because they thought they might look down on them (Ahern et al., 2007). By hiding and withdrawing socially, overt discriminating behavior by others is indeed avoided. The effects of secrecy, social withdrawal, and avoidance of help all result from stigma. *Label avoidance* is also a consequence of anticipated stigma (Corrigan et al., 2014): not talking about substance use problems, trying to hide for as long as possible, and, ultimately, not seeking professional or informal help. These are all strategies to avoid being labeled as having an SUD and to escape stigma. Anticipating stigma from one's family and from the healthcare system is particularly consequential, since these are major sources of help (Smith et al., 2016). Unfortunately, families are also victims of stigma: although evoking less negative reactions than people who use substances, family members are still held responsible for their relatives' substance use problems compared to other mental disorders, and are viewed as more likely to be contaminated by the disorder and are more likely to be socially avoided (Corrigan et al., 2006).

Self-Stigma

Another consequence of public stigma is *self-stigma*. According to Corrigan's progressive model of self-stigma (Corrigan et al., 2011), being aware of negative public attitudes entails, to some degree, agreement with these attitudes, since we are all part of our cultural environment and share

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prevalent stereotypes about certain groups. If someone develops an SUD, this agreement with negative stereotypes about other people with SUD provokes an inner conflict: to what extent do these stereotypes apply to me? If I agree that people with SUD are weak and unreliable, am I also weak and unreliable now that I have a substance use problem? Studies among people with alcohol use disorder consistently show that stronger awareness of prevalent negative stereotypes is associated with agreement, which in turn is associated with applying these stereotypes to oneself (Schomerus, Corrigan, et al., 2011; Stolzenburg et al., 2018). Self-applying stereotypes is then correlated with harm, for example with reduced self-esteem. The progressive model of self-stigma has been shown to be predictive of drink-refusal self-efficacy, even when controlling for current depressive symptoms, severity of dependence, and duration of the problem (Schomerus, Corrigan, et al., 2011). Label avoidance can also be a strategy to avoid self-stigma: a study among untreated persons with depression showed that the more people endorsed stigmatizing attitudes and were thus more prone to self-stigma, the less likely they were to attribute their own current symptoms to mental illness and feel a need to seek help (Stolzenburg et al., 2017). Conceivably, many people with substance use problems avoid self-stigma and shame by delaying problem recognition, denying that there is a concern or reframing compulsory substance use as continuous free choice. Anticipated self-stigma might thus be a particularly severe barrier to early help-seeking and recovery (Figure 1). A lot of the harm stigma is doing occurs within the individual, invisible from the outside, and seemingly unrelated to any imminent discriminatory behavior. But nevertheless, the internal harm caused by stigma is a mirror of societal attitudes and behaviors that are experienced, anticipated, and finally internalized by people with SUD (Smith et al., 2016).

Structural Stigma

Stigma extends beyond the individual level. Structural stigma is inherent in laws, regulations, and guidelines that work to the disadvantage of people with SUD, even if the people following the rules have no intention to stigmatize. Criminalizing substance use is an example of structural stigma – the "war on drugs" has produced countless victims and still influences policing practices, for example, by increasing police brutality, particularly against young black men (Cooper, 2015). A qualitative study among injecting drug users revealed how police crackdowns impaired their capacity to engage in harm reduction (Cooper et al., 2005). Structural stigma

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leads to inferior access to health care for people with SUD in general (Livingston, 2020), and to psychiatric help in particular. Frequently, sustained abstinence is a precondition to entering certain services like psychotherapy, resulting in services excluding people with one problem too many. The separation of health services for people with SUD from services for people with mental illness that has developed over decades in many countries also results in barriers for people with SUD to receive adequate mental health care. A commissioned review in Australia stated that "differing institutional cultures, aetiological concepts, philosophical underpinnings, educational requirements, administrative arrangements, and screening and treatment approaches" as well as "issues pertaining to the lack of consistent definitions and conceptual frameworks for comorbidity . . . lack of communication, collaboration, and linkages between the sectors" all contribute to inferior care for people with dual diagnoses, that is, a substance use plus another mental disorder (Canaway & Merkes, 2010). The separation of services is a prime example of structural discrimination, particularly of people with co-occurring disorders. Again, label avoidance and reluctance to disclose a substance use problem are likely and harmful strategies to avoid structural discrimination in healthcare settings (Figure 1).

Structural stigma is of course related to population attitudes. With regard to healthcare spending preferences among the general population, alcohol use disorder has consistently been assigned the lowest priority. A series of surveys in 2001, 2011, and 2020 in Germany monitored spending preferences of the public for nine common disorders. Spending for cancer treatment was consistently most popular, spending for depression care became more and more popular over time, while spending for the treatment of alcohol use disorder consistently enjoyed by far the lowest priority (Schomerus et al., 2021).

Where Do We Need to Go?

The Need for Concept Change: Labeling and a Continuum of Substance Use–Related Problems

The weight of labels seems particularly significant for SUD. We explore labeling and label avoidance as an example of how changing the words (and the underlying concepts) related to SUD could help eliminate its stigma. Admitting to the SUD label has long been seen as central to acknowledging the severity of the problem, and initiating the process of

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recovery, while avoiding the label has been viewed as "denial" and an impediment to accepting help or perceiving necessity for change (Howard et al., 2002). Some self-help approaches, like the 12-step program by Alcoholics Anonymous, and frequently professional treatment settings as well, expect people to submit under an illness label before any recovery process can start. At the same time, Link's modified labeling theory describes how assignment of a label changes the experience of someone with mental illness, increases withdrawal and secrecy, decreases social support, and results in worse mental and physical health outcomes (Link et al., 1989). This theory has been applied and empirically tested to people with SUD (Glass et al., 2013). Avoiding the label of an SUD thus seems like a healthy response, given the threat of public stigma, self-stigma, and structural stigma. But label avoidance is also a serious impediment to early problem recognition, and early help-seeking (Figure 1). So, there is a labeling dilemma and, probably, changing the significance of SUD labels could show a way out.

In an opinion piece in 2013, Jürgen Rehm and colleagues argued that rather than adhering to a yes or no diagnosis of "addiction," a continuum of mild, moderate, and heavy substance use would be sufficient (Rehm et al., 2013). SUD are dimensional conditions with no natural threshold (Hasin et al., 2013), and the DSM-5 accordingly grades severity with the number of criteria met from 2 to 11, categorized into mild, moderate, and severe SUD. This is quite a break from the traditional binary views of addiction.

Continuum views of substance use problems seem to have the potential to lower the stigma of SUD. Population studies show that people who have a continuum view of alcohol use disorder express more pro-social emotions for someone with alcohol use disorder, experience less fear (Schomerus et al., 2013), and have less desire for social distance (Schomerus et al., 2013; Subramaniam et al., 2017), a finding that is in line with various studies about other mental disorders like depression or schizophrenia (Peter et al., 2021). An intervention study among people with harmful drinking (but no addiction experience) found that providing them with a continuum model of alcohol problems made them <u>more</u> likely to recognize their drinking problem, compared to respondents receiving a binary, categorical intervention (Morris et al., 2020). Hence, there is preliminary evidence that a continuum model of SUD could reduce stigma and facilitate early problem recognition and help-seeking. Ultimately, label avoidance could become less necessary by reducing the labels' weight, stressing the dimensionality of substance use problems and promulgating a continuum model.

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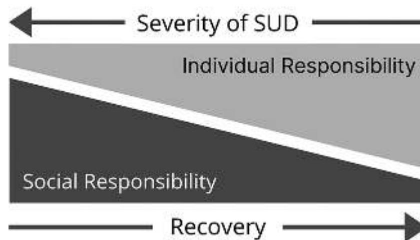

Figure 2 A dynamic model of responsibility in SUD

Responsibility

Another conceptual issue that drives stigma, and hence also offers a way to reduce it, is responsibility. Perceptions of responsibility, or blame, are central to the stigma of SUD. There is a perceived contradiction between an illness model of SUD, which implies low personal responsibility, and a behavioral model, where responsibility is central. While it is evident that severe SUD impairs someone's ability to take responsibility, for example while being intoxicated or in times of severe compulsive substance use, it is also clear that recovery without taking responsibility is difficult to imagine. A broader and dynamic conceptualization of responsibility may resolve this apparent contradiction. First, the focus on the individual needs to be replaced by a focus on individuals within their social context. There is a responsibility of the social environment for substance use, in terms of availability of and access to substances, but also in terms of provision of help, both within the healthcare system and on a personal level. This "social responsibility" (Williamson, 2012) has a dynamic relation to the individual responsibility of someone with an SUD. In a simplified model, both individual and social responsibility can be viewed as being in a dynamic balance, which changes according to the severity of the substance use problem. The more severe a substance use problem, the more responsibility has to be taken by the social environment, by providing help, for example. Recovery would then be a process of regaining individual responsibility (Figure 2). This model could counter the dynamics of blame in SUD stigma, pointing to our social responsibility particularly for people with severe SUD, but would also highlight the necessary growth of individual responsibility during recovery. It also aligns with ongoing biological research on regaining control over drug intake (Heinz et al., 2020).

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Protest, Contact, and Education

However, conceptual changes to SUDs will not suffice to effectively erase the stigma of SUD. Eliminating the stigma of SUD will likely involve the three core strategies against public stigma: protest, education, and contact (Corrigan & Penn, 1999), but against the backdrop of the specific social function of SUD stigma, they are particularly challenging. Starting with protest, or social activism, it would be necessary to highlight the injustices of stigma and chastise stigma offenders, for example by protesting unequal access to health care for people with SUD. To enable protest, the widespread blame and shame surrounding SUD and the resulting self-stigma need to be overcome. We need empowerment and broad alliances to make protest feasible. The chapters of this book make a strong case against the fundamental injustice of SUD stigma, including voices of people with lived experience who are leading the way to protest stigma and discrimination. The same holds true for contact, the personal meeting of members of the general population with members of the stigmatized group. Contact is an indispensable cornerstone of any antistigma initiative. It has long been established that contact is among the most important parts of antistigma interventions, and the principles of strategic stigma change established by Corrigan (2011) describe how contact is best employed: targeted, local, credible, and continuous (Corrigan, 2011). For example, a contact-based targeted intervention for police officers to reduce alcohol stigma is probably most effective if the person with lived experience is a police officer, or someone with previous contact with the police from a shared cultural background (local and cultural proximity), who is in recovery from alcohol use disorder (credibility). The intervention should be part of a long-term antistigma strategy (continuity). Contact involves disclosure of people with lived experience, which may be particularly challenging with a condition as severely stigmatized as SUD. Hence, we need to create an environment making disclosure easier. We are proud that this book has offered some room for voicing the lived experiences of some of the authors.

Education, finally, challenges inaccurate stereotypes about SUD, replacing them with factual information. For example, the stereotype that people with SUD are weak-willed can be countered by the fact that behavioral change is similarly challenging for people with other behavior-related conditions, like type 2 diabetes (Sellman, 2010). Education has to relate directly to the social function of SUD stigma. First, we have to show that stigma does not solve the problem of SUD, but adds to its harm. Second, acknowledging that stigma is there for a reason also means that we have to show there are better ways to deal with SUD, without stigma. The

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