Drogenkonsum in Geschichte und Gesellschaft
Drug Use in History and Society

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**Hang Su [Ed.]**

# Breaking the Silence

## Confronting Stigma and Substance Use Disorder

Nomos

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**Drug Use in History and Society**

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# Introduction

*Hang Su, Yifan Xu*

In a world where the complexities of human experience are often oversimplified, the intertwined issues of stigma and substance use disorder (SUD) demand a more nuanced exploration. Stigma, a pervasive societal force, manifests as deeply ingrained negative attitudes and discrimination against individuals based on certain characteristics or behaviours. It is a powerful social construct that can diminish self-worth, restrict opportunities, and perpetuate exclusion, impacting the lives of many in profound ways.

Substance use disorder, commonly known as addiction, is a multifaceted medical condition characterised by the compulsive use of substances, despite adverse consequences. It affects millions globally, cutting across all demographics and socioeconomic statuses. SUD is not merely a failure of willpower or a moral failing; rather, it is a complex interplay of genetic predispositions, environmental influences, and psychological factors. Understanding this condition requires a compassionate and informed perspective, recognising it as a chronic disease that necessitates ongoing management and support.

In this book, both ‘substance use disorder’ (SUD) and ‘substance use disorders’ (SUDs) are used interchangeably to reflect the complexity of this condition. While ‘substance use disorder’ refers to the condition in general, ‘substance use disorders’ may be used to refer to various specific types of the disorder (e.g., alcohol use disorder, opioid use disorder). However, both terms are intended to describe the same overall condition related to problematic substance use.

The relationship between stigma and substance use disorder is deeply intertwined and mutually reinforcing. Stigma surrounding SUD not only exacerbates the struggles faced by those battling addiction but also serves as a significant barrier to seeking and receiving effective treatment. Individuals with SUD often internalise societal stigma, leading to feelings of shame, guilt, and unworthiness. This internalised stigma can hinder recovery efforts, fostering a sense of isolation and hopelessness. Additionally, public stigma—manifested through discriminatory policies, biased media portrayals, and societal attitudes—perpetuates harmful stereotypes and myths about addiction, further marginalising those affected.

This book aims to unpack the complex dynamics between stigma and substance use disorder, exploring their interplay and the impact they have on individuals and society at large. Through a combination of personal narratives, scientific research, and critical analysis, we will delve into the origins of stigma, its manifestations, and its consequences for those living with SUD. Personal stories will provide a human face to the abstract concepts, highlighting the lived experiences of individuals who navigate the dual burdens of addiction and societal judgment.

By understanding the roots and impacts of stigma, we can begin to dismantle these harmful perceptions and replace them with empathy and knowledge. This book will highlight successful strategies for reducing stigma, including educational initiatives, media advocacy, and supportive community programmes. We will explore the importance of language in shaping attitudes, demonstrating how thoughtful communication can foster a more supportive environment for those with SUD.

Moreover, we will present actionable steps for individuals, families, and communities to combat stigma and support recovery. This includes advocating for policies that promote treatment over punishment, engaging in open and honest conversations about addiction, and creating inclusive spaces where people can share their experiences without fear of judgment.

In sharing these insights and stories, our goal is to inspire a shift in how society views and addresses substance use disorder. We aim to move from a paradigm of blame and exclusion to one of understanding and inclusion. By shedding light on the human side of addiction, we hope to foster a culture of compassion where every person affected by SUD can find the support and respect they deserve.

Chapter 1 provides a comprehensive definition of stigma and its various forms, including public stigma, self-stigma, and structural stigma. It explores the historical context of stigma related to mental illness and SUD, highlighting the deep-rooted prejudices that persist in society.

Chapter 2 provides an in-depth look at SUD, exploring their clinical definitions and diagnostic criteria. It explains the complexities of SUD, which encompass psychological, biological, and social dimensions. The chapter details the criteria used to diagnose SUD.

Chapter 3 examines the wide-ranging consequences of stigma on individuals with mental illness and SUD. It discusses how stigma leads to discrimination in healthcare, employment, and social interactions, exacerbating the struggles of affected individuals. The chapter also explores the impact of stigma on treatment outcomes and recovery.

Chapter 4 delves into the intricate relationship between stigma and SUD, highlighting how stigma affects the perception, treatment, and recovery of individuals with SUD.

Chapter 5 focuses on effective strategies and notable success stories in reducing stigma associated with mental health conditions and SUD. It presents a comprehensive overview of interventions and approaches that have proven successful in various settings and highlights real-life examples of stigma reduction efforts.

Chapter 6 explores the changing views on stigma associated with SUD and mental health conditions and outlines the future steps necessary to further reduce stigma. It looks at ongoing debates, new trends, and innovative strategies aimed at creating a more inclusive and supportive society.

Chapter 7 summarizes the issues of discrimination and stigmatization related to gaming addiction, provides a structured analysis of the stigma of behavioral addiction, and points out future research directions.

Chapter 8 introduces the issue of HIV related discrimination and stigma in Spain, including the epidemiological situation, severity, and sharing of measures and experiences on how to eliminate stigma.

This journey is about more than just changing minds; it’s about changing lives. We invite you to join us in this endeavour, to listen, learn, and act. Together, we can build a future where stigma no longer stands in the way of recovery and where every individual is treated with dignity and care.

# List of Acronyms

Introduction

substance use disorder (SUD)

substance use disorders (SUDs)

Chapter 2

World Health Organization (WHO)

disability-adjusted life year (DALY)

Organisation for Economic Co-operation and Development (OECD )

Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)

International Classification of Diseases, Eleventh Revision (ICD-11)

American Psychiatric Association (APA)

Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)

phencyclidine (PCP)

methylenedioxymethamphetamine (MDMA)

Methylenedioxyamphetamine (MDA)

gamma-aminobutyric acid (GABA)

selective serotonin reuptake inhibitors (SSRIs)

Chapter3

not in my backyard (NIMBY)

Americans with Disabilities Act (ADA)

Center for Epidemiological Studies Depression scale (CES-D)

Chapter4

methadone maintenance treatment (MMT)

Chapter 5

Mental Health First Aid (MHFA)

International Labour Organization (ILO)

Americans with Disabilities Act (ADA)
Veterans Affairs (VA)
a: World Health Organization. Licence: CC BY-NC-SA 3.0 IGO.

Chapter 6
National Institutes of Health (NIH)
brain disease model of addiction (BDMA)

Chapter 7
gaming disorder (GD)
the International Classification of Diseases (ICD-11)
animation, comics, and games (ACG)

Chapter 8
Sexually Transmitted Infections (STIs)
gay men and other men who have sex with men (GBMSM)
antiretroviral therapy (ART)
people living with HIV (PLHIV)
pre-exposure prophylaxis (PrEP)
sustainable development goals (SDG)
health-related quality of life (HRQoL)
Spanish Union of Insurance and Reinsurance Entities (UNESPA)
non-governmental organizations (NGOs)
the State AIDS Coordinator (CESIDA)
the scientific societies Spanish Interdisciplinary AIDS Society (SEISIDA)
High-Level Meeting (HLM)
Sustainable Development Goal (SDG)
European Commission (EC)
European Union (EU)
African Union (AU)
United Nations (UN)
Trade-Related Aspects of Intellectual Property Rights (TRIPS)

# Chapter One: Understanding Stigma

*Yifan Xu, Shuo Li*

## *1. Exploring the Concept of Stigma*

Human beings are inherently social creatures who require extensive social acceptance and interaction. However, why do humans sometimes reject members of their own kind? This rejection often stems from the concept of stigma, a social construct with roots tracking back to ancient Greece. The Greeks, known for their proficiency in using visual aids, originated the term 'stigma' to describe bodily marks designed to signify something unusual and negative about a person's moral status. These marks, whether cut or burned into the body, indicated that the bearer was a slave, a criminal, or a traitor—someone tainted and socially shunned, particularly in public spaces (Goffman 1963, p. 3).

Erving Goffman's groundbreaking work, *Stigma: Notes on the Management of Spoiled Identity* (1963), has served as a catalyst for extensive research on stigma throughout the years. Definitions of stigma vary across different studies, a phenomenon Link and Phelan (2001) attribute to two primary factors. First, the concept of stigma has been applied to a wide range of circumstances. Second, the interdisciplinary nature of stigma research has led to different conceptualisations owing to varying frames of reference (Link/Phelan 2001, p. 363).

In this chapter, to delve deeper into the concept of stigma, several key works with distinct frameworks are reviewed, with Goffman's seminal contribution serving as the starting point.

### Stigma as an Attribute

Goffman's seminal work in 1963 involved extensive interviews, literature reviews, and other research methods. He defined stigma as 'an attribute that is deeply discrediting', viewing the stigmatised person as 'reduced in our minds from a whole and usual person to a tainted, discounted one' (Goffman 1963, p. 3). Goffman categorised stigma into three types: abominations of the body, blemishes of individual character, and tribal stigma (Goffman 1963, p. 4).

He described abominations of the body as physical deformities. Blemishes of individual character included traits such as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, which could be inferred from a history of mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicide attempts, and radical political behaviour. Tribal stigma related to race, nationality, and religion and could be passed down through generations, affecting all members of a family equally (Goffman 1963, p. 4).

Goffman also emphasised the importance of the 'visibility' of a particular stigma (Goffman 1963, p. 48). He argued that the extent to which a stigma is noticeable impacts its ability to communicate the individual's condition. For example, the stigma associated with ex-mental patients is less noticeable compared to that of blind individuals, making blindness a more visible stigma.

In summary, Goffman's work laid a foundation for understanding the complexities of stigma, its various forms, and the role of visibility in shaping social perceptions and interactions.

## Stigma as a Mark

In 1984, Jones et al. introduced their perspective on stigma, defining it as a 'mark' that discredits individuals when associated with deviations from societal norms (Jones et al. 1984, p. 9). They framed stigma within cognitive categorisation processes, suggesting that it arises when a mark connects an individual to undesirable traits, leading to discrediting.

Jones et al. identified six dimensions of stigma:

a) Concealability: this concerns the ease with which a stigmatising trait can be hidden or observed (e.g. facial disfigurement vs. homosexuality).
b) Course of the mark: this considers whether the mark becomes more evident or debilitating over time (e.g. multiple sclerosis vs. blindness).
c) Disruptiveness: this refers to how much a stigmatising trait (e.g. stuttering) disrupts social interactions.
d) Aesthetics: this relates to personal perceptions of the unattractiveness of the stigma.

e) Origin of the stigmatising mark: this examines whether the mark is inherited, accidental, or intentional, and includes individual responsibility.
f) Peril: this reflects the perceived risk posed by the stigmatising condition to others (e.g. having a highly contagious, deadly disease vs. being overweight).

Like Goffman, Jones et al. stressed that the visibility of a stigmatising condition amplifies its negative impact on interactions, underscoring the significance of visibility in understanding stigma.

### Interrelated Components of Stigma

In their article 'Conceptualizing Stigma', Link and Phelan (2001) explained stigma as a combination of labels, stereotypes, separation, status loss, and discrimination. They emphasised that power plays a role in stigma (Link/Phelan 2001, p. 63). Link and Phelan highlighted two main challenges in understanding stigma. First, many researchers study stigma without directly experiencing it themselves, which can lead to a disconnect between theory and reality. This is akin to criticisms in anthropology, where early anthropologists relied heavily on theories without conducting fieldwork. Second, stigma research has often focused too much on individual experiences.

To address these challenges, Link and Phelan proposed describing stigma through a set of interrelated components, which provides a more comprehensive conceptualisation (Link/Phelan 2001, pp. 367–375):

a) Labelling differences: identifying and labelling human differences.
b) Stereotyping: linking labelled individuals to negative characteristics, creating stereotypes.
c) Separation: categorising labelled individuals to separate 'us' from 'them'. For example, referring to individuals as 'epileptics' or 'schizophrenics' rather than as people with epilepsy or schizophrenia.
d) Status loss and discrimination: this leads to unequal outcomes, seen in both individual and structural discrimination. For instance, treatment facilities for mental illness or substance use disorders are often located in disadvantaged areas.
e) Dependence on power: stigmatisation relies on social, economic, and political power to enforce stereotypes and discrimination.

They also noted that stigmatised groups might label and stereotype non-stigmatised individuals, but these stereotypes do not have the same impact due to power imbalances. Addressing these power differences is essential to understanding and combating stigma.

Link and Phelan further discussed the consequences of stigma, including status loss, discrimination, and unintended effects of coping mechanisms. They offered principles for combating stigma, emphasising the need for comprehensive approaches that target its root causes. These approaches should aim to change attitudes and beliefs or address power imbalances (Link/Phelan, pp. 379–381).

## Evolutionary Views of Stigma

In the same year that Link and Phelan's work was published, Kurzban and Leary (2001) approached the concept from an evolutionary perspective. They argued that the reason why people are stigmatised is 'because they possess a characteristic viewed by society or a subgroup as constituting a basis for avoiding or excluding other people'. Specifically, they proposed that humans have cognitive adaptations geared towards avoiding poor social partners, affiliating with cooperative groups for competitive advantage, and steering clear of those more likely to carry diseases (Kurzban/Leary 2001, pp. 187–188).

The authors identified three evolutionary pressures possibly linked to stigma: dyadic cooperation adaptations, coalition exploitation adaptations, and parasite avoidance adaptations. Dyadic cooperation adaptations involve avoiding unfavourable social partners, influenced by selection pressures tied to potential gains from reciprocal altruism and the impact of others' actions in one's social circle. Coalition exploitation adaptations encompass the exclusion and exploitation of social out-groups. Parasite avoidance adaptations relate to avoiding prolonged contact with individuals more likely to carry diseases (Kurzban/Leary 2001, pp. 192–200).

The evolutionary perspective differs from others by suggesting that stigmatising conditions are not universally addressed. However, criticisms have been raised. Some scholars argue that evolutionary perspectives on stigma overlook the viewpoint of the stigmatised individual and overly focus on internal factors rather than the societal influences shaping social exclusion (Yang et al. 2007, p. 1525).

## Moral Dimensions of Stigma

Yang et al. (2007) broadened the scope of stigma to encompass moral experience, viewing it through an anthropological lens. They proposed that stigma's fundamental impact lies in jeopardising or devaluing what individuals hold most dear, or in actually eroding those cherished values. Their definition posits stigma as an 'essentially moral issue in which stigmatized conditions threaten what is at stake for sufferers' (Yang et al. 2007, p. 1524).

The authors extensively explored the Chinese notion of 'face' (*mianzi*), which signifies one's moral standing within the local community. In Chinese society, individuals both possess and bestow 'face' upon others. Losing face is described as deeply humiliating, often manifesting physically as an inability to confront others, a visible deterioration of facial expression, or a sensation of being stripped of identity (Kirmayer/Sartorius 2009; Kleinman et al. 1978; Kleinman/Becker 1998; Yang et al. 2007). This example illustrates how morality shapes stigma and its various dimensions. Yang et al. (2007) introduced the concept of 'moral experience', defining it as the everyday engagements that define individuals' core values. They also introduced the notions of 'moral-somatic', where values are intertwined with physical experiences, and 'moral-emotional', where values intersect with emotional states (Yang et al. 2007, pp. 1528–1532).

This anthropological perspective enriches stigma research by framing it as a socio-somatic process (Yang et al. 2007, pp. 1524–1530), exemplified notably in the Chinese experience of 'face' and its loss. In Chinese culture, mental illness carries stigma, leading individuals to manifest psychiatric issues through somatic symptoms (Kleinman et al. 1978). Somatisation, experiencing distress through physical symptoms, varies in cause and presentation among individuals (Kirmayer/Sartorius 2009). Anxiety and depression can be presented as physical ailments such as hypertension or chronic respiratory diseases in China (Zhou et al. 2017). Sociosomatics, akin to somatisation, explores how social processes shape bodily experiences. When individuals cannot articulate social issues, they may develop emotional and somatic symptoms to cope, often resulting in physical diagnoses to avoid mental illness stigma (Groleau/Kirmayer 2010; Kleinman/Becker 1998).

The authors also utilised Goffman's framework to argue that stigma arises from social interaction, rather than being solely an individual trait (Yang et al. 2007, p. 1527). Goffman's concept of a 'moral career' (Goffman 1963, p. 32) describes how stigmatised individuals internalise societal views and navigate changing social identities. Individuals with mental illness shift from a ‘normal’ to a ‘discreditable’ status, and upon disclosure, to a ‘discredited’ status, as they manage information about their identity. Thus, stigma emerges as individuals adopt new social identities through interaction with constructed categories.

### Section Conclusion

The exploration of stigma reveals its multifaceted nature and profound impact on individuals and societies. From Goffman’s seminal framework to Jones et al.’s dimensions and Link and Phelan’s interrelated components, each perspective offers valuable insights into the complexities of stigma and its impact on individuals and society. Additionally, evolutionary and cultural perspectives further enrich our understanding by shedding light on the adaptive explanation and moral dimensions of stigma.

By synthesising these perspectives, we gain a comprehensive understanding of stigma as a social construct deeply intertwined with perceptions, stereotypes, power dynamics, and moral values. This holistic approach underscores the importance of addressing stigma through comprehensive strategies that target its root causes and promote social inclusion and acceptance.

## *2. Stigma Versus Prejudice*

While stigma and prejudice are often used interchangeably, they represent distinct yet interconnected concepts. Both terms involve negative attitudes and beliefs towards individuals or groups, but they operate in different contexts and have unique implications. Understanding the nuances between stigma and prejudice is essential for unravelling the complexities of social interactions and identity formation. By delineating these concepts, we aim to foster a deeper appreciation of their intricacies.

The term ‘prejudice’, originating from the Latin noun *praejudicium*, has undergone semantic evolution over time. Its transformation unfolds in three stages. Initially, to the ancients, *praejudicium* denoted a judgment based on prior decisions and experiences. Subsequently, in English, it evolved to signify a judgment formed hastily or prematurely, without due examination of the facts. Finally, the term acquired its contemporary emotional connotation of favourability or unfavourability that accompanies such premature judgments (Allport 1954, p. 6). In its simplest form, prejudice can be defined as thinking ill of others without sufficient warrant. Allport (1954) specifically defined ethnic prejudice as 'an antipathy based upon a faulty and inflexible generalization. It may be felt or expressed. It may be directed toward a group as a whole, or toward an individual because they are a member of that group' (p. 9).

Building on this understanding of prejudice, Phelan et al. (2008) compared stigma and prejudice, drawing two conclusions regarding their differences: the one-animal conclusion and the two-animal conclusion. The one-animal conclusion suggests that models of stigma and prejudice are either parallel (describing the same phenomena in different terms) or complementary (describing different parts of one overarching process). The two-animal conclusion proposes that these concepts may be contradictory (describing conflicting phenomena) or disconnected (describing distinct and unrelated processes) (Phelan et al. 2008, p. 359).

Phelan et al. (2008) argued that prejudice is primarily related to one's attitudes and thus has attitudinal components, while stigma is a broader process. Stigma models place more emphasis on targets, particularly in terms of stereotypes, identity, and emotions, whereas prejudice models focus more on the perpetrators, including individual discriminatory behaviour outside interactions (Phelan et al. 2008, p. 360). These differences reflect the contrasting foci in the two seminal works on prejudice and stigma: Allport (1954) clearly focused on the perpetrator, while Goffman (1963) focused more on the target.

Furthermore, Phelan et al. (2008) identified a distinction between 'group' characteristics (those shared by family members) and 'individual' characteristics (occurring more sporadically within families), which is significant in understanding models of prejudice and stigma. This distinction, uncovered by their examination of models of prejudice and stigma, led them to review 162 articles with the word 'stigma' in the title and 139 articles with the word 'prejudice' in the title, revealing that in most cases (62%), prejudice was connected with race or ethnicity, while stigma dealt with illness, disability, or behavioural or identity deviance (these articles are based on a search of PsycInfo from 1955–2005, see Table 1).

*Table 1: Types of human characteristics associated with 'prejudice' and 'stigma' in journal articles, based on a search of PsycInfo from 1955 to 2005 (Phelan et al. 2008, p. 362).*

| | Prejudice (N = 139)(%) | Stigma (N = 162)(%) |
|---|---|---|
| Race or ethnicity | 62 | 4 |
| Gender | 7 | 2 |
| Behavioral/identity deviance | | |
| Sexual orientation | 3 | 4 |
| Other deviance | 4 | 8 |
| Illness/disability | | |
| Mental illness | 0 | 38 |
| Substance use | 0 | 4 |
| HIV/AIDS | 1 | 16 |
| Other illness/disability | 6 | 22 |
| Other characteristic | 6 | 0 |
| Unspecified characteristic | 11 | 2 |

They then proposed three functions of stigma and prejudice: exploitation/domination, enforcement of social norms, and avoidance of disease. These functions respectively maintain power dynamics, societal norms, and health preservation (Phelan et al. 2008, p. 362).

Through their work, the authors concluded that although models of prejudice and stigma essentially describe the same phenomena using different terminology, the discernible differences in their functions prompted them to identify three subtypes of the functions of stigma and prejudice. They propose that prejudice can be seen as attitudinal components, focusing specifically on the attitudes of perpetrators, while stigma encompasses a broader process rooted in common individual experiences (Phelan et al. 2008, pp. 360–361).

## *3. Examining the Different Types of Stigma*

As previously mentioned, scholars have various interpretations of the concept of stigma. Goffman viewed stigma as an attribute, identifying three types of it. Jones and colleagues considered stigma a mark, listing six components. Link and Phelan conceptualised stigma through five interconnected components. Kurzban and Leary explored it from an evolutionary perspective, while Yang and colleagues added moral and cultural dimensions (Goffman 1963; Jones et al. 1984; Kurzban/Leary 2001; Link/Phelan 2001; Link/Phelan 2006; Yang et al. 2007). These diverse approaches lead to multiple ways of categorising stigma.

Despite these differing approaches, scholars generally agree that stigma is a social construct. This section explores stigma across three societal levels: structural (involving laws, regulations, and policies), public (encompassing attitudes and behaviours of individuals and groups), and self-stigma (internalised negative stereotypes) (National Academies of Sciences, Engineering, and Medicine 2016, p. 4).

Structural stigma, as defined by Hatzenbuehler and Link (2014), involves ‘societal-level conditions, cultural norms, and institutional practices that constrain the opportunities, resources, and well-being for stigmatized populations’ (p. 2). This type of stigma exists in both public and private institutions, including businesses, courts, government entities, professional groups, school systems, social service agencies, and universities. Structural stigma can perpetuate discrimination, influencing public and self-stigma. Examples include restrictions on civil rights, such as serving on a jury or holding political office, and discriminatory hiring or admissions policies based on stereotypes (National Academies of Sciences, Engineering, and Medicine 2016, p. 5).

Public stigma manifests through the behaviours of individuals and groups in society, including educators, employers, healthcare providers, journalists, police, judges, policymakers, and legislators. The media, with its broad reach, significantly impacts stigma at all levels. Despite efforts to educate media professionals about various social issues, stereotypes often persist in reports and public discourse. Social media can either perpetuate stigma or promote inclusive attitudes. Public stigma encompasses negative attitudes, beliefs, and behaviours within a community or cultural context, collectively referred to as negative social norms. Intersecting stigmas, such as those related to race or poverty, can exacerbate discrimination and injustice. Public stigma predisposes communities or social groups to fear, reject, avoid, and discriminate against stigmatised individuals (Parcesepe and Cabassa 2013; Corrigan et al. 2009, p. 140; National Academies of Sciences, Engineering, and Medicine 2016).

Transitioning from structural and public stigma, we now explore self-stigma and its internal effects on individuals.

Self-stigma occurs when individuals internalise the negative attitudes and beliefs held by society. This internalisation lowers their self-confidence and may deter them from disclosing their conditions due to fear of being labelled and discriminated against. As a result, they might avoid seeking help or treatment, hindering early diagnosis and intervention. This avoidance exacerbates the social burden of untreated conditions, leading to issues like chronic disease, victimisation, crime, incarceration, lost productivity, and premature death (National Academies of Sciences, Engineering, and Medicine 2016, pp. 4–5).

Self-stigma, which does not stem from a lack of insight or a deliberate embrace of negative social norms, is defined by the impact on individuals who internalise societal stigma. It often emerges from previous experiences of discrimination or rejection. This internalisation can cause individuals to deny their symptoms and reject treatment, further isolating them from essential social supports. Like low self-efficacy, self-stigma poses a significant barrier to recovery for those affected (Corrigan et al. 2014; Corrigan et al. 2009, p. 140; National Academies of Sciences, Engineering, and Medicine 2016, pp. 21–22).

In summary, stigma operates on different levels: structural (laws and policies), public (societal attitudes), and self-stigma (internalised beliefs). These contribute to discrimination and hinder individuals from seeking help. Addressing stigma comprehensively is crucial for fostering a more inclusive and supportive society.

## *4. Conclusion*

In conclusion, the exploration of stigma in this chapter has unveiled its multifaceted nature and significant impact on individuals and society. From Goffman's foundational framework to Jones et al.'s dimensions and Link and Phelan's interrelated components, we gain a comprehensive understanding of stigma's complexity. Evolutionary and cultural perspectives further enrich this understanding, highlighting how adaptive explanations and moral dimensions shape stigmatisation processes.

Understanding stigma as a social construct deeply embedded in perceptions, stereotypes, power dynamics, and moral values is crucial. This holistic approach emphasises the need for comprehensive strategies to address stigma, aiming to dismantle its root causes and foster a more inclusive and supportive society. By recognising and addressing the structural, public, and self-stigma, we can mitigate the adverse effects of stigma on individuals with substance use disorders, thereby promoting recovery and social integration.

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# Chapter Two: The Reality of Substance Use Disorder

*Hang Su, Yifan Xu, Peishan Wu*

## *1. Overview of Substance Use Disorder*

Substance use disorder is a significant global public health issue. According to the World Health Organization (WHO), approximately 1.8% of the global disease burden was attributable to substance use disorders in 2012, with 1.2% linked to alcohol use disorders and 0.6% to drug use disorders. In 2013, around 27 million people worldwide suffered from drug use disorders, nearly 50% of whom injected drugs, and an estimated 1.65 million were living with HIV. Since 2006, the number of people using illicit drugs has risen by 38 million, reaching 246 million in 2013. The burden of substance use disorders varies significantly by region (Figure 1). For instance, the disability-adjusted life year (DALY)—a measure combining the years of life lost due to premature mortality and the years lived with disability—rate for low-, middle-, and non-OECD (Organisation for Economic Co-operation and Development) high-income countries in the European Region is five times higher than that of the Eastern Mediterranean Region, where alcohol consumption is banned in many countries (WHO 2015, pp. 155–156).

Before delving into the classifications of SUD, it is important to clarify the notion of a substance. A substance is any natural or synthesised product that has psychoactive effects, altering perceptions, thoughts, emotions, and behaviours (Nolen-Hoeksema 2014, p. 396). Importantly, using a substance does not inherently indicate that an individual has SUD.

To gain a comprehensive understanding of SUD, one must explore its classification systems as outlined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) and the International Classification of Diseases, Eleventh Revision (ICD-11). The DSM-5, issued by the American Psychiatric Association (APA), serves as the primary classification tool for mental disorders in clinical practice, research, policymaking, and reimbursement within the United States. Conversely, the ICD-11, published by the WHO, serves as a global standard for classifying diseases, including mental disorders.

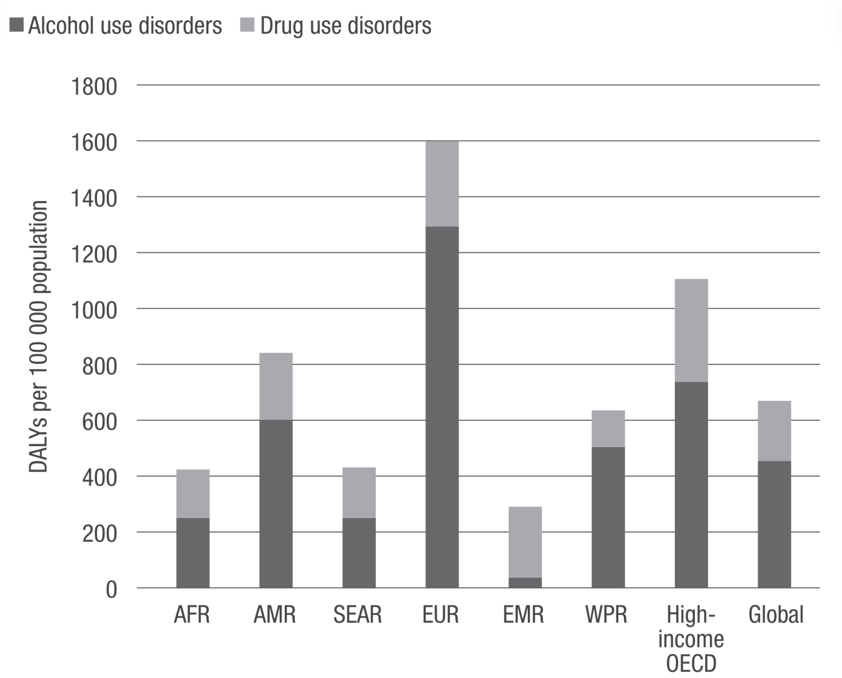


*Figure 1: DALYs for substance use disorders by region and globally, 2012 (WHO 2015, p. 156).*

This chapter will cover the classification of SUD according to DSM-5 and ICD-11 criteria, various theories regarding SUD, and the available treatments for this mental disorder.

## 2. DSM-5

Throughout the history of DSM criteria, four conditions have been pivotal in defining individuals' substance use: intoxication, withdrawal, abuse, and dependence. In DSM-5, substance abuse and dependence were consolidated into a single diagnosis—substance use disorder—due to challenges in distinguishing between abuse and dependence in clinical and research settings and the low reliability of the substance abuse diagnosis. This new diagnosis combines the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV; with the release of the DSM-5, the APA switched Roman numerals to Arabic numerals to allow for easier updates and revisions.) categories of substance abuse and substance dependence into a single disorder measured on a continuum from mild to severe. Each specific substance (except caffeine, which cannot be diagnosed as a substance use disorder) is addressed as a separate use disorder (e.g. alcohol use disorder, stimulant use disorder), but nearly all substances are diagnosed based on the same overarching criteria. In this unified disorder, the criteria have been both combined and strengthened. In DSM-IV, a diagnosis of substance abuse required only one symptom, whereas a mild substance use disorder in DSM-5 requires two to three symptoms from a list of eleven. Drug craving has been added to the list, while problems with law enforcement have been removed due to cultural considerations that make this criterion difficult to apply internationally.

In DSM-IV, abuse and dependence were differentiated, with abuse seen as an early or mild phase and dependence as a more severe manifestation. However, the severity of abuse criteria could overlap substantially with those of dependence. The revised DSM-5 diagnosis of substance use disorder aligns more closely with patients' symptomatic experiences, streamlining clinical understanding.

Moreover, the diagnosis of dependence often caused confusion, as it was commonly associated with 'addiction', despite dependence being a potential normal physiological response to a substance (APA 2013; Hasin et al. 2013; Nolen-Hoeksema 2014). ***Substance Intoxication***

Substance intoxication involves behavioural and psychological changes due to the physiological effects of a substance on the central nervous system. Individuals become intoxicated soon after ingesting a substance, with the level of intoxication increasing with the amount consumed. Intoxication decreases as the substance levels in the blood or tissue decline, but symptoms may persist for hours or days after the substance is no longer detectable in the body. Specific symptoms of intoxication depend on the substance taken, its dosage, the user's tolerance, and the context of use. A diagnosis of substance intoxication is given only when the behavioural and psychological changes significantly disrupt social and family relationships, cause occupational or financial problems, or place the individual at significant risk for adverse effects such as traffic accidents, severe medical complications, or legal issues. Substance intoxication is common among individuals with a substance use disorder but can also occur in those without one (Nolen-Hoeksema 2014, p. 398).

### Substance Withdrawal

Substance withdrawal involves physiological and behavioural symptoms arising when heavy, prolonged substance use is abruptly reduced or discontinued. These symptoms typically oppose those of intoxication and must cause significant distress or functional impairment for diagnosis (Nolen-Hoeksema 2014, pp. 398–399).

### Substance Abuse

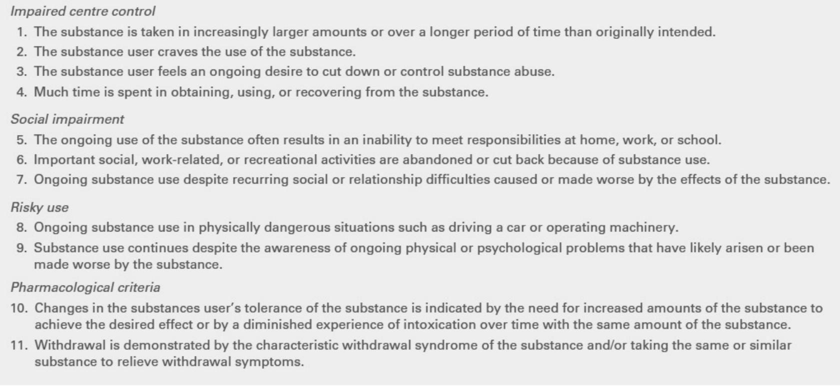
Substance abuse was diagnosed when recurrent use of a substance led to significant harmful consequences in four categories: failing to fulfil important obligations at work, school, or home; using the substance in physically hazardous situations, such as while driving; encountering legal problems due to substance use, such as arrests for drunk driving or possession of illegal substances; and continuing to use the substance despite recurrent social or legal problems. DSM-IV required that the person show repeated problems in at least one of these categories within a twelve-month period to be diagnosed with substance abuse (Nolen-Hoeksema 2014, p. 399).

### Substance Dependence

The diagnosis of substance dependence in DSM-IV was closest to what people often refer to as drug addiction. Those dependent on a substance frequently show tolerance—they experience diminished effects from the same dose and need increasingly larger amounts to achieve intoxication. For instance, long-term smokers may need more than 20 cigarettes a day, an amount that would have made them ill when they first started smoking. A person highly tolerant of a substance might have very high blood levels without feeling its effects. The risk for tolerance varies greatly among substances (Nolen-Hoeksema 2014, p. 399).

### DSM-5 Criteria for SUD

DSM-5 criteria for substance use disorder encompass impaired control, social impairment, risky use, and pharmacological criteria, requiring the presence of two or more symptoms within a year for diagnosis (see Figure 2). Severity is classified as mild (two to three criteria), moderate (four to five), or severe (six or more) (APA 2013; Nolen-Hoeksema 2014).



*Impaired centre control*

1. The substance is taken in increasingly larger amounts or over a longer period of time than originally intended.
2. The substance user craves the use of the substance.
3. The substance user feels an ongoing desire to cut down or control substance abuse.
4. Much time is spent in obtaining, using, or recovering from the substance.

*Social impairment*

5. The ongoing use of the substance often results in an inability to meet responsibilities at home, work, or school.
6. Important social, work-related, or recreational activities are abandoned or cut back because of substance use.
7. Ongoing substance use despite recurring social or relationship difficulties caused or made worse by the effects of the substance.

*Risky use*

8. Ongoing substance use in physically dangerous situations such as driving a car or operating machinery.
9. Substance use continues despite the awareness of ongoing physical or psychological problems that have likely arisen or been made worse by the substance.

*Pharmacological criteria*

10. Changes in the substances user's tolerance of the substance is indicated by the need for increased amounts of the substance to achieve the desired effect or by a diminished experience of intoxication over time with the same amount of the substance.
11. Withdrawal is demonstrated by the characteristic withdrawal syndrome of the substance and/or taking the same or similar substance to relieve withdrawal symptoms.

*Figure 2: Criteria for substance use disorder in DSM-5 (Nolen-Hoeksema 2014, p. 400).*

DSM-5 identifies ten substance classes linked to substance use disorder: alcohol, stimulants (including cocaine), caffeine, cannabis, hallucinogens and phencyclidine (PCP), inhalants, opioids, sedatives/hypnotics/anxiolytics, tobacco, and other/unknown substances (APA 2013; Nolen-Hoeksema 2014).

## Section Conclusion

In summary, the evolution of DSM criteria for substance use disorder reflects an effort to improve diagnostic accuracy and reliability. The transition from DSM-IV to DSM-5 marks a significant shift in how substance use disorders are defined and categorised, emphasising a continuum of severity and consolidating previous distinctions between abuse and dependence. By focusing on a unified set of criteria, DSM-5 aims to provide a clearer, more comprehensive understanding of substance use disorders, facilitating better diagnosis and treatment across diverse clinical settings.

## *3. ICD-11 Criteria for SUD*

In ICD-11, the term ‘disorders due to substance use’ is used similarly to the term ‘substance use disorder’ in DSM-5. These disorders encompass conditions resulting from the single or repeated use of substances with psychoactive properties, including certain medications. Typically, initial use of these substances produces pleasant or appealing psychoactive effects that are rewarding and reinforcing with repeated use. With continued use, many of these substances have the potential to produce dependence and cause various forms of harm to both mental and physical health. Additionally, the harmful non-medical use of non-psychoactive substances is also included in this category.

Disorders due to substance use are classified by first identifying the specific substance used. In ICD-11, there are 18 substance classes: alcohol, cannabis, synthetic cannabinoids, opioids, sedatives/hypnotics/anxiolytics, cocaine, stimulants (including amphetamines, methamphetamine, or methcathinone), synthetic cathinones, caffeine, hallucinogens, nicotine, volatile inhalants, 3,4-methylenedioxymethamphetamine (MDMA) or related drugs (including 3,4-methylenedioxyamphetamine, MDA), ketamine and phencyclidine (PCP), other specified psychoactive substances (including medications), multiple specified psychoactive substances (including medications), unknown or unspecified psychoactive substances, and non-psychoactive substances.

In summary, ICD-11’s approach to disorders due to substance use aligns closely with DSM-5’s category of substance use disorders. It emphasises the potential for dependence and the associated mental and physical health risks of both psychoactive and non-psychoactive substances (WHO 2021).

## *4. Theories of SUD*

Understanding SUD involves exploring a complex interplay of factors. This section delves into the biological, psychological, and sociocultural factors and gender differences that contribute to the development and progression of SUD.

### Biological Factors

The brain's 'pleasure pathway' plays a significant role in shaping our experience of reward and reinforcement. This pathway originates in the ventral tegmental area of the midbrain, extends through the nucleus accumbens in the limbic system, and reaches into the frontal cortex. It is densely populated with neurons sensitive to dopamine, a neurotransmitter crucial for reward processing. Various regions of the frontal cortex, including the orbitofrontal cortex, dorsolateral frontal cortex, and inferior frontal gyrus, are essential for regulating impulses and managing the urge to use alcohol or drugs. When the reward system overrides the control network, it can heighten the inclination towards substance use, potentially contributing to the development of substance use disorders by disrupting impulse control and decision-making.

As substance use continues, the brain undergoes changes that further entrench the cycle of addiction. Although prolonged substance use leads to decreased sensitivity to the substance's rewarding effects, individuals become more sensitive to cues associated with their substance use, like specific locations or paraphernalia. These conditioned responses to drug-related cues can trigger intense cravings, potentially leading to relapse. Additionally, stress activates reward systems, further enhancing cravings. Chronic drug use also disrupts activity in the brain's frontal regions involved in impulse control, making it even more challenging for individuals to resist these cravings.

Genetic factors also significantly influence the neurotransmitter systems involved in the rewarding effects of substances. Family, adoption, and twin studies collectively suggest that genetics contribute to about 50% of the variability in the risk of substance use disorders. There appears to be a shared genetic vulnerability to substance use disorders in general, rather than to specific substances, explaining why individuals prone to one substance are often susceptible to others. Research on genes controlling the dopamine system, particularly variations in the dopamine receptor gene (DRD2) and dopamine transporter gene (SLC6A3), underscores their impact on how the brain processes dopamine and perceives substances like nicotine. Additionally, genes governing gamma-aminobutyric acid (GABA) have implications for substance use disorders, notably in alcohol use (Nolen-Hoeksema 2014, pp. 417–418).

## Psychological Factors

Social learning theories propose that children and adolescents may adopt substance use behaviours by observing their parents and significant others within their culture. Even at the preschool age, children of heavy drinkers are more likely than their peers to recognise alcoholic beverages and perceive alcohol consumption as a routine part of daily life. When parents frequently get drunk or drive while intoxicated, they inadvertently teach their children that these behaviours are acceptable, increasing the likelihood that the children will engage in similar behaviours.

Cognitive theories of alcohol use disorders emphasise the role of individuals' expectations of alcohol's effects and their beliefs about the appropriateness of using it to cope with stress. People who believe that alcohol will alleviate their distress and who lack more adaptive coping mechanisms (such as problem-solving skills or supportive relationships) are more inclined to drink alcohol when upset, leading to social problems associated with drinking. Longitudinal studies of the sons of parents with alcohol use disorders have shown that men who use alcohol to cope and relax are more likely to develop alcohol use disorders themselves.

A constant personality trait consistently linked to a higher risk of substance use disorders is behavioural undercontrol, which is characterised by impulsivity, sensation-seeking, and a propensity for antisocial behaviours, such as breaking laws. Individuals with high levels of behavioural undercontrol tend to experiment with psychoactive drugs at an earlier age, consume larger quantities, and are more likely to be diagnosed with substance use disorders. This trait is strongly familial, and twin studies suggest that genetic factors partly contribute to it. Consequently, genetics may influence behavioural undercontrol, which in turn affects the likelihood of developing substance use disorders (Nolen-Hoeksema 2014, pp. 418–419).

## Sociocultural Factors

The reinforcing effects of substances, such as the highs produced by stimulants and the calming effects of depressants and opioids, can be particularly appealing to individuals experiencing chronic stress. Consequently, rates of substance use disorders are higher among people living in poverty, women in abusive relationships, and adolescents whose parents frequently engage in violent conflicts. For these individuals, the effects of substances may seem especially rewarding, and they may feel they have little to lose by using them.

Environmental factors, including societal attitudes toward substance use, also shape consumption patterns. Societies that strongly discourage alcohol use, often due to religious beliefs, tend to have lower rates of alcohol abuse and dependence. Conversely, cultures like many in Europe permit moderate alcohol consumption but discourage excessive drinking and irresponsible behaviour while intoxicated, resulting in lower prevalence of alcohol-related disorders (Nolen-Hoeksema 2014, p. 419).

### Gender Differences

In many cultures, substance use, particularly alcohol use, tends to be more socially acceptable for men. Heavy drinking is often associated with traditional notions of masculinity and is frequently modelled by cultural icons and heroes. In contrast, heavy drinking by women was historically viewed as inappropriate. However, societal acceptance of heavy drinking among women has increased in recent generations, leading to a rise in alcohol use among young women.

Despite this shift, women generally exhibit fewer risk factors for substance use disorders compared to men. They are less likely to display personality traits such as behavioural undercontrol and sensation-seeking, which are linked to substance use disorders. Additionally, women are less likely to use alcohol to alleviate distress and less likely to expect positive outcomes from drug consumption.

When individuals develop substance use disorders, patterns and reasons for use can differ based on gender. Men typically begin using substances in social settings with friends, whereas women are more often introduced to substance use by family members, partners, or significant others. Because women's substance use is more closely tied to their intimate relationships, treatments that involve their partners tend to be more effective in reducing substance use disorders among women (Nolen-Hoeksema 2014, pp. 419–420).

## *5. Available Treatments for SUD*

Treating substance-related disorders is challenging, and media stories about celebrities repeatedly entering and exiting rehab underscore the difficulties in achieving lasting success. In this section, we review the most common and well-supported biological and psychosocial treatments.

### Biological Treatments

Medications can help individuals withdraw from substances, reduce cravings, and maintain controlled use. These treatments include antianxiety drugs, antidepressants, and drug antagonists.

#### Antianxiety Drugs, Antidepressants, and Drug Antagonists

For some individuals, emotional support is enough to manage withdrawal symptoms. However, others may require medication. Benzodiazepines, which have similar depressant effects to alcohol, can help those dependent on alcohol by reducing tremors, anxiety, pulse, and respiration rate, as well as stabilising blood pressure. The dosage is decreased daily to avoid dependence on benzodiazepines.

Antidepressants are sometimes prescribed for individuals with both substance dependence and depression; however, their effectiveness without accompanying psychotherapy is inconsistent. Responses to selective serotonin reuptake inhibitors (SSRIs)—a class of antidepressants that increase serotonin levels in the brain—can vary significantly from person to person. Antagonist drugs, which block or alter the effects of addictive substances, help reduce cravings. Naltrexone and naloxone, both opioid antagonists, block the effects of opioids like heroin, theoretically reducing the desire and likelihood of use. These drugs, however, must be administered cautiously due to the potential for severe withdrawal symptoms. Naltrexone also helps treat alcohol dependence by blocking endorphins released during drinking, which reduces cravings and alcohol consumption. Acamprosate, another medication, works on glutamate and GABA receptors implicated in alcohol cravings, and has been shown to help maintain abstinence better than a placebo. Disulfiram (Antabuse) discourages alcohol consumption by causing unpleasant effects such as nausea and dizziness, but it requires strong motivation for continuous use (Nolen-Hoeksema 2014, p. 420).

### Methadone Maintenance Programmes

Gradual withdrawal from heroin can be managed with methadone, an opioid that produces less potent and shorter-lasting effects than heroin when taken orally. Methadone helps alleviate severe withdrawal symptoms for individuals dependent on heroin. Additionally, if heroin is used while on methadone, its intense psychological effects are blocked because methadone occupies the same receptors. Although the ultimate goal is to wean patients off methadone, some individuals remain on it for years under medical supervision.

Methadone maintenance programmes are controversial. Critics argue that these programmes merely substitute one dependency for another, albeit a legal one provided by a physician. However, proponents contend that methadone maintenance is essential for preventing heroin-dependent individuals from relapsing and returning to street drug use (Nolen-Hoeksema 2014, pp. 420–421).

### Psychosocial Treatments

Several behavioural and cognitive techniques have proven effective in treating substance use disorders. These techniques share common goals. The first goal is to motivate the individual to stop using the addictive substance. People who enter treatment are often ambivalent about quitting and may have been coerced into treatment. The second goal is to teach patients new coping skills to replace substance use as a way to manage stress and negative emotions. The third goal is to change the reinforcements for substance use, such as encouraging individuals to disengage from social circles that promote drug use. The fourth goal is to enhance support from non-using friends and family members. Finally, fostering adherence to pharmacotherapies in conjunction with psychotherapy is crucial (Nolen-Hoeksema 2014, p. 421).

### Behavioural Treatments

Behavioural treatments often use aversive classical conditioning, either alone or with other therapies. For instance, disulfiram (Antabuse) makes alcohol consumption unpleasant or toxic, leading to conditioned responses of nausea and vomiting. Through operant conditioning, individuals learn to avoid alcohol to prevent these aversive reactions. Although aversive conditioning can reduce alcohol consumption in the short term, 'booster' sessions may be needed to maintain its effectiveness over time.

Covert sensitisation therapy uses imagery to create negative associations with alcohol use, effectively reducing alcohol consumption. Contingency management programmes provide reinforcements, such as employment, housing, or vouchers, for abstaining from substances. Studies show that individuals dependent on heroin, cocaine, marijuana, or alcohol are more likely to remain in treatment and achieve abstinence when given incentives contingent on drug-free urine specimens (Nolen-Hoeksema 2014, pp. 421–422).

### Cognitive Treatments

Cognitive interventions help clients identify situations where they are most likely to drink and lose control, as well as explore their expectation that alcohol will help them cope in difficult situations. Therapists challenge these expectations by reviewing the negative effects alcohol has on behaviour. For example, if a client drank heavily at a party due to anxiety, the therapist might have the client recount any embarrassing behaviour while intoxicated, challenging the notion that alcohol was helpful. Therapists also teach clients to handle stress in adaptive ways, such as seeking help from others or engaging in active problem-solving. Additionally, clients learn to decline alcohol and handle social pressure using assertiveness skills.

In most cases, cognitive-behavioural therapists encourage abstinence, especially for clients with a history of frequent relapses. If a client aims to drink socially and the therapist believes this is achievable, therapy may focus on teaching controlled drinking. Studies have shown that cognitive-behavioural approaches are effective for treating abuse of and dependence on alcohol, cannabis, nicotine, heroin, amphetamines, and cocaine (Nolen-Hoeksema 2014, pp. 422–423).

## *6. Conclusion*

Substance use disorder is a complex and multifaceted issue that affects millions of people worldwide. The evolution of diagnostic criteria from

DSM-IV to DSM-5, as well as the comprehensive classification in ICD-11, underscores the importance of accurate diagnosis and treatment. Understanding the biological, psychological, sociocultural, and gender-related factors that contribute to SUD is crucial for developing effective interventions. By addressing these factors and utilising both biological and psychosocial treatments, we can better support individuals in overcoming SUD and improving their quality of life.

This chapter has highlighted the significant changes in the diagnostic criteria for SUD, the underlying theories explaining the disorder, and the various treatment options available. Moving forward, continued research and a compassionate approach are essential in confronting the stigma and challenges associated with SUD, ultimately breaking the silence and fostering a more supportive environment for those affected.

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# Chapter Three: Consequences of Stigma

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Stigma, an insidious societal force, profoundly impacts both individuals and communities. Stigma associated with mental health conditions and substance use disorders continues to be a pervasive issue that significantly affects individuals at multiple levels (structural, public/social, self). This chapter delves into the multifaceted consequences of stigma, shedding light on how it permeates structural, public, and personal spheres. Understanding the extent of these impacts is crucial for developing effective interventions and fostering a more inclusive and supportive society for those grappling with these challenges.

## *1. Understanding the Different Types of Stigma*

Stigma, as defined in Chapter 1, can be classified into three main types: structural stigma, public stigma (also referred to as social stigma by some scholars, such as Livingston 2020), and self-stigma.

### Structural Stigma

Structural stigma is embedded within the rules, policies, and procedures of social institutions, which arbitrarily restrict the rights and opportunities of individuals living with mental health and substance use issues. It represents the societal and institutional manifestation of attitudes, beliefs, and behaviours that perpetuate prejudice and discrimination. Unlike individual prejudice or discrimination, structural stigma involves higher-order discrimination linked to human rights. It is reinforced through laws, internal policies, the procedures of private and public institutions, and the practices of professionals and decision-makers. Although overt instances of structural stigma may have diminished, they have left a legacy of disparity and covert structural barriers that continue to create inequality and injustice for those affected by mental health and substance use issues (Livingston

2020; National Academies of Sciences, Engineering, and Medicine 2016; Thornicroft et al. 2022).

### Public/Social Stigma

Public or social stigma occurs when community members endorse negative stereotypes and act in discriminatory ways towards people with mental health and substance use issues. This form of stigma creates fertile ground for both self-stigma and structural stigma. Widespread endorsement of stereotypes, such as the belief that those with mental health issues are dangerous, leads to regressive reforms and punitive policies, including reduced funding for mental health services or the expansion of coercive interventions. Such policies can reinforce social stigma, inhibiting progressive reforms and inclusive healthcare policies such as the expansion of harm reduction strategies. Public stigma encompasses attitudes held by the general public and specific subgroups, such as first responders or clergy, whose norms may differ from those of the broader society.

Public stigma persists partly because structural stigma, in the form of laws, regulations, and policies, appears to endorse prejudice and discrimination. It is characterised by the link between stereotypes, negative attitudes, and discriminatory behaviours against people with mental health conditions. This stigma can manifest as avoidance, maintaining social distance, paternalistic approaches (benevolent stigma), or supporting coercive policies. Public stigma can be understood through three components: knowledge (or ignorance), attitudes (prejudice), and behaviours (discrimination). Ignorance often results from a lack of detailed knowledge or misinformation spread by popular discourse, while prejudice involves negative emotional reactions. Discriminatory behaviours lead to social exclusion and rejection, causing harm by being both anticipated and experienced (Livingston 2020; National Academies of Sciences, Engineering, and Medicine 2016; Thornicroft et al. 2022).

### Self-Stigma

Self-stigma involves the perceptions and experiences of individuals living with mental health and substance use issues, acting as a significant barrier to seeking help and adhering to treatment. People with lived experience of mental health conditions or substance use disorder frequently cite fear of stigma and anticipation of negative reactions—such as being perceived as crazy or weak, feeling embarrassed or ashamed, and fearing others' opinions—as major reasons for not seeking treatment. As these individuals become aware of public stigma and related discriminatory practices, they internalise the perceived stigma and apply it to themselves.

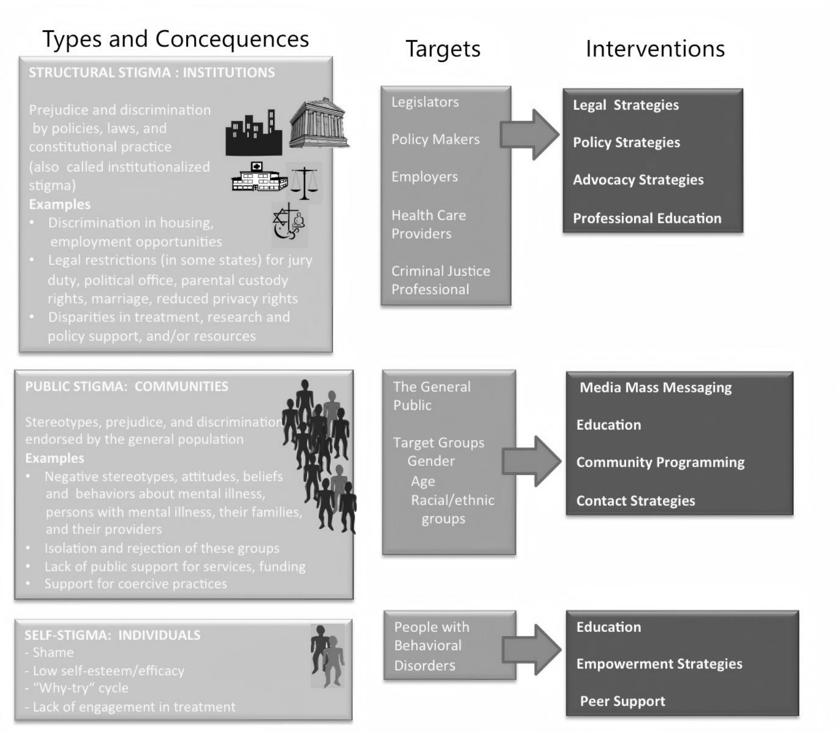

*Figure 1: Types, consequences, targets, and interventions of stigma (National Academies of Sciences, Engineering, and Medicine 2016, p. 43).*

Self-stigma occurs when individuals with mental health conditions acknowledge negative stereotypes, agree with them, and turn them against themselves. This internalisation can lead to the abandonment of important life goals, such as seeking employment or forming friendships, due to feelings of unworthiness or the perceived inability to succeed. Negative beliefs diminish self-esteem and self-efficacy, causing individuals to question the value of trying. However, not all reactions to societal stigma are negative;

some individuals may respond with righteous anger, which can enhance self-esteem. Overcoming self-stigma involves developing stigma resilience, a process that empowers people with mental health conditions to counter internalised stigma and take positive actions in their lives (Livingston 2020; National Academies of Sciences, Engineering, and Medicine 2016; Thornicroft et al. 2022).

Figure 1 illustrates these three main types of stigma and their consequences, as well as potential targets for change and interventions aimed at altering stigmatising attitudes, beliefs, and behaviours.

## *2. Consequences and Impacts of Stigma*

As discussed in Chapter 2, substance use disorders, referred to as 'disorders due to substance use' in the ICD-11, are considered a form of mental illness. Thus, it is essential to explore the consequences and impacts of stigma related to both mental illness and SUD.

### Structural Impacts

Globally, individuals with mental health conditions often face restrictions in employment, voting, property ownership, marriage, and divorce. These conditions can cause long-term impairments, impacting daily life and social contexts and leading to disabilities. Structural stigma also manifests in the underfunding of mental health research and treatment compared to physical health. People with mental health conditions have less access to healthcare and often receive lower quality services than those with physical health conditions, contributing to a significant mortality gap—ten years overall and 20 years for severe conditions. This structural disadvantage is perpetuated across generations, exacerbated by the interrelationship between poverty and poor mental health (Thornicroft et al. 2022).

Structural stigma includes persistent prejudice and discrimination in public and private institutions, healthcare systems, and the criminal justice system.

## Structural Stigma in Public and Private Institutions

Despite misconceptions about the dangerousness and violence of people with mental illness, these individuals are at higher risk of victimisation and unfair treatment by authorities. Plaintiffs with mental illness often face poorer legal outcomes in employment discrimination suits compared to those without mental illness. Discrimination in housing and employment is more prevalent among people with mental illness, leading to higher rates of homelessness. Additionally, stigmatising attitudes from landlords often result in poor housing conditions. Structural stigma is evident in segregated housing and community resistance to mental health facilities, exemplified by the 'not in my backyard' (NIMBY) phenomenon (Link/Phelan 2001; National Academies of Sciences, Engineering, and Medicine 2016).

In employment, many individuals with mental health conditions choose not to disclose their condition due to fear of discrimination. This can result in difficulties finding or retaining employment, limiting economic opportunities. Individuals may face unequal work opportunities, be assigned less responsibility, be denied promotions, and experience workplace bullying. Lack of employment and income due to stigma contributes significantly to poverty among people with mental health conditions (Thornicroft et al. 2022).

In the arena of higher education, laws like the Americans with Disabilities Act (ADA) prohibit discrimination against students with psychiatric disabilities and require reasonable accommodations for these individuals. However, fewer than one in four students with a mental illness seek treatment or support services. These students often report less social engagement, lower graduation rates, inadequate services, and harsher academic discipline.

As for people with substance use disorders, they face structural stigma in many forms, including barriers to treatment such as lack of insurance, high treatment costs, and limited access to programmes. Fear of workplace discrimination and previous negative job experiences are additional challenges. Legislative measures like the ADA are often more restrictive for SUD than for mental illness (National Academics of Sciences, Engineering, and Medicine 2016).

## Structural Stigma in Healthcare and Treatment Systems

In the US healthcare system, stigma contributes to disparities in funding for mental versus physical disorders and fosters negative attitudes among healthcare professionals. Structural stigma results in low-quality care for mental and substance use disorders, limited access to treatment, fragmented bureaucracy, overuse of coercive care approaches, and inadequate funding compared to physical healthcare. These factors negatively impact clinical and personal recovery outcomes, increasing the frequency and duration of illness and hospitalisation. Nevertheless, there is evidence of these effects from North America, Europe, and East Asia, suggesting that structural stigma negatively affects clinical and personal recovery outcomes globally. Stigma is associated with increases in the number of episodes of being unwell, the duration of condition, and psychiatric hospitalisation (National Academies of Sciences, Engineering, and Medicine 2016; Thornicroft et al. 2022).

Parity laws for mental and substance use disorders aim to combat structural inequities in healthcare coverage. States with parity laws have higher service utilisation rates among low-income groups. However, increased access to care does not guarantee high-quality, evidence-based treatment.

Structural stigma is also evident in the lower prioritisation and funding of behavioural health services and research compared to physical health. This underinvestment limits the availability of evidence-based services, particularly in facilities serving vulnerable populations. Stigma leads to low insurance reimbursements, contributing to shortages of mental health providers. Even with available providers, insurance benefits for behavioural health services are often more restrictive than for physical health (National Academies of Sciences, Engineering, and Medicine 2016).

## Structural Stigma in Criminal Justice Systems

In the criminal justice system, structural stigma is evident in the disproportionate representation and treatment of people with mental illness. More than half of jail and prison inmates in 2005 had mental health problems, with many experiencing multiple arrests and limited access to treatment. People with mental illness in correctional facilities face higher rates of abuse, solitary confinement, longer sentences, and parole denials compared to inmates without mental illness. Community supervision often involves more intense scrutiny and higher rates of technical violations for individuals with mental illness.

Policies treating substance use disorders primarily as criminal issues contribute to a stigmatising environment. Harsh antidrug messages and criminal sentences for drug use marginalise people with SUD, promoting social exclusion and perpetuating stigma (National Academies of Sciences, Engineering, and Medicine 2016).

## Public/Social Impacts

Public stigma leads to social segregation and diminished self-efficacy among people with mental and substance use disorders. Stigmatising beliefs about their competency restrict opportunities and may lead to coercive treatment. Despite the importance of social support for recovery, stigma contributes to social exclusion for individuals with substance use disorders and their families.

Misconceptions about mental health conditions, such as beliefs about dangerousness or incompetence, exacerbate public stigma. These misconceptions hinder understanding and acceptance of mental health conditions as treatable. Public stigma often results in social rejection, abuse, and neglect, including verbal and physical humiliation, sexual abuse, and violence. Young people with mental health conditions face additional stigma, impacting their relationships, social inclusion, and willingness to seek support.

Fear of social rejection is a significant stigma experience among adolescents, affecting their social identity and capital. Stigma from family members and school staff further complicates their ability to seek help and engage in community activities. The intergenerational perspectives on mental health highlight differences in understanding and support between young people and their parents (National Academics of Sciences, Engineering, and Medicine 2016; Thornicroft et al. 2022).

## Personal Impacts

Self-stigma significantly affects individuals by lowering self-esteem and self-efficacy, leading to harmful psychological feelings of embarrassment and shame. This reduction in self-esteem and self-efficacy can result in what Corrigan refers to as the 'why try' effect, where individuals refrain from attempting important activities due to an expectation of failure. This loss of confidence negatively impacts hope, quality of life, recovery, stigma resistance, and social functioning, and may increase suicidality (Corrigan et al. 2009; National Academics of Sciences, Engineering, and Medicine 2016; Thornicroft et al. 2022).

Among individuals with mental health and substance use disorders, low self-efficacy is linked to failure in pursuing work or independent living. Conversely, higher self-esteem correlates with goal attainment (e.g. symptom reduction, financial and academic success), improved quality of life (e.g. satisfaction with work, housing, health, and finances), and increased help-seeking behaviour. Research indicates a negative relationship between stigma and help-seeking behaviours. Self-stigma also hinders recovery and community integration. Those who disclose their experiences report lower levels of self-stigma. Members of racial and ethnic minorities, youth, men, military service members, and health professionals are disproportionately deterred from seeking help due to fear of stigma. Additionally, public stigma influences both the reported experiences of stigma and self-stigma, as well as the reluctance to use services (National Academics of Sciences, Engineering, and Medicine 2016).

Self-stigma is closely related to public stigma. Individuals with mental health conditions who perceive greater public stigma view their condition as more threatening. They report higher levels of self-stigma and hopelessness, poorer recovery, and reduced quality of life. These effects are often mediated by self-stigma and lack of social support. For those who anticipate or experience high levels of discrimination, psychological distress and shame increase, while empowerment and quality of life decrease. In more collectivistic cultures, the connection between self-stigma and experienced discrimination is stronger. Self-stigma is a prominent barrier to service to accessing mental health services from both parents' and professionals' perspectives, manifesting as shame about needing help, perceived parental failure, and fear of being labelled. Additionally, lack of information and awareness about services are significant barriers to accessing care. From the professionals' perspective, effective advertisement and service promotion through media such as leaflets, posters, the internet, local newspapers, radio stations, newsletters, and parenting forums facilitate access to services (National Academics of Sciences, Engineering, and Medicine 2016; Thornicroft et al. 2022).

### *3. The Enduring Effects of Stigma*

Link and colleagues (1997) conducted a longitudinal study involving 84 male patients with dual diagnoses of mental illness (primarily schizophrenia) and substance abuse. These patients completed one year of treatment in their assigned programmes, with 48 in a therapeutic community and 36 in a community residence. The demographic breakdown of the sample revealed that 63% were African American, 23% were Hispanic, and the remaining 14% were white or of other ethnicities. The average age was 34, and the mean educational attainment was slightly less than eleven years. A significant portion (58%) had a diagnosis of non-affective psychotic disorder (mainly schizophrenia), 14% had a major mood disorder (mainly bipolar disorder and major depression), and the remaining 28% had other diagnoses (Link et al. 1997, p. 181).

The study involved interviews conducted at the beginning of treatment when patients were highly symptomatic and addicted to substances, and again after one year of treatment, when symptoms had significantly reduced and patients were largely free from drugs and alcohol. The study measured the primary independent variable of stigma and several control variables, including substance abuse, social functioning, and various dimensions of psychiatric symptomatology. The dependent variable chosen was depressive symptoms, measured by the Center for Epidemiological Studies Depression scale (CES-D), due to its theoretical and empirical relevance to stigmatisation (Link et al. 1997, p. 180).

The authors conceptualised the stigma process through three components: culturally induced beliefs about devaluation and discrimination (measured by a 15-item scale), experiences of rejection (a 12-item scale), and coping mechanisms with stigmatisation, including secrecy (an 8-item scale) and withdrawal (a 4-item scale) (see Figure 2). The results indicated that 65% of participants believed most people look down on those who abuse substances, 72% believed most employers would not hire such individuals, and 62% thought most young women would not marry someone with a history of drug abuse. Additionally, 6% reported being denied medical treatment, 16% were denied an apartment, and 24% received lower wages due to their drug abuse history. Opinions were split on whether to keep a history of drug abuse a secret, with 52% saying yes and 48% saying no, and a large majority (76%) thought it unwise to inform a potential employer about past drug problems. Furthermore, 57% would avoid applying for a job if they knew the employer did not want to hire former drug addicts (Link et al. 1997, pp. 183–184).

*Perceived Devaluation/Discrimination*

1. Most people believe that former mental patients cannot be trusted.
2. Most women would not marry a man who has been a patient in a mental hospital.
3. Most people believe that a man who has been hospitalized for mental illness is dangerous.
4. Most people think less of a person after he has been hospitalized for mental illness.
5. Most people look down on people who have been hospitalized for mental illness.
6. Most people think that mental patients are just as intelligent as the average person.
7. Most employers will not hire a person who has been hospitalized for mental illness.
8. Do you believe that many people are afraid of those people who have been patients in mental hospitals?
9. Most people believe that drug addicts cannot be trusted.
10. Most women would not marry a man who has been addicted to drugs.
11. Most people believe that a man who has been addicted to drugs is dangerous.
12. Most people think less of a person after he has been hospitalized for drug problems.
13. Most people look down on people who have been hospitalized for drug problems.
14. Most people think that drug addicts are just as intelligent as the average person.
15. Most employers will not hire a person who has been addicted to drugs.

*Rejection Experiences*

1. Did some of your friends treat you differently after you had been a patient in a mental hospital?
2. Have you ever been avoided by people because they knew you were hospitalized in a mental hospital?
3. Have people used the fact that you were in a mental hospital to hurt your feelings?
4. Have you ever been refused an apartment or a room because you had been a patient in a mental hospital?
5. Do you sometimes avoid people because you think they might look down on people who were in a mental hospital?
6. After being hospitalized for mental illness were people uncomfortable around you?
7. Did some of your friends reject you after they found out you were using drugs?
8. Did some of your family give up on you when they found out you were using drugs?
9. Were some people afraid of you when they found out you used drugs?
10. Have people treated you unfairly because they knew you were a drug addict?
11. Do you sometimes avoid people because you think they might look down on people who have had a drug problem?
12. Have some employers paid you lower wages because they knew you had a drug history?

*Secrecy*

1. Do you sometimes hide the fact that you were a patient in a mental hospital?
2. Do you think it is a good idea to keep your history of mental hospitalization a secret?
3. Would you advise a close relative who had been treated for mental illness not to tell anyone about it?
4. Do you wait until you know a person well before you tell them you have been a patient in a mental hospital?
5. Do you sometimes hide the fact that you were once addicted to drugs?
6. Do you think it is a good idea to keep your history of drug use a secret?
7. Would you advise a close relative who had a serious drug problem not to tell anyone about it?
8. Do you wait until you know a person well before you tell them about your problem with drugs?

*Withdrawal—Employment*

1. Would you apply for a job if you knew the employer was going to ask about your history of mental hospitalizations?
2. Would you apply for a job if you knew the employer didn't like to hire former mental patients?
3. Would you apply for a job if you knew the employer would ask about your history of drug use?
4. Would you apply for a job if you knew the employer didn't like to hire former drug addicts?

*Figure 2: Item wording for the stigma variables (Link et al. 1997, p. 188).*

At the one-year follow-up, there was no decline in the perception of stigma, stigma coping orientations, or recall of rejection experiences (see Table 1). Despite improvements in their mental health and substance use disorders, patients continued to be affected by stigma. Thus, the authors suggested that stigma has enduring effects that cannot be easily reversed.

*Table 1: Means, standard deviations, and paired t-test for stigma scales at baseline and one-year follow-up (Link et al. 1997, p. 184).*

| **Variable** | **Baseline Means (s.d.)** | **Follow-Up Means (s.d.)** | **Significance of Paired *t*-tests (*p*)** |
|---|---|---|---|
| **Perceived Devaluation/Discrimination** | 2.72<br>(.40) | 2.76<br>(.41) | n.s. |
| **Rejection Experiences** | .46<br>(.27) | .42<br>(.26) | n.s. |
| **Secrecy** | .57<br>(.28) | .57<br>(.31) | n.s. |
| **Withdrawal** | .43<br>(.37) | .44<br>(.37) | n.s. |

The study hypothesised that stigma has lasting effects on depressive symptoms, even with effective mental health and substance abuse interventions. The authors tested this hypothesis in a longitudinal study of males who showed significant short-term improvement in psychiatric and substance abuse conditions from treatment entry to one-year follow-up. The results supported the hypothesis, revealing that perceived devaluation/discrimination and reported discrimination experiences continued to negatively impact these people despite overall improvement due to treatment.

An alternative explanation for the association between stigma measures and depressive symptoms posits that stigma measures might be confounded with psychiatric symptoms. In this view, perceptions of stigma are influenced by symptomatology—depressed individuals are sensitive to slights, and paranoid individuals suspect others of harmful intentions. However, the study found little change in stigma measures from baseline to one-year follow-up, casting doubt on this alternative explanation. The stability of stigma measures despite significant symptom improvement suggests that the impact of stigma is not merely a reflection of symptomatology (Link et al. 1997, p. 186).

When someone is labelled with a mental illness or substance use disorder, beliefs about societal treatment become personally relevant, leading to heightened expectations of rejection. This anticipation of rejection undermines confidence, disrupts social interactions, and impairs social and occupational functioning. Actual experiences of rejection often accompany these negative labels (Link et al. 1997, p. 179).

Stigma was once considered a minor issue, with some scholars arguing that its effects were small and transient (Gove 1982). However, the study found that devaluation/discrimination and rejection experiences significantly contributed to depressive symptoms at follow-up, surpassing the impact of baseline depressive symptoms. These findings suggest that stigma has substantial effects comparable to other stress-related factors typically considered important in social science research. While the effects might dissipate over a longer period, their persistence at one year indicates they likely endure beyond this point and should be taken seriously in the context of mental health and substance abuse treatment (Link et al. 1997, p. 187).

In conclusion, the study highlights the fundamental importance of addressing stigma for individuals with mental illness and substance use disorder. Despite improvements from treatment programmes, stigma remains a significant issue that affects patients' quality of life and the long-term benefits of treatment. Healthcare providers are thus challenged to address stigma directly to enhance treatment outcomes. The findings also support a modified labelling perspective, showing that stigma has enduring negative effects on depressive symptoms, demonstrating a 'package deal' of positive and negative outcomes resulting from official labelling.

## *4. Conclusion*

In conclusion, the chapter underscores the profound and enduring effects of stigma on individuals with mental health conditions and substance use disorders. From structural barriers in healthcare and employment to personal struggles with self-esteem and social acceptance, stigma manifests in numerous detrimental ways. Addressing these issues requires a concerted effort to dismantle structural barriers, promote public awareness, and support individuals in overcoming self-stigma. By doing so, we can pave the way towards a more equitable and compassionate society, where individuals are not defined by their conditions but are empowered to thrive.

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# Chapter Four: The Relationship Between Stigma and Substance Use Disorder

*Hang Su, Yifan Xu*

The previous chapters have laid the foundation for understanding stigma and its impact on mental health and substance use disorders. We have explored the definitions, types, and consequences of stigma, as well as the specifics of SUD. This chapter aims to delve deeper into the intricate relationship between stigma and SUD, examine how different factors influence stigma related to SUD, compare perceptions of SUD versus other mental illnesses, and explore the role of stigma as a barrier to seeking care.

## *1. Understanding the Relationship Between Stigma and SUD*

Stigma is a significant barrier to treatment for individuals with SUD, deeply affecting both the onset and progression of the condition. It manifests as fear of judgment and discrimination, often preventing people from seeking help. This leads to untreated conditions and exacerbates the cycle of addiction. Stigma is pervasive in both public and private spheres, resulting in social exclusion, negative stereotypes, and internalised shame.

The relationship between stigma and SUD is bidirectional. Stigma not only contributes to the onset and exacerbation of substance use disorders but also acts as a barrier to treatment and recovery. Individuals with SUD face significant obstacles in accessing healthcare services, including discriminatory attitudes from healthcare providers and inadequate treatment options. This lack of access can result in untreated conditions and a cycle of addiction that is difficult to break.

The impact of stigma on recovery is profound. One critical aspect is self-stigma, or the internalisation of negative societal attitudes. Self-stigma can erode an individual's self-esteem and self-efficacy, resulting in a lack of motivation to pursue recovery. This phenomenon, known as the 'why try' effect, causes individuals to give up on important activities and goals due to an expectation of failure (Corrigan et al. 2009a). Consequently, stigma not only hinders initial help-seeking but also undermines long-term recovery efforts by fostering a sense of hopelessness and low self-worth.

Moreover, stigma can obscure the true burden of substance use disorders in the population, as individuals may be reluctant to disclose their struggles due to fear of judgment. Social exclusion and isolation, resulting from stigmatising treatment, can lead to further drug use, directly exacerbating the disease. Ignoring or rejecting individuals who use drugs serves as a powerful social penalty, potentially spurring further drug-taking behaviours. This creates a vicious cycle where isolation drives continued substance use, worsening the condition (Volkow 2020).

Addressing self-stigma is critical for improving treatment outcomes and supporting long-term recovery. Individuals who internalise societal stigma may develop feelings of worthlessness and hopelessness, undermining their motivation to seek help and engage in recovery efforts. This internalised shame can lead to social withdrawal and isolation, further compounding the challenges faced by those with SUD.

It is crucial to delve deeper into the underlying factors that contribute to and perpetuate stigma. Exploring these factors will provide valuable insights into the societal, cultural, and institutional influences that shape public perceptions and attitudes towards individuals with SUD. This understanding is vital for crafting strategies to mitigate stigma and improve support for those affected by substance use disorders.

## Factors Influencing Stigma

Several factors contribute to the stigma associated with substance use disorder, including blame, stereotypes of dangerousness and unpredictability, knowledge about SUD, contact and experience, media portrayals, and race and ethnicity (National Academies of Sciences, Engineering, and Medicine 2016 pp. 36–41).

### Blame

Individuals with substance use disorders are generally considered to be more responsible for their conditions than those with depression, schizophrenia, or other mental disorders. The belief that a person's substance use disorder is the result of their own behaviour influences attitudes about the value and appropriateness of publicly funded alcohol and drug treatment services (National Academies of Sciences, Engineering, and Medicine 2016). Several studies consistently show that individuals with SUD are rated significantly more to blame for their condition (59%–67%) compared to individuals with other psychiatric disorders, such as schizophrenia (4%–6%) (Yang et al. 2017).

## Stereotypes of Dangerousness and Unpredictability

People with substance use disorders are often viewed as more dangerous and unpredictable than those with other mental health conditions, such as schizophrenia or depression. A survey conducted in the United States found that a vast majority of respondents considered it likely for a cocaine- or alcohol-dependent person to harm others (Link et al. 1997). However, people are less likely to endorse the stereotype of violence if they have had direct contact with individuals who have mental and substance use disorders and have not experienced violent acts by people with these disorders.

Stereotypes of dangerousness can influence public policy, often resulting in the restriction of rights for persons with SUD. Public policy debates frequently highlight beliefs about the dangerousness of individuals with mental illness and substance use disorders. Epidemiological reviews indicate a higher relative risk of violence among people with mental illness compared to those without, though the risk remains small. The risk of violence is higher for those with co-occurring SUD and antisocial personality disorders. Additionally, the risk of suicide, another form of violence, is increased by concurrent substance use, symptoms such as hopelessness and depression, psychotic disorders, bipolar disorder, and environmental factors like access to guns and media reporting of suicide (National Academies of Sciences, Engineering, and Medicine 2016).

## Knowledge about SUD

The public often views individuals with substance use disorders as weak-willed, despite evidence showing they are as likely to adhere to treatment as those with other chronic medical conditions, such as hypertension or diabetes. Unfortunately, national surveys in the US from 1996 and 2006 indicate that this misperception has increased over time (Kuppin/Carpiano 2006; National Academies of Sciences, Engineering, and Medicine 2016).

Healthcare practitioners outside the field of behavioural health also lack knowledge about SUD, leading to misdiagnosis and inadequate treatment regimens. Additionally, negative attitudes towards individuals with mental or substance use disorders are prevalent among healthcare providers. For example, despite high remission rates for alcohol dependence found in population-based studies, many health professionals continue to view alcoholism as incurable. In one study, nurses' self-reported lack of knowledge related to behavioural health was associated with greater fear and avoidance of people with substance use disorders, demonstrating the link between lack of knowledge and 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 (National Academies of Sciences, Engineering, and Medicine 2016).

## Contact and Experience

People's immediate social networks and their contact with individuals who have substance use disorders significantly influence their understanding and opinions about these conditions. However, increased contact does not always reduce stigmatising beliefs. Some studies indicate that contact with individuals who have substance use disorders can sometimes increase levels of stigma, especially among health professionals, whose negative attitudes often intensify over time despite more frequent interactions.

Several factors might explain why contact with individuals who have substance use disorders sometimes deepens stigma. These include the severity of symptoms, the stage of recovery, the quality of contact-based interventions, the fidelity of intervention implementation, and the quality of peer training provided to those offering contact services.

Conversely, there is evidence suggesting that contact can reduce stigma towards people with substance use disorders. For instance, medical students in Australia reported more positive attitudes towards illicit drug users after engaging with them in small-group settings. Additionally, in a qualitative study of pharmacists and drug users in a needle exchange programme in the United Kingdom, both groups reported a decreased sense of stigma with increasing contact and familiarity. Reviews of similar studies found that college students with at least 50% of their friends using drugs scored lower on public stigma measures. Moreover, individuals with a family member who had an alcohol use disorder reported lower levels of stigma towards alcohol users compared to those without a diagnosed family member. It is important to note that lower levels of stigma do not imply support for substance misuse but reflect more positive attitudes towards people with substance use disorders.

Despite these variations in outcomes, the majority of available evidence suggests a strong and consistent inverse relationship between contact as an intervention and the level of stigma. Increased contact with individuals who have substance use disorders is generally associated with lower levels of stigma (National Academies of Sciences, Engineering, and Medicine 2016).

## Media Portrayal

The media play a crucial role in stoking fear and intensifying the perceived dangers of individuals with substance use disorders. Media often depict treatment as unhelpful and portray pessimistic views of illness management and the possibility of recovery. Recent research suggests that the broad reach of US media and the volume and intensity of negative coverage about substance use disorders contribute to increasing stigma globally. Media portrayals often focus on individuals with untreated and symptomatic substance use disorders rather than those on a path to recovery, perpetuating negative stereotypes and stigmatising attitudes (National Academies of Sciences, Engineering, and Medicine 2016).

## Race and Ethnicity

Individuals of ethnic and racial minorities access mental health care at a lower rate than white individuals, and when they do, the care they receive is often suboptimal. Several factors influence access, including quality of care and rates of treatment for substance use disorders among ethnic and racial minorities and immigrant groups. Quality of care is compromised by language barriers and provider misunderstandings of cultural ideas about illness, health, and treatment. Although most healthcare professionals agree that cultural competency training is important, lack of cultural awareness remains a problem in many healthcare settings. Providing physical and behavioural health services in integrated care settings has been shown to increase participation in substance use disorder treatment for racial and ethnic minorities (National Academies of Sciences, Engineering, and Medicine 2016).

African Americans in the United States have been highly stigmatised and subject to discrimination. For many years, opioid addiction was seen primarily as a condition affecting disadvantaged minority groups, leading policymakers to deprioritise addiction treatments. However, with the recent spread of opioid addiction (both prescription and heroin) to white populations, public and political demand for appropriate treatments has increased. Some of the stigma associated with substance use disorders may stem from assumptions about the race or ethnicity of those affected by SUDs. The impact of this intersectionality on stigma could be further explored through a hypothetical vignette study. A vignette study is a research method where participants are presented with hypothetical scenarios and asked to respond to them. In this case, participants could be given a description of a person with a substance use disorder, with the race or ethnic identity of the individual being varied and randomly assigned to different participants. This would help explore whether assumptions about race or ethnicity influence stigma toward individuals with substance use disorders (Yang et al. 2017).

In conclusion, the relationship between stigma and SUDs is multifaceted and pervasive, significantly impacting both individuals and society at large. Stigma acts as a formidable barrier to treatment, exacerbating the onset and progression of SUDs by discouraging help-seeking behaviours and perpetuating negative stereotypes. Factors such as blame, stereotypes of dangerousness, inadequate knowledge, limited contact, media portrayal, and racial disparities all contribute to the perpetuation of stigma. Healthcare providers, despite their critical role in treatment, are not immune to stigmatising attitudes, which can undermine the quality of care received by individuals with SUDs. Addressing these issues requires comprehensive strategies that promote education, increase empathy, and dismantle discriminatory practices, ultimately fostering a supportive environment conducive to recovery and well-being for all individuals affected by SUDs.

## *2. Perceptions of SUD Compared to Other Mental Illnesses*

Public perceptions of SUD often differ markedly from those of other mental illnesses. SUD is frequently viewed through a moral lens, with individuals seen as making poor life choices rather than suffering from a medical condition. This perception is reinforced by media portrayals that depict people with SUD as criminals or morally weak, further entrenching negative stereotypes and social stigma.

Despite being categorised within the broader spectrum of mental illnesses, SUD is perceived as more blameworthy and dangerous compared to other mental health conditions. Individuals labelled with drug addiction are often seen as more responsible for the onset and continuation of their condition than those with mental illnesses or physical disabilities. This belief leads to greater stigma and a lower likelihood of receiving help. For example, people with SUD are viewed as more responsible for their health condition compared to those with physical disabilities or other mental illnesses, resulting in less empathy and support (Corrigan et al. 2009a).

Structural stigma significantly impacts the treatment and perception of SUD compared to other mental health conditions. This stigma manifests in healthcare, policy, and community settings, where punitive approaches and exclusionary practices are common. Healthcare providers and policymakers often focus on punishment rather than treatment for SUD, as seen in policies like mandatory minimum sentences for drug offenses. Similarly, structural discrimination against individuals with mental illnesses is evident in the location of treatment facilities, which are often isolated or situated in disadvantaged urban neighbourhoods. For instance, in Shanghai, both voluntary and mandatory rehabilitation facilities for SUD are located in rural areas, reinforcing stigma and isolation. Programmes like clean needle exchanges also face 'not in my backyard' (NIMBY) opposition, illustrating societal discrimination (Link/Phelan 2001).

Phelan et al. (2008) argue that stigma can be understood as a response to perceived threats, with norm enforcement and disease avoidance being particularly relevant to SUD. Norm enforcement arises because SUD is seen as a violation of social norms, prompting societal efforts to defend against perceived social disorder. Disease avoidance, while typically related to contagious diseases, manifests in the fear of addiction, leading people to distance themselves from those with SUD. This fear exacerbates social isolation and exploitation of individuals with SUD, further degrading their social status (Phelan et al. 2008).

Studies have shown that the public perceives individuals with SUD as more dangerous and unpredictable compared to those with other mental illnesses. Two nationally representative studies in the Netherlands and the United States revealed that 71%–87% of respondents believed people with an addiction were prone to violence. Similarly, UK studies from 1998 to 2003 indicated that individuals with drug addiction were viewed as more dangerous and unpredictable than those with severe depression, panic attacks, dementia, or eating disorders. These findings are consistent across multiple surveys and countries, with dangerousness being a significant contributor to stigmatising attitudes (Yang et al. 2017).

When it comes to treatment perceptions, beliefs about the appropriateness of different treatments vary significantly between mental health conditions and SUD. Medication, psychiatrists, general physicians, and therapists are commonly endorsed as appropriate treatments for mental health disorders. In contrast, for alcohol and drug dependence, prescription medication is less likely to be viewed as appropriate. Instead, non-biological treatments like therapy, talking to family or friends, and self-help groups are more commonly endorsed (Kuppin/Carpiano 2006). While the public recognises the need for formal treatment for mental illnesses like depression and schizophrenia, they are less likely to endorse biologically focused treatments for substance abuse. Beliefs in biological causation are significantly associated with views on treatment appropriateness, particularly formal treatment options. Conversely, non-biological causal beliefs do not strongly predict recommendations for non-biological treatments (Kuppin/Carpiano 2006).

Overall, the perception of SUD compared to other mental illnesses is significantly more negative, affecting how society views and treats individuals with SUD. The stigma, structural discrimination, and differing treatment perceptions contribute to the marginalisation and inadequate support for those suffering from substance use disorders.

## *3. Stigma as a Barrier to Treatment and Recovery*

The relationship between stigma and substance use disorder is bidirectional, with stigma both contributing to the onset and exacerbation of SUD and acting as a barrier to treatment and recovery. Stigmatised individuals often face significant obstacles in accessing healthcare services, including discriminatory attitudes from healthcare providers and inadequate treatment options. This lack of access can result in untreated conditions and a difficult-to-break cycle of addiction.

Effective treatment for substance use disorders is available, but stigma, particularly public or social stigma, remains a significant barrier to accessing and receiving help (Keyes et al. 2010). Stigma among substance users has been linked to lower self-efficacy and a higher likelihood of experiencing discrimination. Several factors contribute to this stigma, including the association of substance use with social and economic problems, involvement in illegal activities to procure substances, co-existing stigmatising health conditions like HIV, engagement in risky behaviours, and societal moralistic views towards substance use disorders themselves (Gyawali et al. 2018).

Additionally, the stigma surrounding substance use disorders, particularly opioid use, is often reinforced by social, political, and legal systems in many parts of the world. This can lead to legally permissible discrimination against individuals with substance use disorders in certain situations. Substance use disorders are frequently viewed not as health concerns but as criminal issues. In some regions, drug use can even result in summary execution (Corrigan/Nieweglowski 2018; Livingston et al. 2011).

Two broad sets of barriers related to stigma undermine care-seeking and service participation. Person-level barriers include attitudes and behaviours such as avoiding treatment or dropping out prematurely, poor mental health literacy, beliefs in treatment ineffectiveness, lack of a supportive network, and perceived cultural irrelevance of treatments. Provider and system-level barriers include lack of insurance, financial constraints, staff cultural incompetence, and workforce limitations, all of which are influenced by stigma (Corrigan et al. 2014).

A study by Keyes et al. (2010) found that individuals with a lifetime diagnosis of alcohol use disorder were less likely to utilise alcohol services if they perceived higher stigma toward individuals with alcohol disorders. This perceived stigma was more common among males, non-white individuals, those with lower income and education levels, and those who were previously married. However, individuals who reported close contact with a person with an alcohol disorder reported lower perceived stigma. The connection between highly stigmatised views of alcoholism and underutilisation of services suggests that stigma reduction should be integrated into public health efforts to promote alcohol treatment (Keyes et al. 2010).

Stigma is also associated with low investment in mental health care. Barriers to accessing mental health care include lower insurance benefits than for physical conditions, low reimbursement rates for mental health providers, and restricted insurance coverage for people with mental health conditions, especially in low-income settings. Prejudice by healthcare staff has been linked to worsened health outcomes due to diagnostic overshadowing, where physical symptoms are misattributed to mental health conditions. These forms of health discrimination contribute to reduced life expectancy among people with mental health conditions. Surveys show that families can also create substantial barriers to help-seeking among adolescents, who may fear their families will not take their problems seriously, decreasing their willingness to seek support (Thornicroft et al. 2022).

Healthcare providers, despite their critical role in treating individuals with SUD, are not immune to the stigma surrounding these conditions. Negative attitudes among medical professionals can significantly impact the quality of care and overall treatment experience for patients with SUD. This perpetuates stigma and hinders effective treatment outcomes (Volkow 2020).

A study conducted in Shanghai, China, examined healthcare providers' attitudes towards people with SUD, finding high levels of public stigma. Over one third of participants expressed concern about their safety due to their work, reflecting occupational stereotypes. Over 80% held discriminatory attitudes towards individuals in recovery, with nearly 90% agreeing that employers would not consider hiring a former substance user over other candidates. These findings highlight widespread discriminatory attitudes among staff related to SUD, affecting employment and social interactions and reinforcing self-stigma among patients (Lei 2021).

Previous international studies have shown similar negative attitudes among healthcare providers towards patients with SUD. A 2019 study in China's methadone maintenance treatment (MMT) clinics found high levels of public stigma, with providers viewing patients as responsible for their unemployment and undeserving of sympathy. These providers also perceived patients as dangerous and were less willing to interact with them (Lei 2021).

While stigma is frequently cited as a barrier to treatment in various studies involving individuals with SUDs, its influence on treatment-seeking decisions varies significantly across different populations. In some cases, compounded stigmas—such as those related to mental illness, homelessness, or interactions with staff at rehabilitation facilities—can strongly impact substance users' decisions to seek treatment. However, there are instances where stigma is not the primary concern, especially when individuals do not perceive their substance use as problematic. Stigma may also manifest indirectly, through concerns about others' perceptions or feelings of embarrassment. Without concentrated efforts to standardise the definition and measurement of self-stigma and perceived social stigma, the exact magnitude of their effect on treatment-seeking decisions remains uncertain (Hammarlund et al. 2018).

In conclusion, stigma significantly impedes both the treatment and recovery of individuals with substance use disorders. By perpetuating negative stereotypes and fostering discriminatory attitudes among healthcare providers, stigma creates substantial barriers to accessing effective care. Addressing and reducing stigma is essential to improving treatment outcomes and ensuring that those with SUD receive the support and compassion they need to overcome addiction and achieve long-term recovery.

## 4. Conclusion

The relationship between stigma and SUD is complex and multifaceted. Stigma creates significant barriers to treatment and recovery, rooted in public perceptions and institutional practices. It prevents individuals from seeking necessary help and perpetuates self-stigma, which undermines their confidence and hope for recovery. Compared to other mental illnesses, SUD often faces harsher judgment and punitive measures rather than supportive interventions.

Various factors, including blame, stereotypes of dangerousness and unpredictability, knowledge about SUD, contact and experience, media portrayal, and race and ethnicity, contribute to the stigma associated with SUD. Addressing this stigma is essential for improving the lives of individuals with SUD and supporting their recovery.

Understanding these complex dynamics is crucial as we move forward. In the next chapter, we will explore strategies to challenge and reduce stigma, paving the way for a more inclusive and supportive approach to treating substance use disorders.

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# Chapter Five: Strategies and Success Stories in Reducing Stigma

*Yifan Xu, Shuo Li*

Stigma surrounding mental health conditions and substance use disorders presents a pervasive challenge, hindering individuals from seeking help and receiving adequate care. This chapter explores a variety of innovative strategies and inspiring success stories from around the world that aim to dismantle this stigma. We will examine the effectiveness of educational campaigns, such as Australia's Beyond Blue initiative, which has successfully raised awareness and understanding of mental health issues. Additionally, we will delve into contact-based interventions like Canada's Opening Minds programme, which has demonstrated the power of personal narratives in changing attitudes. Through these case studies and more, this chapter provides a comprehensive overview of how targeted efforts can shift societal perceptions and foster environments that support recovery and inclusion.

## *1. Different Agendas and Goals of Challenging Stigma*

Reducing stigma related to mental illness and substance use disorder is a multifaceted challenge that requires targeted strategies. Two primary agendas to addressing stigma are the services agenda and the rights agenda. Understanding these distinct agendas is crucial for effectively combating stigma and promoting positive change (Corrigan 2015).

The services agenda aims to remove stigma as a barrier to seeking evidence-based services by framing mental illnesses as treatable disorders. This approach encourages increased engagement with mental health services, emphasising the importance of treatment and care. The rights agenda, inspired by civil rights movements, seeks to eliminate discrimination and promote affirming attitudes and behaviours towards people with mental illness. This approach treats stigmatisation as a civil rights violation, focusing on eradicating discriminatory practices and improving opportunities for those affected (Corrigan 2015).

Not all efforts to combat stigma are equally effective. It is essential to distinguish between the services and rights agendas to develop targeted strategies that address specific aspects of stigma. This distinction helps in measuring success appropriately—whether through increased service engagement or improved employment opportunities and accommodations. Different groups drive these agendas within the mental health system. The services agenda is often championed by individuals who have benefited from treatment, their families, and service providers. They support health communication and public service campaigns aimed at broad populations. On the other hand, the rights agenda is driven by those who have experienced discrimination. Advocates use grassroots efforts, including personal stories of recovery, to challenge local discrimination and promote community opportunities (Corrigan 2015).

Understanding the different approaches to reducing stigma sets the stage for exploring specific strategies and success stories. The following sections will delve into various initiatives and examples that have effectively reduced stigma, highlighting their impact in different contexts.

## *2. Anti-Stigma Approaches and Strategies*

To effectively challenge stigma, a range of strategies have been developed and implemented. These include education, mental health literacy campaigns, direct contact with affected individuals, peer services, protest and advocacy efforts, and legislative and policy changes. Each of these approaches offers unique benefits and challenges, and their combined efforts contribute to a comprehensive strategy for reducing stigma. In this section, we will explore these anti-stigma strategies in detail, examining how they have been applied and the successes they have achieved.

### Education

Educational strategies play a crucial role in reducing stigma by addressing myths and misconceptions by providing factual information. These strategies include literacy campaigns, public awareness efforts, and various training activities, effectively contrasting myths about mental illness with accurate data (Corrigan 2011; WHO 2022).

For instance, campaigns might counter the myth that people with mental illness are violent by presenting statistics showing that homicide rates among people with mental illness are similar to those in the general population (Corrigan et al. 2012). While much of the evidence on educational interventions focuses on mental illness stigma, the approaches used can provide valuable insights for addressing stigma related to substance use disorders as well.

Educational campaigns can be scaled from local to national levels, contributing to their effectiveness. They aim to combat public stigma, reduce self-stigma, improve stress management, and boost self-esteem when included in cognitive-behavioural therapy. Acceptance and commitment therapy also benefit from educational components.

However, evidence on the long-term effectiveness of educational interventions in reducing public stigma is mixed. Scotland's See Me campaign aimed to normalise mental illness in public perception. Surveys conducted two years after the campaign's start showed an 11% drop in the belief that the public should be protected from people with mental health problems and a 17% drop in the perception that mentally ill people are dangerous. A meta-analysis of public stigma-reduction interventions found decreases in stigma related to mental illness, psychosis, depression, and combined diagnoses, with no significant advantage for internet-based interventions over face-to-face ones. Shorter interventions have shown varied results. Canada's In One Voice social media intervention, for example, improved attitudes toward mental health issues and reduced social distance after one year but did not significantly enhance knowledge or confidence in helping someone with a mental health problem. This suggests that brief media campaigns may not result in lasting behaviour change (Livingston et al. 2011; National Academies of Sciences, Engineering, and Medicine 2016).

A review of European anti-stigma programmes found significant changes in adolescents' beliefs and attitudes in response to education. Adolescents, whose beliefs about mental illness vary more than those of adults, showed greater responsiveness to educational interventions. Corrigan and colleagues (2012) found that education was more effective than contact-based interventions in changing stigmatising attitudes among adolescents. Additionally, younger adults are more likely than older adults to view help-seeking as a sign of strength and believe that suicide is preventable.

Educational campaigns highlighting the genetic components of mental illnesses like schizophrenia have had unintended stigmatising consequences. While these messages aim to reduce blame, they can emphasise the 'differentness' of mentally ill people and imply a low chance of recovery, reinforcing self-stigma and inhibiting the pursuit of wellness goals.

Although these biogenetic messages were initially successful in decreasing attributional stigma, they are no longer considered sufficient by themselves (Corrigan et al. 2012).

To further enhance the effectiveness of educational strategies, research indicates that combining education with social contact yields better outcomes than education alone (Corrigan et al. 2012; Thornicroft et al. 2022).

## Mental Health Literacy Campaigns

Promoting mental health literacy through health communication campaigns effectively reduces stigma by enhancing understanding of mental illnesses. This knowledge aids individuals in recognising, managing, and preventing mental health issues, leading them to seek appropriate treatment (Corrigan 2015).

Schools play a crucial role in addressing the mental health needs of young people through mental health literacy programmes. Endorsed by educators, health professionals, and policymakers, these programmes have shown success in improving knowledge, attitudes, and help-seeking behaviour. However, before implanting these programmes on a national scale in the United States, more research is needed to ensure their effectiveness. It's essential that mental health education is recovery-focused and tailored to different age groups' developmental and cognitive levels (National Academies of Sciences, Engineering, and Medicine 2016).

A key initiative in this domain is Mental Health First Aid (MHFA), which originated in Australia and has been significantly expanded in the United States and Canada. This eight-hour course teaches basic skills to help others with mental health problems or experiencing crises, demonstrating its effectiveness in reducing stigmatising attitudes and beliefs (Corrigan 2015; National Academies of Sciences, Engineering, and Medicine 2016). MHFA's success highlights the potential impact of structured, in-person training programmes.

Beyond schools, mental health literacy campaigns aim to encourage individuals and families to seek necessary services. Early diagnosis and treatment lead to better outcomes, yet access to high-quality, culturally informed treatment remains limited, particularly for racial and ethnic minority groups. The behavioural model of health service use illustrates the stages families go through in seeking help, starting with problem recognition. This stage is critical as families are more likely to seek treatment for symptoms attributed to illness, rather than family relations or personality factors. Addressing the specific needs of minority groups, campaigns promoting biogenic explanations of mental and substance use disorders, though generally ineffective in reducing perceptions of dangerousness and social distance, can reduce blame and encourage help-seeking behaviours. By targeting ethnic minority parents and trusted community figures with messages about the biological underpinnings of mental illnesses, these campaigns may help close the treatment gap between white and minority groups (National Academies of Sciences, Engineering, and Medicine 2016).

In conclusion, improving mental health literacy through targeted campaigns and programmes can significantly reduce stigma, encourage early diagnosis and treatment, and promote better mental health outcomes. Addressing cultural and accessibility barriers remains crucial in ensuring these benefits reach all segments of the population.

## Contact with Affected Individuals

The contact hypothesis, first proposed by Allport in 1954, suggests that contact with members of a stigmatised group can reduce prejudice, particularly under conditions of equal status, collaboration, motivation, repeated interactions over time, personal interactions, and institutional support (Allport 1954; Kolodziej/Johnson 1996). This hypothesis applies to both direct (face-to-face) and indirect (e.g. simulated, video, online) forms of contact, all aiming to foster positive interactions between individuals with mental health conditions and specific target groups (Thornicroft et al. 2022).

Strategies based on the contact hypothesis aim to shift negative attitudes through interactions with people living with mental health conditions, employing methods like direct social contact, simulated or video contact, and online interactions in healthcare settings (WHO 2022). Research shows that such contact strategies, especially when combined with education, are more effective than education alone in changing attitudes and behaviours (Corrigan 2011).

Effective contact strategies involve targeting key groups such as employers and healthcare providers, implementing local programmes, ensuring credibility, aligning roles with the target group, and maintaining continuous contact for sustained impact (Corrigan 2011). Studies indicate that face-to-face contact, compared to mediated forms like video, tends to have a greater effect on attitude change (Corrigan et al. 2012; Kolodziej/Johnson 1996).

Historically, individuals without stigmatising conditions have had limited meaningful contact with those who do have them, leading to discomfort and distrust. Contact interventions aim to bridge this gap, facilitating positive interactions and reducing stigma, while also empowering individuals and boosting self-esteem, particularly through online platforms that provide anonymity and accessibility (National Academies of Sciences, Engineering, and Medicine 2016).

Combining contact with education enhances its impact on attitude change and intended behaviours, as evidenced by meta-analyses showing significantly larger effect sizes compared to education alone. In-person contact has been consistently found to be more effective than video contact for reducing social distance and changing attitudes (Corrigan et al. 2012). However, the effectiveness of contact-based interventions varies across different stigmatising conditions, and longer durations of contact do not always lead to greater attitude changes (Kolodziej/Johnson 1996; Pescosolido et al. 2008).

In conclusion, while contact-based interventions are crucial for reducing stigma, their success depends on careful implementation and consideration of context-specific factors.

### Peer Services

Peer support services in mental health care leverage personal experiences to provide knowledge sharing, emotional support, social interaction, practical assistance, and advocacy. They demonstrate consistent, modest effects across various mental health conditions and interventions. These services come in diverse forms, from face-to-face self-help groups to online therapy led by trained peers and one-on-one mentoring or befriending services, all aiming to support recovery confidentially and without judgment.

Peer supporters, who may be hired staff, advocates, or volunteers with personal experience, connect with individuals facing mental health challenges by sharing their first-hand knowledge. They serve as listeners, educators, coaches, advocates, partners, and mentors, often sharing common characteristics like age or ethnicity, fostering comfort and confidence in seeking help. For example, the Michigan Peer-to-Peer Depression Awareness Program had students act as peer advocates, raising depression awareness and connecting peers with resources. Post-implementation, students felt more comfortable discussing mental health issues and were more likely to seek help.

Integrating contact-based strategies through peer services effectively combats public and self-stigma. Peers within healthcare teams provide non-judgmental, non-discriminatory services, aiding others in identifying problems and suggesting coping strategies. Organisations such as Active Minds which operates on college campuses, exemplify this approach with programmes such as their Speakers Bureau, where trained peers share their stories and insights to foster understanding and reduce stigma surrounding mental health issues.

Peer support counters the discrimination, rejection, and isolation faced when seeking treatment, enhancing long-term treatment utilisation and empowering peer providers in their recovery. These services advance rights and service agendas by promoting treatment-seeking, expanding employment opportunities, improving quality of life, and boosting self-efficacy.

Recognition of the value of peer support is evident in guidelines from the Centers for Medicare & Medicaid Services and the Substance Abuse and Mental Health Services Administration. While some advocate for professionalisation and standardised training, others caution against medicalisation. The National Federation of Families for Children's Mental Health's certification programme exemplifies moves towards uniform standards, reducing stigma and promoting family-driven behavioural health services. This certification programme sets standards for parents supporting others raising children with behavioural health challenges, fostering a peer support workforce. A certification commission ensures competency in essential domains, aligning with broader efforts to enhance behavioural health care quality and accessibility (National Academies of Sciences, Engineering, and Medicine 2016; Thornicroft et al. 2022; WHO 2022).

In conclusion, peer support services are vital in mental health care, offering emotional support and reducing stigma through shared experiences. These services empower individuals and improve care quality, creating a more inclusive and supportive environment.

## Protest and Advocacy

Protest strategies in mental health care aim to formally challenge stigma and discrimination through various advocacy methods such as public demonstrations, letter writing campaigns, petitions, and product boycotts (WHO 2022). These efforts are rooted in civil rights agendas and seek to highlight and criticise negative portrayals of mental health conditions in media and societal discourse (Thornicroft et al. 2022).

Typically led by individuals with lived experience of discrimination and their advocates, these grassroots campaigns utilise tactics like letter writing and public demonstrations to engage both opinion leaders and the general public. The goal is to suppress negative attitudes, eliminate harmful stereotypes, and advocate for legislative reforms that protect rights, increase access to resources, and reduce disparities.

While protest strategies have the potential to raise awareness and mobilise support, they are among the least studied approaches in stigma reduction efforts. It is important to monitor the outcomes of these campaigns as they can sometimes inadvertently reinforce negative attitudes through psychological reactance or unintended consequences.

Health professionals, particularly psychiatrists and psychologists, are increasingly encouraged to leverage online platforms for advocacy and education, combating stigma by promoting accurate information and challenging stereotypes (National Academies of Sciences, Engineering, and Medicine 2016). This proactive engagement aims to shift public perceptions and foster a more supportive environment for individuals living with mental health conditions.

In conclusion, protest strategies play a critical role in challenging mental health stigma, advocating for rights, and promoting societal change. However, careful evaluation and strategic implementation are essential to maximise their effectiveness and avoid unintended consequences in stigma reduction efforts.

### Legislative and Policy Change

Legislation and regulation at national and international levels are crucial for promoting and protecting mental health in the workplace, thereby reducing stigma. The International Labour Organization (ILO) Convention on Occupational Safety and Health (No. 155) and its Recommendation (No. 164) urge countries to develop policies that safeguard workers' mental health. This convention encourages employers to integrate mental health into workplace policies, facilitating organisational interventions (WHO 2022).

In the United States, legal and policy interventions have a long history of protecting stigmatised groups. The Americans with Disabilities Act (ADA) was amended in 2008 to include individuals with mental illness, even if medication reduced their symptoms. This amendment acknowledges intermittent symptoms and discrimination based on perceived impairments, contrasting with legislation applying arbitrary criteria across various mental illnesses.

Addressing structural stigma is crucial for promoting mental well-being. Structural stigma can be intentional or unintentional, overt or covert. Policies excluding people with mental illness from health insurance coverage exemplify overt structural stigma, while the failure to distinguish between mental health apprehensions and suicide attempts on criminal records illustrates covert structural stigma. Research shows that individuals with mental illness prefer approaches addressing institutional and structural discrimination over public education alone. A US survey found significant discrimination in employment (52%), housing (32%), law enforcement (27%), and education (24%).

Comprehensive approaches are needed to address structural stigma, involving multidisciplinary and multilevel strategies. Engaging groups such as lawyers, journalists, educators, and business owners can help tackle the root causes of structural stigma. Anti-stigma efforts should not solely focus on public education and attitude change ('soft goals') but should also pursue legislative and policy changes ('hard goals') to promote social equity and improve the quality of life for individuals with mental and substance use disorders.

Advocacy organisations have been instrumental in driving policy changes that promote mental health awareness and protect individual rights. Successful legislative efforts, such as the Mental Health Parity and Addiction Equity Act, have reduced discrimination in healthcare settings and ensured equal access to mental health services (National Academies of Sciences, Engineering, and Medicine 2016).

In conclusion, addressing structural stigma through comprehensive legal, policy, and advocacy efforts is essential for creating a more inclusive society and improving the well-being of individuals with mental health conditions and substance use disorders

## *3. Successful Campaigns Around the World*

This section explores the outcomes of large-scale anti-stigma campaigns conducted both within and outside the United States. Highlighted campaigns include national-level initiatives from Australia (Beyond Blue), Canada (Opening Minds), and England (Time to Change). In the United States, significant campaigns reviewed include the Eliminations of Barriers Initiative and What a Difference a Friend Makes, as well as state-based initiatives like the California Mental Health Services Authority. Additionally, efforts by the US Departments of Defense and Veterans Affairs (VA) aim to reduce mental health stigma and promote treatment-seeking among military personnel and veterans, featuring campaigns such as Make the Connection and the Real Warriors campaign.

Similar large-scale efforts have been implemented in other countries. Scotland's See Me campaign, initiated in 2002, mobilises people and groups to work collaboratively, focusing on changing negative behaviours and addressing human rights issues. Denmark's One of Us campaign, a newer initiative, targets young people, the labour market, service users and providers, and the media. Spain's 1decada4 campaign aims to increase social acceptance of mental illness by making it more visible, emphasising that one in four people will experience a mental disorder in their lifetime. Figure 1 illustrates three well-known global campaigns (National Academies of Sciences, Engineering, and Medicine 2016; WHO 2022).

### Time to Change: England's Anti-Stigma Campaign

Time to Change was England's largest programme aimed at reducing stigma and discrimination against people with mental health problems. Since its inception in 2008 until it came to an end in 2021, the campaign focused on raising awareness and changing attitudes through a multifaceted approach that included social marketing, mass media activities, community events, grassroots projects, and targeted work with key stakeholders such as medical students, teachers, employers, and young people.

A key element of the campaign was fostering social contact between people with and without mental health problems. Community events facilitated positive interactions, which helped reduce stigmatising attitudes. Many participants reported high levels of selective disclosure and positive intergroup interactions, crucial for breaking down 'us versus them' thinking. People without mental illness who experienced positive contact factors were more likely to support individuals with mental health problems in the future.

| CAMPAIGN AND COUNTRY | ACTIVITIES | KEY FINDINGS |
|---|---|---|
| **TIME TO CHANGE**<br>Anti-stigma campaign<br>England | • Social marketing and media activity.<br>• Local community events.<br>• Grants for projects led by people with lived experience.<br>• Targeted interventions for stakeholders, e.g. students, teachers, employers, and young people.<br>• Research and evaluation. | • Social marketing and media activity was most effective at influencing intended behaviour toward people with mental health conditions.<br>• Grassroots contact-based projects were particularly effective at reducing self-stigma.<br>• Public awareness was strongly associated with campaign activity and increased awareness was associated with more favourable attitudes. |
| **BEYONDBLUE**<br>Mental health literacy programme<br>Australia | • Focus on depression and anxiety.<br>• Media advertising and training.<br>• School-based programmes.<br>• Mental health first aid training.<br>• Community discussion forums.<br>• Mental health champions.<br>• Research and evaluation. | • States with more activity saw more improvement in public awareness about depression and the benefits of treatment.<br>• Training programmes delivered moderate increases in knowledge about mental illness.<br>• Public perception of depressed people as dangerous and unpredictable persists. |
| **OPENING MINDS**<br>Contact-based education<br>Canada | • Targeted interventions for stakeholders (youths, health care providers, employers and employees, news media).<br>• Mental health champions.<br>• Research and evaluation. | • Big media campaigns were not effective at changing attitudes.<br>• Programmes that target a specific mental health condition may reduce stigma more effectively than those targeting mental ill-health in general.<br>• The quality of the contact matters more than the duration: stories of hope and recovery were the most successful. |

*Figure 1: Successful national campaigns (WHO 2022, p. 84).*

The campaign also made significant strides in media impact, increasing the number of balanced, anti-stigmatising articles about mental health in newspapers across England. The mass media component effectively influenced intended behaviours towards people with mental illness. For example, survey responses to the item 'In the future, I would be willing to live with someone with a mental health problem' showed consistent improvement.

Time to Change also demonstrated the cost-effectiveness of long-term, national-scale anti-stigma efforts. Repeated exposure to the campaign significantly improved public knowledge, attitudes, and intended behaviours towards mental health issues. The cost per person for improved intended behaviour was relatively low, highlighting the campaign's efficiency compared to other public health initiatives (National Academies of Sciences, Engineering, and Medicine 2016, pp. 82–85).

Overall, Time to Change contributed significantly to reducing public stigma around mental health in England, emphasising the importance of multifaceted, sustained efforts in changing public perceptions and behaviours.

### Opening Minds: Canada's Contact-Based Interventions

Opening Minds is a national initiative in Canada focused on using contact-based interventions to reduce stigma associated with mental illness. Launched by the Mental Health Commission of Canada in 2009, it has a ten-year mandate and an annual budget of USD 2 million. This programme aims to change attitudes and behaviours towards individuals with mental health conditions and encourage the elimination of discrimination. It is the largest systematic effort of its kind in Canadian history and received the Global Innovator Award at the Together Against Stigma International Conference in 2015.

Initially, Opening Minds started with a small public education media campaign, which proved ineffective. Shifting strategies, the commission issued a request for interest to government agencies, universities, stakeholders, and grassroots anti-stigma programmes across Canada, all of which used contact-based education. Researchers partnered with these programmes to evaluate and scale up effective initiatives.

The campaign targeted four groups: youth aged twelve to 18, healthcare providers, employers, and the news media. Consistent evaluation strategies across these settings helped identify the most effective activities, aiming to develop replicable, evidence-based models. Findings showed that while contact-based education was the most effective anti-stigma effort, the success of these programmes depended on delivering messages of hope and recovery.

For healthcare professionals, both short and long programmes were effective if they included various forms of contact-based education, such as live personal testimonies and recorded events. Successful programmes often offered incentives like continuing education credits or paid time off. A meta-analysis of over 20 'Understanding Stigma' programmes highlighted that the quality of contact was more important than its duration, with recovery and inclusion messages driving positive change.

Programmes focusing on specific mental illnesses tended to reduce stigma more effectively than general ones. Future efforts will identify the most successful programme components, understand variations in stigma reduction among different audiences, and determine the processes that facilitate positive changes in attitudes and behaviours.

An analysis of over 20,000 print articles and 1,300 television reports revealed that Canadian media frequently linked mental illness with crime and violence, with less than 25% of articles including voices of individuals with lived experiences or mental health experts. To combat this, Opening Minds partnered with journalism schools to develop a curriculum featuring contact-based education, ideally delivered by graduates. They also distributed 5,000 copies of the media resource guide, Mindset: Reporting on Mental Health (Corrigan 2015; National Academies of Sciences, Engineering, and Medicine 2016, pp. 88–91).

In conclusion, contact-based education emerged as the preferred strategy for stigma reduction. Partnerships with community and grassroots groups, combined with systematic evaluation and standardised interventions, were key to developing best practices. Moving forward, the focus will be on scaling up these successful approaches for nationwide implementation, ensuring that the positive impacts of Opening Minds continue to grow and benefit more Canadians.

## Beyond Blue: Australia's Mental Health Literacy Programme

Beyond Blue, an Australian mental health literacy programme, is a significant initiative addressing label avoidance and care-seeking behaviour. This social marketing campaign, which has been active for nearly 20 years, includes public service announcements that frame depression as a treatable condition. It has achieved notable penetration, with 60% of Australians being aware of the programme. Awareness of the campaign is linked to better recognition of mental illnesses and a greater understanding of the benefits of treatment.

In the 1990s, the Australian government launched a national initiative to improve the mental health knowledge and skills of primary care practitioners and other health professionals. However, the importance of public knowledge was initially overlooked. To highlight this gap, researchers introduced the concept of ‘mental health literacy’, defined as the knowledge and beliefs about mental disorders that aid in their recognition, management, or prevention. Key components of mental health literacy include recognising disorders in oneself and others, knowing available professional help and treatments, understanding effective self-help strategies, providing aid and support to others, and preventing mental disorders.

Beyond Blue, initially launched as ‘Beyond Blue: the national depression initiative’, now addresses both depression and anxiety. Its goals include raising public awareness, reducing stigma, supporting consumers and caregivers, promoting prevention and early intervention, enhancing primary care training, and conducting applied research. The initiative disseminates information through television, radio, the internet, and print media. Notably, Beyond Blue partnered with Schools Television to raise awareness and engaged well-known actors to share their personal experiences with mental illness.

Funded primarily by the Australian national government, with additional support from state governments and non-governmental sources, Beyond Blue began as a five-year initiative in 2000 but continues to operate. Surveys conducted before and during the implementation of Beyond Blue allowed researchers to track trends in public attitudes. Respondents viewed vignettes of depressed individuals and answered questions about various interventions and their perceived effectiveness. States with higher levels of campaign activity showed greater improvements in public awareness, beliefs about treatment efficacy, and positive attitudes towards people with depression.

The Mental Health First Aid training programme, a part of Beyond Blue’s efforts, has shown moderate increases in knowledge about mental illness and smaller effects on attitudes and behaviours, with improvements sustained over six months. The programme aims to train 11% of Australian adults, with 2% trained and certified so far. The programme’s sustainability is supported by fees paid by individuals and organisations for the training.

The concept of mental health literacy has become a national and state policy goal. A survey at the ten-year mark of the campaign found that 87% of Australians were aware of Beyond Blue's work. Between the first Beyond Blue report in 2004 and the second in 2009, there was a significant increase in the availability of primary care services for depression. However, while public awareness increased, it remains unclear whether stigma and discrimination against people with depression decreased. Despite a steady decrease in social distance over time, public perceptions of people with depression as dangerous (68%) and unpredictable (52%) persist (Corrigan 2015; National Academies of Sciences, Engineering, and Medicine 2016, pp. 85–88).

Beyond Blue's comprehensive approach highlights the importance of public education in improving mental health literacy and reducing stigma, demonstrating the value of sustained, multifaceted efforts in addressing mental health issues.

## *4. Conclusion*

Reducing stigma associated with mental health conditions and substance use disorders requires a comprehensive and multifaceted approach. The initiatives discussed in this chapter, from Australia's Beyond Blue to Canada's Opening Minds, highlight the importance of combining educational efforts with personal contact and community involvement. Educational campaigns have proven effective in increasing awareness and understanding, while contact-based interventions have shown that personal stories of recovery can significantly alter public attitudes. Furthermore, legislative and policy changes play a crucial role in supporting these efforts and ensuring sustained impact. As we move forward, it is essential to continue evaluating and refining these strategies, scaling up successful approaches, and fostering collaborations between governments, communities, and grassroots organisations. By doing so, we can create a more inclusive and supportive society where individuals with mental health conditions and SUD feel empowered to seek help and embark on their recovery journeys.

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# Chapter Six: Shifting Perspectives and Future Actions

*Yifan Xu, Shuo Li*

In the ongoing battle against stigma associated with substance use disorders and mental illnesses, evolving perspectives and innovative approaches play pivotal roles. This chapter delves into the intricate dynamics of how perceptions and language shape stigma, the challenges inherent in evaluating stigma reduction initiatives, and actionable recommendations for the future. By examining debates such as the brain disease model of addiction, the functional roles of stigma in society, and the importance of person-centred language, this chapter provides a comprehensive analysis of current efforts and future directions. Ultimately, it seeks to offer a roadmap for stakeholders aiming to create a more inclusive and supportive environment for individuals affected by SUD and mental illnesses.

## *1. Functionality and Stigma*

Addressing stigma requires attention to be paid to its functional roles in society. Phelan et al. (2008) argue that the stigma associated with both SUDs and mental illnesses, whether rooted in exploitation/domination dynamics or norm enforcement, necessitates structural changes in power relations and social norms. Efforts to eradicate stigma must therefore go beyond individual attitudes to include systemic reforms that address inequalities and promote inclusive policies across healthcare, criminal justice, and social service sectors. Understanding the functional roles of stigma can guide the development of comprehensive strategies that address its root causes and manifestations.

## *2. Language and Communication Challenges*

Language norms are continuously evolving, and consensus on preferred terms among patient groups is not always achieved. However, researchers, clinicians, and others who engage with or discuss mental and substance use disorders are encouraged to use neutral, person-centred language to avoid potential stigmatisation. This approach emphasises that a disorder or illness is only one aspect of a person's life, rather than the defining characteristic. For example, it is recommended to describe someone as 'a person with schizophrenia' or 'a person with psychosis' rather than 'schizophrenic' or 'psychotic'. Similarly, rather than labelling someone with drug addiction as an 'addict' or 'abuser', they should be described as having a substance use disorder or an addiction. Likewise, someone should be referred to as 'a person with an alcohol use disorder' rather than 'an alcoholic'. The term 'alcoholic' should not be used as an adjective, either; for instance, 'alcohol-associated liver disease' is preferred over 'alcoholic liver disease' to reduce the potential stigma affecting people needing care for liver disease, including those requiring liver transplants.

Additionally, it is crucial to avoid terminology that implies a negative value judgment. For instance, when discussing suicide, it is more appropriate to say 'died by suicide' instead of 'committed suicide', as 'commit' connotes criminality or sin. Suicide attempts should be described as 'survived a suicide attempt', similar to how one might describe someone who has survived cancer or a heart attack. In substance use contexts, terms like 'clean' and 'dirty' should be avoided when referring to drug toxicology results (i.e. negative or positive urine tests), and 'clean' should not be used to describe someone who is abstinent from drugs or in recovery from a drug use disorder. Importantly, the word 'abuse', both as a noun and a verb, should be replaced by 'misuse' or 'use'. Although 'abuse' was once a diagnostic category and still appears in some surveys, its removal from the DSM-5 in 2013 marked a significant shift towards conceptualising addiction as a treatable medical condition rather than a form of misbehaviour. Despite this, the term 'abuse' remains in the names of some National Institutes of Health (NIH) Institutes studying addiction, though there is growing interest in changing these names to reflect current understandings of addiction as a disorder (Volkow et al. 2021).

The significance of language lies in its power to reflect and reinforce attitudes and behaviours. The Lancet Commission advocates for person-first language, such as 'a person with a mental health condition', over identity-first language. However, the choice of terms should ultimately rest with those directly affected. Additionally, certain terms may be stigmatising in specific languages. For instance, in Arabic, the term *soha aklia*, meaning 'mental health', can be stigmatising as it hints at impaired mental capacities. In contrast, *soha nafsia*, meaning ‘psychological health’, is preferable because it avoids these negative implications (Thornicroft et al. 2022).

Some phrases can victimise, criminalise, or misrepresent individuals with mental health conditions, such as ‘commit suicide’. Terms like ‘mental illness’ or ‘mental disorder’ can carry negative connotations, although they are used in the ICD and DSM. Despite some people viewing these diagnostic terms as devaluing labels, diagnoses are necessary for communication among health workers, individuals with lived experiences, family members, and policymakers, as well as for planning and financing treatments and care.

Effective communication strategies are essential for reducing stigma. Strategies that use personal narratives to engage audiences and highlight structural barriers to treatment are particularly promising. Current research suggests these strategies can increase public support for policies benefiting people with mental illness or substance use disorders without increasing stigma. However, communication strategies that link mental illness with violence can increase individuals’ willingness to pay taxes to improve the public mental health system, but they also elevate stigma. Messages focused on barriers to treatment offer a compelling alternative to stigmatising, violence-focused messaging for advocates and policymakers interested in promoting policies to strengthen the treatment system (McGinty et al. 2018).

Considering the high burden of substance use disorders around the world, particularly the ongoing opioid epidemic, it is critical to develop new communication strategies that can increase public support for evidence-based public health and medical policies to prevent and treat the morbidity and mortality associated with substance use disorders. Communication efforts should focus on specific policies with proven benefits, such as harm reduction initiatives, safe consumption sites, syringe exchange programmes, and increasing access to medication-assisted treatment for substance use disorder.

## *3. Challenges in Evaluating Stigma Reduction Initiatives*

Evaluating the effectiveness of large-scale stigma reduction initiatives presents significant methodological challenges. Studies often rely on non-randomised designs, self-reported data susceptible to social desirability biases, and inadequate differentiation of attitudes towards different behavioural health disorders. Moreover, longitudinal assessments are hindered by the lack of baseline data and standardised outcome measures that capture nuanced changes in stigma perception over time. Comprehensive evaluations must address these limitations by employing robust methodologies that measure behavioural outcomes, financial costs, unintended consequences, and long-term sustainability across diverse populations and intervention settings (National Academies of Sciences, Engineering, and Medicine 2016).

Specific challenges in assessing the impact of large-scale stigma reduction initiatives include discrepancies in survey methodologies, limited data granularity that obscures community-level impacts, and inadequate representation of minority experiences. These initiatives often face barriers in measuring structural changes resulting from policy interventions and fail to adequately capture differential impacts on marginalised groups. Overcoming these challenges requires collaborative efforts to improve data collection, enhance methodological rigor, and prioritise equity in evaluating stigma reduction efforts across diverse sociocultural contexts (National Academies of Sciences, Engineering, and Medicine 2016).

## *4. Changing Perspectives*

The previous discussion on language and communication challenges illustrates the importance of how we talk about mental illness and substance use disorders. This ties into broader debates about the conceptualisation of these conditions. One such debate is the framing of SUD as a 'brain disease' to combat stigma. Proponents argue that emphasising the biological underpinnings of addiction can shift perceptions away from viewing it as a moral failing (Hall et al. 2015). This aligns with the importance of person-centred language, aiming to reduce stigma by focusing on the medical aspects of the condition.

However, critics like Dr Joan Trujols (2015) challenge this perspective, asserting that the brain disease model of addiction (BDMA) may inadvertently reinforce stigma by overshadowing the socio-environmental factors influencing addiction. This critique emphasises the need to consider the broader context of an individual's life, much like the argument for using language that reflects that a disorder or illness is only one aspect of a person's identity.

Hall et al. (2015) acknowledge the limited empirical support for BDMA's stigma-reducing effects and highlight potential unintended consequences on self-efficacy and perceived control among individuals with SUD. This underscores the complexity of stigma reduction strategies and the necessity for evidence-based approaches that integrate both medical and psychosocial dimensions of addiction and mental illness.

By examining these perspectives, we can see that both language and conceptual frameworks play critical roles in shaping public attitudes and policies. This holistic view reinforces the need for nuanced communication strategies that consider all facets of an individual's experience with mental health conditions and substance use disorders.

## *5. Recommendations for Future Action*

To advance stigma reduction efforts in substance use disorders and mental illnesses, several key recommendations emerge:

a. Research and evidence: invest in longitudinal studies that examine the long-term impacts of stigma reduction strategies on behavioural outcomes and quality of life among individuals with SUD and mental illnesses.
b. Policy and advocacy: advocate for policy reforms that integrate stigma reduction into healthcare policies, promote anti-discrimination laws, and support equitable access to evidence-based treatment.
c. Community engagement: foster partnerships between healthcare providers, advocacy groups, and community stakeholders to develop culturally sensitive stigma reduction interventions.
d. Education and training: provide training programmes for healthcare professionals and educators on stigma reduction, emphasising the use of person-centred language and empathetic communication in clinical practice and public outreach.
e. Evaluation and accountability: implement comprehensive evaluation frameworks that measure the effectiveness, cost-effectiveness, and sustainability of stigma reduction initiatives, ensuring accountability and continuous improvement.

By addressing these recommendations, stakeholders can collaborate effectively to create a more inclusive and supportive environment for individuals affected by substance use disorders and mental illnesses, ultimately reducing stigma and improving outcomes across global communities.

## 6. Conclusion

As we navigate the complex landscape of stigma reduction in substance use disorders and mental illnesses, it is clear that multifaceted strategies are essential for meaningful progress. This chapter has explored the nuanced debates surrounding the brain disease model of addiction, highlighted the critical role of language in shaping perceptions, and addressed the significant challenges in evaluating large-scale stigma reduction initiatives. The recommendations for future action emphasise the importance of research, policy advocacy, community engagement, education, and rigorous evaluation. By embracing these strategies, stakeholders can foster a more empathetic, evidence-based, and equitable approach to addressing stigma, ultimately improving outcomes and quality of life for those affected by SUD and mental illnesses. The path forward requires collaborative effort and sustained commitment to dismantling the barriers of stigma and promoting a culture of understanding and support.

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# Chapter Seven: Characteristics, causes, effects, and interventions of gaming disorder stigma: a scoping review

*Changyi Shen, Peishan Wu*

Using Arksey and O'Malley's scoping review framework, we explore the characteristics, causes, effects, and interventions of gaming disorder (GD) stigma discussed in studies from January 1, 2000, to April 10, 2024, in databases including EBSCO, Wiley Online Library, Web of Science, Google Scholar, Cochrane Library, PubMed, Ebase, CNKI, WanFang, and VIP. After three independent screenings, the two authors independently extracted and summarized the data. Ultimately, 32 studies—published between 2009 and 2024—met the inclusion criteria. From these, 10 themes of GD stigma were extracted. These included three themes related to GD stigma characteristics ("holistic stigma," "emphasis on dangerousness," and "transition from stigmatization to rectification"), three themes investigating causes of GD ("bias in media coverage," "technological panic and social control," and "cognitive differences, bias, and inadequacy"), three themes about GD stigma effects ("social exclusion and discrimination," "obstruction of seeking help," and "occurrence of mental problems"), and one theme discussing stigma intervention ("recommendations for GD stigma intervention"). After discussing and summarizing the studies, we propose a model of GD stigma formation. Future studies on GD stigma should improve research quality, expand research content and objects, increase research on stigma mechanisms, and promote the development of intervention measures, thus providing individuals in need with timely and efficient treatment, as well as a tolerant and positive recovery environment.

Gaming disorder (GD) was officially included in the *International Classification of Diseases* (11th Revision) in 2018. The International Classification of Diseases (ICD-11) defines GD as an addictive disorder with the following core symptoms: (1) persistent gaming behavior (online or offline), characterized by impaired gaming control (initiation, frequency, intensity, duration, termination, context, etc.), the prioritization of gaming over other interests and daily activities, and the escalation of gaming behavior despite the occurrence of negative consequences; (2) continuous or episodic and recurrent patterns of gaming, generally lasting an extended period (e.g., more than 12 months); (3) significant impairment in important areas of functioning (personal, family, interpersonal relationship, educational, occupational, etc.) caused by gaming; and (4) the lack of a better explanation (e.g., another mental disorder or the effects of substance abuse or medication [1].

In China, Internet games have become an important component of people's daily entertainment because of the growth and popularity of the Internet. Children and adolescents are one of the main—and growing—users of Internet games [2]. According to the "Fifth National Survey Report on Internet Use of Minors," the number of minor Internet users had reached 193 million by 2023, with 67.8% frequently playing games online (increasing 5.5% compared to 2021) and 19.6% reporting Internet dependence [3]. The GD prevalence rate ranged between 2.4% and 7.5% according to epidemiological research on the Chinese population [4]. As children and adolescents are a high-risk group for GD, the GD risk population may rise with the growing base of young game players.

Meanwhile, gaming addiction and Internet addiction have attracted increased concern from parents, teachers, and other related groups. In China, games and gamers are often portrayed negatively in daily life, although numerous studies have shown that playing games has beneficial effects, such as providing pleasure, reducing stress, relieving mood, promoting social interaction, and promoting cognitive development [5, 6]. However, negative media publicity with headlines such as "Internet Addiction," "Excessive Game Recharge," "Teenage Internet Addicts", etc. makes the public constantly vigilant and suspicious of games and GD [7]. To avoid the negative effects of gaming, some adolescents with gaming behavior are taken by parents to hospitals and even "Internet addiction schools" for treatment, even if they do not meet the typical diagnosis of GD. This often strains the parent-child relationship and causes family conflicts [8]. In short, gaming, game behavior, game players, and GD patients face stigmatization in China.

Stigma is a common and cross-cultural phenomenon, occurring when unique or unusual characteristics of individuals are identified as deviations from social norms or morality. Stigmatized individuals may face problems such as labeling, separation from mainstream society, loss of status, and discrimination [9]. In the area of addiction, stigmatization reduces sufferers' motivation for treatment and prevents beneficial transformation. Accordingly, knowledge about how addiction stigmatization works could help to reduce stigma, and so help addicts receive timely treatment and intervention. Previous stigma studies have mainly focused on substance addiction.

Few studies have paid attention to GD stigma and there is still no review for GD stigma. Existing studies on GD have mainly concentrated on epidemiology [4], pathogenesis [10], effect factors [11], negative outcomes [12], and interventions [13]. In this chapter, we analyze current GD stigma studies based on Arksey and O'Malley's scoping review framework and summarize relevant studies using four aspects: stigma characteristics, causes, effects, and interventions. Our goal is to provide a knowledge map and ideas for future research.

## *1. Materials and methods*

### 1.1 Research questions and inclusion criteria

This chapter answers the following questions: (1) the characteristics and manifestations of GD stigma; (2) the causes of GD stigma; (3) the effects of GD stigma; and (4) how to reduce the stigma of GD.

Following Arksey and O'Malley's “PCC' principle” [14], the inclusion criteria included three elements. (1) Participants: We investigated GD stigma in various groups of people, so all types of populations were included. (2) Concept: The key concepts of this study are GD and stigma. However, we expanded the retrieval scope of GD to get more comprehensive materials, because while the concept of GD was formally introduced in 2018, concerns about “Internet Addiction” have existed longer. Additionally, to achieve more comprehensiveness, we enlarged the definition of stigma because stigma is highly subjective. (3) Context: Stigma may occur anywhere, so our context was broad.

The exclusion criteria of our study included: (1) studies in which the full text was not available; (2) studies not written in Chinese or English; (3) studies that have been published repeatedly; (4) studies not published formally; and (5) studies that did not cover GD stigma in their core conclusions.

### 1.2 Search strategy

We searched English databases including EBSCO, Wiley Online Library, Web of Science, Google Scholar, Cochrane Library, PubMed, and Ebase. Chinese databases included CNKI, WanFang, and VIP. We used English and Chinese search terms as presented in Table 1. Table 2 shows an example of our search strategy. The search included citations formally published from January 1, 2000, to April 10, 2024.

*Table 1 Search terms for GD stigma studies*

| Concept | Concept 1<br>Gaming disorder | | Concept 2<br>Stigma | |
|---|---|---|---|---|
| Search terms | Chinese:<br>Internet addiction OR gaming addiction OR Internet overuse OR smartphone addiction OR video game disorder OR game OR problematic Internet gaming OR problematic smartphone gaming OR video gaming OR online game OR electronic sports OR e-sports OR phone game OR smartphone gaming OR smartphone game dependence OR game dependence OR smartphone dependence | English:<br>gaming disorder OR Internet gaming disorder OR problematic smartphone use OR problematic social networking site use OR problematic gaming OR gaming behavior OR gamer | Chinese:<br>stigma OR stigmatizing attitudes OR stigmatization OR discrimination OR social exclusion OR social discrimination OR prejudice OR label OR attitudes | English:<br>stigma OR stigmatization OR social stigma OR discrimination OR social discrimination OR stereotyping OR stereotype OR prejudice OR misconceptions OR beliefs OR perceptions OR opinions OR attitudes OR perspectives OR experiences OR views OR shame OR blame OR label OR harm OR disadvantage |

*Table 2 Example of search strategy in Chinese and English databases*

| Database (example) | Search strategy | Number of search outcomes |
|---|---|---|
| PubMed | (("Stigma"[Title/Abstract] OR "Stigmatization"[Title/Abstract] OR "social stigma"[Title/Abstract] OR "Discrimination"[Title/Abstract] OR "social discrimination"[Title/Abstract] OR "Stereotyping"[Title/Abstract] OR "Stereotype"[Title/Abstract] OR "Prejudice"[Title/Abstract] OR "Misconceptions"[Title/Abstract] OR "Beliefs"[Title/Abstract] OR "Perceptions"[Title/Abstract] OR "Opinions"[Title/Abstract] OR "Attitudes"[Title/Abstract] OR "Perspectives"[Title/Abstract] OR "Experiences"[Title/Abstract] OR "Views"[Title/Abstract] OR "Shame"[Title/Abstract] OR "Blame"[Title/Abstract] OR "Label"[Title/Abstract] OR "harm"[Title/Abstract] OR "disadvantage"[Title/Abstract]) AND ("gaming disorder"[Title/Abstract] OR "internet gaming disorder"[Title/Abstract] OR "problematic smartphone use"[Title/Abstract] OR "problematic social networking site use"[Title/Abstract] OR "problematic gaming"[Title/Abstract] OR "gaming behavior"[Title/Abstract] OR "gamer"[Title/Abstract])) AND (2000/1/1:2024/4/15[pdat]) | 268 |
| CNKI | (Subject:(stigma + attitudes + stigmatizing attitudes + stigmatization +discrimination + social exclusion + social discrimination + prejudice +label)) AND (Subject:(Internet addiction + gaming addiction + Internet overuse +smartphone addiction + video game disorder + game + problematic Internet gaming + problematic smartphone gaming + video gaming + online game + electronic sports + e-sports + phone game + smartphone gaming +smartphone game dependence)) | 3087 |

### 1.3 Study selection and data extraction

All citations were imported into EndNote X9 after the search to remove duplicates. Following the inclusion and exclusion criteria, three researchers then screened the citations independently by browsing the titles and abstracts, and subsequently reviewed full texts for further selection. For studies the researchers disagreed on including, a decision of whether to include it was made in discussion by the three researchers. Two researchers then extracted the following data from the studies that were included: authors, country, publication date, article type, study type, study design (study subjects, sample size, methods, and data collection tools), and conclusions (characteristics and manifestations, causes, effects, and interventions of stigma).

## *2. Results*

### 2.1 Search results

A total of 4,036 studies were identified from relevant databases, comprising 3,168 published in Chinese and 868 published in English. After screening, 32 studies from 17 countries were included. Figure 1 presents the flowchart describing the screening process.

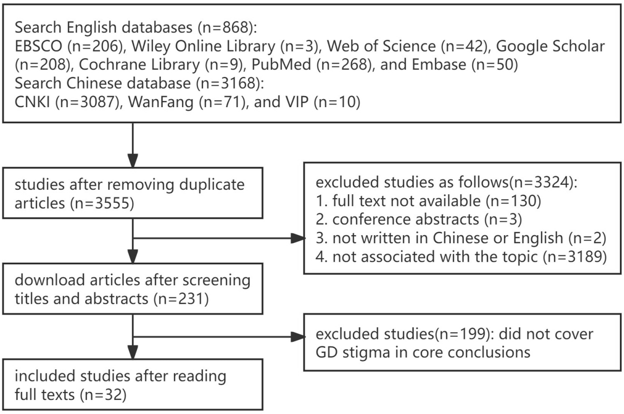

*Figure 1 Flowchart of study screening*

### 2.2 Study characteristics

The included 32 studies [7, 15-45] were published between 2009 and 2024. They encompass data on 10,939 participants across different populations and include 6,315 reports. We analyzed and summarized the general characteristics of the 32 studies by country, article type, study type, methodology, study subject, and study situation. The overall distribution is presented in Table 3. In addition, we summed up the studies' conclusions and abstracted information about the study target, data collection tools and analysis methods, characteristics and manifestations of stigma, causes of stigma, effects, and interventions of stigma. These summaries are included in Annex 1. Our analysis identified 10 themes of GD stigma: three themes relevant to characteristics, one related to causes, three concerning its effects, and one discussing interventions.

*Table 3 General distribution of included studies*

| Characteristics | Type and numbers |
|---|---|
| Country | China (n=16) [Mainland China (n=15), Hong Kong (n=1)]; Australia (n=3); USA (n=2) ; Germany (n=1); Japan (n=1); South Korea (n=1); Hungary (n=1); Italy (n=1); UK (n=1); Indonesia (n=1); Transnational study (n=4) |
| Article type | Research article (n=21); Thesis dissertation (n=6); Commentary (n=3); Letter (n=1); Letter to editor (n=1) |
| Study type | Qualitative research (n=7); Quantitative research (n=15); Mixed methods research (n=5); N/A (n=5) |
| Study subject (a) | Reports (n=9); Gamers (n=5); Public (n=9); Medical professionals (n=2); Students (n=4); Teachers (n=2); Parents (n=1); ACG* fans (n=1); N/A (n=5) |
| Study situation (b) | Online (n=12); Media materials (n=10); School (n=5); Treatment facility (n=2); Cybercafe (n=1); N/A (n=5) |

### 2.3 Characteristics of GD stigma

Among the 32 studies, 29 studies referred to the characteristics of GD stigma [7, 15-22, 24-28, 30-45]. After analyzing the conclusions of these 29 studies using thematic analysis, we abstracted three central themes of GD stigma characteristics: boundary ambiguity, emphasis on dangerousness, and the transition from stigmatization to rectification.

#### 2.3.1 Holistic stigma

Despite the ICD-11 clearly describing the diagnostic criteria of GD, consensus has not been reached in the scholarly literature. Consequently, GD stigma appears to have the characteristic of a "holistic stigma;" namely, the general public receives and incorporates concepts without clear boundaries (such as games, gaming behavior, problematic Internet use, gamers, gaming disorder, etc.) and stigmatizes these activities broadly and "holistically." In total, 10 studies discussed "holistic stigma." We identified two manifestations of "holistic stigma": (1) controversy over GD diagnosis and (2) boundary ambiguity.

Controversy has persisted since the inclusion of GD in the ICD, with the central topic of whether GD diagnosis leads to increased stigmatization. Four of the included studies discussed the issue. Galanis et al. [16], Kiraly et al. [21], and Pontes et al. [30] expressed concerns that the inclusion of the GD diagnosis in the ICD may stigmatize casual gamers. They also worried the inclusion may lead to misdiagnosis of highly engaged but non-problematic gamers. These three studies also indicated the existence of GD-related problems and suggested that more specific diagnostic criteria would both increase public attention to GD and reduce stigma. They also called for further research to verify the arguments. Reviewing data from the National Hospital in Japan, Higuchi et al. [19] indicated that game-related stigma had existed before the publication of ICD-11, so it is not exclusively a product of GD diagnosis. Furthermore, they argue that clear diagnostic criteria would help distinguish between normal game behavior and addictive behavior in order to improve the ability and quality of diagnosis and intervention. Although numerous scholars argue that clear diagnosis criteria for GD can reduce stigma, most of them emphasize its positive effects on diagnosis and treatment from a medical rather than a social perspective. More research is thus needed to explore the role of GD diagnosis in reducing social discrimination and exclusion.

From the perspective of social cognition, it is often difficult for the general public to distinguish concepts such as game, gaming behavior, problematic gaming, gaming addiction, and gaming disorder. In daily narratives, problems such as overgeneralization, concept confusion, and concept misapplication often occur, showing the boundary ambiguity of GD stigma. Six studies referred to this problem. To investigate the public stigma towards different types of gamers, Galanis et al. [17] investigated public stigma toward different types of gaming. They conducted a randomized controlled trial and reported the existence of stigma across all types of gamers. They also found that gamers meeting the criteria of GD faced the highest levels of stigma, while the level of stigma against casual and regular gamers was relatively low. The study also indicated that health information had no significant effect on stigma and stigma was related to the severity of gaming behavior. Wong et al. [32] interviewed adolescents in Internet cafes in Hong Kong and found that those young people were worried about being regarded as "teenage Internet addicts" by teachers and parents for their gaming behavior in Internet cafes. In their perception, playing games in an Internet cafe was often equated with being an Internet addict. Monley et al. [28] reported that the general public viewed all gamers as potential problematic gamers, without distinguishing between healthy gaming and problematic gaming. Additionally, holistic stigma was quite prevalent in media reports. In China, games and gamers were often associated with negative consequences such as drugs and crimes. This is concretized in a media framework that frames games as harmful to youth and may cause some of the stigmatization.

### 2.3.2 Emphasis on dangerousness

An emphasis on dangerousness is the most significant characteristic of GD stigma. It has two specific manifestations: (1) associating gaming with negative concepts such as crime, immorality, and incompetence; (2) emphasizing the negative consequences of gaming. Of the studies we analyzed, 22 studies addressed this topic.

Associating gaming with negative concepts such as crime, immorality, and incompetence refers to people's tendency to view gaming behaviors and gamers as contrary to social ethics and dangerous. Eight of the studies summarized the social images of games and gamers in Chinese media reports, reporting that in early years games were described by the media as "flood and monster," "electronic heroin," and "electronic opium" [7, 34, 36]. These descriptions linked games with concepts such as crime and substance abuse, implying that games are harmful and addictive, which also contributed to the construing of gamers as criminals, immoral, and incompetent individuals. Specifically, game players were described as: (1) people with negative traits (callous, withdrawn, violent, impulsive, irritable, etc.); (2) troubled teenagers or people with negative behaviors (truancy, violence, crime, and other extreme behaviors); (3) victims of addictive gaming (with physical and mental problems, suffering academic failure and employment difficulties, and even dying due to over-gaming) [7, 34, 38, 41, 42, 44, 45]. In addition to media portrayals, eight studies investigated games' and gamers' images in other populations and found similar results. Li et al. [39] found that the public perceived ACG culture (a subculture centered around animation, comics, and games) as in conflict with mainstream values and as having immoral components. According to this study, the public considered ACG fans to be deviant and lacking moral fiber. Zhao et al. [33] reported that in the marriage market, gamers were commonly considered to be aggressive, socially incompetent, and lazy, and therefore less likely to be chosen as a marriage partners. Yan et al. [43] analyzed college students' perceptions of games and indicated that college students often attached negative characteristics (e.g., wasting time, wasting money, addictive, isolated from reality, with monotonous gameplay patterns, full of violence, fraud, and pornography, etc.) to games. Liu et al. [40] investigated teachers' attitudes toward online games and reported that teachers tended to view teenagers who played online games as being mischievous, unmotivated, and socially inept. They also found that teachers perceived gaming to affect learning, induce violent tendencies, and lead to exposure to pornography or other unhealthy information. Miriyagalla et al. [27] reported that people tended to assume players of high-violence games may have moral problems, including negative traits such as unkindness and lack of sympathy. Kuss et al. [24] and Lopez-Fernandez et al. [26] note an additional stigma faced by female gamers: women were often considered unsuitable for games, not affected by gaming addiction, and not even real gamers, which resulted in further discrimination and marginalization as well as sexualization and objectification that prevented them from seeking help. Monley et al. [28] compared the attitudes of the American public toward gamers and non-gamers and indicated that adult non-gamers may have the stereotype of gamers as lonely young males with poor social skills. Although some studies have demonstrated that relevant stereotypes do not correspond to the actual images of gamers [23], the perceptions of games and game-related things were mostly negative across most groups.

Another significant manifestation of the perceived danger of gaming is revealed in the focus on gaming's negative consequences. A total of seven studies mentioned the negative opinions of different populations about gaming in their conclusions. Those opinions can be divided into two categories, one addressing negative biopsychosocial consequences and the other discussing intervention effects of GD. In terms of negative biopsychosocial consequences, five studies indicated a common belief among different populations that GD can cause impairment in personal, family, interpersonal, educational, occupational and other fields, specifically manifesting as: (1) Conflict between gaming and daily life: Individuals immersed in games would ignore daily activities and responsibilities, thus interfering with normal socialization and possibly resulting in academic and career failure, and even crime; (2) Reduction in social interaction: Individuals immersed in games would reduce real-life social interaction, contributing to less social support, interpersonal frustration, social avoidance, and a sense of loneliness; (3) Health problems: Long-term gaming may inflict physical problems (e.g., visual and auditory damage, cardio-cerebrovascular disease, obesity, cervical spondylosis, sudden death, etc.), and may increase the risk of anxiety, depression, sleep disorders, addiction, and other mental disorders; and (4) Family relationship problems: Indulgence in games may stimulate conflicts between family members and teenagers [18, 20, 25, 28, 32].

Additionally, Casale et.al [15] compared the stigma of Internet game disorder, problematic smartphone use, and problematic social networking site use, and revealed that the public considered symptoms of Internet game disorder to be more severe and difficult to control. In terms of GD intervention effects, two studies examined the perceptions of medical professionals toward GD treatment. These studies indicated that professionals recognized the risks and causes of GD, but there were cognitive differences in treatment efficacy and controllability of GD. Hanafi et al. [18] reported that psychiatrists view GD as a chronic disease that is difficult to control. Koski-Jännes et al. [22] compared the attitudes of addiction treatment professionals from Finland and France toward GD and gambling disorders, and reported that French professionals had less confidence in GD treatment, and considered GD harder to cure.

### 2.3.3 Transition from stigmatization to rectification

Despite the persistence of GD stigma, there has been a gradual transition from stigmatization to rectification, which was reported in six of the studies we reviewed. Miriyagalla et al. [27] surveyed 1,084 people about stereotypes of gamers and found that their stereotypes were overall positive, in contrast to the negative impressions generally reported in previous studies. The transition is particularly evident in Chinese media. Five studies investigated the variation of game-related media coverage in China and revealed that there was a gradual change from homogeneous negative reports to more pluralistic and balanced content, as well as a transition from media attitudes focusing on the negative aspects of gaming to more focus on games' economic and cultural value [34-36]. He et al. [37] described this transition as “from e-heroin to created in China.” The media portrayals of gamers have also become more varied from the original “deviants” and “teenage Internet addicts” to include “athletes” and “e-sports talents” following the development of the electronic sports industry.

## 2.4 Causes of GD stigma

A total of 17 studies referred to the causes of GD stigma in their conclusions. After thematically analyzing the conclusions of these 17 studies, we abstracted three themes about the cause of GD stigma: bias in media coverage, moral panic and social control, as well as cognitive differences, bias, and inadequacy.

### 2.4.1 Bias in media coverage

Bias in media coverage is one cause of GD stigma. According to Walter Lippmann, news reporting is a process of selecting and processing objective reality to form symbolic reality [46]. Consequently, the way media processes and shapes the image of games determines how people view things related to games. Screening the citations, we found 13 studies suggested that negative media coverage or reporting bias is a contributory cause of GD stigma [7, 21, 25, 27, 30, 33, 34, 36-38, 41, 42, 44, 45].

There are two forms of media coverage bias. One is adopting methods that highlight adverse consequences, thus associating games, GD, and gamers with crimes, immorality, and other negative images through labeling and demonizing [7, 25, 27, 30, 33, 36, 37, 45]. Additionally, to increase attraction, the media often exaggerate conflicts and contradictions in reports and use emotional expressions to dramatize the stories, which reinforces the stigmatization of games, GD, and gamers [21, 34, 36, 38, 41, 44]. The other form of media coverage bias is to deprive relevant people of the right to speak and adopt an outside perspective.

### 2.4.2 Technological panic and social control

Technological panic and social control are environmental causes of GD stigma. Seven studies referred to this theme. The growth of the gaming industry has been driven by the rapid development of technology and the gaming business, which also raises concerns about potential risks, including technological panic about GD. This technological panic often results in more social control, such as unreasonable restrictions and regulations on the gaming industry, which also affects the image of gaming as normal entertainment [7, 30, 34, 36-38, 42]. In China, the image of the gaming industry has experienced a shift from negative to positive over its development. Likewise, public policies have transitioned from strict regulation and crackdowns in the early years to support for the development of the gaming industry in recent years. Nevertheless, because of the long-term supervision and restrictions of the gaming industry, people still hold negative attitudes toward games, gamers, and GD to some extent [7, 42]. Furthermore, despite the implementation of more new policies on the regulation and development of the gaming industry, changing the public's cognitive bias toward games and game players is still a challenge [34, 38].

### 2.4.3 Cognitive differences, bias, and inadequacy

Differences and bias in cognition are cognitive contributors to GD stigma. Seven studies referred to this issue. Besides the impact of media bias on public cognition, different populations reveal differences in their understanding of normal gaming behaviors and GD. A study on Indonesian psychiatrists' perceptions of GD noted that 85% of psychiatric residents lacked adequate knowledge of GD to effectively diagnose and treat it [18]. Kiraly et al. [21] considered whether the public actually understands the definition of GD or confuses it with normal gaming entertainment. They also noted how the inclusion of GD as an official psychiatric disorder also contributes to the stigmatization of GD patients as psychotics. Lee et al. [25] indicated that the public tendency to view GD simply as a personal problem rather than a widespread social-cultural phenomenon would aggravate stigma, similar to how alcoholism is often reduced to personality problems. Wong et al. [32] revealed that parents and teachers lacked understanding of games and were unable to distinguish among GD, internet addiction, and normal gaming behaviors, which encouraged the stigmatization of GD. He Pengpeng considered that the lack of scientific education and research on GD has led to a superficial understanding of GD, preventing the public from realizing the essence of GD and dealing with it properly [36].

Intergenerational cultural differences also contribute to stigma between generations. Older East Asian generations often emphasize educational and professional achievements, personal responsibility, and compliance with social norms. On this view, gaming implies a waste of time, a distraction from daily activities, and even irresponsibility and immorality, which results in the moral condemnation of gamers by older generations [34, 36]. Li et al. [39] noticed that the differences and conflicts between ACG and mainstream cultures also fostered concerns, biases, and even stigma among the mainstream population regarding the internet usage and gaming behaviors of ACG fans.

### 2.5 Effects and interventions on GD stigma

A total of 22 studies referred to the effects and interventions of GD stigma in their conclusions. Among them, 18 studies explored the impact of GD stigma. We abstracted three themes from these: social exclusion and discrimination; increased difficulties in seeking help; and the occurrence of mental problems. Regarding interventions on GD stigma, one study discussed the impact of different types of information on public perceptions of GD and 11 studies suggested interventions only in their conclusions. We summarized these ideas as “recommendations for GD stigma intervention.”

#### 2.5.1 Social exclusion and discrimination

The most direct effect of GD stigma is social exclusion and discrimination toward both those living with GD and normal gamers [15, 16, 19, 21, 28, 30, 32, 33, 39, 41, 42, 45]. This is manifested in the following ways: further social distance [15, 21, 28, 30, 44], stronger negative emotional reactions (mainly anger and blame) from the public [15], less understandability [15, 42], restrictions in marriage, employment, and education [16, 33, 41], and cultural exclusion and closure [32, 39, 45].

### 2.5.2 Increased difficulties in seeking help

Social exclusion and discrimination also make help-seeking more difficult for those living with GD [16, 17, 22, 24, 26, 28-30, 32, 33, 41], which is manifested in the following two aspects. One is the level of helpers' willingness to offer assistance. In a study among Finnish and French addiction treatment professionals, Koski-Jännes et al. [22] reported that perceptions of GD individuals affected professionals' willingness to treat patients as well as the application of treatment methods, especially when they viewed GD as more difficult to cure or as an individual problem. Furthermore, Peter et al. [29] indicated that people were less willing to help GD patients with financial difficulty. The second is that stigmatized people may be reluctant to seek help or have difficulty expressing their needs. Studies have found this is particularly prevalent among female gamers or patients. Kuss et al. [24] suggested that stereotypes about women may lead the public to ignore the negative impact of gaming behaviors on their lives, and thus ignore the possibility that they could be GD patients. Lopez-Fernandez et al. [26] reported that GD may not be fully recognized in the female population, making it more difficult for female patients to get treatment and support.

### 2.5.3 Occurrence of mental problems

The social exclusion and help-seeking obstruction caused by GD stigma can further induce or exacerbate mental health problems of patients, specifically manifested in psychological distress (e.g., impaired self-identity, low self-esteem, self-blame, and self-stigma) [16, 41, 44] and aggravated psychiatric problems (e.g., anxiety, depression, social phobia, and GD) [16, 28, 32].

### 2.5.4 Recommendations for GD stigma intervention

The existing empirical studies on GD stigma interventions are still insufficient. Only one study we reviewed specifically investigated the effects of different types of information in intervening in people's perception of GD, referred to the effects of different types of information on perceptions of GD. Ren et al. [31] reported that narrative messages were more effective in making adolescents adopt the medical view of GD. They further found that improving immersion in narratives can effectively affect their attitudes, while the adolescents. Another 11 studies [16, 19, 21, 25, 28, 34, 36, 41, 42, 44, 45] only outlined the main directions for stigma intervention. These include: (1) strengthen studies on GD, including empirical research on GD stigma, studies on the impact of GD diagnosis (e.g., on public perceptions, public health, and society), studies on GD intervention and prevention, and transnational scientific cooperation; (2) promote the standardization and popularization of the GD diagnostic system; (3) strengthen education and increase health promotion activities to raise public awareness of GD; (4) stress media responsibility and appeal for coverage based on gamers' perspective and multiple perspectives, as well as calls for media neutrality, increasing positive reporting, attention to individual differences, etc.; (5) improve social support for gamers, patients, and other relevant groups; (6) improve system construction and focus on the social responsibility of gaming companies.

## *3. Discussion*

### 3.1 Improvement of study quality and expansion of study content

Several selected citations showed that stigma studies on topics such as games, gamers, and GD had existed long before the inclusion of GD in the ICD-11. This suggests that GD stigma is a long-standing social and cultural phenomenon. For the studies we reviewed, there are two problems.

The first is the lack of high-quality studies on GD stigma. Among the included studies, only three of the 15 quantitative studies designed experiments to compare differences in GD stigma among the public [15, 17, 29]. Only four of the remaining 12 studies used scales for measurement [18, 23, 26, 33]. These included: (1) outcome indicators related to stigma level, including social distance, general stigma level, stigma attribution, dangerousness, perceptibility, and exposure level, etc.; (2) outcome indicators related to illness perception, including perceptions of addictive disorders, GD, and problematic gaming; (3) outcome indicators related to stigma consequences, including similarity in mate selection, mental health level, coping strategies, social motivation, and self-identity. The other eight studies used self-made questionnaires to evaluate outcome indicators related to GD stigma.

It is thus clear that there is still an absence of effective and accepted measurement tools for assessing stigma and relevant outcome indicators around GD. Because stigma is always complex, further research is needed to assess whether the existing outcome indicators can comprehensively reflect the multiple dimensions of stigma. Moreover, cultural difference is another essential background factor that needs to be considered in stigma research. Furthermore, how to define GD is also a key issue in GD stigma studies. Although the diagnostic criteria for GD were not established until 2018, the concepts of gaming addiction and Internet addiction had appeared in previous studies. It is thus important for researchers to determine whether these concepts are the same as GD.

Secondly, the topics and objects of GD stigma studies need to be further expanded. Existing studies focus primarily on describing how stigma manifests, the overall level of stigma, and differences based on different levels of gaming engagement, etc. In contrast, studies on GD stigma formation mechanisms and interventions are lacking. As for the objects of study, existing studies focus on the media, the public, and gamers. The relationship between media and GD stigma has been particularly popular in China [7, 34-38, 41, 42, 44, 45], where the media sources are mainly from mainstream media reports such as People's Daily. However, in recent years, newly emerging media types, such as self-media and we-media, have been continuously expanding their influence on public perception. Therefore more research is needed on the roles of different types of media. Moreover, in China, the issue of GD stigma is not just related to media coverage. The effect of parents, teachers, and gamers (especially adolescents) on GD stigma all need more scholarly attention.

### 3.2 GD stigma formation model

Based on the scoping review of the 32 included studies, this study integrated the manifestations, causes, and effects of GD stigma to propose a model of GD stigma formation. In this model (shown in Figure 2), cognitive differences, bias, and inadequacy are the cognitive bases for GD stigma formation, which determine individuals' original perceptions of concepts such as gaming, GD, and gamer. In this process, GD stigma has already developed to a certain extent in some groups due to cultural differences and the stigma of mental disorders. Technological panic and social control are the environmental bases of GD stigma formation, which induce negative perceptions and value orientation about games and the gaming industry, potentially contributing to the negative cultural and value environment for GD stigma. Of course, with the reduction of panic and the loosening of social control, such values and perceptions could turn neutral or even positive. Since technological panic and social control are affected by media reporting, media coverage bias contributes to the formation of GD stigma, particularly by constructing specific negative images and emphasizing the negative values of gaming culture. Meanwhile, GD stigma creates biopsychosocial dilemmas for individuals, which in turn provides more negative materials for media coverage.

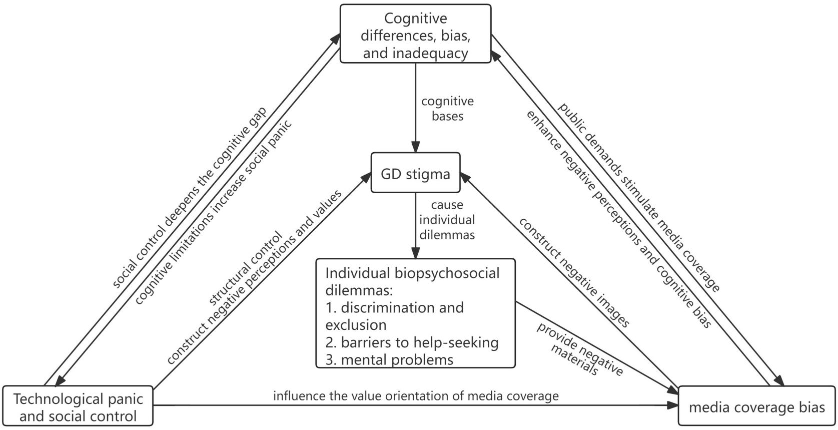

*Figure 2 Model of GD stigma formation*

Cognition, environment, and media also interact with each other, in addition to influencing GD stigma. Differences, bias, and inadequacy in cognition increase public panic toward technology and promote the strengthening of social control, which further prevents the public from better understanding game-related things. Furthermore, technological panic and social control influence the value orientation of media coverage, increasing negative reports and thus contributing to cognitive divergences and bias. At the same time, public discontent with the negative consequences of gaming behavior also encourages the media to report negative information. Thus, we can see that GD stigma is a complicated process, and therefore interventions against stigma rely on cooperation across multiple systems and fields.

## *4. Deficiencies and prospects*

This study only described and summarized the included literature without conducting rigorous quality and reporting assessment of its own. Additionally, the GD stigma formation model proposed above is an ideal model based on summarizing the conclusions of the included studies. This means it lacks evidence to verify its effectiveness and only provides theoretical reference for future studies.

With the advancement of the gaming industry and the spread of gaming culture, there would be an expected expansion of the gaming population base and, consequently, an increasing risk of GD. This warrants that more attention be given to GD stigma research. Our analysis suggests that future research should concentrate on the following aspects:

First, the development and screening of GD stigma measurement tools should be intensified. It is also necessary to increase qualitative studies to explore the concept connotation of GD stigma through interviewing different populations, as well as developing GD stigma scales on this basis. Also, in quantitative studies, the design of outcome indicators and the selection of measurement tools should be improved to enhance methodological quality.

The second aspect is to expand the content and objects of studies. Future research should concentrate on the mechanism of GD stigma formation—especially on the cognitive, environmental, and media factors proposed in the model above—to obtain quantitative evidence and confirm the causal relationships among these factors. Furthermore, because the stigmatization of GD is a dynamic process, more longitudinal studies are needed in addition to cross-sectional studies to better understand the formation and development of GD stigma. Relatedly, GD stigma intervention is also an important research direction. Future studies could try to construct systematic intervention models for GD stigma through intervention attempts at the macro, meso, and micro levels. In terms of study objects, our analysis suggests increasing targeted studies on different populations, especially on groups related to GD stigma, such as teachers, parents, patients, and normal gamers.

The final aspect is to validate the theoretical model proposed in this study. Based on the literature review, we presented a GD stigma formation model that summarized the roles of cognitive, environmental, and media factors in stigma formation. Though more empirical studies are needed to validate the model, it provides a framework for future studies to conduct validation, optimization, and refinement.

It is undeniable that GD stigma exists in the public and media, causing problems for both gamers and patients. Further research is needed to explore the mechanism of GD stigma and to develop research-based intervention tools aimed at providing timely and effective treatment, as well as a tolerant and positive rehabilitation environment for individuals in need.

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## *Annex1: Characteristics of included studies*

| First author and published year | Study target | Data collection tools and analysis methods | Conclusions | | | |
|---|---|---|---|---|---|---|
| | | | Characteristics and manifestations of GD stigma | Causes of GD stigma | Effects of GD stigma | Intervention recommendations |
| Silvia Casale, 2023 | To compare public perception towards Internet game disorder, problematic smartphone use, and problematic social networking site use | 1. Questionnaire: Illness Perception Questionnaire (IPQ-R), Blame/Personal responsibility subscale of the Universal Stigma Scale (USS), The Vanity Attribution Scale (VAS), Dangerousness subscale of the Attribution Questionnaire (AQ), Social Distance Scale (SDS), Concealability/Noticeability measure.<br>2. Analysis methods: chi-square | 1. Internet game addiction is more serious and symptomatic, easily viewed as a moral issue, and difficult to be understood by others.<br>2. Problematic smartphone use is less dangerous and relatively controllable.<br>3. Problematic social networking site use is a milder form of addiction, motivated by demands of social intercourse rather than addictive behaviors. Patients often have obvious vanity and are easier to be blame. | N/A | 1. More severe negative emotional reaction<br>2. Further desired social distance<br>3. Less understandability | N/A |

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| | | test, Mann-Whitney U test | | | | |
| Christina R. Galanis, 2023 | To explore the effects of GD information on public stereotypes of gamers | 1. Questionnaire: Attribution Questionnaire (AQ), Universal Stigma Scale (USS)<br>2. Analysis methods: Two-way analysis of variance (ANOVA), Tukey post hoc analysis, Repeated-Measures ANOVA, Bayesian analysis | 1. Problem gamers gained higher stigma scores than regular gamers and casual gamers.<br>2. Health information had no significant effect on stigma scores.<br>3. On the blame and responsibility subscale of the USS, participants in the addition group gained lower scores than participants in the non-addiction group, suggesting that addiction information may reduce blame and responsibility towards gaming behavior. | N/A | 1. Impaired self-identity<br>2. Social isolation<br>3. Anxiety and depression<br>4. Disorder for help-seeking<br>5. Self-discrimination<br>6. Stigma transmission<br>7. Employment and education restrictions<br>8. Aggravate symptoms | N/A |
| Christina R. | 1. Call for research to test stigma-related | N/A | 1. Risk of stigma: The inclusion of GD into the formal diagnosis system | N/A | 1. Effects on the gaming industry: By using its public platform and | 1. Most of the current stigma-related arguments are based on speculation, |

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| Galanis, 2021 | arguments against GD<br>2. Explore the effects of GD diagnosis on public attitudes, gamer communities, and regulation policies<br>3. Emphasize the need to scientifically evaluate the effects of GD diagnosis in terms of public health and public perception | | may stigmatize casual gamers, especially young people.<br>2. Misdiagnosis: GD diagnostic guide may mislabel highly engaged but non-problematic gamers as pathological gamers. | | force, the global gaming industry's support for scholars who challenge GD would influence the diagnosis acceptance and research of GD.<br>2. Effects on policy and treatment: It has been proposed that GD diagnosis would lead governments to conduct restrictive regulatory measures and unsafe treatment protocols, which has negative effects on gamers and the whole society. | therefore more studies are needed to test whether GD diagnosis leads to stigma.<br>2. The effects of GD diagnosis on different types of players, including casual gamers and problematic players, need to be studied to explore its influence on public perception.<br>3. The public health and social effects of GD diagnosis need to be scientifically evaluated through rigorous research rather than intuition. |
| Enjeline Hanafi, 2019 | To determine the perception of Internet addiction among psychiatric residents in an ur- | 1. Questionnaire: the illness perception questionnaire revised version for addiction (IPQ-A), | In the residents' perspective, Internet addiction is:<br>1. emotionally stressful;<br>2. understandable;<br>3. cyclical; | 1. Lack of knowledge: 85% of surveyed residents felt their current knowledge of Internet addiction was inadequate | N/A | N/A |

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|  | ban area of Indonesia | self-made questionnaire<br>2. Analysis methods: Two-way ANOVA, Tukey post hoc analysis, Repeated-Measures ANOVA, Bayesian analysis | 4. difficult to control;<br>5. a chronic disorder ;<br>6. addiction that may cause significant impairment in personal, family, social, educational, occupational, or other important areas of life. | to make diagnosis and management decisions.<br>2. Education: Senior residents presented a deeper understanding of the consequences of Internet addiction than junior residents, suggesting that education and clinical experience may improve the perception of Internet addiction.<br>3. Uncertainty in diagnosis and management: Lack of perception and knowledge leads to uncertainty of residents in diagnosis and management of Internet addiction. |  |  |
| Susumu Higuchi, 2017 | To emphasize the necessity of recognizing GD as a diagnosis category in the | N/A | Existing stigma | N/A | Stigma may influence policy making and induce unfair treatment or discrimination against gamers. | 1. Prevent stigma: Defining functional impairment as a core criterion of GD to prevent overdiagnosis and moral panic. |

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| | ICD-11, and demonstrate its positive effects on clinical practice, research, and policy development. | | | | | 2. Avoid overdiagnosis: Clearly defining the criteria of GD in the ICD-11 can help to reduce overdiagnosis and stigma.<br>3. Improve stigma-related situations: Drawing a clear boundary between normal play and GD can improve stigma-related situations. |
| Zaheer Hussain, 2009 | To explore the attitudes, feelings, and experiences of online gamers | Semi-structured interviews; thematic analysis | 1. Self-recognition of addiction<br>2. Negative effects of game addiction: immersiveness of game, time management issues, social effects and personal consequences of addiction<br>3. A metaphor for addiction: Compare MMORPGs to “new cocaine”, emphasizing high | N/A | N/A | N/A |

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| | | | addictive potential of them.<br>4. Cognitive ambiguity in addiction criteria<br>5. Prevention and control of addiction | | | |
| Orsolya Király, 2017 | To support the inclusion of GD in the ICD-11 as a formal diagnosis. Emphasize the potential benefits of this inclusion and the necessity for future research. | N/A | 1. The existence of GD-related reality problems: Some players suffer significant functional and psychological impairment due to their gaming manner.<br>2. Concerns about stigma: The inclusion of GD in the ICD-11 is more likely to reduce rather than intensify stigma, by regarding problematic gaming behavior as a disorder rather than a personal weakness or moral failure. | 1. Media scaremongering<br>2. Generational differences<br>3. Lack of GD knowledge<br>4. Misunderstanding of diagnostic criteria<br>5. Public attitudes towards mental disorders<br>6. Risks of overdiagnosis and overtreatment | Social isolation: Negative views from society may make GD patients feel isolated, therefore affecting their social relationships and engagement. | The necessity of diagnostic criteria: The study supported the inclusion of GD in the ICD-11 as a formal diagnosis, considering it will contribute to improving the quality of further studies, standardizing assessment criteria, and clarifying relevant controversies. |
| Anja Koski- | To investigate treatment pro- | Self-made questionnaire; de- | 1. Cognition of addiction risk: Compared to treat- | N/A | Selection of treatment strategies: Cognition and | N/A |

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| Jannes, 2017 | fessionals' perceptions towards excessive behaviors, and how their attitudes vary by cultural background, occupation, and other background factors. | scriptive statistics, Logistic regression analysis | ment professionals in Finland, professionals in France were more likely to consider a high risk of addiction or dependence after gambling attempts and Internet use.<br>2. Opinions about chances of recovery: Treatment professionals in France had less confidence in the chances of recovery and significantly less trust in treatment than Finnish professionals, both for gambling addiction and Internet addiction.<br>3. Responsibility attribution: Professionals in both two countries emphasized more responsibility of individuals than society for solving their own addiction problems. | | perceptions may influence professionals' willingness to offer assistance to addicted individuals and the application of “evidence-based” treatment strategies. | |

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| Rachel Kowert, 2014 | To systematically assess the stereotypes of online game players and clarify whether social, physical, and psychological impairments are present in these gamers. | 1. Questionnaire: self-made questionnaire, gaming motivation scale, Game Addiction Scale (the short form), Berlin Social Support Scale (an abridged version), Social competence subscales of the California Psychological Inventory (CPI), problematic gaming scale<br>2. Analysis methods: descriptive statistics, ANOVA analysis, regression analysis | 1. Insufficient empirical support for stereotypes: The online gaming population does not match the negative characteristics described in popular culture.<br>2. Relationship between game engagement and stereotypical characteristics: Gamers with higher involvement levels may better fit the relevant stereotypes (e.g., unpopular, unattractive, lazy, socially incompetent). | N/A | N/A | N/A |
| Seung-Yup Lee, 2017 | To clarify the harms of GD, demonstrate the | N/A | GD stigma manifests as: | 1. Inadequate knowledge of GD | N/A | 1. Standardized Diagnostic System: Establishing a standardized diagnostic |

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| | necessity of its inclusion in ICD-11, and refute the concerns of Aarseth et al. | | 1. regarding gaming addiction as a kind of disease;<br>2. believing that gaming addiction needs treatment, and the ICD-11 would help increase public cognition and understanding of gaming addiction as well as promote treatment and prevention;<br>3. considering gaming addiction to be similar to alcohol use disorder and require the same attention and treatment, as they are both addictive and harmful;<br>4. Emphasizing that it is dangerous to deny the dangers of gaming addiction;<br>5. considering gaming addiction as not limited | 2. Misunderstanding by the media and the public<br>3. Opposition from the gaming industry<br>4. Lack of standardized diagnosis and treatment | | system would contribute to the correct identification and treatment of GD.<br>2. Public education and health promotion activities: Strengthen education and increase health promotion activities to reduce public misunderstanding of GD.<br>3. Position of internationally recognized authorities: The inclusion of GD in the ICD-11 by the World Health Organization (WHO) may help progressively obsolete inappropriate treatment methods, and promote evaluation and management of healthcare professionals considering the best interests of the patient, which would help |

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| | | | to children and adolescents;<br>6. simply treating gaming addiction as an individual problem;<br>7. regarding gaming addiction as a natural transitional developmental phenomenon in children and adolescents, and ignoring the positive aspects of gaming addiction. | | | reduce infringement of children's rights. |
| Corey M. Monley, 2023 | To demonstrate the development process of problematic gaming through self-determination theory. | Semi-structured focus group interviews; thematic analysis | 1. Stereotypes: Gamers may be stereotyped as lonely, socially incompetent young males and be stigmatized by adult non-gamers (ANGs).<br>2. Pathologization of gaming behavior: The frustration of gaming addicts' needs for autonomy, competence, and relatedness in real life | N/A | Stigmatization would have negative effects on gaming addicts, including social exclusion, impaired social interaction, and mental problems, which may cause gaming addicts to hide their gaming behavior and avoid seeking help. | 1. Treatment and prevention of GD: The study suggests that treatment and prevention strategies should focus on helping individuals meet basic psychological needs in real life, instead of just limiting gaming time.<br>2. Experiences of gaming addicts: The study emphasizes the importance |

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| | | | may be ignored, denying that they may seek satisfaction of these needs through gaming, leading to the view of gaming addiction as a disease.<br>3. Overgeneralization: All gamers are regarded as potentially problematic without distinguishing between healthy and problematic gaming behavior. | | | of gaming addicts' voices and experiences to comprehensively understand their needs and difficulties. |
| Samuel C. Peter, 2019 | To compare public stigma levels towards three different kinds of behavior addiction and to compare them to the stigma of individuals with financial crises suffering simi- | 1. Questionnaire: The Social Distance Scale (SDS), the Attribution Questionnaire (AQ-27), Level of Contact Report (LOCR)<br>2. Analysis methods: ANOVA analysis, ANCOVA analysis | 1. Perception of controllability: The public tends to perceive gaming addiction and online gambling addiction as controllable.<br>2. The public regards online gambling and gaming addiction as inappropriate and to be blamed. | N/A | 1. Stigma is regarded as a major barrier for individuals seeking treatment and other help. Stigmatized individuals may experience shame, embarrassment, and fear of being identified or judged, which prevents them from seeking help. | N/A |

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| | lar levels of impairment and distress. | | 3. The public prefers to keep a further social distance from addicts.<br>4. Gaming addiction is considered as dangerous as online gambling.<br>5. Addicts are believed to require isolation and compulsive medical treatment. | | 2. People are less willing to help addicts with financial problems. | |
| Halley M. Pontes, 2022 | To provide a more comprehensive perspective to promote the understanding as well as treatment of GD and to reduce stigma, promoting the development of research and practice in this field. | N/A | 1. Stigma of healthy gamers: It is concerned that diagnosis of GD may stigmatize healthy gamers without functional impairment, resulting in false categorization of them as problematic individuals.<br>2. Over-pathologization: It is concerned that normal gaming behavior may be over-pathologized even if they do | N/A | 1. Inappropriate selection of treatments<br>2. Social exclusion and isolation<br>3. Unreasonable restrictions and regulations of the gaming industry, which influence the acceptance of games as normal entertainment<br>4. Barriers to treatment and help-seeking<br>5. Stigma not only influences the mental health and social function of in- | N/A |

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| | | | not cause actual effects or impairment in life. | | dividuals, but also leads to biased social cognition and understanding of GD issues. | |
| Yuchen Ren, 2022 | To compare the impact of narrative messages and informational messages on attitudes towards adolescent GD. | 1. Questionnaire: self-made questionnaire;<br>2. Analysis methods: multivariate ANOVA, mediation effect analysis, moderation effect analysis | N/A | N/A | N/A | 1. Compared with the informational messages, narrative messages result in more positive attitudes of adolescents and are more effective in making them adopt the medical view of GD.<br>2. Narratives influence adolescents' attitudes to GD by increasing their immersion.<br>3. Adolescents' level of behavior involvement (e.g., frequency of playing video games) moderates the effect of narratives on attitudes and attitude certainty.<br>4. Attitude certainty: Narratives influence adoles- |

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| | | | | | | cents' attitudes to GD as well as increasing their attitude certainty. |
| Olatz Lopez-Fernandez, 2019 | The study aimed to:<br>1. construct an international profile for female gamers;<br>2. determine predictive factors associated with perceived internet gaming disorder (IGD);<br>3. recognize female gamers who may face the risk of developing online gaming addiction and identify their characteristics. | 1. Questionnaire: Internet Gaming Disorder Scale – Short Form (IGDS9-SF), Online Game Motivation Scale (OGMS), Antecedents of Identification (AoI), Embodied Presence (EP), Coping Strategies (CS), Symptom Checklist-27-Plus (SCL-27-Plus), Body Shape Questionnaire-8c (BSQ-8c), Bem Sex Role Inventory – Short Form (BSRI) | 1. Gender stereotypes: A female gamer may not be viewed as a real or hard-core player.<br>2. Sexualization of female characters: Female characters in games are often hypersexualized and objectified.<br>3. Social expectations: It is generally considered that females are less likely to be addicted, while males are more likely to become problematic gamers. | N/A | As there are still controversies over GD diagnosis and treatment, female gamers may face more barriers in seeking help. Inadequate cognition of GD in the female population may add difficulties for them in accessing appropriate treatment and support. | N/A |

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| | | 2. Analysis methods: descriptive statistics, correlation analysis, regression analysis | | | | |
| Irene Lai Kuen Wong, 2016 | The study aimed to:<br>1. explore the reasons for gaming in Internet cafes;<br>2. assess the perceived benefits and harms of gaming;<br>3. identify psychological and social risk factors for GD. | Semi-structured interviews; thematic analysis | 1. Negative aspects of gaming: People often focus on the negative effects of games, such as time management problems, decline in academic performance, physical and mental health problems, and family relationship problems.<br>2. Concerns about stigma: Some adolescents are afraid of being caught by parents or teachers playing games in Internet cafes and are fearful of being labeled as "teenage Internet addicts".<br>3. Lack of cognition: Some adolescents believe | 1. lacking knowledge of games<br>2. overemphasizing negative effects<br>3. lacking scientific cognition | 1. Effects on mental health: Stigma would increase the psychological burden of adolescents, leading to anxiety, depression, and other negative emotions.<br>2. Preventing help-seeking: Stigma would prevent adolescents from seeking help for fear of being labeled as "teenage Internet addicts".<br>3. Effects on social integration: Stigma would lead to social exclusion of adolescents and interfere with their social integration. | N/A |

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| | | | their gaming behaviors are normal and can hardly realize their own addiction tendency.<br>4. Denying addiction: Some addicted teenagers may deny their addictive gaming behaviors and refuse to seek help, believing they can control their gaming behaviors.<br>5. Self-acceptance: Some adolescent addicts may accept their addictive gaming behaviors as a lifestyle. | | | |
| Upekha Pathumi Miriyagal, 2023 | To investigate the content of social stereotypes of video game players, especially exploring how stereotypes vary with game | self-made questionnaire; ANOVA | 1. Positive stereotypes of gamers: Social stereotypes of gamers are generally positive, which contrasts with the image of negative stereotypes in previous studies.<br>2. Stereotypes of players in high-level violence | Game content, media reports of high-violence games, and the conflict between social moral expectations and game content lead to negative perceptions and stigma towards high-violence games and their gamers. | N/A | N/A |

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| | violence level and gamer identity. | | games are more negative in terms of morality, and the public may consider these players as morally questionable.<br>3. Stereotypes of players in high-level violence games are also more negative in terms of warmth, and these players are often perceived as less friendly and caring, and even cold or cruel.<br>4. Effects on gamer identity: Low-identifiers have more negative stereotypes of players in high-violence games, while high-identifiers hold a slightly more positive view. | | | |
| Wei He, 2018 | To explore how People's Daily, as a representative of China's | keywords retrieval in game reports of the People's Daily; | 1. In the early years, media reports often stigmatized games and gamers, especially by adopting | 1. Negative framework of media reports<br>2. Effects of policies and regulations | N/A | N/A |

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| | mainstream media, reported and built the image of games in the past 40 years, and to reveal the ideological changes beyond the transforming discourse of game reports. | Critical Discourse Analysis (CDA) | a reporting framework of "damage adolescents", which constructed a stereotypical portrayal of gamers as "perpetrators/victims/rescued", lacking direct interviews and presentation of the gamers' voice. 2. Ideological transformation: With the development of the Chinese gaming industry, especially the rise of original games, the social perception of games gradually transformed from negative to positive, and games were accepted as a part of Chinese creation.<br>3. Changes in reporting framework: The framework of game reports changed from "damage adolescents" to "industri- | 3. Moral panic: Social concerns and criticisms lead to moral panic towards GD, as GD is considered a social threat.<br>4. Use of metaphors<br>5. Lack of multiple perspectives<br>6. Differences in social value and perceptions<br>7. Boom of the gaming industry<br>8. Education and family factors<br>9. Social panic and misunderstanding of new technology | | |

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| | | | al economy" and "a new way of entertainment".<br>4. Reduction of stigma: As games have become a common and familiar part of social life in recent years, and with the boom of the gaming industry, game-related stigma has reduced. | | | |
| Xin Han, 2015 | To explore the development orientation of the public opinion field of online games, based on the reports of traditional public media since 2004. | keywords retrieval in media reports, semi-structured interviews;<br>content analysis | 1. Changes in media image: The media image of online games experiences a transition from stigmatization to neutrality and rationalization.<br>2. Reduction of stigma: The dominance of negative media reports in the public opinion field has been challenged, though there is still a negative tendency in online game reports. | 1. Transition of social cognition<br>2. The development of online gaming industry attracts the media's attention to its positive aspects, resulting in more reports focused on the economic benefits of the gaming industry.<br>3. Enhancement of media responsibility<br>4. Diverse demands of audiences motivate the | N/A | N/A |

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| | | | 3. Attitudes of the media: Although some reports emphasize the potential addictive or negative consequences of online games, the media begins to present more comprehensive comments on online games.<br>4. Opinions of game addicts: Adolescent gamers notice the changes in media reports and recognize the positive effects of these changes on gaming environment. | media to report more comprehensively.<br>5. Policies and regulations influence the reporting direction and encourage the media to pay more attention to positive aspects of online gaming industry.<br>6. Evolution of cultural and social values: The evolution of cultural and social values leads to a more tolerant attitude towards the entertainment methods of adolescents. | | |
| Dehuan Liu, 2015 | To explore the cognition and attitudes of teachers towards adolescent online gaming and to analyze the influence factors. | self-made questionnaire; independent sample t-test, factor analysis, logistic regression analysis | 1. Teachers tend to regard teenagers who frequently play online games as poor in performance, mischievous, and unmotivated, while less likely to consider them as smart, self-controlled, and self-confident. | Teachers' perceptions of parents' attitudes may influence teachers' attitudes towards teenage online gaming. | N/A | N/A |

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| | | | 2. There is bias in teachers' evaluation of the social communication competence of online gaming teenagers, considering them to be less socially competent than students who don't play games.<br>3. Most teachers acknowledge that playing online games can relieve academic pressure, improve reflexes and develop intelligence.<br>4. Teachers believe that playing games may induce violent tendencies, influence studying, and lead to exposure to pornography or other unhealthy information.<br>5. Teachers hold conservative attitudes to online games and are mainly | | | |

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| | | | against teenagers playing them.<br>6. Teachers playing games themselves have more positive perceptions of teenage online gamers and have higher evaluations on games' positive effects. | | | |
| Daocheng Yan, 2014 | To reveal the differences and similarities between mainstream official news websites and commercial news websites in constructing media images of young online gamers. | keywords retrieval in Sina Net and People's Daily Online; content analysis | Stigma can be manifested by:<br>1. associating gaming with crimes;<br>2. emphasizing the health problems caused by game addiction;<br>3. emphasizing the social dysfunction caused by game addiction;<br>4. associating game addicts with character defects;<br>5. viewing game addiction as a symbol of family education failure; | 1. Exaggeration of individual cases: The Internet media often reports and exaggerates typical cases of online teenage gamers from different perspectives, constructing negative images of these gamers.<br>2. Emphasis on negative consequences: Reports tend to focus on negative consequences of game addiction, such as crime, physical problems, and mental problems. | The existence of stigma widens the gap between teenage online gamers and their educators, interfering with the normal socialization process of them, and may lead to exclusion from mainstream society. | 1. Internet reports should take improved measures. The mainstream Internet media should appraise teenage online gamers from a comprehensive, fair, and objective perspective, and the official media should guide the public to focus on the image construction of young gamers.<br>2. The management should regulate the online game industry devel- |

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| | | | 6. considering game addicts as lacking social responsibility. | | | opment and recognize the positivity of online games. |
| Daocheng Yan, 2013 | To explore how media coverage constructs the stigma against teenage online gamers and indicate the effects of stigma. | keywords retrieval in Baidu News;<br>content analysis | Teenage Internet gamers are often associated with negative labels such as lack of responsibility, troubled teenagers, criminal tendency, violent personality, and characters of irritable, callous, cruel, and manic. | 1. Demonization measures: (1) deprivation of discourse (2) dramatization (3) strongly emotional statements (4) labeling<br>2. Dominance of commercial values<br>3. Effects of market demands | 1. Stigma may result in psychological imbalance and even mental problems.<br>2. Stigma may obstruct the socialization process of teenage online gamers. | 1. Reporters should keep a neutral perspective and give teenage gamers more opportunities to express their own opinions.<br>2. Media reports should comprehensively consider the family, school, and social backgrounds of young online gamers, instead of criticizing them from a single perspective.<br>3. More expert opinions should be adopted in reports to provide a deeper and more comprehensive perspective. |
| Hongwei Yan, 2011 | To explore the social representations of Chinese university students to- | Open-ended questionnaire for word association test, self-made online game so- | 1. Negative social representations of online games: Online games are viewed as wasting time, wasting money, addic- | N/A | N/A | N/A |

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| | wards online games, and to discuss the possible causes of online game stigma. | cial representation scale;<br>descriptive statistics, factor analysis, ANOVA | tive, isolated from reality, single mode, full of violence, fraud, pornography, and other unhealthy information.<br>2. The universality of stigmatization: The average score of positive representations towards online games is significantly lower than that of negative representations, and there are differences among various populations. | | | |
| Shuo Wang, 2023 | To reveal the discourse characteristics and strategies in the People's Daily's coverage of teenage video gamers, and to explore how the discourse con- | conducting keywords retrieval in game reports of the People's Daily;<br>content analysis | 1. Non-confrontational stage (1983-1999): Video games were regarded as a gambling form of entertainment, and young video gamers were described as “deviants”, associated with crime and misconduct, and labeled as “gamblers”, “tru- | 1. Concerns about addiction<br>2. Social anxiety<br>3. Neglect of individuals' voice<br>4. Neglect of economic and cultural backgrounds<br>5. Blame for social problems on games | Teenage video game players may face challenges in social identity due to stigma and have difficulty gaining social acceptance and understanding. | The article suggests:<br>1. strengthening the media's sense of responsibility;<br>2. increasing public awareness of video games;<br>3. providing more policy support;<br>4. reporting the positive aspects of e-sports; |

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| | tributes to the transformation of these teenage players' media image. | | ants", "unhealthy" and "outcasts".<br>2. Contradictory stage (2000-2018): The image construction of teenage video gamers began to diverge. On the one hand, they were labeled as "addicts"; on the other hand, the rise of e-sports gave some young gamers new identities as "athletes".<br>3. Stable stage (2019-2022): The image of teenage video gamers was further positively constructed. As e-sports were included in sports events, e-sports players were given positive status as "members of the national team" and were regarded as "e-sports talents". | 6. Single perspective of the media coverage<br>7. Strict regulation and crackdown on video games in early policy discourse | | 5. emphasizing the role of video games in spreading culture and strengthening cultural confidence;<br>6. providing appropriate family and school guidance;<br>7. enhancing industry self-discipline;<br>8. building and improving social support systems for young video gamers;<br>9. encouraging scientific research on the effects of video games;<br>10. adopting multiple perspectives in reporting and considering video games;<br>11. promoting de-stigmatization;<br>12. enhancing international cooperation. |

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| Pengpeng He, 2021 | To reveal the media and text presentation characteristics of the video game reporting discourse in People's Daily, the discourse characteristics and influencing factors of video game coverage in different periods, the impact of discourse on social practices, and the effects of discourse on social concept construction, gamers' identity and the gaming | conducting keywords retrieval in game reports of the People's Daily;<br>content analysis | 1. Negative labels: Online games are considered electronic drugs. Gamers are described as lonely, unsociable, and having irregular life habits.<br>2. Health problems: Some reports associate video games with physical and mental health problems in adolescents.<br>3. Blame for social problems: Video games are regarded as the source of juvenile delinquency, academic failure, and other social problems in some situations.<br>4. Emphasis on addiction: The addictive consequence of video games is overemphasized, describing games as an irresistible temptation. | 1. Psychosocial factors: panic and anxiety towards new technologies and phenomena, conservative attitudes<br>2. Cultural and cognitive differences: cultural barriers, generational cognitive gap<br>3. Tendency of media coverage: negative reports, clickbait headlines<br>4. Influence of policies and regulations: negative orientation of early policies, regulation vacancies<br>5. Deficiency in knowledge popularization and education: lack of proper guidance, deficiency in popularization of relevant knowledge | N/A | The research suggests:<br>1. raising public awareness;<br>2. emphasizing media responsibility;<br>3. strengthening science education;<br>4. increasing policy support;<br>5. strengthening family education;<br>6. improving the anti-addiction system;<br>7. providing professional guidance;<br>8. establishing the social support system;<br>9. increasing cross-department cooperation;<br>10. enhancing cultural guidance;<br>11. strengthening international communication;<br>12. increasing research investment. |

| First author and published year | Study target | Data collection tools and analysis methods | Conclusions | | | |
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| | | | Characteristics and manifestations of GD stigma | Causes of GD stigma | Effects of GD stigma | Intervention recommendations |
| | industry development. | | 5. The public lack recognition of the video games' positive effects.<br>6. Pathologization labels: In some reports, gaming addiction is described as a pathological state similar to other addictive disorders, which may lead to public bias and discrimination against gaming addicts.<br>7. Excessive attention: Although it is necessary to pay attention to the problem of gaming addiction, over-concern may result in neglect of the positive effects and entertainment value of proper gaming. | 6. Social values and moral judgment: value conflicts, moral panic<br>7. Interests drive: The rapid development of gaming industry attracts the market's attention to the problem of game addiction, which may be driven by economic benefits and lead to exaggeration of game addiction problem.<br>8. Group psychology and collective behavior: conformity effect, collective behavior | | |
| Ying Gao, 2020 | To explore the effects of mainstream media's reports of on- | conducting keywords retrieval in game reports of People's Daily | 1. From negative to positive: In the early years, online games were labeled negatively as "elec- | 1. emphasis on traditional social concepts on educational and occupational achievements | N/A | 1. The media should further understand the online game market and |

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| | | | Characteristics and manifestations of GD stigma | Causes of GD stigma | Effects of GD stigma | Intervention recommendations |
| | line gaming on the youth and propose suggestions and strategies to promote the healthy development of gaming industry and the overall growth of adolescents. | and China Youth Daily;<br>content analysis, descriptive statistics | tronic opium" and "flood and monster". Since 2011, positive images have begun to appear in reports of online games.<br>2. Focus on negative consequences: Most of the WeChat reports of People's Daily and China Youth Daily are negative, concentrating on the harm of online games.<br>3. Negative image of gamers: Traditionally, game players may be portrayed as a group of addicted and idle people, and this image still exists in some reports.<br>4. Perspective differences: Media practitioners may not be able to fully understand and present the diversity and complexity of gamers | 2. negative media coverage<br>3. lack of comprehensive understanding<br>4. the opinion that online games are barriers to academic and personal development<br>5. social anxiety and panic<br>6. excessive attention of policies and regulations to negative outcomes of online games<br>7. intergroup gap<br>8. economic factors<br>9. rapid development of technology | | report from the online gamers' position.<br>2. The media should adopt a balanced reporting method to avoid overemphasizing the negative effects of online games.<br>3. The media should establish effective communication with online gamers. |

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| | | | due to differences in age, educational background, and social experience. | | | |
| Yuwei Qiao, 2017 | To analyze the bias in the media image of teenage online gamers and to explore the causes of bias. | keywords retrieval in game reports from Sina.com, self-made questionnaire, semi-structured interviews; content analysis, descriptive statistics, correlation analysis | 1. Cognitive bias: The public often has a stereotype of young online gamers and game addiction, considering teenage online gamers to be problematic teenagers addicted to games and with abnormal behaviors, and view game addicts as “good-for-nothing” people lacking self-control.<br>2. Attitude orientation: Teachers and parents are relatively tolerant of teenagers' online game behaviors, but parents are more concerned about the game addiction problem. Social members take a more | The sentimental and dramatic reporting language attracts people's attention to the negative content, while depriving the discourse of young online game players and conducting biased attributions to them. | 1. Negative self-perception: Game addicts may have negative comments about their own behaviors due to the stigma, leading to mental problems such as low self-esteem and self-blame.<br>2. Rejection of seeking help: Gaming addicts may be ashamed to seek help due to the fear of discrimination, which worsens their addiction.<br>3. Social exclusion: Game addicts may have difficulties in integrating into society due to social exclusion, which affects their normal life and work. | 1. The government should strengthen regulative legislation and provide resources and support.<br>2. The media should improve quality, report objectively, and guide positively.<br>3. Society should create a tolerant atmosphere to provide support and understanding, and strengthen home-school cooperation.<br>4. Game companies should shoulder social responsibility actively, develop more healthy games, and provide supporting tools. |

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| | | | negative attitude towards online gaming teenagers, considering that they should reflect on themselves instead of seeking help. | | | |
| Guo Huang, 2014 | By exploring the effects of politics, economics, and mainstream culture on the attitudes and decisions of teenage online gamers, the study described the "speechless" state of young gamers influenced by the three powers. | analyzing reports from China Youth Daily, People.com, and Legal Report in CCTV from 2008 to 2013 | 1. Demon image: Gamers are described as having violent tendencies, impulsive and irritable, and committing crimes such as theft, robbery, murder, and rape.<br>2. Victim image: Gamers are described as addicted to online gaming, resulting in physical, mental, and social life abnormalities, and are associated with physical weakness, psychopathy, declining grades, employment difficulties, and even dying due to over-gaming. | 1. Media factors: imbalance of the number of negative reports, construction of extreme images, adoption of the "other perspective", emotional expression, compliance with the market logic<br>2. Social factors: social control, social anxiety, cultural differences<br>3. Policy factors: over-regulation, limited policy publicity, lack of communication between departments | N/A | N/A |

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| | | | Characteristics and manifestations of GD stigma | Causes of GD stigma | Effects of GD stigma | Intervention recommendations |
| Qunjun Wen, 2014 | The research aimed to:<br>1. analyze the presentation of the image of online game players on mainstream news websites;<br>2. explore the real-life state of online gamers;<br>3. compare the image of online gamers in media reappearance with the real state of gamers;<br>4. discuss the causes of bias in news. | keywords retrieval in reports from Sina, Netease, Sohu, and People websites, self-made questionnaire, semi-structured interviews;<br>content analysis, descriptive statistics | 1. Negative image of online gamers: Gamers are often viewed as a group of people having negative behaviors and are addicted to games.<br>2. Negative image of online games: “mental opium”, “Internet addiction”<br>3. Losing of voice: Online game players lack the right to speak in the public opinion field.<br>4. Mental disorder labels: Game addiction is regarded as a kind of mental disorder that needs to be treated and cured.<br>5. Over-treatment: Game addicts may be overtreated, bringing gamers psychological burdens and interfering with their normal lives. | 1. Media factors: News bias such as the phenomenon of “rehashes” and “advertising news”, commercial operations, and the absence of journalism professionalism contribute to the stigma formation.<br>2. Social factors: social anxiety, differentiated attitudes of different cultures towards online games<br>3. Gamers' own factors: Gamers' addictive and negative behaviors promote the building of negative images, contributing to stigma formation.<br>4. Internet factors: Internet violence and Internet addiction increase the stigmatization of games and gamers. | N/A | N/A |

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| | | | Characteristics and manifestations of GD stigma | Causes of GD stigma | Effects of GD stigma | Intervention recommendations |
| | | | | 5. Policy factors: Excessive regulation and the lack of game-related policies lead to inadequate public cognition of online games and gamers. | | |
| Shuguang Zhao, 2022 | To investigate the social interaction between gamers and non-gamers in the real world, especially in the marriage market in China, and to explore how different attitudes towards games influence the interaction. | 1. Questionnaire: fictional marriage partner descriptions, ideal marriage partners similarity rating (IMPSR), participants' subjective reports of game situation, demographic information<br>2. Analysis methods: ANOVA, mediation effect analysis, moderation effect analysis | 1. Stereotypes: Gamers are stereotyped as a group of people with negative features such as aggressiveness, lack of social skills, laziness, etc.<br>2. Prejudice in the marriage market: Non-gamers would prefer not to choose gamers as potential mates.<br>3. Misunderstanding of gaming addiction: The public may view all gaming behaviors as potentially gaming addiction.<br>4. In-group preference and out-group discrimination: Male gamers may | 1. Moral panic<br>2. Negative media coverage | 1. Stigma may result in unfair treatment of gamers, affecting their social opportunities and interpersonal relationships.<br>2. Impact on marriage mate selection: Non-gamers may exclude gamers as potential mates based on negative perceptions of games, reducing gamers' opportunities in the marriage market. | N/A |

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| | | | tend to select marriage partners among other gamers. | | | |
| Daria J. Kuss, 2022 | The study investigated female gamers' identities, positive and negative perceptions of gaming behaviors, and their gaming experiences. | Semi-structured interviews; thematic analysis | 1. Social stereotypes: The public tends to believe that female gamers won't be addicted to gaming and that female-oriented games are easy forms of entertainment.<br>2. Neglect of female gaming addiction by medical institutions<br>3. Social discrimination against female gaming addiction: Female gamers may suffer from discrimination and blame while admitting they have addiction problems. | N/A | Due to stereotypes, the public believes female gamers are hardly affected negatively by their gaming behaviors, thus neglecting their possible problem of gaming addiction. | N/A |
| Yungeng Li, 2023 | To explore the association between teenager use and obses- | self-made questionnaire;<br>descriptive statistics, correlation | 1. Childish image: ACG culture is regarded as the culture of children, with | 1. Cultural differences: The differences between ACG and mainstream culture easily contribute | 1. Psychological pressure: Stigma brings ACG fans mental pressure and | N/A |

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| | sion with ACG platforms, and to discuss the psychosocial mechanisms. | analysis, moderated mediating effect analysis | childish and superficial content.<br>2. Social communication barriers: ACG fans are considered indulging in the virtual world, introverted, and lacking real-life social skills, and are labeled as “otaku”.<br>3. Lower moral evaluation: ACG culture is considered not to conform the mainstream values, with unhealthy components. ACG fans are regarded as “outcasts” with lower moral levels.<br>4. Restrictions on activity participation: ACG activities are seen as abnormal and not appropriate for public participation. And ACG fans are worried to be discriminated against or excluded by | to misunderstanding and prejudice.<br>2. Social structure: The relative weakness of the ACG fan community makes it easier to become the target of stigma. | leads to feelings of inferiority and anxiety.<br>2. Social exclusion: Stigma contributes to social exclusion of ACG fans and adds to their difficulties in integrating in mainstream society.<br>3. Cultural closure: Stigma promotes the closure of ACG culture and hinders its communication and integration with the mainstream culture. | |

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| | | | others for their participation in ACG activities. | | | |

# Chapter Eight: Addressing HIV Related Stigma and Discrimination in Spain

*Julia del Amo Valero, Ana Koerting, Javier Gómez, Juan Hoyos, Pedro Gullón, Javier Padilla,*

## *1. HIV Epidemiological Data in Spain and Spain's Renewed Commitment to Achieve SDG 3.3 by 2030*

According to data published in 2023, it is estimated that over 150,000 people are living with HIV in Spain of whom 7.5% are unaware of their status (HIV, STI, and Hepatitis B and C Surveillance Unit, 2023). Around 3,000 new HIV cases were diagnosed in 2022 (last available data) representing a 23.8% decline compared to 2019 (HIV, STI, and Hepatitis B and C Surveillance Unit, 2023). The number of new HIV diagnoses has been steadily declining since 2018, aided by increased access to testing and diversification of HIV testing modalities as well as by the 2015 recommendation to start antiretroviral treatment regardless of the CD4 cell count. Indeed, Spain continues to make strides in addressing the HIV epidemic, though challenges remain in certain key areas such as the persistence of late HIV diagnoses, which still account for about 45% of all cases (HIV, STI, and Hepatitis B and C Surveillance Unit, 2023). Late diagnosis delays access to treatment, worsens health outcomes, and increases the likelihood of transmission.

The populations most affected by HIV in Spain are Gay Men and other men who have sex with men (GBMSM), representing the largest proportion of new diagnoses. Other vulnerable populations include heterosexual individuals from certain migrant communities and people who inject drugs (HIV, STI, and Hepatitis B and C Surveillance Unit, 2023). Although Spain has achieved high levels of antiretroviral therapy (ART) coverage, with over 98% of diagnosed individuals receiving treatment, there remain barriers to care for certain marginalized groups, particularly undocumented migrants and people in economically disadvantaged contexts. (HIV, STI, and Hepatitis B and C Surveillance Unit, 2023). Advancements in treatments and healthcare have significantly improved the life expectancy and quality of life for people living with HIV (PLHIV) (Jarrín, I. et al., 2024) However, stigma and discrimination remain a challenge.

In terms of prevention, Spain has made significant advances in the availability and uptake of *Pre-exposure prophylaxis (*PrEP)—which has proven effective in reducing new infections—since its inclusion in the Spanish National Health system in November 2019. As of July 2024, it was estimated 30,000 people at high risk of HIV were on PrEP programs throughout the country (Division of HIV, STI, Viral Hepatitis, and Tuberculosis Control, 2024). However, disparities in access to PrEP and testing services continue to affect certain populations

Therefore, despite substantial progress, Spain still faces several challenges in its response to HIV. While free and anonymous testing services are widely available, barriers such as stigma, fear of disclosure, and geographic location of HIV testing services can limit the use of these resources. Late diagnosis continues to be a major concern, delaying treatment and increasing transmission risk. Health inequalities, particularly among undocumented migrant and marginalized groups, remain persistent barriers to prevention and treatment. In short, as highlighted above, HIV-related stigma and discrimination continue to be major obstacles in Spain.

Spain's progressive coalition government, formed in May 2018, made eliminating HIV-related stigma by 2030 (sustainable development goals (SDG 3.3)) a public health priority, restructuring its national response based on scientific evidence, universal healthcare principles, and human rights. The strategy has included reinvigorating the involvement of people living with HIV as well as multisectoral governance. It also meant the reconvening of the Plenary of the National Commission for the Coordination and Monitoring of AIDS Prevention Programs, which had not been convened for four years. With less than six years remaining until 2030, Spain is committed to achieving the UNAIDS targets: diagnosing 95% rates for diagnosis, starting treatment, and viral suppression (UNAIDS, 2024). Additionally, Spain aims to reduce new HIV infections by 90% and eliminate stigma and discrimination. Data from 2021-2022 indicate that 92.5% of people living with HIV in Spain are diagnosed, 96.6% are receiving treatment, and 90.4% have suppressed viral loads (HIV, STI, and Hepatitis B and C Surveillance Unit, 2023). The rate of those undiagnosed decreased from 13% in 2017-2019 to 7.5% in 2021-2022, a decline most likely attributable to the implementation of PrEP strategy which prompts people at high risk to get tested in close collaboration with civil society organizations (HIV, STI, and Hepatitis B and C Surveillance Unit, 2023). As well as

PrEP, increased visibility of the HIV response and enhanced testing efforts are also likely contributors to the decline of the undiagnosed fraction. These figures indicate that Spain has exceeded the 90-90-90 targets set by UNAIDS for 2020 and is now working toward the 2030 goals. As part of this renewed commitment, Spain has reinvigorated its relationship with UNAIDS, recommitting to universal health and human rights and actively engaging in UNAIDS governance and the financial contributions necessary to sustain global progress toward ending the HIV epidemic.

This commitment is outlined in the *Strategic Plan for the Prevention and Control of HIV and Sexually Transmitted Infections (STIs) 2021-2030* (Ministry of Health, 2023), which aims to promote prevention, early diagnosis, treatment, chronic care, and improvements in the quality of life for PLWH, while focusing on addressing the stigma and discrimination associated with HIV and STIs in Spain.

## *2. What is Stigma and its Impact on PLHIV*

Throughout history, few infectious diseases have had the high levels of stigma and discrimination that HIV infection faces. This stigma has had, and continues to have, an enormous impact on people's lives and jeopardizes the epidemiological goals of controlling and ending the pandemic. The elimination of HIV-related stigma and discrimination is not only a goal in its own right; it is also instrumental to ending AIDS as a public health problem by 2030. Furthermore, ending HIV-related stigma and discrimination is a key aspect not only of effective prevention and control measures, but also to guarantee and protect the personal dignity and rights of those affected by HIV (Ministry of Health, 2024).

Stigma is described as a process by which a person or group is attributed a characteristic that discredits them in the eyes of others. These characteristics are often arbitrary but serve to identify and ostracize those who deviate from social norms. Closely related to stigma is discrimination, which involves unfair and unequal social treatment of those who are stigmatized (Ministry of Health, 2024). Discrimination has various forms and manifestations. Stigma can manifest through both actions and omissions, either directly or indirectly, and may spread through associations. Different forms of stigma and discrimination demand tailored responses and interventions. While stigma operates in the realm of social perception, discrimination manifests in unfair actions directed at individuals. The two are interconnected, with stigma reinforcing and legitimizing discriminatory behavior..

HIV-related stigma is rooted in social inequalities and other forms of pre-existing stigmas linked to gender, ethnicity, sexuality, nationality, and behaviors deemed unacceptable in various cultures (Ministry of Health, 2024). Intersectional stigma, referring to the experiences of individuals who are subjected to multiple forms of stigmatization simultaneously, affects people living with HIV in a negative way, as it combines the stigma associated with HIV with other social stigmas and inequalities. This creates a new form of inequality that is more complex and harmful than the simple sum of individual inequalities. Intersecting stigmas, such as those related to aging, sexual preference, HIV, and social inequalities, negatively impact the health-related quality of life (HRQoL) of individuals living with HIV. These stigmas affect mental health, access to healthcare, and overall well-being, with common challenges including social isolation, financial instability, and healthcare access barriers across different regions. Many individuals experience violations of their human rights because of HIV-related stigma and discrimination. This also creates significant obstacles to prevention, diagnosis, and treatment efforts. Fear, ignorance, and rejection perpetuate the spread of HIV and foster harmful misconceptions (Hsieh, E., et al. 2022). The psychological impacts of stigma include guilt, low self-esteem, and depression, while practical consequences include denial of services and violations of labor, health, and social rights.

People living with HIV continue to face discrimination in various sectors, including healthcare, education, and employment. Exclusions in employment—often dating back to the early years of the HIV epidemic when less was known about transmission and treatment was not available—too often remain in place today. In Spain, a 2018 comprehensive review across national, regional, and local levels uncovered a number of such exclusionary practices. These included, for example, restrictions on public employment in the police, customs services, and correctional facilities, as well as their respective training institutions. Restrictions like these are not limited to Spain. However, there is no clinical reason to exclude someone with HIV from employment (though there may—in exceptional cases—be some restrictions around viral load for medical staff performing or assisting in exposure-prone medical procedures) (Ministry of Health, 2023). Since 2018, Spain has been trying to overcome these anachronistic restrictions by updating its medical exclusion criteria for public employment. We describe this in detail in the next section.

Insurance can also be impossible or very difficult to get for people with HIV, or prohibitively expensive. Not having life insurance can have a knock-on effect on other issues, such as getting a mortgage to buy a home. Similarly, the EU's requirement that one have health insurance to be eligible for a student visa means some students with HIV from certain countries are either unable to study in EU countries or study without a right of access to HIV care and its complications. Some EU countries have attempted to reverse this situation. In 2018, Spain recognized the right of people with HIV to purchase private insurance without discrimination based on their HIV status. However, the implementation of this rule remained unsatisfactory and some insurance companies continued to refuse coverage for people with HIV or impose onerous conditions based on their serological status (Ramiro Avilés, M.A., Bolívar Oñoro M.V, 2022). Consequently, the Spanish Ministry of Health has begun a collaboration with the Spanish Union of Insurance and Reinsurance Entities (UNESPA) to review the processes for insuring people with HIV. In section 3, we describe this collaboration and its achievements.

Stigma in healthcare settings is also a major barrier to the well-being of people living with HIV, and understanding its drivers is key to addressing it. A 2023 survey of healthcare workers in 54 countries across Europe and Central Asia assessed their knowledge of HIV-related topics like U=U, PEP, and PrEP. Among the 18,348 respondents, correct knowledge was reported by 61.25% for U=U, 55.70% for PEP, and 40.74% for PrEP, with only 31.29% showing comprehensive knowledge across all topics. Sociodemographic factors such as being male, younger, a medical doctor, and having more experience with HIV-positive patients were linked to higher knowledge levels. Training on infection control, HIV stigma, and discrimination was also indicative of improved knowledge. These findings underscore the need for targeted training to address gaps in HIV knowledge and reduce stigma in healthcare (European Centre for Disease Prevention and Control, 2024).

Addressing HIV stigma and discrimination will not only benefit people living with HIV; the response to HIV can and does have impacts that go beyond those who are HIV positive. Part of reducing HIV stigma also requires us to tackle stigmas and discrimination faced by key populations and vulnerable groups, such as men who have sex with men, transgender individuals, sex workers, people who inject drugs, incarcerated individuals, and migrants. This will improve their health and well-being, increase their economic and social participation, and benefit society as a whole. Prioritizing the involvement of patients and communities in decision-making and developing integrated, person-centered care will lead to better standards and outcomes across the healthcare system. Ultimately, reaffirming one's commitment to zero HIV stigma and discrimination is also a reaffirmation of one's commitment to human rights-based policies and practices.

## 3. *Spain's Commitment to Ending HIV-Related Stigma:* The Social Pact for Non-Discrimination and Equal Treatment Associated with HIV

In November 2018, the Spanish Ministry of Health launched the *Social Pact for Non-Discrimination and Equal Treatment Associated with HIV* (Social Pact) (National AIDS Plan, 2018) with the goal of eliminating HIV-related stigma and discrimination. The pact guarantees equal treatment and opportunities, non-discrimination, respect for human rights, and recognition of the diversity of people affected by HIV. The origins of the pact date to a 2011 initiative proposed by community activists and those affected by HIV, but it took several years before it could be implemented. This follows a common trend. Over the years, civil society activists have played a central role in the fight for the rights and the improvement of the quality of life of people with HIV. These activists have primarily been people with or affected by HIV. They have organized, supported one another, educated the public, clinicians and politicians, and insisted on their rights. This continues to be the case today. In response to such activism, research has been produced, medical practice transformed, and laws and policies changed—even if very often too slowly and too randomly.

The Social Pact represented, and still does, significant progress in protecting the rights of people living with HIV. Key to its success has been the establishment of alliances with various sectors, including governmental bodies, regional and local administrations, non-governmental organizations (NGOs), scientific societies, trade unions, universities, and the media (National AIDS Plan, 2018). The Pact covers all areas of life, both public and private, through the promotion of policies and actions aimed at:

- Promoting equal treatment and opportunities for people with HIV.
- Working toward social acceptance.
- Reducing the impact of stigma on people with HIV.
- Generating knowledge to guide anti-discrimination policies.

The pact aims to address the various manifestations of stigma: structural stigma (rooted in institutions and manifested in laws, policies, and cultural norms), enacted stigma (external expression of stigma as discrimination), public stigma (stigmatizing attitudes held by the general public), and stigma by association (stigma experienced by those associated with stigmatized individuals such as relatives or health care workers).

One of the ways the pact tried to tackle structural stigma and protect the labor rights of people with HIV was the *Agreement of the Council of Ministers of November 2018* (Ministry of the Presidency, Relations with the Cortes and Equality, 2019). This agreement approved instructions to update medical exclusion criteria for public employment. Previously, HIV, diabetes, celiac disease, and psoriasis were considered grounds for exclusion in certain public sector jobs, such as the security forces, armed forces, customs surveillance, and prison staff. The agreement sought to remove or limit these conditions as general causes for exclusion and ensure that public employment access is based on the most up-to-date medical and scientific evidence and sensitive to the individual clinical situations of applicants. This agreement, which was an unprecedented step in the recognition of the rights of PLWH, was published in the Official State Gazette on February and endorsed the need to base the evaluation of job applicants on individual assessments in accordance with the duties to be performed for the posts, and in agreement with current scientific evidence.

Furthermore, a technical interministerial committee was set up to implement this agreement between the Ministry of Territorial Policy & Public Administration, the Ministry of Health, the Ministry of Defense, the Ministry of Treasury, the Home Office, and the Ministry of Presidency, Parliamentary Relations & Equality. An advisory committee was also set up by members from public administration and civil society. From January 2019 to present, the team has reviewed the drafts of public calls for exams for civilian and military officials, health professionals and administrative staff to identify the explicit and/or implicit references to generic exclusions for any of the medical conditions included in the Council of Ministers' agreement: HIV diabetes mellitus, psoriasis or celiac disease. Moreover, the committee has made suggestions to these drafts provided justifying each proposal for amendment and/or omission all together and met and exchanged difficulties and challenges to make the process more efficient and productive, and to understand the inherent technical hitches associated to changing norms which themselves depend on other norms.

Since the agreement's approval, a coordinated effort has been made between relevant entities and ministerial departments to remove these barriers to public employment. As a result, conditions like HIV, diabetes, celiac disease, and psoriasis are no longer considered blanket exclusions but instead evaluated on an individual basis using the most current medical and scientific evidence.

To monitor the Social Pact, a coordinating committee was created comprising of the Division for the Control of HIV, STIs, Viral Hepatitis, and Tuberculosis, the Autonomous AIDS Plans of Andalusia, Catalonia and the Basque Country, the State AIDS Coordinator (CESIDA), the scientific societies Spanish Interdisciplinary AIDS Society (SEISIDA), GESIDA, the Network of Associations Working Positively, and the University of Alcalá in Madrid. Since the social pact was implemented, this committee has been monitoring all the actions carried out.

The pact also remains open for others to join. Organizations, institutions, and individuals can join to support and develop commitments to eliminate stigma and discrimination associated with HIV and AIDS, guaranteeing equal treatment and opportunities, as well as spaces of non-discrimination.

Furthermore, an online communication plan was developed with its own website (https://pactosocialvih.es), social media engagement (i.e., Facebook, Twitter, Instagram, and YouTube), and a blog. The goal was to both make the situation of people living with HIV visible and promote activities related to the Social Pact.

All in all, the evidence suggests that since the launch of the Social Pact, Spain has taken important steps toward creating a legal framework attentive to those stigmatized and discriminated against because of HIV. The focus has been on promoting human rights and incorporating current scientific-medical evidence and support. Notable examples include:

- The *Interterritorial Health and Social Services Councils* issued a joint declaration on October 9, 2019 ensuring that people with HIV are not discriminated against when accessing residential care homes for the elderly or disabled. Another interterritorial collaborative effort involved working with the *Institute for Older People and Social Services* and the *Directorate General for Equal Treatment and Diversity* (Interterritorial Council of the National Health System, 2019).
- *Law 15/2022* on *Equal Treatment and Non-Discrimination*, which, for the first time at the national level, includes HIV serological status as a reason for non-discrimination (Government of Spain, 2022).
- *Law 39/2022 on Sports*, which introduces measures to promote equality and combat discrimination, including provisions for HIV-related dis-

crimination. It guarantees access to sports for all individuals, regardless of HIV status (Government of Spain, 2022).
- *June 2023 modification of Royal Decree 2487/1998* was amended to remove the exclusion of people with HIV from armed private security positions (Ministry of the Interior, 2023).
- *The Universal Health Bill* was approved by the government in May 2024 and published in the Official Bulletin of the General Courts on June 28, 2024. The aim of the regulation is to establish measures that safeguard the universality of the National Health System and minimize health inequalities (Congress of Deputies, 2023).

The Social Pact also spurred other initiatives. These have included a *partnership between the General Directorate of Public Health, the State Coordinator of HIV and AIDS, and the University of Alcalá in 2021,* with an annual allocation from the Ministry of Health of €90,000 (Ministry of Health, 2021). This partnership focuses on a number of actions summarized below. The third edition of the cross-sectional survey on the beliefs and attitudes of the Spanish population toward people with HIV was conducted in 2021. Its main findings are summarized in section 3.1. Also, for the first time, a study on how stigma is experienced by people with HIV in Spain was conducted in 2023 in collaboration with Seisida. The main findings are summarized in section 3.2.

Further, the Ministry of Health of Spain in close collaboration with the Social Pact committee has continued working on identifying current legal norms in the Spanish legal system—across all levels and in all areas of health, social services, access to public employment, etc.)—which either directly, indirectly, or by association discriminate against people with HIV or those who interact with them, or limit their rights. The Ministry of Health of Spain in close collaboration with the Social Pact committee has also produced materials aimed at ensuring that people with HIV are aware of their rights as well as the legal mechanisms for protecting those rights and reporting when they have been violated. Finally, we worked on strategies to facilitate the labor integration of people with HIV, ensuring equal opportunities for women and men both in access to and maintenance of employment. One example of this is the "Manual of Good Business Practices" created in collaboration with the NGO *Trabajando en Positivo* and now used by public companies and the civil service (Trabajando en Positivo, 2023).

Over the years, the Social Pact has made significant strides in raising awareness of the stigma and discrimination faced by people with HIV. This has been achieved through online communication strategies, a dedicated website, and campaigns aimed at eliminating HIV-related stigma and discrimination, particularly during the commemoration of World AIDS Day.

### EXAMPLE OF GOOD PRACTICES

#### Ensuring access to life insurance for people with HIV

Despite the 2018 reform of the **Insurance Contract Law**, people living with HIV still face discrimination when accessing benefits and insurance. To address this, the Ministry of Health's **HIV Control Division** and the **Spanish Union of Insurance and Reinsurance Entities (UNESPA)** are working together to ensure compliance with anti-discrimination regulations and raise awareness among insurance companies. This collaboration aims to eliminate practices that hinder equal opportunities and perpetuate stigma and discrimination.

As part of this effort, a study was conducted to calculate the life expectancy of people with HIV, aiding decision-making in the insurance sector. One key finding from the study is that individuals with HIV who have started antiretroviral therapy (ART) in recent years, with high CD4 counts and no prior AIDS diagnosis, have a life expectancy comparable to the general population, especially among men who have sex with men (MSM) (Jarrín, I. et al., 2024).

## 3.1. The Magnitude and Evolution of HIV-Related Stigma and Discrimination in Spain (2008-2021)

In 2008, the Spanish Interdisciplinary AIDS Society (SEISIDA) led the first nation-wide study of public stigma—i.e., the stigmatising attitudes held by the general public. This study aimed at assessing the level of knowledge that the general population had about aspects related to HIV infection and better understanding existing attitudes in Spain toward people with HIV. The study used a telephone survey administered to a representative sample of the Spanish population (n=1607). A correlational study was also conducted to examine the relationship between different variables in predicting prejudice and discrimination toward people with HIV. This same survey was subsequently conducted in 2011 and 2022.

Fuster-Ruiz de Apodaca, M.J. & Prats (2022) have analyzed the evolution of the survey results since 2008 and have revealed a significant decrease in most indicators of public stigma toward people living with HIV (PLHIV). These indicators included levels of discomfort around PLHIV, avoidance behavior, agreement with discriminatory policies, and blame attribution. However, the area improving the least was the intention to avoid people with HIV. In 2021, 10% of the population expressed that they would not want any kind of relationship with someone living with HIV, and only 9% claimed they would be comfortable having a PLHIV as a neighbor. The most relevant predictors of stigma in 2021 were consistent with previous surveys, highlighting the persistence of misconceptions about HIV transmission, fear of the virus, and the lack of personal experience of PLWH.

### 3.2. The Experience of Stigma among People Living with HIV: HIV Stigma Index in Spain, 2023

HIV-related stigma is a critical determinant in the quality of life of PLHIV, and addressing it is a priority of the Social Pact for Non-Discrimination and Equal Treatment associated with HIV. For the first time in 2023, SESIDA, in collaboration with CESIDA and the University of Alcalá, carried out a study focusing on describing the stigma experiences of PLHIV and analyzing their health-related quality of life (HRQoL) and psychological well-being (Fuster-Ruiz de Apodaca, M.J., et al., 2024). The findings emphasized the prevalence of anticipated stigma, with high levels of concern about rejection by sexual partners (66.1%) and fears of losing employment or being treated differently by coworkers (41.2% and 34.5%, respectively). In terms of actual experiences of stigma and discrimination, the most common forms were rejection by a sexual partner (32.5%) and receiving discriminatory remarks (27.6%). Moreover, 19.9% of respondents claimed they had chosen not to engage in sexual or romantic relationships in the past 12 months because of stigma. Respondents also showed a high tendency to internalize stigma. In 2023, despite 98.4% of the sample being on antiretroviral treatment (ART) and 94.5% having had undetectable viral loads in the previous 12 months, two-thirds were still worried about transmitting HIV to others. When it came to disclosing their serostatus, only 11% of participants lived openly and voluntarily with HIV. The most common form of discrimination in non-specialized healthcare settings was physical contact avoidance or the use of disproportionate preventive measures (10.8%). Additionally, 6.9% had experienced the need to disclose their HIV status to obtain health insurance. Despite the relatively low instances of structural stigma, only 51.7% of participants were aware of Spain's anti-discrimination laws. These findings underscore the importance of prioritizing interventions that target anticipated stigma and self-exclusion, as these factors significantly impact the quality of life of PLHIV in Spain.

## *4. HIV-related stigma and discrimination elimination as a priority of the Spanish EU Presidency.*

In alignment with Spain's agenda, the elimination of HIV-related stigma and discrimination was established as a political priority for the Spanish Presidency of the Council of the European Union in the second half of 2023. The decision to prioritize the elimination of HIV-related stigma and discrimination during Spain's EU Presidency led to key milestones:

- Spain's EU Presidency was inaugurated with an event on July 3, 2023, at the Ministry of Health, which paid tribute to the HIV community's activism and commitment, and recognized their leadership in defending their dignity during the 1980s and 1990s.
- An opinion paper was released by the European Economic and Social Committee, outlining measures to combat HIV-related stigma (2023).
- A joint technical document "HIV-Related Stigma and Discrimination: The Challenge" was prepared in collaboration with UNAIDS, WHO/Euro, ECDC, and SEISIDA (Ministry of Health, 2024).
- A high-level meeting in Seville on September 15, 2023, titled *HIV and Human Rights: Political Action to Achieve Zero Stigma*, which highlighted the political commitment of the participating countries to addressing this issue. https://www.sanidad.gob.es/ciudadanos/enfLesiones/enfTransmisibles/sida/VIHyDerechosHumanos/home.htm
- On September 15, 2023, Spain joined UNAIDS' Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination (UNAIDS, 2023). It was the second EU country after Luxembourg to make this commitment.
- A special session at the European Parliament in Brussels was held on December 1, 2023 (World AIDS Day) and chaired by Vice President Marc Angel and attended by Spain's Minister of Health, Mónica García; Christine Stegling, Deputy Executive Director of the Policy, Advocacy and Knowledge Branch at the Joint United Nations Programme on HIV/

AIDS (UNAIDS); and María José Fuster-Ruiz, Director of the Spanish AIDS Society (SEISIDA). https://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2023/december/20231201_wad-brussels

The primary goal of the High-Level Meeting (HLM) held, in Seville was to discuss various strategies and agreements to promote the elimination of HIV-related stigma and discrimination in social, political, and institutional spheres. This effort is crucial for achieving the Sustainable Development Goal (SDG) 3.3 by 2030, both within the EU and in the context of global health. The event was attended by the Spain's Minister of Health, the Mayor of the Town Hall of Seville, the Hungarian State Secretary for Health, the Director of ECDC, the Deputy Executive Director of UNAIDS, and 130 representatives from diverse sectors involved in the HIV response, including EU member states, international organizations (ECDC, WHO, WHO/Euro, UNAIDS), state, regional, and local governments, scientific societies, NGOs, and civil society (Ministry of Health, 2024).

### 4.1. Spain Joins the UNAIDS Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination

The unique and pivotal role of UNAIDS goes beyond its focus on HIV, addressing broader health inequalities, advocating for sexual and reproductive health, championing universal healthcare, and defending human rights, particularly for the most marginalized communities. One of the key strengths of UNAIDS lies in its ability to build trust between these communities and public authorities, creating a bridge that is essential for effective public health interventions.

The current global backlash against human rights and reproductive health rights is having a harmful impact on the response to the HIV/AIDS pandemic and future public health challenges. Achieving zero stigma and discrimination is not only a goal in itself but also instrumental in ending AIDS, as the involvement of marginalized communities is crucial for the success of the global HIV response.

The Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination, promoted by UNAIDS, provides a framework for reaching the goal of zero discrimination (UNAIDS, 2023). As part of the EU's Global Health Strategy, the European Commission (EC) has the potential to promote this partnership among Member States and support it financially, enhancing the collective effort toward a stigma-free environment for people living with HIV.

During the signing event, the Executive Director of UNAIDS emphasized that current attacks on human rights are a threat to freedom, democracy, and health. HIV-related stigma, discrimination, and the criminalization of key populations—such as LGBTQI communities, sex workers, and drug users—undermine public health efforts and hinder the global targets to end AIDS. UNAIDS is at the forefront of resisting these attacks, advocating for sexual and reproductive health and rights, and standing with the most marginalized communities. Currently, 38 countries, including 14 from Africa, have joined the Global Partnership for Action (UNAIDS, 2023).

On September 15, 2023, as previously mentioned, Spain joined the UNAIDS Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination, becoming the second EU country to sign. Later, during the 25th International AIDS Conference in 2024 in Munich, Germany joined the Global Partnership. https://www.unaids.org/en/topic/global-partnership-discrimination

Persistent inequalities in the global HIV response continue to hinder progress toward ending the epidemic. However, as UNAIDS highlighted in its 2022 World AIDS Day report *Dangerous Inequalities*, these gaps can be closed. The UNAIDS Global AIDS Strategy 2021–2026: *End Inequalities, End AIDS* (2021) is grounded in human rights, gender equality, and dignity, advocating for a world free of stigma and discrimination for all people living with HIV. This strategy sets clear goals and policies for engaging countries and communities in addressing HIV-related inequalities and ultimately ending the AIDS epidemic.

Spain has called for UNAIDS to receive both political and financial support from the European Commission to strengthen its efforts. In 2023, Spain renewed its commitment to the Global Fund for HIV, tuberculosis, and malaria with a contribution of 130 million euros for the next three years. This was a 30% increase from the amount granted for the previous three years, matching funding increases from other countries. https://www.theglobalfund.org/en/government/profiles/spain/

In October 2024, the Spanish government approved a new contribution of 1 million euros to UNAIDS to support its efforts to end AIDS by 2030 as part of the Sustainable Development Goals. The announcement was made following a meeting between the Spanish Minister of Health, Mónica García Gómez, and the Executive Director of UNAIDS, Winnie Byanyima, in Madrid.

https://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2024/october/20241015_spain

### 4.2. Continuation of the legacy of the Spanish presidency

The actions led by Spain's EU Presidency represented a significant step forward in Europe's ongoing fight against HIV-related stigma and discrimination. During the Belgium Presidency of the EU in 2024, Spain supported the side-talk "Drawing attention to the crucial role of UNAIDS in reaching EU, AU and UN global health goals for 2030" which took place during the European Union & African Union High Level Event. The event was aimed at drawing attention to the crucial role of UNAIDS in reaching European Union (EU), African Union (AU), and United Nations (UN) global health goals for 2030. The side-talk was organized by Belgium, the Netherlands, and Spain following on the political priority "Elimination of HIV-related stigma and discrimination" set by the preceding Spanish Presidency.

As a consequence of flagging this political priority, the EUXHealth program—which is the EC's main instrument for implementing EU health strategy, announced a joint action on vaccine-preventable cancers and addressing HIV/AIDS, tuberculosis, and hepatitis. The action calls for initiatives that address stigma and discrimination against people living with HIV and the identification and transfer of best practices for addressing HIV/AIDS, tuberculosis, and viral hepatitis (European Commission website). This joint action will be developed during 2025 and 2026 and different EU countries are working to eliminate HIV related stigma.

## *5. Conclusion: The Legacy of HIV Responses to Eliminate HIV-Related Stigma and Discrimination beyond HIV*

The legacy of HIV responses in reducing HIV-related stigma and discrimination extends beyond the immediate scope of HIV itself to impact broader public health policies, legal frameworks, and societal attitudes toward marginalized groups. One of the most significant legacies lies in the efforts to address all forms of stigma and discrimination by advocating for systemic changes that promote inclusion and equity. HIV responses have driven new legislation aimed at dismantling legal barriers that previously limited access to healthcare. For example, countries have adopted Universal Health Care policies that do not just benefit people living with HIV but are also designed to prevent discrimination based on socioeconomic status, race/ethnicity, gender identity, or other identities. In many ways, the HIV response has catalyzed a "health-in-all-policies" approach, which ensures that public health considerations permeate policies from various sectors. By engaging different administrative bodies, this approach supports a cross-sectoral commitment to fostering healthier living conditions for all communities, particularly those historically side-lined by traditional health and social policies.

In addition to legislative reform, public health approaches to HIV have demonstrated the importance of designing policies that address stigma and discrimination directly. Modern HIV responses have shown how inclusive and privacy-sensitive data use can inform effective public health policies while protecting the rights of marginalized groups. As a result, legislation now often incorporates strict privacy safeguards and offers individuals greater control over their personal information, creating a model that extends beyond HIV data practices to other health areas where stigma is a factor.

Central to the HIV response has been a firm commitment to upholding individuals' rights around information, consent, and confidentiality, particularly concerning HIV testing. This emphasis on patient autonomy has been pivotal in reshaping broader health policy approaches to consent and information-sharing practices. Recognizing that HIV was historically stigmatized—and that fear of discrimination prevented many from seeking testing and care—HIV advocacy efforts have championed policies where informed consent and patient-centered rights are foundational. By requiring clear communication about testing and the right to privacy, these policies have increased patient trust in healthcare systems, setting a standard that has since influenced other areas of medical testing and treatment. Today, this patient-rights framework helps ensure that individuals feel empowered in their healthcare choices, knowing that they are respected participants rather than passive recipients of care.

This framework also underscores the critical importance of access to treatment. The HIV response mobilized a robust global push to expand access to life-saving medications, challenging traditional intellectual property practices that made essential drugs prohibitively expensive for low- and middle-income countries. Through persistent advocacy, these efforts led to ground-breaking measures, such as patent pooling and voluntary licensing, which allowed for the production of affordable generic antiretrovirals. This shift in intellectual property policy proved transformative, demonstrating that health crises could necessitate—and justify—renovating traditional intellectual property frameworks to prioritize public health. This has prompted new health policy frameworks, such as TRIPS (Trade-Related Aspects of Intellectual Property Rights) flexibilities, which allow countries to issue compulsory licenses in cases of public health emergencies. The HIV movement's advocacy for such measures has reverberated throughout global health, encouraging countries to prioritize public health over patent rights in situations where critical drugs are necessary.

Beyond HIV, this legacy has proven influential in responses to other health crises, such as the COVID-19 pandemic and the recent MPOX outbreak. The response to COVID-19, for example, saw calls for similar intellectual property flexibility to ensure equitable access to vaccines, diagnostic tools, and therapies. This further points to the HIV response's lasting impact on intellectual property policy by promoting the idea that lifesaving medications should be a global common good rather than restricted commodities. In the case of MPOX, there has been a conscious effort to collaborate with civil society organizations to ensure that documentation and public health messaging are carefully crafted to avoid inadvertently stigmatizing affected communities. This commitment to inclusivity, drawn from the lessons of HIV responses, reflects an ongoing shift in public health —where policies are developed not just to control disease but to respect and protect the dignity of all individuals, regardless of health status or group identity.

In sum, the HIV response's legacy is evident in a transformed public health framework that increasingly recognizes the need to fight all forms of stigma and discrimination. The HIV response has demonstrated that a rights-based approach—rooted in informed consent, patient autonomy, and equitable access to treatment—strengthens healthcare systems by making them more responsive and inclusive. This legacy continues to guide global health policies, underscoring the fundamental truth that healthcare access should be governed not by market forces but by principles of human dignity and equity.

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# Conclusion

*Hang Su, Jiang Du*

*Breaking the Silence: Confronting Stigma and Substance Use Disorder* encapsulates a comprehensive exploration into the intricate dynamics of stigma surrounding mental illness and substance use disorders. Across its detailed analysis, the book highlights the pervasive and detrimental impact of stigma on individuals, families, communities, and society as a whole.

Throughout its pages, the book underscores stigma not just as a social issue, but as a formidable barrier that impedes access to treatment, hampers recovery efforts, and perpetuates cycles of discrimination and marginalisation. It emphasises how stigma undermines self-worth, erodes social support networks, and exacerbates the challenges faced by individuals seeking help and support.

Central to the book's message is the critical role of language and perception in shaping stigma. It advocates for the use of respectful, person-centred language that honours the dignity and humanity of individuals affected by mental illness and SUD. By promoting empathetic communication and challenging stereotypes, the book aims to foster environments where individuals feel empowered to seek assistance without fear of judgment or prejudice.

The examination of stigma's broader societal impacts reveals its insidious reach into healthcare systems, employment opportunities, criminal justice proceedings, and overall quality of life. It illuminates how stigma contributes to disparities in healthcare access and outcomes, limits employment prospects, and perpetuates cycles of poverty and social exclusion. This comprehensive view underscores the urgent need for multifaceted strategies that address stigma at individual, social, and structural levels.

The book navigates the complexities of the brain disease model of addiction, acknowledging the importance of medical interventions while also emphasising the role of social determinants and environmental factors in shaping substance use behaviours. It advocates for an integrated approach that combines medical treatment with psychosocial support, recognising that effective care requires addressing both the biological and social dimensions of addiction.

In its call to action, *Breaking the Silence* outlines actionable steps to combat stigma and promote societal change. It advocates for robust public awareness campaigns, policy reforms that prioritise harm reduction and treatment accessibility, and collaborations across sectors to build supportive communities. By empowering individuals, families, healthcare providers, policymakers, and community leaders to challenge stigma, the book envisions a future where all individuals affected by mental illness and SUD receive equitable care, support, and opportunities for recovery.

In conclusion, *Breaking the Silence: Confronting Stigma and Substance Use Disorder* underscores the profound impact of stigma on individuals and society. The book highlights the necessity of shifting perspectives and implementing effective stigma reduction strategies to foster a more compassionate and understanding environment for those affected by mental illness and SUD. By acknowledging the complexities of stigma and advocating for comprehensive approaches, this book aims to inspire action and change in addressing one of the most pressing public health challenges of our time.

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