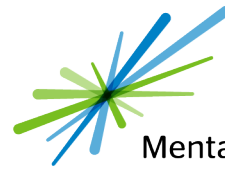


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# Structural Stigma in Health-Care Contexts for People with Mental Health and Substance Use Issues

A Literature Review

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# Executive Summary

People living with mental health and substance use issues need prompt access to quality health care. Sometimes they receive it, but often they do not. Significant barriers stand in the way when people with lived experience\* seek access to care, with many challenges worsened further still by stigma. Even when people living with mental health and substance use issues do gain access, they are more likely than others to receive an inferior quality of health-care services.

Systematic problems with accessing and receiving quality health care severely compromise the health and well-being of people living with mental health and substance use issues. This experience also increases the chance that they will acquire other health conditions, have their illnesses go untreated, and experience health-related crises. It also reduces their longevity — people with lived experience die 10 to 25 years earlier than people who do not have to face these challenges.

The health-care system is consistently identified as a major contributor to health disparities among people living with mental health and substance use issues. Scholars have illustrated how the health-care system participates in the production of structural stigma: the ways it produces inequities and injustices for people living with mental health and substance use issues. The policies of health-care institutions and the practices of health-care practitioners can systematically deprive their right to quality health care.

This report provides a review of the research and literature pertaining to structural stigma in health-care contexts, including how it affects people living with mental health and substance use issues, how it is expressed in the health-care system, and how it can be reduced.

Broadly speaking, the literature on structural stigma in health-care contexts focuses on two key issues: access and quality. Structural stigma surfaces when policies and practices produce inequitable access to health care for people living with mental health and substance use issues. This access is compromised in several ways: through the inequitable distribution of resources, the undertreatment of health problems, the withholding of services, and the fragmented care. Structural stigma is also expressed when people systematically receive a lower quality of care. The serious issues impinging on quality of care include negative attitudes and poor practices among health-care practitioners, adverse health-care interactions and experiences, and the overuse of coercive or paternalistic approaches.

A comprehensive strategy for addressing structural stigma in health-care contexts for people with lived experience include a combination of approaches that seek to (1) improve the attitudes and practices of health-care practitioners and others (e.g., trainees, decision makers), (2) strengthen the integration and coordination of care, (3) achieve parity for mental health and substance use issues, (4) expand access to effective treatment, (5) establish mechanisms to monitor structural stigma, (6) foster the inclusion and participation of people living with mental health and substance use issues, and (7) enhance and enforce protections for people with lived experience.

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\* This report uses “people with lived experience” synonymously with “people living with mental health and substance use issues.”

# Preamble

## Background

This report summarizes the research and literature on structural stigma in health-care contexts [1].\* The work was commissioned by the Mental Health Commission of Canada (MHCC), which has been leading and contributing to a range of stigma-related initiatives since 2007. Among them is the Opening Minds program that identified health-care practitioners as a key target group. The current report aims to provide a more focused discussion of how structural stigma affects people living with mental health and substance use issues and identify approaches for reducing structural stigma in health care.

## Method

The narrative review was performed from September to November 2019. Keyword combinations were entered into several electronic databases (PubMed, PsycINFO, Web of Science, CINAHL, Google Scholar). The following main phrases (with their variations and synonyms) were included: (1) mental health and substance use issues (or mental illness, mental disorder, addiction, etc.), (2) structural stigma (or institutional discrimination, barriers, inequities, disparities, etc.), (3) and health care (or health policy, health-care system, mental health services, etc.). After retrieving references, each of the titles and abstracts were reviewed for relevance. Full-text articles of the relevant records were then obtained for further review. Additional records were identified by scanning article reference lists. While the primary aim of the search was to retrieve peer-reviewed articles, highly relevant grey literature (e.g., technical reports, position statements, theses) was also included. The documents retrieved were entered into a reference management program. Altogether, pertinent information from almost 300 documents was extracted, synthesized, and woven into this report.

## Terminology

Readers should note how a few widely used terms in this report are being defined. In keeping with established definitions [2], *Stigma* includes discrimination. *Health care* refers to the formal health-care service delivery system, which includes services delivered by regulated health-care practitioners and eligible for coverage from public or private health insurance plans.<sup>†</sup> *Mental health and substance use issues* has been adopted for this report, given that both narrow (e.g., specific disorders such as schizophrenia) and general (e.g., mental health clients, service users) terms are used throughout the literature. This phrasing is meant to encompass the broad spectrum of difficulties people face with respect to their psychological well-being and consumption of substances, including illnesses as defined

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\* The report updates and extends [Mental Illness-Related Structural Stigma: The Downward Spiral of Systemic Exclusion](#), a 2013 MHCC report by the same author that summarized the literature on mental illness-related structural stigma across numerous institutional contexts.

<sup>†</sup> Such a definition omits informal services offered by non-governmental and service-user organizations, unregulated and alternative care providers, and other forms of support (e.g., mutual support groups, caregivers). Although the informal service system is integral to the well-being and recovery of people with lived experience, it was absent from the literature searched and was therefore considered out of scope for this review.

by diagnostic classification systems. It is acknowledged that such an inclusive term has the potential to overlook important ways that structural stigma varies between distinct conditions.

## Levels of stigma

There is no doubt that stigma denigrates the value of people who have a mental illness as well as the social and professional support systems designed to support them. It maintains mental health programs and issues at a low level of priority for governments and funders, creates serious inequities in the quality and availability of treatments, and undermines the quality of life and recovery possibilities for people with a mental illness. (p. 462)

Arboleda-Flórez and Stuart [3]

This report focuses on the stigma associated with mental health and substance use issues, while specifically exploring how it is woven into the fabric of health-care institutions and systems. People living with mental health and substance use issues are highly stigmatized. They are devalued, rejected, shamed, and excluded based on a socially discredited health condition. A useful way to think about stigma is through its three forms: self, social, and structural.

Self-stigma involves the perceptions and experiences of people living with mental health and substance use issues. It is a key deterrent in seeking help and adhering to treatment [4-6]. People with lived experience frequently cite the fear of stigma and the anticipation of negative reactions (e.g., being perceived as crazy or weak, feeling embarrassed or ashamed, being afraid of what others might think) as major reasons for not seeking treatment [7-9].

Social stigma occurs when community members endorse negative stereotypes and act in harmful and discriminatory ways toward people living with mental health and substance use issues [10]. It supplies a fertile ground for self-stigma and structural stigma. Widespread endorsement of these stereotypes (e.g., dangerousness) produces regressive reforms and punitive policies, such as reduced funding for mental health and substance use services or an expansion of coercive interventions [11-13]. In turn, regressive reforms and punitive policies can reinforce social stigma [12-14], a dynamic that also inhibits progressive reforms and inclusive health-care policies (e.g., the expansion of harm reduction strategies).

Structural stigma is rooted in the rules, policies, and procedures of social institutions that arbitrarily restrict the rights and opportunities of people living with mental health and substance use issues [1, 15]. It is reinforced in laws, the internal policies and procedures of private or public institutions and systems, and the practices of professionals and decision makers. A prior literature review has documented examples of structural stigma across various institutional systems and social contexts, including employment and income, housing, and education [1]. Although overt cases of structural stigma may have diminished, they have produced a legacy of disparity and have been replaced with covert structural barriers that continue to create inequality and injustice for people living with mental health and substance use issues.

On average, people carry six stigmatizing attributes; for example, unemployed, working class/poor, overweight, smoker, depressed, or voluntarily childless [16]. These attributes interact in complex ways to produce differential experiences of stigma, a phenomenon known as intersectional stigma [17]. Research demonstrates how the effects of stigma are exacerbated when people living with mental

health and substance use issues experience other forms of oppression produced by racism, sexism, classism, xenophobia, homophobia, etc. [e.g., 18, 19-23]. It is important to bear in mind how intersectional stigma influences people's access to and experiences with the health-care system [24].

## Structural stigma in health-care contexts

Stigma in health facilities undermines diagnosis, treatment, and successful health outcomes. Addressing stigma is fundamental to delivering quality healthcare and achieving optimal health. (p. 1)

Nyblade et al. [25]

Research consistently identifies the health-care system as a significant contributor to stigma related to mental health and substance use issues. It mainly contributes through its production of structural stigma [24, 26], which worsens health outcomes and is a major population health problem [27]. Among people living with mental health and substance use issues, structural stigma fosters unmet needs, delayed help seeking, and treatment withdrawal; consequently, it is regarded as a fundamental cause of population health inequity [28, 29]. As such, scholars recommend that, in any effort to reduce stigma, the health-care system be given high priority [30].

Health-care systems can work in ways that impinge on the rights of people living with mental health and substance use issues, including the right to quality health care. There is growing evidence that this denial of rights is a contributing factor in health disparities, including excess morbidity and early mortality [30]. People living with mental health and substance use issues are at increased risk of comorbid physical health issues and poor physical health care [31]. They are also more likely to experience chronic physical health issues, such as diabetes, heart disease, stroke, hypertension, and epilepsy [31]. People with lived experience develop such chronic illnesses at an earlier age and die more quickly following onset [32]. They also experience poorer outcomes after being diagnosed with physical health issues and following surgery [33].

People living with mental health and substance use issues die younger than other people. Research indicates that they should expect to live around 10 to 25 fewer years [27, 34-38]. These early deaths tend to be caused by comorbid physical health issues, primarily cardiovascular disease [31, 33-35]. Other chronic health conditions, including respiratory illness, diabetes, cancer, tobacco-related illness, and obesity, also contribute to excess morbidity and early mortality [30, 37]. In England, a study of 18,201 people living with severe mental illness found that they had a significantly higher risk, compared to the general population, of respiratory disease, cardiovascular disease, cancers, and death [39]. Mortality from respiratory disorders and cardiovascular disease was elevated by up to four times; from suicide, it was five to 10 times higher across almost all ethnic minority groups [39]. Co-occurring substance use issues doubled the risk of mortality from unnatural causes [39].

The reasons for excess morbidity and early mortality among people living with mental health and substance use issues are complex and involve multiple factors. Clinical factors (e.g., side-effects from psychiatric medications), health behaviours (e.g., poor diet, smoking), and environmental and social factors (e.g., poverty, unemployment) are major contributors [36, 37, 40]. Factors pertaining to health-care practitioners and systems add to the problem [36]. Research suggests that health-care-system-

related factors explain 10 to 25 per cent of the variability in health and longevity among people living with mental health issues [37, 38]. This association highlights the importance of targeting the health-care system in seeking to improve the health of people with lived experience and extend their life expectancy [38].

Health disparities are worsened when people do not receive necessary health-care services. Of major concern is the fact that a substantial proportion of people living with mental health and substance use issues live with untreated needs [41]. Roughly 600,000 people in Canada live with unmet mental health needs, and more than a million have these needs only partially met [42]. Common reasons why people living with mental health and substance use issues do not engage with the health-care system include the cost and affordability of services, a preference to self-manage their health issues, and transportation problems [41-43]. This lack of engagement also intersects with barriers produced by gender, race, class, sexuality, nationality, and other identity characteristics [44]. People with lived experience report that the health-care system is a key reason they stay away from treatment. About one in five people in Canada with an unmet or partially met mental health need see the health-care system as a barrier to getting care [42].

Negative experiences with the health-care system can deter people from accessing and using health-care services. Studies have revealed that such experiences in health-care settings are pervasive for people living with mental health and substance use issues [e.g., 45, 46, 47]. One systematic review indicated that 16 to 44 per cent of them have experienced mental illness-related discrimination in mental health care settings (17 to 31 per cent in physical health-care settings) [24]. A study in England examining the experience of 3,579 people living with mental health issues showed that 30 per cent reported discrimination from staff in mental health (29 per cent in the area of physical health) [48]. Such occurrences also have an economic impact. Prior experience with discrimination in health-care settings has been linked to increased costs for associated health-care service use [5, 49-51].

Although studies examining health disparities, mortality gaps, barriers to help seeking, and negative health-care experiences among people with lived experience are useful for understanding structural stigma in health care, few can directly tie structural stigma to poor health outcomes. Deficiencies in the health-care system are known to have a role in producing health disparities, but questions remain about the degree to which structural stigma is implicated. One study to examine the impact of structural stigma assessed its relationship with quality of life among 787 people living with mental health issues in the U.S. [52]. Using indicators of state-level mental health expenditures and mental health parity to measure mental illness-related structural stigma, it found that the people in states with higher levels of structural stigma reported lower levels of quality of life. Another U.S. study investigated the effect of mental illness-related structural stigma on the health of 152,236 people, including 5,860 people living with mental health issues [53]. Using indicators of mental health expenditures, availability of mental health care (e.g., mental health professional workforce shortages, number of psychiatric beds), and unfair treatment (i.e., charges of mental disability-related employment discrimination) to measure structural stigma in 25 states, the study found that higher mental health expenditures were associated with small improvements in health outcomes, both for people who were and were not living with mental illness.

Broadly speaking, the literature on structural stigma in health-care contexts focuses on two key issues: access and quality. Structural stigma surfaces when policies and practices produce inequitable access to



health care for people living with mental health and substance use issues. It is also expressed when they systematically receive a lower quality of care. Since these issues severely compromise people's health and well-being, the following discussion is organized around two themes: inequitable access and poor quality.

## Inequitable access to health care

Access to and use of health-care services are influenced by a myriad of factors, often organized into person, practitioner, and system domains [30, 32, 35, 53-55]. The person and practitioner domains relate to the respective beliefs, knowledge, behaviours, and resources of people living with mental health and substance use issues and practitioners. The system domain involves structural elements, such as institutional policies, procedures, and the distribution of resources. Most relevant to structural stigma are the practitioner and system domains.

People living with mental health and substance use issues have greater difficulty accessing health care, compared to the general population [55]. In part, this difficulty occurs because practitioner- and system-related issues discourage them from accessing the care they need. This review found three major areas of inequitable access for people with lived experience:

- the under-resourcing of mental health and substance use services as well as issues with health insurance coverage
- the ways people are deprioritized, undertreated, and otherwise denied access to care
- the systemic separation of mental health, substance use, and physical health services

### **Underfunded and uncovered**

Many nations, including Canada, underfund mental health and substance use services relative to the disease burden and in comparison to the resources allocated to physical health care [55-59]. Similarly, the allocation of international financial assistance to mental health issues falls significantly short of the global disease burden and the contributions made to other health issues (e.g., HIV) [60]. The systematic and chronic underfunding of mental health and substance use services is widely recognized as a key indicator of structural stigma [1, 24, 61, 62]. Stigma is expressed when governments and decision makers do not make equitable investments in the mental health and substance use service systems. It is channeled when insurance companies do not supply fair coverage and reimbursements for such services, a reduction that is also evident in the funding gap for mental health and substance use research. These structural inequities reflect and reinforce the ways people living with these issues are devalued and deprioritized in society [63].

As a result of underfunding, people have greater difficulty accessing appropriate care for mental health and substance use issues than they do for physical health [55, 61, 64]. The chronic and severe shortage of mental health and substance use practitioners contributes to excessive delays in accessing care [65]. As well, any mental health and substance use services people might eventually access will be less effective and of lower quality. To mention only three examples: individuals might be able to access short-term services in times of crisis but not longer-term services in other times of need; cheaper medications may be made available instead of comparatively newer and more effective medications that carry fewer side effects [66, 67]; and people might have access to pharmacological interventions but not other forms of care known to be equally or more effective, such as psychological therapies [68].

As Clement et al. has argued, the inequitable allocation of resources results in delayed care, poor services, and service user dissatisfaction, thereby acting as a powerful deterrent for help seeking and access to care [5].

Gaining access to appropriate care often carries a significant financial cost, which many people living with mental health and substance use issues simply cannot afford [52]. They frequently cite high cost as the most significant barrier to care [43, 65]. For instance, Feder et al.'s study of almost two million people living with opioid use disorders in the U.S. found that the most common reason for not receiving substance use treatment was financial (e.g., no insurance coverage) [9]. This lack of affordability intensifies health disparities and treatment inequities among people who are further marginalized by other identity characteristics (e.g., race, immigration status). Even in countries like Canada, with universal access to publicly funded health-care services, access to evidence-based mental health and substance use services (e.g., psychotherapy) is exceedingly difficult and beset by affordability issues. The unfair policies and practices of private health-care insurers is a frequent topic of discussion in the literature and has been deemed an especially potent form of structural stigma in other countries, including the U.S. [69, 70]. Denying coverage, providing lower limits, setting extraordinary restrictions, and excluding evidence-based treatments are but some of the unfair methods insurance providers employ to systematically prevent people living with mental health and substance use issues from receiving appropriate care [61, 70, 71].

Related to the inadequate funding levels for mental health and substance use services are the historic and ongoing inequities in the allocation of scientific funding [72-79]. Although mental health and substance use issues are a tremendous cost and burden to society, researchers in this area receive much less funding than the colleagues who study other health conditions. One study in Australia found that mental health research not only received lower levels of funding than most other health conditions (e.g., cancer, cardiovascular disease), it was also underfunded relative to its disease burden and any funding increases had not kept pace with those of other health conditions [76]. This inequitable distribution is problematic because it hampers the development of evidence-based policies and services for mental health issues.

### **Deprioritized, undertreated, and denied**

In addition to being deprioritized in the allocation of health-care funding, the literature supplies other examples of how mental health and substance use issues are systematically deprioritized in health-care contexts, contributing to health-care inequities and health disparities.

“Overshadowing” at the diagnostic and treatment levels are common topics of discussion in the literature [55, 70, 80]. Diagnostic overshadowing occurs when health-care practitioners ignore and overlook the physical health concerns of people living with mental health and substance use issues, resulting in a failure to identify and diagnose health issues. Treatment overshadowing refers to biases in treatment decisions that impede the provision of appropriate physical health care for people living with mental health and substance use issues. In part, overshadowing is produced by stigma. In his seminal work, *Stigma: Notes on the Management of Spoiled Identity*, Erving Goffman defines stigma as an “attribute that is deeply discrediting” and that reduces the bearer “from a whole and usual person to a tainted, discounted one” (p. 3) [81]. In doing so, Goffman references a prevailing stereotype: that people living with mental health and substance use issues are unreliable and untrustworthy. These

beliefs cause health-care practitioners to mistrust and disbelieve people [32] so that somatic complaints effectively get misattributed to and erased by mental health and substance use issues.

Not being believed and having the seriousness of one's concerns underestimated is a prevailing experience among people living with mental health and substance use issues who seek care for physical health issues [82]. One participant in a study examining the experiences of people living with schizophrenia shared the following experience with diagnostic overshadowing: "Until they discovered what I have (kidney stones), they didn't listen to me, it was all due to nerves, whenever I said my stomach ached, this side ached, it was nerves" (p. 18) [83]. Another participant in a study examining how people in Canada with mental health issues experience emergency departments echoed that sentiment: "Once you're identified as a psych patient, even if you have a physical problem like a migraine, you're still treated as a psych patient" (p. 128) [84]. Diagnostic and treatment overshadowing lead to the underdiagnosis and undertreatment of physical health issues among people living with mental health and substance use issues. The resulting escalation of physical health issues not only prevents early intervention, it also contributes to an increased risk of emergency situations, adverse events, and premature death [32, 80, 85]. Anticipating such experiences, people with lived experience delay help seeking, hide their issues from health-care practitioners, downplay their need for pain medication, and seek alternative services. As one participant from a study examining health-care experiences among people who inject drugs put it, "When it comes down to it, a lot of the times that I need to get medical attention, I put it off and put it off and put it off, because I don't want to face the embarrassment that they make me feel, and that's not fair. It's not" (p. 83) [45].

Stigma contributes to the systematic denial of access to preventive services and routine care for physical health issues among people living with mental health and substance use issues. Because of stigma, they are less likely to receive (1) vaccinations, (2) blood pressure and cholesterol monitoring, (3) surgical interventions for cardiovascular disease, (4) cerebrovascular arteriography or warfarin following stroke, (5) standard levels of diabetes care, (6) routine cancer screening (including mammography), (7) cervical smear tests, (8) osteoporosis screening, (9) medical treatments for arthritis, and (10) comprehensive assessment and treatment following a diagnosis of a physical health issue [30, 32, 85-87]. Not only are people with lived experience more likely to present late with appendicitis and have more complications and worse outcomes following surgery [30], they wait longer on services for physical health issues [82, 88].

The literature also references the policies and practices of primary care centres and emergency departments in connection with structural stigma. A study in Canada examining primary care experiences among 85 people living with mental health and substance use issues and 17 health-care practitioners found a range of system-level barriers to accessing primary care. These barriers included long wait times for appointments, inadequate counselling supports, "one issue per visit" policies, and difficulty finding a consistent primary care physician [89]. The study participants attributed these kinds of experiences to two main problems: (1) the widespread belief that people living with mental health and substance use issues are undesirable patients, and (2) the general disinclination among primary care practitioners to take people with complex needs onto their caseloads. Studies have also found that people living with mental health and substance use issues are less likely than others to be referred to services and specialists by primary care practitioners [70]. Stigmatizing attitudes among health-care practitioners, including pessimism about a person's future adherence to treatment, have been implicated as a contributing factor to this problem [54]. Additionally, primary care practitioners face

greater challenges when referring people to mental health and substance use services, compared with physical health services, something which may deter them from linking people to appropriate care [63].

People living with mental health and substance use issues commonly report being denied services by health-care practitioners in primary care clinics, hospitals, emergency rooms, pharmacies, and dental centres [62, 90, 91]. What this means for them was reflected in a comment from a participant in a study in Australia examining their experiences: “One time I went into hospital for something. One of the doctors said, ‘She’s a bloody drug user. No use keeping her in hospital for the night. May as well just treat her and let her go, because she won’t stay in hospital’” (p. 65) [92]. People living with opioid use disorders, especially those who receive opioid agonist treatment (e.g., methadone), have difficulty finding post-acute care facilities to take them in [88, 93]. Problems accessing pain management medication, from being branded a “med-seeker,” is another significant issue faced by this group [45]. This type of situation was conveyed by a participant in a study examining the experiences of people who received methadone maintenance treatment:

I just had surgery and everything and it’s [they were]\* like “don’t give the user any pain killers, don’t give the user anything” . . . that I can definitely tell that’s like the flag goes up as soon as they hear I’m on methadone or I’m an ex-user. I definitely have been treated differently because of that. (p. 118) [94]

Another participant in a study examining barriers for accessing care among people who inject drugs shared a similar experience:

They talk to me like I am a piece of shit . . . I can’t stand the place, but I am scared if I go to another surgery [medical clinic] they will give me nothing. Then what am I going to do? I am going to be in the shit. (p. 149) [95]

Other examples in the literature describe ways the health-care system deprioritizes people living with mental health and substance use issues. When health-care resources are scarce or stretched (which is almost always), there is a tendency to prioritize physical health issues ahead of mental health and substance use issues [96]. The triage practices of emergency departments may themselves signal that people with lived experience are a low priority (i.e., systematically assigning them to non-urgent categories and increasing their wait times for emergency care) [84, 85]. A participant in a study examining the health-care experiences of people living with substance use issues explained how this problem may arise in emergency departments:

In emerg . . . [if]† an IV-drug user is there with their cellulitis, or some older gentleman is there with cellulitis, maybe because he’s a diabetic, and you got one space; I can tell you who’s going to get it, right? — even if that IV-drug user’s cellulitis is much worse — because that’s a druggie. He did it to himself. (p. vi) [62]

The routine of an acute care hospital (e.g., busy, lacking time, depersonalized) and its physical environment (e.g., non-therapeutic, sterile, lacking privacy, noisy) also pose challenges for caring for people living with mental health and substance use issues [97]. As with diagnostic overshadowing, health-care practitioners may neglect and deprioritize the physical health needs of people with lived experience [55]. For instance, women with mental health issues report that health-care practitioners

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\* Bracketed in the original.

† Bracketed in the original.

offer them few opportunities to discuss issues beyond their mental illness, such as menstrual irregularities and sex [98]. Studies note that some health-care practitioners have a “diminished desire to treat” people living with mental health and substance use issues, which stems from both stigmatizing attitudes and a lack of education and training [99].

The frameworks for measuring the performance of health-care systems can also contribute to devaluing mental health and substance use issues. The literature notes how health-care systems employ relatively few quality indicators pertaining to mental health and substance use services or issues compared to physical health care [53, 61, 70], which validates the adage, “what gets counted, counts.” It has also been suggested that existing performance indicators to assess quality pertaining to mental health and substance use issues are poorly operationalized and measured [61].

### **Disintegrated and fragmented**

Fragmented care is the default type of care people living with mental health and substance use issues receive [53]. Despite the strong relationship between mental health, substance use, and physical health, health-care services for each of these issues are commonly provided in separate locations by distinct groups of practitioners. The literature points to this artificial separation — and the lack of coordination and interagency collaboration between systems — as a major barrier to health care for people living with mental health and substance use issues [27, 55, 70, 100]. Institutional policies and systems that fragment or verticalize care (e.g., separate clinics, flagging patient records to distinguish them) promote stigma, impede access to care, and produce poor health outcomes [25].

Scholars note that fragmented care is one of the legacies of deinstitutionalization [101]. Rather than receiving services in a single centre (e.g., a large psychiatric institution), people’s health-care needs are attended to by different subsystems that lack integration, coordination, and continuity [32]. This legacy complicates the care pathways of people living with mental health and substance use issues, since they are shuffled from one practitioner or clinic to another. It also contributes to the problem of health-care practitioners perceiving a particular health issue as outside their scope of practice [32].

Despite the high prevalence of physical health issues among people living with mental health and substance use issues, practitioners in these service sectors may not see that their scope of practice also involves physical health needs. As a result, they may not screen, assess, or provide care planning for physical health issues [31, 55]. Similarly, physical health practitioners may not see that their role or responsibility must consider or attend to mental health and substance use issues [102], which exacerbates many of the issues previously noted, such as diagnostic and treatment overshadowing, denial of services, and deprioritizing people living with mental health and substance use issues. The unwillingness of physical health practitioners to consider mental health needs was described in the following way by a participant in a study examining the barriers that people living with mental health and substance use issues experience when trying to access primary health care:

Well, you know, it’s a kind of subtle message that says “well, look. [sic] I am here for your physical health” and they don’t look at the big picture — how the mental impact on the physical, you know, and that we are a whole . . . “I can’t help you, sorry. I want to help you, but my area, is the body.” (p. 7) [89]

This kind of experience is especially concerning given the fact that people are most likely to seek help for mental health and substance use issues in primary care settings [27].

Connected with this reluctance among health-care practitioners is the lack of training and education for them to acquire the necessary knowledge and skills to assess and treat physical health, mental health, and substance use issues [32]. Mental health professionals may lack the knowledge and confidence to attend to physical health and substance use issues [31]; substance use service practitioners might lack comfort dealing with mental health and physical health issues; and physical health practitioners often lack competencies to identify and address mental health and substance use needs. Acute care hospital staff have cited poor mental health literacy (and resulting feelings of inadequacy) as a major challenge to providing effective care to people living with mental health issues [97]. Similarly, community-based primary care physicians may not have learned about or acquired the skills to manage substance use disorders. As one participant mentioned in a study examining physicians' perceptions of treating people living with opioid use issues, "the topic [substance use disorders] wasn't really pressed upon very much. So, we didn't get a lot of formal training in that area of medicine . . . unless you actively sought it out . . . it's more like a fringe topic" (p. 350) [103].

## Poor quality of health care

Many people living with mental health and substance use issues do experience compassionate and effective care when receiving health-care services [96]. However, numerous studies have highlighted that stigmatizing health-care encounters are pervasive [45-47, 67]. The stigma associated with mental health and substance use issues has a detrimental impact on the quality of health-care services people with lived experience receive. This influence has been referred to as one of the most pernicious and powerful forms of structural stigma [35, 70, 82, 104].

Unfortunately, people living with mental health and substance use issues expect inequity and unfairness when they access the health-care system [96]. Doubts about the effectiveness of mental health and substance use services further discourages them from seeking help [43]. In part, these perceptions are driven by the absence of evidence-based practices in mental health and substance use services as well as by the lower quality of care provided to them [53]. For instance, one study found that having a mental illness increased a person's chances of being admitted to a health-care facility (nursing home) with deficient quality of clinical care [105]. Negative interactions with practitioners are also prominently featured in the health-care experiences of people living with mental health and substance use issues [62, 104, 106, 107]. Structural stigma, manifesting as poor quality of health care, is a major contributor to health disparities and inequitable treatment [108].

This review identified three recurrent areas raised in the literature regarding the poor quality of health care received by people with lived experience: the negative attitudes and practices of health-care practitioners, the adverse interactions reported by people living with mental health and substance use issues, and the health-care system's over-reliance on coercive approaches.

### **Negative attitudes and poor practices**

Practitioners' attitudes and practices shape the quality of health-care interactions for people living with mental health and substance use issues. They exert a significant effect on therapeutic processes, care quality, and health outcomes [109]. Some scholars see these attitudes and behaviours as distinct from structural stigma and prefer to put them in their own domain (sometimes called "professional stigma") [110]. For several reasons, this report includes practitioners' attitudes and behaviours in its definition of structural stigma.

Not only are practitioners agents of the health-care system and, as such, key structural components of organizations and systems, when engaged in stigmatizing practices, they are also the agents of structural stigma [67]. Research indicates that structural stigma most commonly manifests in the realm of professional practices, including the unwritten procedures and practices of health-care practitioners [1]. Organizational culture, resources, and policies are expressed through the practices of health-care practitioners [24]. For instance, coercive practices employed by practitioners might be produced by policies that emphasize risk reduction, compulsory treatment, or institutional care [24]. If the unfair practices of professionals in any institutional system recur or are tolerated or condoned by organizational leaders — and are not rectified despite known problems — they are indicative of structural stigma [1].

Negative attitudes are recognized as a driver of stigma within the health-care context and as a key barrier to care [25, 55, 97, 111]. Numerous literature reviews have been published on this topic [24, 112-121]. These studies have generally found that health-care practitioners are inclined to hold negative views about people living with mental health and substance use issues; however, positive views are also evident [119-121]. Prevailing beliefs among health-care practitioners are that people living with mental health and substance use issues are manipulative, are to blame for their health issues, overuse and misuse resources, are not vested in their own health, and are undeserving of services [119, 122, 123]. Health-care practitioners also have diminished expectations of people living with mental health and substance use issues. Such a view — also known as therapeutic nihilism or prognostic pessimism — leads practitioners to believe that people living with mental health and substance use issues are less likely than other people to follow recommended care plans, make healthy lifestyle changes, succeed in various life domains (e.g., employment, education, relationships), and achieve wellness and recovery [35, 82]. One group of researchers described the issue as follows:

Conveying grim, outdated, pessimistic assumptions about a uniformly deteriorating course and negative outcome is [the] expression of a stigmatic attitude toward the course of illness. In this way, it sustains and perhaps even reinforces the stigma associated with mental illness. (p. 166) [124]

The literature suggests an association between stigmatizing attitudes and poor clinical practices and, in turn, poor health outcomes for people living with mental health and substance use issues. However, the relationship between attitudes and health-care practices is not well understood. Scholars have opined that negative attitudes among health-care practitioners contribute to the creation of an antitherapeutic health-care context that permits the systematic use of objectionable practices. These practices include (1) diagnostic and treatment overshadowing, (2) non-caring and unhelpful behaviours, (3) paternalistic and non-collaborative approaches, (4) the withholding of information and services, (5) employing task-oriented and depersonalized methods, and (6) excluding or rejecting people from services [1, 25, 31, 119, 121]. Beyond the speculation, some empirical evidence supports the idea that attitudes toward mental health and substance use issues influence practice [24]. In one example, a study of 387 primary care physicians in Latin America found that higher levels of stigmatizing attitudes toward mental health issues was associated with feeling unprepared to care for people living with common mental disorders [125]. Stigmatizing attitudes also increased the likelihood that primary care physicians would refer someone with comorbid depression and physical health issues to specialized care (i.e., a psychiatrist) rather than continue their treatment in a primary care setting. In addition, research has established an association between stigmatizing attitudes and a reduced intention to treat people living with mental

health and substance use issues [36, 110]. Attitudes have also been linked to quality of care. A study in the U.S. found that physicians' (n = 270) favourable attitudes toward substance use issues increased the likelihood that they would engage in appropriate clinical practice [126]. Those physicians with positive attitudes more frequently used formal screening tools, screened all new patients, provided help based on people's readiness level, referred people to treatment when required, and provided brief interventions themselves. The degree to which negative attitudes translate into poor clinical practices is an area deserving further investigation.

### **Adverse health-care interactions and experiences**

People's perceptions and experiences of receiving care provides further insight into issues of health-care quality. Research indicates that a substantial proportion of people living with mental health and substance use issues experience stigmatizing interactions across a range of health-care settings (e.g., pharmacies, dental offices, emergency services, acute care hospitals, mental health clinics, substance use services) [58, 68, 94, 127-129]. The frequency with which adverse experiences were reported by people living with mental health issues led one group of researchers to conclude that they were a central aspect of treatment [67]. Concurring with this point, Knaak, Mantler, and Szeto posit that "the pervasiveness with which negative interactions are reported suggests the problem is not isolated to a few insensitive providers but is more systemic in nature — that it is a problem with how healthcare culture prioritizes and perceives people with mental illnesses" (p. 111) [130].

Adverse health-care interactions have been well documented in studies that give people living with mental health and substance use issues the opportunity to speak about their experiences. This report previously highlighted the range of difficulties people with lived experience encounter, such as being treated as untrustworthy and unreliable, being turned away, having to wait longer, and receiving inadequate care. People living with mental health and substance use issues also describe interactions with health-care practitioners that made them feel disrespected, uncared for, devalued, disregarded, excluded, infantilized, insufficiently informed, and hastily diagnosed and medicated [3, 26, 83, 94, 106, 124, 131, 132]. A poignant example was shared by a participant in a study in the U.S. that examined health-care experiences among 66 people who inject drugs: "When you go to a hospital, and you're a drug addict — or an IV drug user, especially — you are treated horribly. . . . Your life isn't as valuable, you're a second or third class citizen, and it's sad" (p. 107) [131].

Negative interactions with health-care practitioners interrupt the initiation and continuity of care for people living with mental health and substance use issues [8, 84]. One systematic review revealed how "service-related factors," including feeling judged and mistreated by health-care practitioners, deterred people living with psychosis from seeking help [133]. Another study found that people who identify as transgendered were less likely to seek mental health care if they had a prior negative experience with the mental health care system or knew someone who had [134]. In addition to deterring help seeking, negative interactions have the potential to damage people's relationships with their health-care practitioners [106] and diminish people's treatment motivation and completion [135]. Having an adverse health-care experience also leads people to conceal issues so they can avoid stigma and improve the prospect of receiving better quality services, something which may ultimately undermine the effectiveness of the care they receive [45].



### **Overuse of coercion, compulsion, and punitive approaches**

One way structural stigma manifests in health-care contexts is through the coercive philosophy of care that underpins the delivery of mental health and substance use services [1, 70, 136]. Support is high among the general public for using coercive approaches toward people living with mental health and substance use issues — which is spurred on by the widespread endorsement of negative stereotypes (e.g., dangerousness) [109, 137]. The deficiencies in the health-care system described earlier (e.g., inequitable access, poor quality of care) create a context in which involuntary hospitalization, compulsory community treatment, forced medications, and other coercive forms of care are leaned on more often than they should be. Consequently, people living with mental health and substance use issues face a much greater risk than others of having their rights and liberties curtailed. The growing reliance on hybridized health-justice interventions (e.g., forensic mental health, drug or mental health courts, police-based crisis response teams) as a means of providing access to health-care services exacerbates these issues by promoting coercive interventions and reinforcing the criminalization of people with lived experience. Scholars also suggest that stigma contributes to the continued overdependence on institutional and restrictive forms of care for people living with mental health and substance use issues [24].

Studies examining the factors affecting people’s decisions to access health-care services have found that the fear of being subjected to coercive interventions is a strong deterrent [7, 26, 43, 138-140]. This is especially true of mental health and substance use services. For example, a study of barriers to care among 202 mental health service users found that 77 per cent feared involuntary hospitalization [8]. Avoidance of health-care services may also be fueled by the fear of punitive consequences, which is very plausible for people using criminalized substances. Parents with mental health and substance use issues may fear that their use health-care services means risking their children’s apprehension [62]. Likewise, people experiencing adverse effects from consuming substances may be reluctant to seek help because of concerns about potential repercussions. The effects of mistrust and fear are particularly potent among people who are highly marginalized and have been exposed to historical and current mistreatment by the health-care system (e.g., racialized, Indigenous, immigrant populations) [23, 141]. This perspective was succinctly captured by a participant in a study examining the stigma associated with opioid use: “The bottom line with marginal populations is that they do not trust health care. There’s huge mistrust” (p. 16) [62].

People living with mental health and substance use issues who have experienced coercive interventions tend to view them as forms of stigmatization [24, 132, 142, 143]. They also point to particular practices, such as using leverage to gain treatment compliance or applying excessive rules, which contribute to their stigmatizing experiences in health-care contexts [67, 107, 144]. Such situations make people feel disempowered, something highlighted by a participant in a study examining the experiences of people receiving compulsory community mental health treatment in Canada: “I felt powerless for ten years, and treated like I couldn’t make decisions for myself” (p. 3) [142]. Structural stigma is also perpetuated by the failure of governments to counterbalance coercive interventions and provide equitable access to voluntary, high-quality health care, ready access to legal and advocacy services, and rigorous assessment of the degree to which coercive practices and policies are achieving their desired effects (e.g., improved health outcomes) relative to their collateral consequences (e.g., deterring help seeking, diminished treatment engagement) [1].

# Addressing structural stigma in health care

You can do workshops till the cows come home, but really you need to actually be changing structures. (p. 35)

Study participant in Knaak et al. [62]

The key to addressing structural stigma in health-care contexts is to identify and reduce institutional and system-level barriers and inequities that diminish people's access to quality care [92, 93, 145]. The goal is to help people living with mental health and substance use issues have healthier and longer lives. As described earlier, health-care systems impede this goal by (1) inequitably distributing resources, (2) undertreating health issues and withholding services, (3) fragmenting care, (4) tolerating negative attitudes and poor practices among practitioners, (5) enabling adverse health-care experiences, and (6) overusing coercive and paternalistic approaches.

Established frameworks for reducing stigma offer useful guidance for addressing structural stigma in health-care contexts. For instance, Arboleda-Flòrez and Stuart highlighted six approaches for effectively countering stigma: education, protest, contact, legislative reform, advocacy, and stigma self-management [3]. Livingston's strategy for addressing structural stigma also emphasized six approaches: legal and policy action, advocacy, inclusive efforts, health-care reform, education, and research [1]. Incorporated into the recommended strategies that follow are elements of both frameworks, along with additional approaches suggested by other scholars and experts in the field. It should be noted, however, that the empirical evidence in this area is scarce. Little research exists on the effectiveness of stigma-reduction strategies at the structural level [146], with the exception of programs aimed at improving practitioners' and trainees' attitudes [147].

Overall, the literature indicates that a comprehensive strategy for addressing structural stigma in health-care contexts for people living with mental health and substance use issues would include a combination of approaches. Such a strategy would work toward:

1. improving the attitudes and practices of health-care practitioners and others (e.g., trainees, decision makers);
2. strengthening the integration and coordination of care;
3. achieving parity for mental health and substance use issues;
4. expanding access to effective treatment;
5. establishing mechanisms to monitor structural stigma;
6. fostering inclusion and participation; and
7. enhancing and enforcing protections.

## 1. Improving attitudes and practices

Since people living with mental health and substance use issues routinely mention health-care practices as a significant source of stigma, efforts should be directed toward educating and training health-care practitioners [92, 119, 148]. Anti-stigma training and continuing education programs should aim to increase practitioners' awareness about (1) how their own beliefs and actions contribute to stigma, (2) what their ethical and legal obligations are under anti-discrimination legislation, and (3) how people

living with mental health and substance use issues experience stigma in the health-care system [144, 149, 150]. In addition, health-care practitioners need more education on the physical health risks and disparities experienced by people with lived experience and on ways to improve their skills and comfort with assessing, monitoring, and managing mental health, substance use, and physical health needs [32, 55, 151]. Ensuring that practitioners feel empowered and are adequately supported to implement positive changes in their practices and organizations is also advised [144, 150]. According to research, the most effective anti-stigma educational programs for practitioners employ multiple forms of social contact with people who have lived experience and place a strong emphasis on recovery [149, 152].

One anti-stigma training program targeting health-care practitioners' attitudes that has demonstrated its effectiveness is the two-hour Understanding Stigma workshop [149, 150]. Developed in partnership with the MHCC, it covers a range of stigma-related topics (e.g., myths) and uses various approaches (e.g., group exercises, discussions, films, and presentations from people with lived experience) to raise practitioners' awareness of their own attitudes; expose them to first-hand accounts about mental illness, health-care interactions, and recovery; facilitate contact with people living with mental illness; and help empower them to make positive changes. Evaluations of the program's implementation in Canada indicated that it produced small-to-medium improvements in practitioners' attitudes toward mental health issues [149].

Another example, provided by Khenti, Bobbili, and Sapag, described the development, implementation, and evaluation of a Toronto-based intervention that focused on stigma associated with mental health and substance use issues in primary care centres [153]. Among its components were site-based teams, contact-based education and training for primary care practitioners, an anti-stigma awareness campaign for health-care practitioners and the public, a recovery-based arts workshop series, and a review of internal policies and procedures. An evaluation found that the intervention produced significant but small improvements in the knowledge and attitudes among primary care practitioners related to mental health and substance use issues.

Although such programs have shown some success with improving practitioners' knowledge and attitudes, caution is warranted. Few studies have assessed the impact of anti-stigma training on practitioners' behaviours or health outcomes [24, 154]. Consequently, uncertainty remains about whether these programs improve health-care practices, enhance health-care experiences, and address inequities and disparities. Similarly, although many of these programs are implemented as brief, one-off training interventions, research suggests that longer interventions using more sophisticated methods are most likely to produce meaningful effects [154]. Scholars argue that training and educating health-care practitioners in the absence of other organizational and system-level changes will have limited impact on structural stigma in health-care contexts [24].

Targeting other groups with educational initiatives is also recommended for reducing structural stigma. Such initiatives include developing material and conducting rights-based training for people living with mental health and substance use issues, which can empower them with knowledge about their rights, access to complaints processes, the availability of rights-based supports and advocacy organizations, and avenues for seeking redress (e.g., human rights tribunals) [92]. One example is a collection of patient-centred materials, developed using a participatory research approach, to help people in British Columbia understand their rights under the provincial *Mental Health Act* [155]. Another key target group for anti-stigma educational efforts consists of students preparing to become health-care practitioners. Several

programs have demonstrated their success with improving the attitudes of medical and nursing students toward working with people with lived experience [113, 147, 156-158]. Educational initiatives may also be directed toward people with influence over resources, laws, and health-care policies, such as legislators, policy makers, insurance industry leaders, and health-care administrators [1, 53, 69, 70, 144]. The goal would be to raise awareness about the types of issues raised in this report and to cultivate support for mental health parity, public health approaches to addressing substance use issues, and other system-level efforts that can reduce structural stigma. Evidence is lacking about how to effectively improve the attitudes of decision makers as well as the degree to which this approach is capable of influencing laws, policies, and resource allocation.

## 2. Strengthening the integration and coordination of care

People living with mental health and substance use issues encounter major challenges resulting from the systemic separation of physical health, mental health, and substance use services. The integration of subsystems of care is crucial for improving access to quality health care [35, 54-56, 70]. Integrating mental health and substance use services into primary health care is seen as an effective way to address structural stigma [63, 159], as Shim and Rust have argued: “Integration of mental health, primary care, and public health is an essential strategy in our efforts to achieve less stigmatized, more optimal, equitable health outcomes for all” (p. 776) [27].

Some strategies to support system-level integration include task-shifting (redistributing health-care responsibilities to other sectors), cross-specialty training, collaborative care models, co-location of services, electronic health records that integrate information across subsystems, and case-manager coordinated care [25, 30, 33, 35, 53]. Another recommended approach is to establish minimum standards for the physical health care of people living with mental health and substance use issues [30]. One example from a European Psychiatric Association position statement articulates standards for psychiatrists to monitor and manage cardiovascular disease and diabetes [30]. Scholars suggest that assessing and monitoring physical health needs should be part of the routine clinical duties of mental health and substance use service practitioners [30, 40, 55]. Similarly, the development and implementation of clinical guidelines to support the provision of methadone maintenance treatment by primary care physicians has shown promise in Nova Scotia for increasing access to services for people living with opioid use disorders [103]. Cunningham, Peters, and Mannix also highlight how better outcomes could be produced by incorporating nurse practitioners into mental health teams and providing training and opportunities for mental health practitioners (e.g., mental health nurses) to work collaboratively with primary care practitioners [32].

There is evidence to suggest that people living with mental health and substance use issues prefer having their needs addressed under one roof, as was expressed by a participant in a study examining treatment barriers among people with lived experience: “I like the fact that [Community Health Centre]\* is a one stop shop. So you can see a nurse. You can see a lab tech. You can see a physician. They’ll make referrals within their system” (p. 9) [89]. Addressing people’s health needs in the way this participant suggests would require interdisciplinary, collaborative, and integrated models of health care.

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\* Bracketed in the original.

### 3. Achieving parity for mental health and substance use issues

Mental health and substance use services are severely underfunded. This deficiency is created by past and current inequities in the allocation of resources by governments and in the benefits offered by health-care insurers. Consequently, parity in health care for mental health and substance use issues is of utmost importance, with some asserting that it is a basic human right [30]. The issue of parity is closely connected to stigma [160], since stigma is fundamentally about equally valuing people living with mental health and substance use issues and people living with physical health issues.

Parity legislation, such as the *Mental Health Parity and Addiction Equity Act* in the U.S. (enacted in 2008), has been embraced as a powerful driver for advancing rights, addressing structural stigma, and reducing health disparities [61, 70]. It aims to rectify health-care inequities through multiple avenues, such as requiring insurance companies to cover mental health and substance use issues at the same level as physical health issues, eliminating or reducing coverage restrictions, and removing misguided clauses related to mental health and substance use issues from insurance policy documents [53, 70, 71]. Yet, despite its potential to improve equality between physical health services and mental health and substance use services, observers warn that increased funding and access to care do not necessarily mean improved quality of care [70]. Consequently, calls for parity in Canada have tended to be more strategic: highlighting the need for governments to make targeted investments in publicly funded evidence-based therapies, a continuum of integrated services, and improvements in quality of care [56].

### 4. Expanding access to effective treatment

“Let’s not lose sight of the fact that effective treatment is one of the best antidotes to stigma” (p. 35) [62]. This insightful remark from a participant in a study examining the stigma associated with opioid use highlights the relationship between stigma and quality of care. Stigma creates a social context (e.g., devaluing, underfunding, deprioritizing) that tolerates substandard care and inhibits the provision of evidence-based treatment for people living with mental health and substance use issues. This situation, in turn, deters help seeking, contributes to the underdiagnosis and undertreatment of physical health issues, and drives poor outcomes, including delayed recovery, excess morbidity, and early mortality.

Offering effective treatment to people living with mental health and substance use issues involves equitable funding for research to support the development, evaluation, and implementation of evidence-based interventions. It also requires more funding for mental health and substance use services and smarter investments. People living with mental health and substance use issues should have access to the same range, quality, and standard of health care enjoyed by people living with physical illnesses. In addition, increasing access to effective treatment means addressing the structural barriers that prevent the expansion and uptake of evidence-based practices and interventions, such as opioid agonist treatment [93]. Improvements must be made as well to the other dimensions of health-care quality (e.g., negative attitudes, discriminatory practices, adverse health-care interactions) that compromise therapeutic relationships and diminish engagement in health-care interventions. Encouraging people to seek help with mental health and substance use issues might also require investing in approaches (e.g., improving the physical appeal of facilities) that destigmatize services and reduce the fear and shame associated with using them [92].

Further, making a concerted effort to reduce coercive practices, compulsory interventions, punitive consequences, and criminalization is necessary for creating a more effective health-care system. The literature calls for investing in early intervention, health promotion, and illness prevention and in orienting systems toward models of care (e.g., recovery-oriented) that support people's choices, address their holistic needs, and uphold their human rights and dignity [1, 56]. Supporting people's mental health and substance use recovery can be achieved through a system that provides a range of services, which include, but extend well beyond, pharmacological interventions and crisis-driven care and align with people's needs, values, and preferences.

## 5. Establishing mechanisms to monitor structural stigma

Knaak, Patten, and Ungar have argued that addressing structural stigma in health-care contexts may best be achieved by leveraging quality-of-care indicators, standards, and processes to identify, monitor, and address inequities in access and quality [161]. They recommend framing stigma as a quality-of-care issue while employing a lexicon and logic that are familiar to health-care practitioners and administrators. Such an approach may accelerate buy-in and diminish opposition to anti-stigma interventions in health-care contexts. Since structural stigma corresponds to the equity dimensions of health-care quality, which have a shared goal of addressing unfairness in policies and practices, it has been suggested that developing and implementing an "equity audit tool" would enhance the ability to identify, monitor, and address instances of structural stigma (i.e., inequities in care) in health-care settings [162].

Several tools referenced in the literature have relevance for monitoring structural stigma in health care at the institutional and system levels. These include:

- The Mental Health and Human Rights Evaluation Instrument (developed for the MHCC), designed to help provincial and territorial governments assess the degree to which their mental health legislation, policies, and standards advance human rights and are consistent with the U.N. Convention on the Rights of Persons with Disabilities [136].
- The Health Equity Impact Assessment tool (developed for the Ontario Ministry of Health) and the QualityRights toolkit (developed for the World Health Organization), used to identify and address stigma in the internal policies and procedures of primary care centres [153].
- The Discrimination and Stigma Scale, used to generate national level data about discrimination experienced by people living with mental health issues (although only two items query health-care experiences) [163].

Using such tools to gather routine data about manifestations of structural stigma in health-care programs, institutions, or systems offer several potential advantages. These include helping health-care administrators identify policy areas in need of improvement, assisting communities to advocate for change, garnering support from policy makers, making comparisons over time and across settings, and evaluating anti-stigma interventions [24, 164].

Another fruitful approach to monitoring system performance in relation to structural stigma would be to identify and compile longitudinal data from existing sources, such as relevant performance indicators, accreditation measures, health-care expenditures, health-care service levels, wait times, registered patient complaints, private litigation efforts, government enforcement, and human rights cases [52, 53,

164, 165]. Additional suggestions include tracking surrogate markers of health-care inequity (e.g., rates of appendicitis with rupture) for people living with mental health and substance use issues [35] and incorporating indicators into accreditation processes concerning stigma-reduction and patient engagement [92, 130].

A key source of information for the current report was primary research examining the health-care experiences of people living with mental health and substance use issues. Continued investment in this type of research is vitally important for building a nuanced understanding of structural stigma and correctly identifying problems and solutions [144].

## 6. Fostering inclusion and participation

A fundamental way to counteract the exclusionary effects of structural stigma is to create opportunities for the inclusion and participation of people living with mental health and substance use issues in health-care contexts [1]. Supporting their meaningful involvement in the design, delivery, and evaluation of health-care services is emphasized throughout the literature [166]. Health-care organizations should ensure that people with lived experience are engaged in decision-making processes for health-care services, such as monitoring the quality of treatment, identifying structural barriers, and developing and implementing improvements [66]. Supporting health-care practitioners' engagement in shared decision making, whereby they collaboratively help people make choices about health care, can also improve perceptions about the quality of care and contribute positively to their health [167]. Employing and supporting people with lived experience as peer support workers, peer navigators, advocates, or as speakers in anti-stigma educational programs simultaneously promotes inclusion and produces better outcomes. Ensuring their involvement in the planning and implementation of any effort to address stigma is an important ingredient of anti-stigma initiatives [92]. As mentioned earlier, organizational performance measures should incorporate indicators of inclusion and participation [92, 168].

## 7. Enhancing and enforcing protections

Since structural stigma often resides in laws and policies, their reform is key to improving access to quality care for people living with mental health and substance use issues [3, 82]. This process includes identifying laws and health-care policies that contribute to structural stigma and working to amend or repeal them. At the same time, accreditation organizations have a role to play in ensuring that health-care organizations establish and implement policies that respect people's rights, guard against coercive practices, reduce inequities and disparities, provide access to quality care, and promote the participation of people with lived experience [58, 169].

Legal and policy reform also involves enacting antidiscrimination laws and providing sufficient resources to implement, monitor, and enforce them [92]. A severe limitation of these laws has been the failure of governments to monitor and enforce people's rights [165] — something noted in relation to the U.N. Convention on the Rights of Persons with Disabilities [170]. Its signatory nations, Canada among them, fail to monitor adherence and are noncompliant with the Convention, including Article 25, which requires state parties to “Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons” (p. 18). Similar concerns have been expressed about the protections offered to people living with mental health and substance

use issues in the *Americans with Disabilities Act* [94, 165]. Enacting laws and policies that encourage and support practitioners (e.g., pharmacists, primary care physicians) to offer evidence-based harm reduction approaches, such as clean needle distribution or methadone prescribing, has promise for reducing the discriminatory discretion that people living with substance use issues experience in the health-care system [103, 171].

Expanding access to rights-based information, grievance processes, and legal and advocacy services is another important way to help people living with mental health and substance use issues challenge structural stigma when it manifests. Inequities often persist because major barriers (e.g., cost) deter people from legally challenging them [165]. Employing peer support workers in health care who can advocate on behalf of people with lived experience has also been identified as a “crucial way of addressing systemic discriminatory cultures and practices, as well as providing direct support for individuals” (p. 93) [92].

Few studies have investigated the effects of legislative and policy action in relation to structural stigma [146]. However, a small body of research does describe interventions that have included health-care policy reforms. Khenti et al. discusses a multi-component intervention study focused on addressing stigma associated with mental health and substance use in Toronto community health centres [153]. Components included site-based teams, contact-based education and training for health-care practitioners, an anti-stigma awareness campaign for health-care practitioners and the public, a recovery-based arts workshop series, and a review of internal policies and procedures. The policy review aimed to identify “potential systemic stigmatizing and discriminatory practices or procedures that present barriers to recovery” (Fig 2. (v), para. 1) and incorporated elements of the QualityRights toolkit and the Health Equity Impact Assessment tool. One participating community health centre undertook the policy review, focusing on protocols for termination, dealing with problematic (e.g., disruptive, violent) behaviours, and no-shows. (Unfortunately, an assessment of its effectiveness has not yet been published.) Another study described an initiative to reduce HIV-related stigma among hospital workers in Vietnam. This intervention, which included staff training, regular staff discussions, and a hospital policy review, aimed to create a friendly, respectful, and supportive hospital environment for patients [172]. The policy review included a collaborative process to develop policies targeting several areas, including access to services, HIV counselling and testing, confidentiality, and practices. A checklist was developed for hospital workers to self-assess and check their engagement in stigmatizing practices, such as showing patients’ HIV status on their hospital files or beds. An evaluation of the intervention found reductions in stigmatizing practices.

## Closing

Two main questions framed this report. The first was, how does structural stigma affect people living with mental health and substance use issues in health-care contexts? The answer provided in the literature was decisive: structural stigma contributes to health disparities and health-care inequities for people with lived experience by compromising their access to quality health care. To the second question, how can structural stigma in health-care contexts be reduced?, the literature’s response suggested a strategy that uses a combination of efforts:



- Improve the attitudes and practices of health-care practitioners and others (e.g., trainees, decision makers).
- Strengthen the integration and coordination of care.
- Achieve parity for mental health and substance use issues.
- Expand access to effective treatment.
- Establish mechanisms to monitor issues pertaining to structural stigma.
- Foster the inclusion and participation of people living with mental health and substance use issues.
- Enhance and enforce protections for people with lived experience.

The topic of structural stigma in health care spans different fields (e.g., stigma, health-care quality, health disparities, disability rights), each with specific subject matter experts and voluminous research literature. Although the current report touched on each of these areas, effectively addressing structural stigma demands that bridges and synergies be built between these fields through the development of multi-disciplinary and diverse teams, networks, and collaborations. A further suggestion to advance this work is to address known knowledge gaps. While children and youth with mental health and substance use issues were within the scope of the current review, there was a dearth of research and literature on structural stigma for this population. Another understudied topic was the connection between attitudes, behaviours, and outcomes. For instance, does reducing stigmatizing attitudes among health-care practitioners improve their practices? And, how does this reduction influence people's health-care experience, service use, and health outcomes? An added subject in desperate need of attention is investigating the effects of different structural stigma interventions, including the approaches recommended in this report. Strengthening the empirical grounds for recommending approaches to structural stigma in health care — extending beyond anti-stigma educational programs — should be a priority.

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