



Mental Health Commission de Commission la santé mentale of Canada du Canada

Combating Mental Illness- and Substance Use-Related Structural Stigma in Health Care A Framework for Action

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Introduction

In 2019, the Mental Health Commission of Canada (MHCC) launched a program to better understand the problem of mental illness- and substance use-related structural stigma in health-care environments. The first year of this program involved the completion of three main research projects:

- a comprehensive <u>literature review</u>
- a qualitative research study based on focus groups consisting of people with lived and living experience of mental health problems and illnesses and/or substance use (forthcoming)
- an <u>environmental scan</u> to assess the need for tools that measure structural inequities in mental illness- and substance use-related care

This research brought into focus a comprehensive picture of structural stigma in health-care environments: how it is experienced, how it impacts health and quality-of-life outcomes, and how we might reshape the way health service delivery and care are provided to persons with lived experience. The main findings were synthesized into seven priorities for dismantling and disrupting structural stigma in health care (see **Figure 1**).

These findings were further summarized in an expanded version of the <u>Action Framework for Building</u> an Inclusive Health System fact sheet from <u>The Chief Public Health Officer's Report on the State of Public</u> <u>Health in Canada</u>. This action framework will be useful for guiding future research, interventions, and initiatives by organizations committed to improving access, the quality of service and care, and wellness outcomes for persons with lived experience.

Background

Stigma has been identified as a major barrier to access, care, and recovery for persons with lived and living experience of mental health problems and illnesses and/or substance use. It operates at multiple levels and in multiple domains, including the health-care system. Stigmatizing processes influence all levels of the design and delivery of care for mental health and substance use and, in turn, impact all organizational areas, from the personal and interpersonal to the structural and institutional.¹⁻⁶

Previous research by the MHCC's Opening Minds initiative provides the backdrop to this report, given its prior development of a validated model of key ingredients and best practices for designing and delivering effective anti-stigma initiatives in health-care contexts.^{7,8} Opening Minds has also evaluated numerous specific interventions and approaches for reducing stigma in health care.⁹⁻¹⁴ Many successful workshops and programs evaluated through Opening Minds are nationally available (via the MHCC or as online programs) to a wide range of health-care provider audiences.

Yet, despite the success of Opening Minds — and as crucial as it is to training programs that reduce stigma for health-care providers — we have learned that training interventions are not enough. For example, while one-off programs tend to result in short-to-medium-term gains in practitioners' attitudes and behavioural intentions, if they are not implemented widely and thoroughly, and not sustained and reinforced, they are much less likely to effect cultural change — a key driver of structural stigma.¹⁵⁻¹⁸ In short, we have come to understand that stigma must be tackled at all levels and across multiple domains to be truly effective over the long term. While such implementation includes training and a focus on reducing personal and interpersonal stigma, it requires greater attention at the level of structural stigma in health-care settings.^{19,20}

We have also learned that the intersectionality of stigma — that is, its effects can be compounded as a result of multiple intersecting inequities or experiences of marginalization — is another key, yet often under-addressed, concern.²¹ This aspect of stigma includes a tendency to focus on combating it in the context of mental illness *or* substance use, but rarely together. Recognizing the overlapping and intersecting nature of substance use and mental illness, which is also part of the stigmatization in these domains, our approach has been to investigate structural stigma in health-care environments through a lens that includes both.

Structural stigma refers to the accumulated activities of organizations and systems that deliberately or inadvertently create and maintain social inequalities for people with lived and living experience of mental health problems and illnesses and/or substance use.

To this end, our intention is to address stigmatization as it relates to mental illness and substance use primarily as a systemic or structural problem, while building on the MHCC's previous research, and on recent and important work from the Public Health Agency of Canada.^{*}

In this report, structural stigma refers to the accumulated activities of organizations that deliberately or inadvertently create and maintain social inequalities for people with lived and living experience of mental health problems and illnesses and/or substance use. It is located in the formal and informal rules and practices of social institutions and is "reinforced in laws, the internal policies and procedures of private or public institutions and systems, and the practices of professionals" (p. 4).²² Structural stigma is particularly dangerous and damaging because it represents the unfairness and inequity embedded into the very fabric of our social institutions, organizations, and shared ways of thinking and acting. It can also allow well-intentioned, unbiased people to act in discriminatory ways.

In addition to highlighting the key activities and research findings from the first year of the MHCC's structural stigma program, this report provides a summarized framework for action. While acknowledging that stigma has different levels (i.e., personal, interpersonal, institutional, population), this framework focuses mainly on the structural or institutional level — and is limited to the context of health-care environments. At that level, it describes how the stigmatization process operates, the promising interventions to address it, and the potential health and quality-of-life outcomes that would result from its reduction and elimination.

^{*} See <u>A Primer to Reduce Substance Use Stigma in the Canadian Health System</u> and <u>Addressing Stigma: Towards a More</u> Inclusive Health System.

That said, it is important to reiterate that all levels of stigma are interconnected and reinforcing. Healthcare institutions do not exist in a vacuum but are part of the fabric of our larger society and culture. As such, health-care systems both shape and are themselves shaped by society's norms, values, and institutions — including laws, political ideologies, government policies and priorities, social beliefs about health, illness, scientific institutions, and education and training systems. The framework for action in this report (see **Figure 2**) should be interpreted through this larger context.

Like the action framework contained in the chief public health officer's 2019 annual report, this framework can be used as a guide for future research, interventions, and initiatives by organizations committed to improving access, quality of service and care, and wellness outcomes for people with lived experience.

Year 1 Research

The overarching objective of the MHCC program is to identify and reduce mental illness- and substance use-related structural stigma at the level of health-care policy, practice, and systems, and within the organizational culture of health care. To this end, Year 1 involved three main activities:

- a comprehensive <u>literature review</u> of mental illness- and substance use-related structural stigma in health-care environments, with key recommendations and suggested approaches²³
- a qualitative research study based on focus groups consisting of people with lived experience to gain a better understanding of their experiences, perceptions, and priorities for addressing mental health- and substance use-related structural stigma in health-care environments²⁴ (forthcoming)
- an <u>environmental scan</u> of existing tools that measure structural inequities in mental illness- and substance use-related care to assess the need for new measurement and audit tools and identify potential partners who could assist their development and implementation²⁵

Key activities and findings

Literature review

The literature review²⁶ revealed two main issues with respect to structural stigma in health-care environments. The first is a systemic failure to provide access to quality care based on the best evidence for persons with lived and living experience of mental health problems and illnesses and/or substance use. This failure occurs mainly through structural mechanisms: the inequitable distribution of resources, the undertreatment of physical health issues, the withholding of services, and the fragmentation of care. The second major issue is that people with lived experience tend to systematically receive a poorer quality of care for both their physical and mental health needs. The main structural sources of such care are the negative attitudes and poor practices of health-care practitioners, adverse health-care interactions and experiences, and the overuse of coercive and paternalistic approaches.

The solution to these issues centred on the need to have a comprehensive strategy with a combination of approaches that aim to

• improve the attitudes and practices of health-care practitioners and other system stakeholders (e.g., trainees, decision makers), while focusing on change at both individual and cultural levels

- strengthen the integration and coordination of care
- achieve equity in resource distribution for mental health and substance use services and research
- expand access to effective treatment
- establish mechanisms to monitor structural stigma
- foster the meaningful inclusion of people with lived experience
- enhance and enforce protections.

Focus groups: Input from people with lived experience

The qualitative research component of the project sought the views and perspectives of 20 people with lived experience through their participation in three focus groups.²⁷ The participants, recruited from MHCC and partner advisory groups by MHCC staff, formed a broad cross-section of people in Canada who have experienced structural stigma because of a mental illness or substance use disorder. They included youths, Indigenous people, mental health advocates, clinical care workers, and peer support workers. Many occupied several roles. For example, some were also family members of individuals who had experienced a mental illness or substance use disorder, including children who had died by suicide or as a result of an overdose. Individual experiences spanned a range of inpatient and community settings in both the mental health and substance use treatment systems.

Discussions with focus group participants centred on personal experiences and examples of structural stigma as well as proposed solutions. The findings were consistent with many of the themes identified through the literature review. The personal examples in particular revealed a number of systemic barriers to quality care: a culture of caring marked by prejudicial attitudes and beliefs; punitive and controlling practices; narrowly focused treatments; a lack of emphasis on recovery principles, person-centred care, and social determinants of health; impersonal and dehumanizing treatment and interactions; diagnostic overshadowing (i.e., having medical conditions ignored or undertreated); poor or inadequate physical spaces for receiving mental health and substance use services or care; and being triaged in such a way that people with lived experience always seemed to be at "the bottom of the list" for care.

People with lived and living experience of substance use, specifically, faced additional stigmatizing barriers. These barriers include being unable to find family doctors willing to support persons on methadone therapy, difficulties changing prescriptions from one geographic location to the other, and the inability to access integrated mental health and substance use care. As well, participants found key problems in the compounding nature of stigma and the fact that many people live with multiple stigmatized identities.

The culture of health care as a workplace was also described as a key source of structural stigma. Participants mentioned an ongoing yet unspoken rule within health care: that providers themselves must be "tough" and "strong," and that having a mental illness or being in recovery would be considered a sign of weakness and possible "professional suicide."

Proposed solutions focused on building a more equitable, integrated, and recovery-oriented model of care. To this end, participants emphasized the importance of enhancing and enforcing legislative protections, focusing on policy change and improvements in service delivery and equity, providing meaningful involvement for people with lived experience in the design and delivery of health services

and in research and advisory roles, and developing metrics to better measure and track access, quality of care, and other outcomes.

Policy and service improvement priorities included greater availability and access to integrated care and to patient-centred and recovery-oriented care; safer (more trauma-informed) use of security personnel in places such as the emergency room; more attention to the accuracy of triage processes and diagnostic overshadowing; additional peer support; better training for health-care providers in mental illness, substance use, and trauma-informed care; eliminating access to care barriers and harm reduction services and supports; and reducing wait times.

The meaningful involvement of people with lived experience included ensuring their ability to influence the design and development of services and policies (e.g., through an advisory capacity or as members of a committee or research team) and strengthening peer support roles in care delivery and training.

Included in the key metrics that participants proposed were wait times, deaths by suicide, clientsatisfaction ratings, and levels of peer support. Focus group members also reinforced the notion that metrics should include meaningful involvement from people with lived experience, so that the outcomes they find important are captured in the tools and approaches being developed.

Environmental scan of structural stigma measures and the identification of potential partners

This component of the project involved key informant interviews with representatives from 13 regulatory, performance measurement, patient safety, health quality, research, and service delivery organizations across Canada and internationally.²⁸ The results of the scan revealed an absence of measures — no key informants were aware of any specific tool or measure intended to target structural stigma or equity in mental health and substance use care. Key areas where structural stigma measures would be useful for addressing concerns about care quality and access included the following:

- Measures to capture inequities in funding for mental health and substance use services and research (e.g., relative to the disease burden and to other services and research), including the need for a mental health and substance use parity act (or something similar) as a basis for accountabilities within federal health transfer payments.
- Perceptions of and satisfaction with care among clients/patients with lived and living experience of mental health problems and illnesses and/or substance use.
- A quality dashboard and other performance indicators specific to mental health and substance use care (e.g., accuracy percentage of emergency department triage, presence of emergency department medical stability protocol, standard referral pathway and adherence; wait time to see a mental health or substance use specialist; equity of followup care).
- Include structural stigma assessment items in institutional reviews and accreditation standards.
- Capture narrative examples of policies, practices, and experiences that reflect structural stigma toward people with lived experience. The value of using narrative examples as content for "implicit cognitive bias" training was also emphasized as way to help illuminate and create buy-in among clinicians and health-care decision makers.

In general, key informants expressed considerable interest in being part of organizational partnerships with the MHCC to work toward developing and implementing measurement or audit tools that would capture and address mental illness- and substance use-related inequities and quality concerns.

A Framework for Action

Taken together, the findings across the three research activities brought into focus a comprehensive picture of the problem of structural stigma in health-care environments: how it is experienced, how it impacts health and quality-of-life outcomes, and what the important strategies and approaches are for reshaping the way health service delivery and care are provided for people with lived experience. The main findings may be synthesized into seven priorities for dismantling and disrupting structural stigma (see **Figure 1**).

These seven priorities would be to (1) prioritize training that improves the attitudes and practices of health-care staff, (2) develop and implement audit, quality and performance measures, and surveillance tools, (3) adopt wellness/recovery-oriented and inclusive models of care, (4) commit to equitable resource allocation for mental health and substance use (MHSU) services and research, (5) foster the meaningful inclusion of people with lived experience (PWLE) throughout the design and delivery of health policy, services, training and research, (6) build policies and practices that are stigma-informed and enhance the provision of culturally safe and trauma- and violence-informed care, and (7) focus on the culture of health care as a workplace.

Figure 1. Key priorities for dismantling and disrupting mental illness- and addictions-related structural stigma in health-care environments

Improve the attitudes and practices of staff, including awareness of implicit bias of structural stigma Measure/monitor equity and performance on access, quality of care, satisfaction, outcomes,

Adopt integrated, recovery-oriented,⁺ accessible, client-centred models of care

Commit to equitable resource allocation for MHSU services and research

Ensure meaningful PWLE involvement in service delivery and advisory, research, training, and peer support roles

Implement/enforce stigma-informed legislation, policies, practices, and protections

Build a stigma free and supportive organizational culture — both attitudinally and structurally

^{*} Satisfaction from providing care.

⁺ In the context of substance use, recovery-oriented care refers to models of care that incorporate harm reduction and quality of life as central pillars.

Key findings are further highlighted in **Figure 2**, which, as noted in the introduction, expands the action framework from the chief public health officer's 2019 annual report.²⁹ While that framework looks at the different stigma levels (i.e., personal, interpersonal, institutional, population), our figure focuses on mental health- and substance use-related stigma specifically at the institutional level, which is most in line with the current understanding of structural stigma. As noted above, this framework for action should be interpreted through a lens that includes the larger social context and the fundamental interconnection of health-care institutions to norms, laws, values, and other institutions.

Figure 2. Combating mental illness- and substance use-related structural stigma in health care:
A framework for action

Level of Stigma	Institutional: health-system organizations, medical and health-care training schools, organizations in the community sector, social services, and those responsible for health policy, standards setting, and monitoring
How Stigma Operates	People with lived experience (PWLE) being made to feel "less than" (deprioritized, undertreated, denied; lack of empathy from staff)
	Physical environment not inclusive or conducive to quality care
	Institutional policies that cause harm (unnecessary interventions that humiliate, denigrate, or compromise dignity; overuse of coercion, compulsion, punitive approaches; policies that restrict access to best-evidence care; failure to implement wellness/recovery-oriented models of care [including harm reduction]; fragmentation of service)
	Diagnostic and treatment overshadowing
	Inequitable investment in services and underfunding of research
	Inadequate training of health-care professionals (mental health and substance use [MHSU] care; cultural safety/culturally responsible care and trauma- and violence-informed care; stigma-informed care)
	Failure to measure and track (quality indicators for MHSU; equity of care for people with MHSU; attitudes and practices at the level of organizational culture; client satisfaction and perspectives)
	Lack of enforcement on existing human rights protections
	MHSU stigma in the workplace (staff feel unable to disclose MHSU problems; inadequate policies and protections; culture is hostile to staff with MHSU issues; inadequate training and support; MHSU providers feel less respected and valued than physical health-care providers)
	Ongoing training targeting conscious and implicit bias for all (clinical and non-clinical) health-care staff (build programs on evidence-based key ingredients and implementation guidelines, including ample use of social contact; ³⁰ implementation and evaluation frameworks should focus on the possibility for cultural change
	Implement cultural safety and humility models and provide training for staff.
Interventions to	Workforce diversity initiatives
Address Stigma	Establish and adhere to resource equity for MHSU care and research.
	Institutional collaboration with the community; policies that support and fund meaningful engagement with PWLE (e.g., policy development, advisory, research, service delivery, peer support/navigation roles)
	Implement trauma- and violence-informed care models and training.
	Adopt and expand recovery-oriented models of care (e.g., integrated models of care, person-centred care, harm reduction models, meaningful involvement of PWLE, trauma- and violence-informed care).

Level of Stigma	Institutional: health-system organizations, medical and health-care training schools, organizations in the community sector, social services, and those responsible for health policy, standards setting, and monitoring
	Implement accountability and monitoring frameworks that include structural stigma reduction indicators for MHSU (e.g., indicators for equity and quality, performance, patient satisfaction, culture change, accreditation standards).
	Conduct regular policy and practice reviews using a stigma-informed lens.
	Strengthen curricula and continuing education for all health-care providers in MHSU on social determinants of health, recovery-oriented care, harm reduction, and stigma-informed care.
	Strengthen and enforce human rights protections and provide easy avenues for client complaints and resolutions.
	Strengthen policies, training, and support for staff to encourage help seeking, protect staff mental health, and improve workplace culture.
Potential Outcomes	An institutional environment that is inclusive, welcoming, diverse, and safe
	Organizations that can meet the needs of all populations, including PWLE
	A reduction in stigmatizing beliefs and attitudes among staff and across the organization
	Improved patient/client ratings of care, satisfaction, and trust
	Improved patient/client outcomes (physical and mental health for PWLE; quality of life for PWLE)
	Earlier engagement in care for PWLE due to earlier help seeking
	Better retention in care and treatment for PWLE
	More appropriate and best-evidence care provided to PWLE
	Greater compassion satisfaction among staff
	Improved mental health of health-care staff
	Less time off work; improved worker retention
	MHSU providers that feel valued and equitably compensated within the health-care system

Adapted from "Table 2 — Action Framework for Building an Inclusive Health System," by the Public Health Agency of Canada, *Addressing stigma: Towards a more inclusive health system*, The chief public health officer's report on the state of public health in Canada (p. 41), 2019, Ottawa, Canada: Copyright 2019 by Her Majesty the Queen in Right of Canada, as represented by the Minister of Health.

Next Steps

Some of the proposed solutions (e.g., equity of resource allocation) must rely on political and legislative action, while others require interventions at various levels of policy and organizational practice, including different departments. But among those that are within the MHCC's scope and mandate to help support, develop, and/or implement, through research and in partnership with other organizations, the commission has identified four key activities for the second year of its structural stigma program:

• Using a case study approach, identify and describe innovative models of care initiated in health regions, hospitals, community health centres, and other health-care settings that incorporate the guidelines in this report and could be promoted as promising practices for disrupting and reducing structural stigma.

- Develop and deliver a training module on mental illness- and substance use-related structural stigma to health-care leaders, decision makers, clinicians, and other agents of the health system. Such training would help raise awareness and frame the problem of structural stigma while fostering urgency among those able to instigate and mobilize change within their organizations, workplaces, and the health system more broadly.
- With interested partners, develop and pilot-test a structural stigma measure(s) that organizations could use to examine its sources, monitor progress in policy and practice changes, and assess the impact of educational interventions for staff and others on the organizational culture of caring.
- Compile and produce stories of "personal experience" as a tool to raise awareness and help Illustrate the ways structural stigma manifests in the health system and in the access, organization, and delivery of care. These stories would reflect the perspectives of people with lived experience as well as health-care providers and other agents of the health system.

In addition, many of the MHCC's ongoing activities in other program and priority areas support the reduction of structural stigma in the health-care sector. These include:

- ongoing advocacy for greater equity in the health-care dollars spent on mental health and substance use care
- encouraging a greater adoption of recovery-oriented practices in health care through the development and promotion of an implementation toolkit³¹
- providing guidance and support to health-care organizations that adopt the National Standard for Psychological Health and Safety in the Workplace³²
- making evidence-based stigma reduction and mental health and resiliency programs available to health-care organizations and providers (through programs like The Working Mind, Understanding Stigma, and others)³³⁻³⁵
- the continuing evaluation and scale-up of programs and approaches shown to be effective in combating opioid- and substance use-related stigma in health-care and first responder populations³⁶

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