

Structural Stigma

**PROGRESS REPORT
YEARS 1 & 2**



ACKNOWLEDGMENTS

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Executive Summary

This report provides a brief overview of the progress made in the first two years of a project focusing on structural stigma in health-care settings. Research has consistently identified the health-care system as a significant contributor to stigma for people with lived and living experience of mental health problems and illnesses and/or substance use. Such structural stigma occurs when laws, policies, and practices produce inequitable access or a lower quality of care. Over the first two years, the goals were to investigate structural stigma in health-care settings in order to develop a conceptual framework, training tools, and audit measures that could be used there to identify and eliminate its sources.¹

YEAR 1 (2019/20)

In the first year, four complementary projects were completed:



Literature review

This review identified key issues pertaining to structural stigma in health-care settings, including (1) the systemic failure to provide access to evidence-based quality of mental health care for persons with mental health and substance use concerns, and (2) the poor quality of care they receive for both their physical and mental health needs. The report noted that the structural barriers built into health systems often make it difficult for health-care providers to deliver a high quality of care.



Environmental scan

Thirteen agencies, reflecting a range of regulatory and performance measurement activities, locally, nationally, and (more selectively), internationally, were contacted. No agency representative knew of any specific tool or measure that would target structural stigma or mental health equity, though a number of potential indicators were discussed.



Qualitative research

Twenty individuals, representing a cross section of people living in Canada who had experienced structural stigma, were interviewed. Their stories painted a grim picture of the detrimental effects of structural stigma, ranging from disenfranchisement, disempowerment, diminished self-esteem, increased morbidity and, in catastrophic circumstances, premature death.

¹ The project was funded by Health Canada through the Mental Health Commission of Canada (MHCC). It continues as a legacy of the MHCC's previous work focusing on stigma and stigma reduction.



A FRAMEWORK FOR ACTION

Findings from the previous three research activities provided a comprehensive picture of the problem of structural stigma in health-care settings: (1) how people who live with mental health and substance use concerns experience it, (2) how it impacts their health and quality of life, and (3) how to reshape the way health services are delivered to them. The framework's main findings were synthesized into seven focus areas, which were to

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

YEAR 2 (2020/21)

Building on the knowledge gained in Year 1, project activities in the second year were organized around three broad themes:



Measures

Three measurement reports were completed. The first, based on the previous literature review, provided a broad framework describing potential assessment domains, methodological considerations, and possible data sources for assessing structural stigma in health-care settings. The second, building on the environmental scan, suggested potential indicators that could be used to assess structural stigma from an organizational perspective, using the Institute of Medicine's quality pillars. The third, based on the Year 1 qualitative study, reviewed the literature for possible measures that could be used to assess quality-of-care elements from the perspective of service users.



Professional training module

The components of a professional training module were mapped out based on best-practice evidence from the educational literature. The module will be directed to health leaders, change agents, and influencers and will allow individuals to engage in reflection and use evidence-informed approaches to address structural stigma in their respective organizations. Trainees will be provided with tools and templates to sustain the skills they develop. The module will be free to all participants.



Awareness raising

Awareness-raising activities centred on the development of stories told from the perspective of (1) people with lived and living experience of mental health problems and illnesses and/or substance use, health-care providers, and other agents within the health system, and (2) case studies from health-care organizations that had successfully implemented projects to disrupt structural stigma. These projects resulted in a number of videos and narratives that can be used (individually or in a series) to highlight the importance of structural stigma in health-care settings and provide examples of how it may be addressed. It is expected that portions of these videos and narratives will be included in subsequent professional training modules. The case studies have been used to develop a report that outlines key recommendations for addressing structural stigma.



NEXT STEPS

- 1 Co-design of structural stigma measures.
- 2 Implementation and evaluation of the structural stigma training module.
- 3 Scaling up best practices from the case studies.
- 4 Exploratory work on intersectional structural stigma and health outcomes.
- 5 Partnership development.

Introduction

This report provides a brief overview of the progress made in the first two years of a project focusing on structural stigma in health-care settings. Research has consistently identified the health-care system as a significant contributor to stigma for people with lived and living experience of mental health problems and illnesses and/or substance use. Such structural stigma occurs when laws, policies, and practices produce inequitable access or a lower quality of care. Over the first two years, the goals were to investigate structural stigma in health-care settings in order to develop a conceptual framework, training tools, and audit measures that could be used there to identify and eliminate its sources.

BACKGROUND

The current structural stigma project continues the legacy of research and development undertaken by the Mental Health Commission of Canada (MHCC) through its Opening Minds anti-stigma initiative. In this context, stigma was defined as occurring at

- the level of the individual (where negative stereotypes are internalized and affect social interactions)
- the interpersonal level (where negative social stereotypes may lead to public intolerance and discriminatory behaviours)
- the broad structural level (where social structures and organizational behaviours result in social and financial inequities for people with lived and living experience)
- the intersectional level (where mental health- and substance use-related stigma intersect with other forms of oppression and marginalization, such as racism, transphobia, and colonization).

Structural barriers were noted in all the groups targeted for anti-stigma interventions: school systems, the media, workplaces, and health-care organizations.

In 2013, the MHCC released [*Mental Illness-Related Structural Stigma: The Downward Spiral of Systemic Exclusion Final Report*](#), a work that summarizes what is known about mental illness-related structural stigma. In 2017, at the request of Health Canada, the MHCC's Opening Minds anti-stigma initiative undertook an 18-month project to develop a better understanding of stigma as it relates to the use of opioids and other substances. The project included a scoping review of the literature, along with in-depth qualitative interviews and focus group meetings with key responders. A range of system-level barriers and service gaps were identified through these investigations, such as punitive or barrier-creating care practices and policies, inadequacies related to access and the quality of treatment options, and the inequitable allocation of resources.

ROADMAP

2019

- Project Start
- Development of Research Team

2020

- *Literature Review*
- *Environmental Scan*
- Qualitative Research
- *A Framework for Action*

2021

Measures:

- *Assessment Framework*
- *Service Users Perspective*
- *Design Prototypes*

Awareness Raising:

- *Personal Stories*
- *Champions and Changemakers*

Professional Training Module

The Structural Stigma Project

YEAR 1

Earlier reviews of the literature highlighted the lack of attention given to structural stigma in health-care settings and the need to develop an action framework, measures, and training tools to monitor and disrupt it. Based on this realization, and the research that recognized the health-care system as a significant contributor to stigma for people with lived and living experience, in 2019 the MHCC set out on a multi-year project to examine structural stigma in health-care settings and develop tools and approaches for dismantling it. In the first year, the project focused on the conceptual framework needed to understand, monitor, and disrupt such structural stigma. At the close of Year 1, four main deliverables (described below) had been produced.



Literature review

A detailed literature review was undertaken to develop a framework and tools that could be used to assess and disrupt structural stigma in health-care contexts with respect to persons with lived and living experience of mental health problems and illnesses and/or substance use. This review identified key issues, including (1) the systemic failure to provide access to evidence-based quality mental health care for people with lived and living experience, and (2) the poor quality of care they receive in relation to physical health needs. It also noted that structural barriers built into health systems often make it difficult for health-care providers to deliver a high quality of care. The assessment framework presented in the report outlines concrete steps for documenting the nature and severity of structural stigma in health-care contexts. [*Structural Stigma in Health-Care Contexts for People with Mental Health and Substance Use Issues – A Literature Review*](#) was released in July 2020.



Environmental scan

An environmental scan was conducted to identify

- tools and measures that health-care organizations use to identify and address structural stigma
- the gaps in monitoring that may perpetuate or ignore the prevalence of structural stigma
- MHCC partners with an interest in further developing and implementing a new audit tool that could identify and address equity gaps in mental health and substance use care.

Thirteen agencies were contacted, reflecting a range of regulatory and performance measurement activities, locally, nationally, and (more selectively), internationally. No agency representative knew of any specific tool or measure that would target structural stigma or mental health equity, though a number of potential indicators were discussed. The scan report, [*Structural Stigma in Health Care for Mental Health and Substance Use: Networking for the Design, Development, and Implementation of an Audit Tool*](#), was released in July 2020.



Qualitative research

A qualitative study was undertaken to (1) better understand how health-care structures create and maintain stigma toward people with lived and living experience, and (2) identify constructs that could inform the development of a measurement framework and audit tool to assess structural stigma from the perspective of those who experience it. Twenty individuals, reflecting a cross section of people in Canada who had experienced structural stigma, were interviewed. Their stories painted a grim picture of structural stigma's detrimental effects, ranging from

disenfranchisement, disempowerment, diminished self-esteem, increased morbidity and, in catastrophic circumstances, premature death. The results of this study will appear in a chapter of a forthcoming book (published by [Oxford University Press](#)) featuring the MHCC's anti-stigma work. They will also provide the impetus for a detailed literature search for measurement tools that could be used to monitor and address structural stigma in the domains most important to those receiving services.



A FRAMEWORK FOR ACTION

Together, these Year 1 activities provided a comprehensive picture of the problem of structural stigma in health-care settings:

- how it is experienced by persons with lived and living experience of mental health problems and illnesses and/or substance use
- how it impacts their health and quality of life
- the gaps in performance audit and measurement tools

The main findings were synthesized into a framework for action that built on the Chief Public Health Officer's [framework](#) for addressing stigma and creating a more inclusive health system. Focusing on mental health and substance use clients, this report identified seven priorities for dismantling structural stigma. These included

(1) prioritizing training to improve the attitudes and practice of health-care staff, (2) developing and implementing audit, quality, and performance measures and surveillance tools, (3) adopting person-centred and recovery-oriented models of care, (4) committing to equitable resource allocation for mental health and substance use services and research, (5) fostering the meaningful inclusion of people with lived and living experience throughout the design and delivery of health policy, services, training, and research, (6) building policies and practices that are stigma-informed to enhance the provision of culturally safe and trauma- and violence-informed care, and (7) focusing on the culture of health care as a workplace. [Combating Mental Illness- and Substance Use-Related Structural Stigma in Health Care – A Framework for Action](#) was released in July 2020.

The Structural Stigma Project

YEAR 2

In the second year of the project, the team focused on the identification and development of tools for (1) measurement, (2) awareness raising, and (3) professional training.



Measures

An important first step in addressing structural stigma is to measure its prevalence and perniciousness. Assessing and monitoring is necessary for understanding its severity, how it materializes, how it varies between populations and sites, and how it changes over time. Also important is understanding the effectiveness of interventions aimed at reducing structural stigma. Routine monitoring in health-care settings (with feedback to these settings) may raise awareness and promote actions to disrupt structural stigma and remove barriers, both for people with lived and living experience who are seeking to access care and those who are working to provide it.

A Framework for Assessing Structural Stigma in Health-Care Contexts for People with Mental Health and Substance Use Issues

This broad framework describes the assessment domains, methodological considerations, and potential data sources for assessing structural stigma in health-care settings, as contemplated in the literature. The assessment domains focus on two key issues: (1) inequitable access to care (including resource distribution, denial of care, and fragmentation of care), and (2) poor quality of care (including practitioner practices, negative experiences, and coercive approaches to care). Methodological considerations include study approaches and designs (e.g., participatory, intersectional, multi-method, cross-level, longitudinal) that seek to assess the degree to which structural stigma leads to negative outcomes, such as health and social inequities, increased morbidity, and premature mortality.

This section also highlights some notable initiatives that have emerged in Canada and elsewhere. The potential data sources described are people with lived and living experience of mental health problems and illnesses and/or substance use, health-care providers, health-care institutions, health insurers, governments, and legislative and legal systems.

Design Prototypes for Measuring Structural Stigma in Health-Care Settings

This report builds on the Year 1 consultations and environmental scan. It uses the Institute of Medicine's six quality pillars as an organizing framework for potential measures. Examples of audit measures under the "Safe" pillar include the use of restraints, the way emergency codes are dealt with in the case of someone with a mental illness (e.g., less security-led and more clinician-led), and the adequacy of infrastructure and space for treating people with lived and living experience. Under "Effective," items include access to evidence-based treatments, continuing education for health-care staff on treatment requirements for people with mental health or substance use concerns, and the availability of medically supported withdrawal management services. Among the "Patient Centred" items are monitoring patient satisfaction, assessing the physical condition of waiting rooms and care environments, and the inclusion of client representatives on governance boards and senior executive teams. "Timely" service measures include continuity of care information, recidivism, and wait-time measures. Under "Efficiency" are items such as the ratio of health-care staff to inpatient

beds, budget allocations to mental health and substance use care, and financial equity across mental health and other services. Finally, “Equitable” pillars include parity of remuneration between mental health providers to non-mental health providers for equivalent work roles, adequate housekeeping and cleaning services to mental health units, and relative capital investments to mental health services compared to other services.

Measuring Structural Stigma in Health-Care Settings from the Perspective of Service Users

This report builds on the qualitative research completed in Year 1. It takes a client perspective and reviews measurement approaches described in the literature that could be used to monitor the extent to which health-care settings offer caring cultures, person-centred care, and recovery-oriented care. Qualities of an ideal measure were considered to include being (1) *grounded* in the experiences of clients and family members, (2) *client directed* so that clients and family members, rather than health professionals, complete the measure, (3) *holistic*, in the sense that measures should apply to the client’s overall experience of care rather than to individual care processes, (4) *person-centred*, such that measures should address the extent to which care meets clients’ needs and is empowering, affirming, and recovery oriented, (5) *generalizable* across the broad range of health and mental health settings, and (6) *psychometrically sound*. Since this review did not uncover a single measure that met these criteria, what is now needed is a new standardized and psychometrically tested instrument to quantify the personal experiences of people with mental health and substance use concerns who have encountered stigma in health-care settings.



Awareness raising

Awareness-raising activities centred on (1) the personal stories of people with lived and living experience of mental health problems and illnesses and/or substance use as well as health-care providers and other agents within the health system, and (2) case studies of health-care organizations that had successfully implemented projects to disrupt structural stigma.

Personal stories

In this part of the project, an external request for proposals was used to commission educational videos of personal stories told by individuals with direct experience of structural stigma in health-care settings. As a result of this process, the MHCC proceeded with the design of four videos to raise awareness of the ways structural stigma manifests in the health system. The stories are meant to represent the perspectives of people with lived and living experience as well as health-care providers and other agents within the health system. The first video is an animated account of structural stigma, which is intended to highlight the problem, raise some urgency in addressing it, and show that positive change is possible. The next three videos draw on footage from interviews of people with lived and living experience and health-care providers. Each highlights a different theme, in keeping with the findings of the Year 1 literature review: access, quality, and finding a way forward. Under the access theme, individuals describe journeys that show how structural stigma has affected their access to care and how care processes can be experienced as traumatizing. The focus of the quality theme video is how people with lived and living experience have systematically received a lower quality of care. The final video highlights opportunities to address and dismantle structural stigma. Q&A narratives are also included with these three main themes.

Champions and Changemakers: Real-World Examples of Approaches that Address Mental Illness- and Substance Use-Related Structural Stigma in Canada's Health-Care System

In August 2020, the MHCC sent out a public call for expressions of interest to identify examples of innovative models of care, quality improvement initiatives, interventions, programs, policies, or practices that showed promise in reducing structural stigma. In addition to raising awareness about structural stigma in Canada's health-care system, the project sought to leverage real-world examples to expand knowledge of the key ingredients for change (features, strategies, or other considerations) that may assist others in reducing structural stigma within their own organizations. The six submissions selected (out of 62 submissions) spanned wide-ranging areas: addiction, justice, mental wellness, residency training, community engagement training, and a dual diagnosis program. The lessons learned included the importance of (1) promoting the meaningful participation of service users and other stakeholders in all aspects of development, implementation, and research, (2) focusing on education and training models that embed the voices and perspectives of people with lived and living experience, (3) implementing models of care that are evidence based, holistic, culturally safe, client centred, and recovery oriented, (4) including a focus on changing inequitable and unjust laws and policies, (5) recognizing the intersecting nature of structural stigma among marginalized groups, (6) having supportive leadership, (7) planning for long-term sustainability, and (8) embedding evaluation and research.



Professional training module

Elements of a structural stigma training module

To prepare for the creation of a structural stigma training program, the team undertook a needs assessment to inform the development and structure of an online self-directed course that would target senior leaders, change agents, and influencers in health-care settings. The best-practice educational literature indicates that, to be successful, a training module would have to improve knowledge, skills, and attitudes as well as challenge, transform, and enlighten learners' beliefs and assumptions about structural stigma and its impacts. The training module being developed will do so by focusing on knowledge building, personal reflection, and transformative learning. Its activities will allow learners to engage in reflection and leverage evidence-informed approaches to address structural stigma. Trainees will also be provided with the tools and templates designed to sustain the skills they are developing. Key outcomes of the module include (1) enhancing knowledge and awareness on the outcomes of structural stigma as it pertains to people with lived and living experience, (2) reflecting on personal attitudes and beliefs, (3) reframing the concept of structural stigma for themselves, (4) identifying opportunities to dismantle structural stigma in their own spheres of influence, and (5) explaining what approaches and tools could be used to do so in their respective settings. The training module will be free for all participants.

Next Steps

Addressing mental health- and substance use-related structural stigma in health-care settings will remain an MHCC priority and is included in its upcoming mandate (2021–26). Building on the work conducted from 2019 to 2021, the commission will continue to address gaps and reduce structural stigma while developing strategies for reshaping the way health services are provided to persons with lived and living experience. These efforts will focus on five key areas:

- 1 Co-design of structural stigma measures:** Building on the three measures reports from Year 2, the MHCC will continue a process of co-production—with people who have lived and living experience, health-care audit and standards organizations, and performance measurement agencies—to identify which prototypes provide the most meaningful outcomes and are the most measurable and practical for implementation.
- 2 Implementation and evaluation of the structural stigma training module:** Based on the structural stigma training module developed in 2020–21, the MHCC will work with partners to deliver and evaluate its impact.
- 3 Scaling up best practices from the case studies:** Working with the case studies of innovative models of care identified in 2020–21, the commission will identify their key ingredients of success and scale up best practices.
- 4 Exploratory work on intersectional structural stigma and health outcomes:** The MHCC will conduct further research on how mental health- and substance use-related structural stigma intersects with other forms of structural stigma (e.g., racism, transphobia, colonization) in relation to accessing care and its effects on health outcomes.
- 5 Partnership development:** The commission will continue to develop partnerships to ensure that the implementation of structural stigma reduction initiatives is sustained and expanded.

**To learn more about these initiatives,
visit the [MHCC's Structural Stigma page](#).**

Appendix

PROMOTION AND KNOWLEDGE TRANSLATION

Throughout the two years of the project, the structural stigma research team has had opportunities to be involved in a number of promotion and knowledge translation activities. These include:

TITLE	AUTHORS	RELEASE DATE	NOTES
Structural Stigma	MHCC Project Staff	August 2020	Brochure available from the MHCC
Catching Blind Spots in COVID-19 Health-Care Planning	Thomas Ungar and Stephanie Knaak	August 2020	Two-pager available from the MHCC
Making the Implicit Explicit: A Visual Model for Lowering the Risk of Implicit Bias of Mental/Behavioural Disorders on Safety and Quality of Care	Thomas Ungar, Stephanie Knaak, and Ed Mantler	September 10, 2020	Journal article available from Health Management Forum
Heads Up! Community Mental Health Virtual Summit	Stephanie Knaak	November 25–26, 2020	Presentation recording available from the Fresh Outlook Foundation
IHI Forum 2020 Scientific Symposium	Thomas Ungar	December 7, 2020	Presentation available from BMJ Open Quality
Structural Stigma Against Mental Illness is ‘Baked In’ to Our Health System, and That Affects Care	Javeed Sukhera	January 27, 2021	Op-ed available from The Conversation
Stigma Reduction for Substance Use and Opioids	Stephanie Knaak and Heather Stuart	December 2020	Book chapter to appear in Keith S. Dobson and Heather Stuart (eds.), <i>The Stigma of Mental Illness</i> , Oxford University Press (in press)
Measuring Structural Stigma	Thomas Ungar and Stephanie Knaak	December 2020	Book chapter to appear in Keith S. Dobson and Heather Stuart, (eds.), <i>The Stigma of Mental Illness</i> , Oxford University Press (in press).
Let’s Talk About The Medical Profession’s Hidden Equity Crisis: Canadians’ Mental Health Care	Thomas Ungar and Louise Bradley	January 28, 2021	Op-ed available from the Globe and Mail
Ghost in the Machine: Tackling Structural Stigma in Health-Care	Structural Stigma Research Team	February 9, 2021	Webinar and Q&A document available from the MHCC
Stigma: From Stereotyping and Discrimination to Compassion and Inclusion	Samaria Nancy Cardinal and Stephanie Knaak	February 2021	Podcast available from the Fresh Outlook Foundation



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