



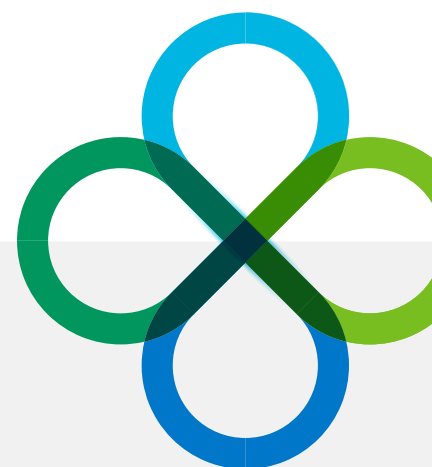
Mental Health
Commission
of Canada

Commission de
la santé mentale
du Canada

Dismantling structural stigma in health care

*An implementation guide
to making real change for
and with people living with
mental health problems or
illnesses and/or substance
use concerns.*





Ce document est disponible en français

Citation information

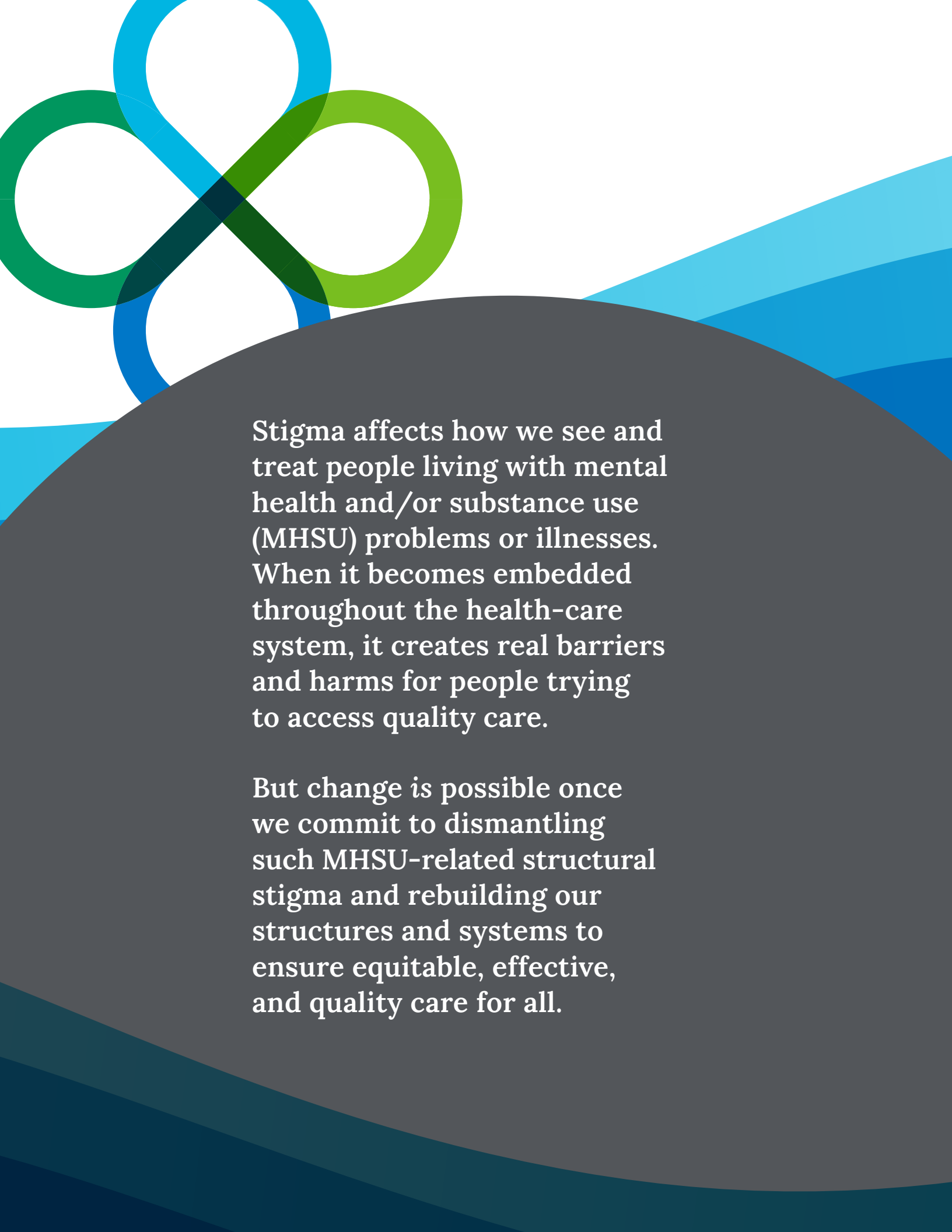
Mental Health Commission of Canada. (2023). *Dismantling structural stigma in health care. An implementation guide to making real change for and with people living with mental health problems or illnesses and/or substance use concerns.* Ottawa, Canada.

© 2023 Mental Health Commission of Canada

The views represented herein solely represent the views of the Mental Health Commission of Canada.

ISBN: 978-1-77318-325-1

Legal deposit National Library of Canada



Stigma affects how we see and treat people living with mental health and/or substance use (MHSU) problems or illnesses. When it becomes embedded throughout the health-care system, it creates real barriers and harms for people trying to access quality care.

But change is possible once we commit to dismantling such MHSU-related structural stigma and rebuilding our structures and systems to ensure equitable, effective, and quality care for all.

ACKNOWLEDGMENTS

The head office of the Mental Health Commission of Canada (MHCC) is located on the unceded traditional territory of the Algonquin Anishinaabe Nation, in what is now called Ottawa, Ontario. As a national organization, we also acknowledge that we work on the traditional lands of many different nations. We give credit to their stewardship and sacrifices and are committed to recognizing and contributing to a new and respectful relationship with the First Peoples.

The MHCC is deeply grateful to the individuals and organizations whose contributions made this guide possible. We extend a special appreciation to the structural stigma research team, whose tireless efforts are helping reduce structural stigma in Canada's health-care system. We are also humbled and inspired by the experiences, approaches, tools, and lessons learned that were shared by the remarkable group of champion and changemaker organizations that contributed to the guide. Their journey to address mental health- and substance use-related structural stigma is a testament to their commitment and leadership, and we are privileged to have learned from them. Thank you all for your invaluable support.

MHCC project staff

Samuel Breau, Carolina Chadwick, Hannah Kohler, Uyen Ta, Karina Urdaneta, Nicholas Watters

MHCC Youth Council and MHCC Hallway Group

Anita David, Connor Lafortune, Alexandra Schuster

MHCC structural stigma research team

Dr. Stephanie Knaak, Dr. Javeed Sukhera

Champions and changemakers

Addiction Recovery and Community Health (ARCH) Program

Janet Butler, Lee Zorniak

Adult Neurodevelopmental Stabilization Unit (ANSU) Dual Diagnosis Program

Oluseye Akinkunmi, Rachel Boehm, Mutiat Sulyman

Biigajiiskaan: Indigenous Pathways to Mental Wellness

Bill Hill Ro'nikonkatste (Standing Strong Spirit), Arlene MacDougall, Jodi Younger

Canadian Resident Matching Service (CaRMS) Service User Committee Initiative

Sacha Agrawal, Rachel Cooper, Gina Nicoll

Centering Madness Course: Building Capacities for Community Engagement

Lucy Costa, Lauren Munro

Health Justice

Nousha Bayrami, Kendra Milne

CONTENTS

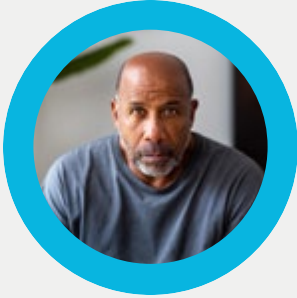
What is MHSU-related structural stigma?	6
What does MHSU-related structural stigma look like in health care?.....	8
Want to learn more?.....	10
About this guide.	11
Who can use this guide	12
How to use this guide.....	13
Important terminology	14
How this guide was developed	16
Identifying the champions and changemakers	17
Building a model for change	19
Key principles for reducing MHSU-related structural stigma	21
Part 1 Context	23
Part 1.1 Identify and ensure a shared understanding of the problem.....	25
Part 1.2 Articulate a clear vision for desired change	31
Part 1.3 Align values across diverse partners.....	39
Part 1.4 Ensure shared governance and payment structures.....	45
Part 2 Success Factors	53
Part 2.1 Build and sustain trust.....	55
Part 2.2 Redistribute power in relationships	61
Part 2.3 Measure and monitor outcomes	67
Part 3 Sustainability	73
Part 3.1 Build capacity and support for potentially disruptive change.....	75
Part 3.2 Anticipate and manage resistance.....	81
Part 3.3 Seek and respond to feedback in a proactive way	87
Part 3.4 Embed change in existing structures	93
MHCC Library of Structural Stigma Resources	98

WHAT IS MHSU-related structural stigma?

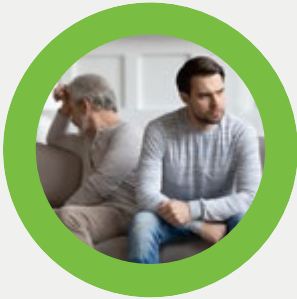
Stigma refers to the negative attitudes and prejudices that cause people with mental health and/or substance use (MHSU) problems or illnesses to be labelled, stereotyped, and feared. When that stigma shapes and is reinforced by an organization's rules, policies, and procedures – whether formally or informally, knowingly, or unknowingly – it becomes **structural stigma**.

There are four types of MHSU-related stigma, which all create barriers to prevention, treatment, and recovery for people with lived and living experience (PWLE) of MHSU problems or illnesses:





Individual stigma occurs when someone internalizes the negative messages about people living with MHSU problems or illnesses and applies them to themselves. It can include shame and feeling less worthy as well as a fear of seeking help.



Interpersonal stigma refers to negative attitudes or behaviours toward people living with MHSU problems or illnesses (or toward their friends and family). It can include endorsing negative stereotypes or prejudicial ideas and speaking or acting in discriminatory ways.



Structural stigma encompasses the organizational and societal rules, policies, procedures, laws, and cultural norms that increase stigma and raise barriers for people seeking to access the help they need. It can affect multiple aspects of everyday life; people living with MHSU problems or illnesses often face arbitrary restrictions related to health care, employment, housing, education, participation in public and civic activities, travel, immigration, reproductive rights, parenting, and more.



Intersectional stigma¹ happens when the stigma related to MHSU problems or illnesses overlaps with other forms of inequity, discrimination, and/or oppression (e.g., racism, transphobia, sexism, colonization, classism, and ableism). These multiple forms of inequity can sometimes be compounded by the health conditions of people living with MHSU problems or illnesses and their experiences in the health-care system.

¹ The term *intersectionality* was coined in 1989 by Kimberlé Williams Crenshaw in the paper “Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics” to conceptualize a person, group, or social problem as affected by a number of discriminations and disadvantages.

What does MHSU-related structural stigma look like in health care?

Structural stigma in health care happens when laws, policies, and systems of care embed negative beliefs, biases, and prejudices about people living with MHSU problems or illnesses in policy and practice. As stereotypes and discrimination become enshrined in different systems (e.g., governance, training, service delivery), health-care organizations can both deliberately and inadvertently create, maintain, and perpetuate a range of social and systemic inequities for such people, including their ability to access and receive quality care.

MHSU-related structural stigma can manifest in the health-care system in many ways. In some cases, MHSU services may be devalued, deprioritized, underfunded, and “othered” compared with physical health services. In other cases, policies are put in place that lead to discriminatory outcomes for people living with MHSU problems or illnesses, which can include:

- **lack of treatment** for individuals with MHSU problems or illnesses, or their symptoms are undertreated or ignored
- **excessive wait times** compared to physical health issues
- **diagnostic overshadowing** (i.e., attributing a person’s symptoms to a psychiatric problem when they may actually suggest a co-existing physical health condition)
- **insufficient staff/resource allocation** to MHSU-related care
- physical space for MHSU patients that is of **lower quality or standard** than the spaces offered in other care areas
- **suspicion, over-monitoring, and hypervigilance** of security professionals, leading to frequent room searches and accusations of theft (especially among Indigenous, immigrants, refugees, and racialized people)
- use of **visible identifiers** intended to flag individuals for violence risk (e.g., arm or wrist bands) but unintentionally stigmatize
- **little or no research** into effective MHSU-related care and treatment, resulting in care practices that are outdated or not evidence-based, or do not incorporate the latest best practices.



SPOTLIGHT

How a lack of funding for research affects care for stigmatized populations

When a population is stigmatized, there is usually a lack of research in an organization to find more effective care methods for that population. As a result, out-of-date practices flourish, causing harm to service users. For example, asylum-like care practices remained in place for the most stigmatized populations for decades after evidence showed that many of these practices were not helpful.

When care models become outdated, it is also a clear indicator that the needs of that population are not a top priority. Any issues or challenges faced by that population typically “fly under the radar” and are allowed to continue. Because patients are often unable to advocate for themselves – and family members who can advocate for them are frequently excluded from the engagement process – their voices never get heard. In addition, many stigmatized populations do not have powerful societal voices advocating for them, such as foundations or major corporations. As a result, they do not receive the latest evidence-informed care.



SPOTLIGHT

How structural stigma affects the physical environment

For many stigmatized populations, the physical environments they receive care in are often of a lower standard than those of other health services. For example, service delivery might take place in old, rundown facilities where regular maintenance does not occur (even for something as simple as repainting the walls every so often). Or else, an organization may continue to use decades-old seclusion rooms that were never upgraded, despite many updates in building materials and design standards that would help reduce patient safety concerns.

It can also mean that patients are cared for in environments that exacerbate their symptoms. Consider a patient with severe autism who is admitted to a psychiatric ward that is painted in loud colours with bright fluorescent lights and has no privacy or noise control. Or consider mental health programs located in buildings or floors previously used by physical health services, meaning they were not designed or equipped with mental health problems or illnesses in mind and may potentially affect patient health and safety.



SPOTLIGHT

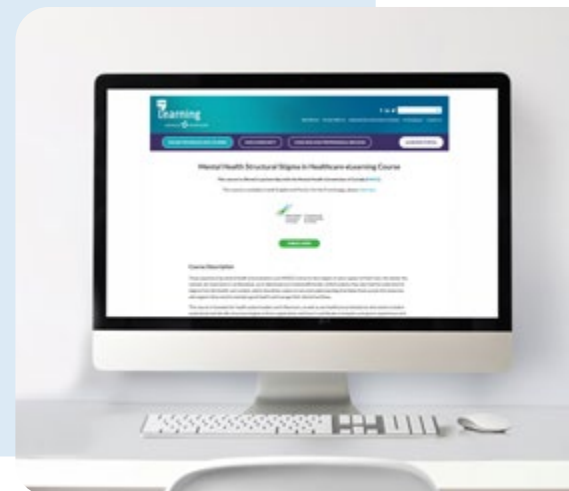
How structural stigma affects the culture of care

When stigma becomes embedded in health-care systems and administrative processes, it can leave people feeling helpless and their voices unheard. Consider the case of Céline, a 17-year-old woman who arrived at the emergency department with her parents, exhibiting symptoms of mania. To protect her safety, she was admitted as a patient under an involuntary admission order yet, because of a shortage of mental health beds, remained in the emergency department for nine days. During that time, Céline was kept in a locked room she could not leave. She was not allowed to go outside for fresh air and had to ask permission to go to the washroom — and she had to be escorted by a protective services worker every time. Her parents, distraught and desperate to rectify the situation, asked to take their daughter home to care for her and seek help from community-based resources. However, they were told this was not possible because the appeal process to reverse an involuntary admission order would take at least five days. There was no immediate mechanism for improving the care provided to Céline. The entire family felt victimized by the system that was supposed to be helping them.

Want to learn more?

For more information about MHSU-related structural stigma, register for the Mental Health Commission of Canada's (MHCC's) [Mental Health Structural Stigma in Healthcare e-learning course](#). This free training will help you identify structural stigma in your organization and understand how it contributes to inequity and poorer health outcomes.

In addition, the MHCC library of structural stigma resources at the end of this guide provides links to personal stories of people who have experienced MHSU-related structural stigma, MHCC research on the extent of the problem in health-care settings, frameworks for assessing and measuring the severity of it in health-care organizations, and more. You will find videos, reports, presentations, fact sheets, webinars, online training, and other useful tools and resources to help you better understand structural stigma and how to dismantle it.

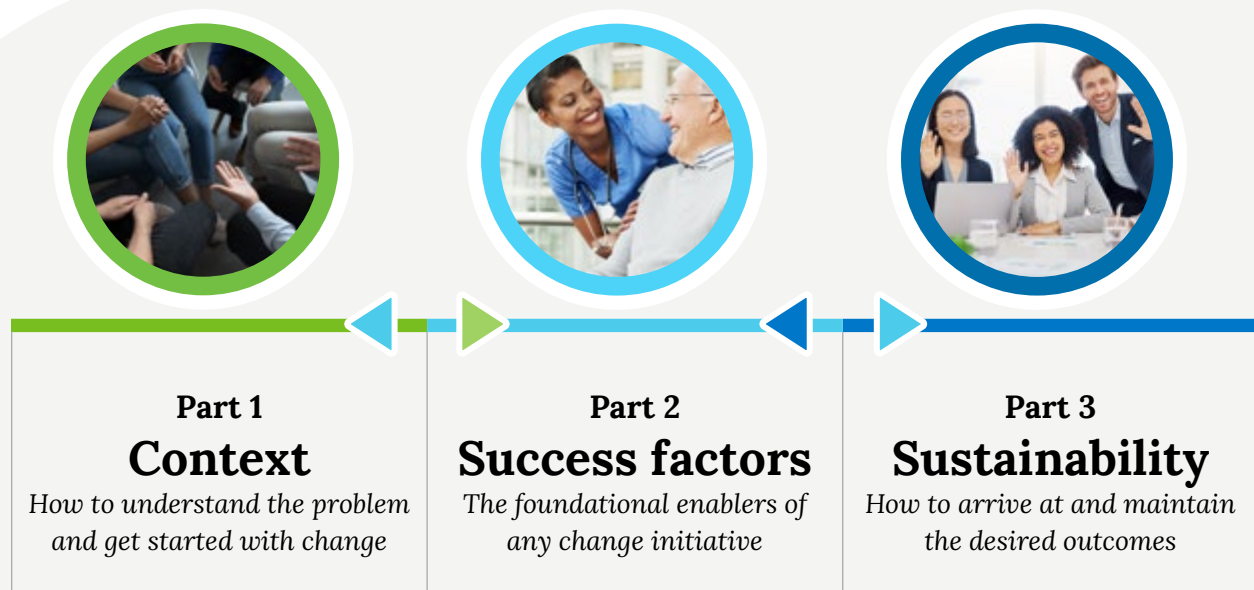


ABOUT this guide

MHSU-related structural stigma is present throughout Canada's health-care systems. Real change can begin only once it is recognized and acknowledged.

The goal of this guide is to share knowledge about the key features of structural change and strategies and the considerations for making it happen — and to provide guidance to those interested in reducing MHSU-related structural stigma in their organizations.

Drawing on real-world insights from organizations across the country, this guide provides practical tips, advice, tools, and resources on 11 components of structural change, from establishing and communicating a vision for change to measuring and monitoring progress over time. These components are grouped into three overarching categories or parts:



These three categories (and the components of change that fall under them) make up the core sections and subsections of this guide.

Who can use this guide

Addressing stigma is top of mind for many organizations in Canada's health-care sector. Some might think they fully understand MHSU-related structural stigma and how to address it, but that's not necessarily the case. The principles and recommendations outlined in this guide can be used by any organization, institution, or agency – of any size and in any jurisdiction across the country – to look at themselves more critically and challenge their existing practices and policies that may be perpetuating structural stigma. The guide is meant for individuals at any level in a health-care organization who can influence, advocate for, or lead efforts to reduce MHSU-related structural stigma. These individuals may include:

- **leaders and administrators** who can influence changes to the way care is provided to people living with MHSU problems or illnesses (e.g., executives, board members, directors, managers, quality improvement leads, professional practice leads, policy advisors/analysts)
- **health-care providers, allied health professionals, health-care workers, personal care, and clerical support workers in health services** seeking to improve quality of care for people living with MHSU problems or illnesses (e.g., physicians, nurses, pharmacists, psychologists, social workers)
- **any other people** interested in addressing MHSU-related structural stigma in health care (e.g., people with lived experience, members of family/patient representative committees).

Every person in an organization should be aware of structural stigma and be able to assess for it. However, while some elements of change can be enacted by people in direct service roles, systemic change requires buy-in and support from an organization's leaders. As such, it is ultimately up to the senior leaders and decision makers – the people who have the power to truly effect change – to come together to implement the recommendations outlined in this guide.



How to use this guide

This guide provides general *principles* based on how other organizations have worked to dismantle MHSU-related structural stigma in health care. It does *not* prescribe a single specific pathway to implementing and realizing transformative change. Take inspiration from what others have done and the resources they have used, then carefully determine how their approaches could be applied or adapted to your organization’s specific context and situation.

Ideally, you will read this document from beginning to end, incorporating aspects of all 11 components of structural change into your organization’s change initiative. However, if you want to start small or are looking for guidance on a particular topic, you can choose to focus on just one or more components as you work to dismantle MHSU-related structural stigma. Keep in mind that change won’t happen overnight. So don’t feel discouraged if you can’t tackle all 11 components of structural change at the same time.



NOTE: Transformative change is a team effort. When “you” or “your” is used in this guide, it refers broadly to your organization as a whole and/or the people involved in the change initiative, rather than to you personally.

Important terminology

You will see the following words and phrases used throughout this guide.

Ableism: Discrimination and social prejudice against people with disabilities and/or people who perceive themselves as being disabled.

Clients: Individuals living with mental health problems or illnesses and/or substance use concerns. This term may not be the one primarily used in all parts of the health-care system, with *patient* and *service user* also commonly used.

Co-design: A process that involves multiple stakeholders (internal and external) in planning to improve systems and services. It is a participatory, reflective, and adaptive process centering on participants as design partners, giving a voice to those who are often excluded.

Culturally appropriate engagement: The process of not only respecting other cultures but also being able to truly understand, communicate with, and interact with people who have diverse beliefs, attitudes, values, and behaviours. This includes conducting meetings and discussions in a way that doesn't make people from different backgrounds uncomfortable or feel left out – for example, by respecting cultural practices when planning the structure and format of meetings, such as including Indigenous sharing circles and smudging ceremonies.

Cultural safety: The process of making spaces, services, and organizations safer and more equitable for people who are marginalized, oppressed, and/or underserved because of their identities.

Intersectionality: The interconnected nature of social categorizations such as race, class, disability, sexual orientation, and gender identity as they apply to a given individual or group. Intersectional identities create overlapping and interdependent systems of discrimination or disadvantage.

Just culture: A philosophy that supports an environment where everyone feels safe, encouraged, and enabled to discuss quality and safety issues, with reporting and learning as key elements. Reporting is conducted in a psychologically safe environment where there is demonstrated respect and support for the individual, with a “no blame” approach that focuses on exploring what went wrong rather than who caused the problem.

Marginalization: A social process by which individuals or groups are intentionally or unintentionally distanced from access to power and resources.

MHSU: Mental health and/or substance use. In this guide, *MHSU problems or illnesses* refers to mental health problems or illnesses and/or substance use concerns.

People-centred care: Care that is focused on and organized around the health needs and expectations of people and communities rather than on diseases. People-centred care extends this concept to individuals, families, communities, and society.

Psychologically safe and brave space: A supportive, non-threatening environment where all participants can feel comfortable to express themselves and share experiences without fear of discrimination or reprisal. Creating these spaces is especially important when dealing with MHSU problems or illnesses, which can be a sensitive area for people and involve deeply personal or traumatic experiences.

PWLLE of MHSU problems or illnesses: People with lived or living experience of mental health problems or illnesses and/or substance use concerns.

Tokenism: The practice of making only a symbolic effort to engage with marginalized communities or clients, especially with respect to hiring and recruitment. It gives the appearance of diversity and inclusion, but all the power continues to be held by those in the dominant group.



How this guide was developed

Since the inception of the Mental Health Commission of Canada (MHCC), stigma reduction has been central to the organization's mandate. This guide is the result of a highly collaborative process with health leaders across Canada, involving more than two years of research, interviews (in group settings and one to one), and facilitated participatory workshops to identify and analyze real-world strategies for successfully overcoming MHSU-related structural stigma in Canada's health-care system.

Identifying the champions and changemakers

In 2019, the MHCC launched a multi-year project to better understand the problem of MHSU-related structural stigma in health-care contexts. Its overarching objective was to identify gaps and reduce stigma at the policy, practice, and system levels and also in the organizational culture of health care itself.

In August 2020, the MHCC issued a public call for expressions of interest to identify examples of innovative models of care, quality improvement initiatives, interventions, programs, policies, or practices related to reducing structural stigma. Specifically, it was looking for those that showed promise in improving access to and the quality of care for PWLLE of MHSU problems or illnesses.

Of the 62 submissions received, the following **six** were selected:

1 Addiction Recovery and Community Health (ARCH)

An Alberta Health Services program that tackles structural stigma by providing a patient-centred, trauma-informed, recovery-oriented model of care for people with substance use problems in a hospital setting. It offers services such as peer support, ID procurement, an in-hospital supervised consumption service, withdrawal and pain management, addiction counselling, an outpatient transitional clinic, and treatment and referral services.

2 Health Justice

It's a non-profit human rights organization whose mandate is to research, educate, and advocate to improve the laws and policies that govern coercive health care in British Columbia.

3 Biigajiiskaan: Indigenous Pathways to Mental Wellness

A partnership between Atlohsa Family Healing Services and St. Joseph's Health Care London that provides culturally safe, specialized care for Indigenous people with serious mental illness, addictions, and concurrent disorders by combining traditional healing medicine, care guided by Indigenous Elders, and ceremony with hospital-based health-care practices and psychiatric treatment in a hospital setting.

4 The Canadian Resident Matching Service (CaRMS) Service User Committee initiative

An initiative which gave a defined role to PWLLE of MHSU problems or illnesses in recruiting and selecting candidates for psychiatry post-graduate training at the University of Toronto between 2017 and 2021.

5 Centering Madness Course: Building Capacities for Community Engagement

A mandatory, embedded, and graded educational module for first-year University of Toronto psychiatry residents, introduced in 2017. The course applies a critical lens informed by disability, equity, and social justice to the dominant understandings of mental health. It is designed and delivered by service users through the Empowerment Council (a patient education and advocacy group funded by the Centre for Addiction and Mental Health).

6 The Adult Neurodevelopmental Stabilization Unit (ANSU) Dual Diagnosis Program

An initiative in which a nine-bed unit at a Nova Scotia hospital (which provides in-patient care and community transition support to patients living with a dual diagnosis of intellectual disability and mental illness) underwent a wholesale transformation of its model of care — moving from a primarily custodial approach to one that prioritizes recovery-oriented principles and positive behaviour support.

To gain a more thorough understanding of each initiative, the MHCC conducted online interviews with each program lead and/or team, as well as with other stakeholders who were identified during those initial interviews (e.g., program participants, organizational leadership, members of governance boards or advisory committees, others involved in program design or delivery).

The results of that research informed [Champions and Changemakers](#), a 2021 report on the six organizations and the lessons learned from their experiences engaging in disruptive change.



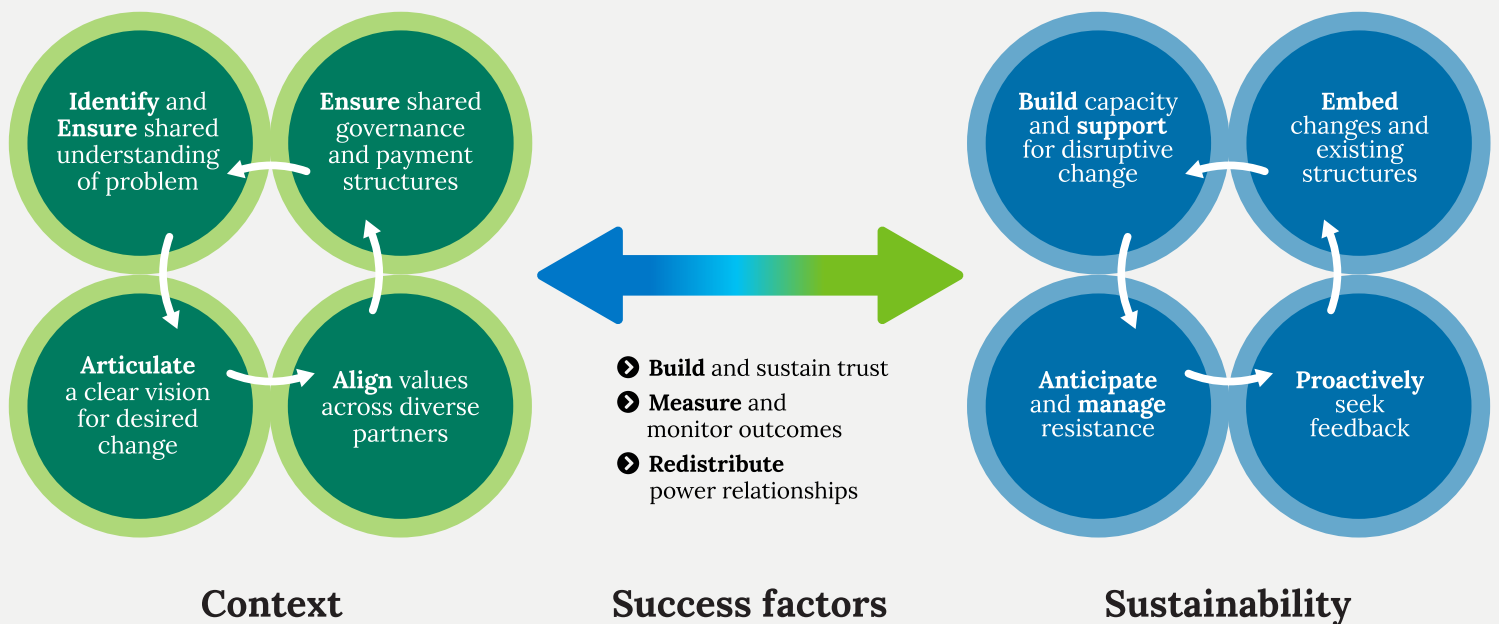
Building a model for change

In May 2022, the MHCC hosted a two-day virtual workshop with representatives from the six champion and changemaker organizations to identify barriers, facilitators, and promising practices for reducing structural stigma in health-care organizations.

Central to these sessions was research conducted by Dr. Javeed Sukhera and Dr. Stephanie Knaak. They used a realist review methodology, which can be employed to understand how different interventions work in different contexts (and why) to determine what works, for whom, and under what circumstances. In this case, they categorized the contexts, mechanisms, and outcomes related to reducing MHSU-related structural stigma at play in each of the champion and changemaker organizations as well as their commonalities. This process helped foster a deeper understanding of how, why, and in which settings interventions to address MHSU-related structural stigma may achieve their intended outcomes.

Emerging from this research was an **11-component theory of change model** that offers the foundational steps to effecting real change: the critical importance of building trust, redefining power in relationships, and tracking outcomes; and the keys to sustaining change over time. During the workshops, participants shared their thoughts on the barriers and facilitators for each component; this feedback informed the development of this guide.


Theory of Change – Dismantling Structural Stigma



A final set of interviews was conducted in late 2022 and early 2023, where the champion and changemaker organizations were asked to dig deeper into how each of them approached specific components of the theory of change model, including the practical steps they took to dismantle structural stigma and the outcomes they achieved.

As described earlier, for the purposes of this guide, the theory of change model has been divided into three distinct sections – context, success factors, and sustainability – to help organizations across Canada’s health-care sector understand and act on it.





KEY PRINCIPLES for reducing MHSU-related structural stigma

Organizations should strive to apply the following lessons, insights, approaches, and strategies for tackling MHSU structural stigma in health-care environments:

1 Centre the voices of people with lived and living experience

Prioritize the meaningful participation of service users, community members, and other PWLLE of MHSU problems or illnesses in the design, delivery, and governance of any initiative for change — and formalize their involvement through established models of co-design and shared leadership. When engaging with PWLLE of MHSU problems or illnesses, create a psychologically safe and brave space that allows all voices to be heard, valued, and respected.

2 Embed change for sustainable results

Make change stick through ongoing education and training² approaches that prioritize the voices and perspectives of PWLLE of MHSU problems or illnesses. Work to embed the change in the structure of your organization by coding it into policies, governance mechanisms, and quality improvement indicators.

² For more information about MHSU-related structural stigma, register for the Mental Health Commission of Canada's (MHCC's) [Mental Health Structural Stigma in Healthcare](#) e-learning course. This free training will help you identify structural stigma in your organization and understand how it contributes to inequity and poorer health outcomes.

3 Model change from within to spread influence

Implement high-quality, evidence-based, holistic, culturally safe, client-centred, and recovery-oriented models of care, guided by the perspectives and input of PWLLE of MHSU problems or illnesses. Ongoing education and engagement – as well as role modelling and leading by example – will help facilitate and support buy-in across your organization and your partners.

4 Acknowledge the intersectional nature of structural stigma and other inequities

Focus on addressing the needs of population groups that face multiple levels of stigma combined with experiences of marginalization and discrimination, such as racism, transphobia, sexism, colonization, classism, and ableism.

5 Get explicit support from senior leadership

Ensure the long-term success and sustainability of any initiative for change by securing buy-in from senior leadership and the support of passionate champions who share the same values.



6 Grow through tension and dissonance

Commit to making collaborative and creative problem-solving part of the change process to meet any administrative or other system-level challenges that occur along the way.

7 Evaluate outcomes through monitoring and measurement

Know the importance of undertaking evaluation and research, setting targets or goals, and monitoring your progress. Evaluation and research design should involve input and direction from PWLLE of MHSU problems or illnesses.



PART 1

Context

Any intervention to address MHSU-related structural stigma first requires an understanding of what is needed: organizational readiness to disrupt existing norms, a clear vision for change, and acceptance of the discomfort that comes with thinking about and doing things differently.

To achieve these aims, health-care organizations must think purposefully about reducing stigma and recognize that previous approaches to address the issue (if any were taken at all) might not have been successful. That means identifying and acknowledging structural inequities and power asymmetries that currently exist in the organization – and then working closely with PWLLE of MHSU problems or illnesses to place them at the heart of the solutions.

In short, this phase is all about setting the context for change and answering the following types of questions:

- *How does structural stigma manifest itself in your organization today?*
- *What conditions will contribute to the success of your anti-stigma intervention?*
- *What changes might need to be made to the norms, policies, and institutional structures that drive your organization's day-to-day work?*

“Our system simply isn’t fulfilling its promise to people with [MHSU problems or illnesses]. One of the issues in accessing care is wait times. I encountered so many people who built up their courage to ask for help only to receive a slip of paper and an 18-month wait. To me, their courage isn’t being honoured by the system... That lack of welcoming ... is considerably worse within the systems designed for people with [MHSU problems or illnesses]. It’s in the ways in which we’ve designed our systems that I think we’ve really dehumanized people when they’re in their most vulnerable state.”

Dr. Javeed Sukhera, Chief of Psychiatry, Institute of Living

What health-care organizations need to do

1.1 Identify and ensure a shared understanding of the problem

Define the issues to be addressed through open and honest conversations

1.2 Articulate a clear vision for desired change

Determine the end goal and the path that all members of the organization must take to get there

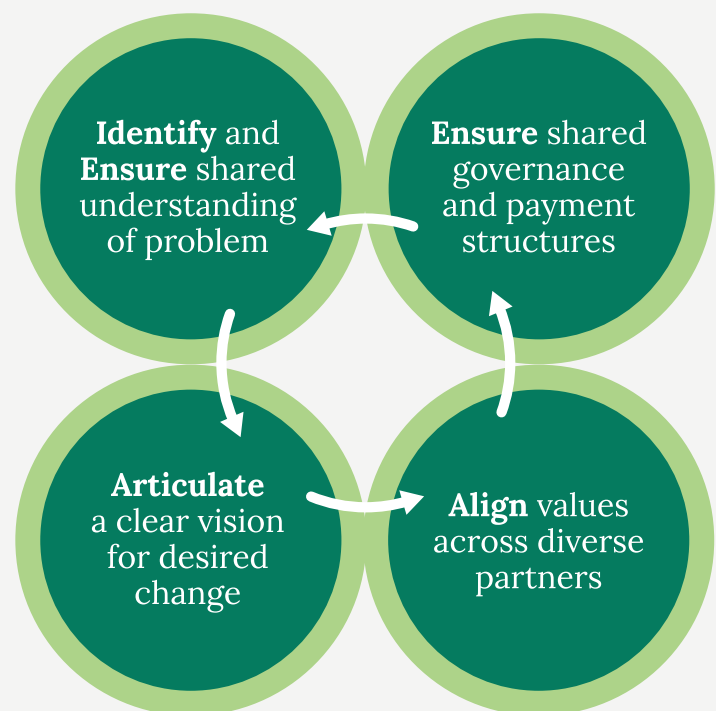
1.3 Align values across diverse partners

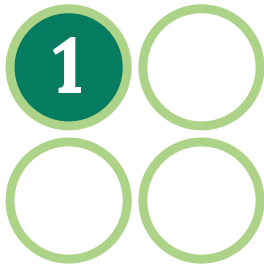
Get all internal and external stakeholders on the same page about the required changes

1.4 Ensure shared governance and payment structures

Move beyond tokenism and advisory models with frameworks that enable a more egalitarian approach to decision making

Part 1 Context





PART 1.1

Identify and ensure a shared understanding of the problem

Dismantling structural stigma requires that senior leaders and decision makers understand and agree that organizational change is necessary to better achieve its mission and enact its values. Ideally, everyone in your organization will also agree on the nature of the issue that needs to be addressed. But such a shared understanding can't be assumed, especially in larger institutions. Often, it must be carefully cultivated by ensuring that all people, at all levels of the organization, can safely share their thoughts, feelings, and concerns. Otherwise, it's easy for those with decision-making power to define the problem (and the solutions) without reflecting the perspectives and needs of people who typically don't hold any power, including those most affected by MHSU-related structural stigma.

Key principles for health-care organizations

Get leadership buy-in and check your organizational readiness for change

The most effective stigma-reduction interventions are those that have support and understanding from all levels of the organization right from the start. Getting buy-in from senior leaders and decision makers is key. If they recognize the issue and agree on its importance to your organization and the community you serve, they are more likely to dedicate time and resources to making change happen. (For tips on how to secure leadership buy-in, see [Build capacity and support for potentially disruptive change](#) and [Anticipate and manage resistance](#) in Part 3.)

For a variety of reasons, your organization and the community it serves may not be ready (or willing) to change just yet. This is OK — as long as you are honest with yourself about whether true structural change can be achieved. If not, it would be misleading, for example, to ask service users and other PWLLE of MHSU problems or illness to come to the table.

Engage broadly and beyond the walls of your organization

Consider the intersecting nature of structural stigma by identifying the needs of population groups that face multiple levels of stigma and marginalization. In addition to people living with MHSU problems or illnesses, chronic diseases, or disabilities, these can include (but are not limited to) immigrants and refugees, sexual and gender minorities, Indigenous people, and people living in poverty.

This will require facilitating a broad and inclusive process that engages all those affected by structural stigma in co-defining the problem. Include a wide range of perspectives: patients or clients and their families (or caregivers); the doctors, nurses, and other professionals who provide care; and researchers and subject matter experts who understand the issue and can inform the development of new models of care. Also reach out to other community health partners, who may be able to offer deeper insights into the populations you serve.

Given the stigma they have experienced, patients, families, caregivers, and other PWLLE of MHSU problems or illnesses may be reluctant to talk with your organization. It will take time and effort to earn their trust. But bringing their voices to the table is key to ensuring that people with power (who may not fully grasp the scope of the problem) don't dominate the initial context-setting discussions. Sustained actions over time, not words or promises, are what will make or break your ability to effectively partner and collaborate with groups that have been systematically mistreated in the past.

Provide psychologically safe and brave spaces

A psychologically safe and brave space provides people with the opportunity to express, discuss, acknowledge, and validate difficult or negative emotions, vulnerability, and challenging life events, all while facilitating and maintaining a growth mindset. It's about creating a space where people feel comfortable having difficult conversations and sharing their thoughts and experiences without judgment. This is particularly vital for PWLLE of MHSU problems or illnesses, who may be asked to dig up their memories of traumatic situations so others can learn from their experiences. It is important that they not be retraumatized when engaging in this emotional labour.



One way to create such spaces is to be very deliberate about how and where those conversations will take place. Outline the steps these conversations will involve in advance so there are no surprises; for example, have set meeting times and a defined agenda and establish cultural-specific protocols as necessary. A neutral facilitator outside your organization can help create a psychologically safe space, as can having agreements on the privacy and confidentiality of anything shared in that space. Paying people for their attendance can also encourage broader participation.

During the meetings, set aside time to address the unexpected. If something doesn't seem to be sitting right with a participant, yet they don't voice any concerns, pause and check in to better understand their thoughts and feelings. Lean into constructive tensions rather than avoiding them. Be aware that PWLLE of MHSU problems or illnesses may act differently than others during a meeting – and that's OK. For example, a person with ADHD may fidget or colour during the meeting, but that doesn't mean they are uninterested in the issue or their voice isn't important.

Promote proactive, open, honest, and ongoing communication

Developing a shared understanding of MHSU-related structural stigma requires listening to and respecting others' opinions. It also requires self-awareness and a willingness to engage with other perspectives, especially among decision makers and people in positions of power. This may make them feel uncomfortable, but that's normal. It's also important for leaders to participate in the safe spaces you create and to model openness and honesty, as this will help people at all levels of the organization feel safe in sharing their own experiences.

Gaining a full understanding of the problem will take more than a single meeting. Keep the conversation going by

- giving people multiple opportunities to share their thoughts and experiences through a series of town halls, circle gatherings, and focus groups, with the option for anonymity to ensure everyone feels safe in providing their opinions
- setting up learning groups that regularly bring together health-care providers, interprofessional care teams, knowledge keepers from the community you serve, and PWLLE of MHSU problems or illnesses to brainstorm how best to address patient or client concerns
- using simple surveys to ask about people's experiences with your services and what they would like to see changed (while always being transparent about how the data they provide will be used).

You must also be open and transparent when communicating to patients, families, caregivers, and other PWLLE of MHSU problems or illnesses. Ensure that they understand what your organization is trying to accomplish – and how they can help you dismantle MHSU-related structural stigma. But don't promise what can't be delivered; be upfront about what is and isn't possible.

Foster shared responsibility for outcomes and accountability

When the work of change is parcelled out across many different working groups, purposes can shift. Establishing and enforcing accountability mechanisms can bring things back into alignment, when necessary.



PUTTING IT INTO PRACTICE

By analyzing submissions to its patient safety incident reporting system, Nova Scotia Health's Adult Neurodevelopmental Stabilization Unit (ANSU) Dual Diagnosis Program realized that its restraint and seclusion practices were based on stigmatizing assumptions: that its clients were likely to be aggressive and violent. That included the frequent use of a safety restraint chair to keep clients in one place, presumably to prevent harm to themselves and others (e.g., staff, patients, family members, visitors).

To identify the underlying issues, ANSU leadership formed an advisory committee that included representation from physicians and staff, an external engagement specialist, patients, and if needed, patients' substitute decision makers (usually family). Interviews were conducted with staff, while patients and families were invited to share their experiences via surveys and focus groups.

With a shared understanding of the root causes of the problem, ANSU could start to make the necessary changes to improve care delivery. That included hiring staff from various disciplines, such as behavioural analysts and recreational therapists, who are better able to engage with patients without relying on restraints. As a result, the team has not had to use its safety restraint chair in more than four years — something that previously was a near-daily occurrence.



PUTTING IT INTO PRACTICE

Co-design with the Indigenous community was an essential element of the Biigajiiskaan: Indigenous Pathways to Mental Wellness program at St. Joseph's Health Care London from the very start, including in the process of identifying the problems the program needed to address. As a referral-based wellness program for Indigenous people with serious mental health problems or illnesses, it was critical that all partners involved in providing care understood how equity and service gaps in mental health care would be defined from an Indigenous perspective.

By hearing from Indigenous individuals about the challenges they faced in trying to access the health system – many were reluctant to come to a hospital, fearful of maltreatment after generations of systemic discrimination – and by exploring Indigenous health models, the team at St. Joseph's was able to identify the nature of the structural stigma that was serving as a barrier to culturally safe and accessible care. From there, the team was able to make changes (both big and small) to help overcome that barrier, such as changing the format of patient electronic charts so information related to the Biigajiiskaan program wasn't relegated to a footnote.



Reflection and discussion questions

- Who currently defines the issue of MHSU-related structural stigma and the need for change in your organization?
- Do your MHSU care practices reflect current knowledge and evidence? How long has it been since your organization updated its care practices or model of care?
- Who needs to be included in your change initiative? Who would traditionally be invited to the table – and who would not?
- Who are the champions for change in your organization? How can they help facilitate a shared understanding of the problem and the need for change?
- Who are the champions for change outside your organization who could help facilitate change?
- What existing organizational structures can be leveraged to facilitate ongoing communication?
- What would be effective and easy-to-implement accountability mechanisms for your organization?
- Is your organization ready to make a real, transformative change? If not, what are the barriers that might be preventing change from happening?

Tools and resources

Talking Circles

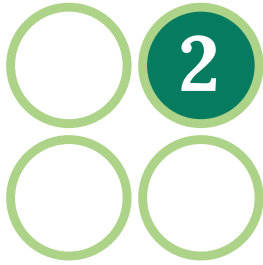
This traditional Indigenous practice for discussion and decision-making focuses on creating spaces that encourage open and equal dialogue, respect for others, and the co-creation of content.

Nova Scotia Health Patient Safety Incident Management Policy

In Nova Scotia, all patient safety incidents are logged in an electronic reporting system, which helps organizations and their staff report on and analyze issues, recommend actions, and monitor improvements.

Systems Leadership for Sustainable Development: Strategies for Achieving Systemic Change

This guide explains the systems leadership approach, which encourages engagement with a broad network of diverse stakeholders to advance progress toward a shared vision for system-level change.



PART 1.2

Articulate a clear vision for desired change

When a strong, collaborative process for defining and understanding the problem of MHSU-related structural stigma in health care has been established, the next step is to clearly articulate the desired future state for your organization and the people it serves – and the path your organization will take to get there. That way, you can ensure that everybody will be able to move forward together in pursuit of the same goals. Just remember that much-needed systemic change takes time to realize. How you communicate your vision and build relationships at this early stage of your change initiative is critical.

Key principles for health-care organizations

Be bold and candid

Don't be afraid to think big and articulate a vision that may seem impossible to achieve or far out of reach. Transformative change that addresses historical harms and injustices requires bold, expansive ideas. If you set the bar too low or limit your thinking, your organization's change initiative will be watered down right from the start.

Centre the voices of people with lived and living experience

Make sure those who were involved in defining the problem have a role to play in articulating your desired future state and how MHSU-related structural stigma should be addressed. When defining your vision for change, prioritize the perspectives and experiences of PWLLE of MHSU problems or illnesses. Ensure that they have an equal opportunity to contribute to the vision, so it is not forced onto them from the top down.

Keep in mind that some patients with MHSU problems or illnesses cannot speak for themselves, as they may be non-verbal or have an intellectual disability. In that case, it is important to include the family and/or caregiver voice as well.

Put in place remuneration policies from the start

Remuneration (payment for work or service) must be a consideration from the very first moment your organization starts thinking about change. Participating PWLLE of MHSU problems or illnesses, including patients and families, should be paid for the time and expertise they provide, both during this visioning stage and throughout the entire change initiative. (For more information, see [Ensure shared governance and payment structures](#) later in Part 1.)

Be prepared for misalignment

Different stakeholders may have different or even competing visions for change. For example, management's vision may be to build a world-class research or care unit, while service users may simply want to help create a place where they will be treated with kindness and respect. External partners will probably bring their own visions to the table as well. Work together to find common ground, taking care to prioritize the voices and perspectives of PWLLE of MHSU problems or illnesses. Remember, your organization will grow through tension and dissonance.

Draw from existing frameworks

It may be helpful to build your organization's vision for change around a framework that already exists. That can include theoretical frameworks for rooting your change initiative in a set of principles or scholarship, such as disability studies, mad studies, queer studies, critical race theory, feminist theory, Indigenous studies, or social movement theory. Or you may look at practical frameworks designed specifically to help guide organizations through the change management process, such as the [Prosci ADKAR model](#), [McKinsey 7-S framework](#), or [Kotter's 8 Steps for Leading Change](#).

There is no right or wrong framework to choose, but there is also no one-size-fits-all framework that will work for every organization. Just avoid borrowing from too many frameworks, or else you may end up with a “buffet” of ideas, which could dilute your organization's vision and focus – and inadvertently steer it back toward the status quo.



Don't reinvent the wheel

Take a look at what other organizations are doing in this space, both in your own community and in other jurisdictions. What can you learn or adopt from their best practices? Talk to specialists and researchers – and consider having them present to your organization's staff, partners, and service users to help inspire change.

Help staff see how they contribute to stigmatizing environments

Staff should be given the opportunity to contribute to your organization's vision for change. But until they acknowledge the ways in which they are harming patients (knowingly or unknowingly), they may not accept that they are helping to reinforce MHSU-related structural stigma. If they don't understand why change is needed, it will be difficult for them to act on the organization's vision for change.

Consider hosting a lunch-and-learn session to present real-world examples of how structural stigma influences their work, including bringing in PWLLE of MHSU problems or illnesses to speak about their experiences. Be open and honest about how staff's actions may be perpetuating structural stigma. Take care to avoid personal accusations, as your vision for change is ultimately about addressing a structural or systemic problem rather than the behaviours of specific individuals. Also be sure to clearly explain how MHSU-related structural stigma affects the organization's ability to achieve its mission and values.

If you can, use this session as an opportunity to educate staff on the care practices that *are* effective for stigmatized populations, as people may not be aware of the latest evidence and research. Ongoing education and training sessions will help reinforce best practices and the vision for change throughout the organization.

Break your vision down into more manageable and contextually relevant pieces

Avoid trying to do everything at once. Instead, break down your organization's vision for change into smaller, more realistic streams of effort. Otherwise, it's easy to get discouraged early by a seeming lack of progress.

Communicate clearly and transparently

To secure alignment across multiple stakeholders, use simple, accessible language so everybody understands the vision being presented. Be clear about how the vision was developed and who was involved. That includes clarifying why addressing MHSU-related structural stigma matters to your organization, its clients, and society as a whole.



Embody your vision in your decisions and actions

If your goal is to create a more compassionate MHSU care system, it is important that the leaders and changemakers in your organization embody compassion in everything they do. That includes how they communicate and build relationships, how the processes of change are designed and implemented, and so on.

Retool as needed

A vision isn't set in stone. Circle back and retool the vision if necessary to better match your organization's current context. (Consider how the COVID-19 pandemic made many health-care organizations reassess their plans and priorities.) Just never lose sight of the primary goal: to dismantle MHSU-related structural stigma in health care.

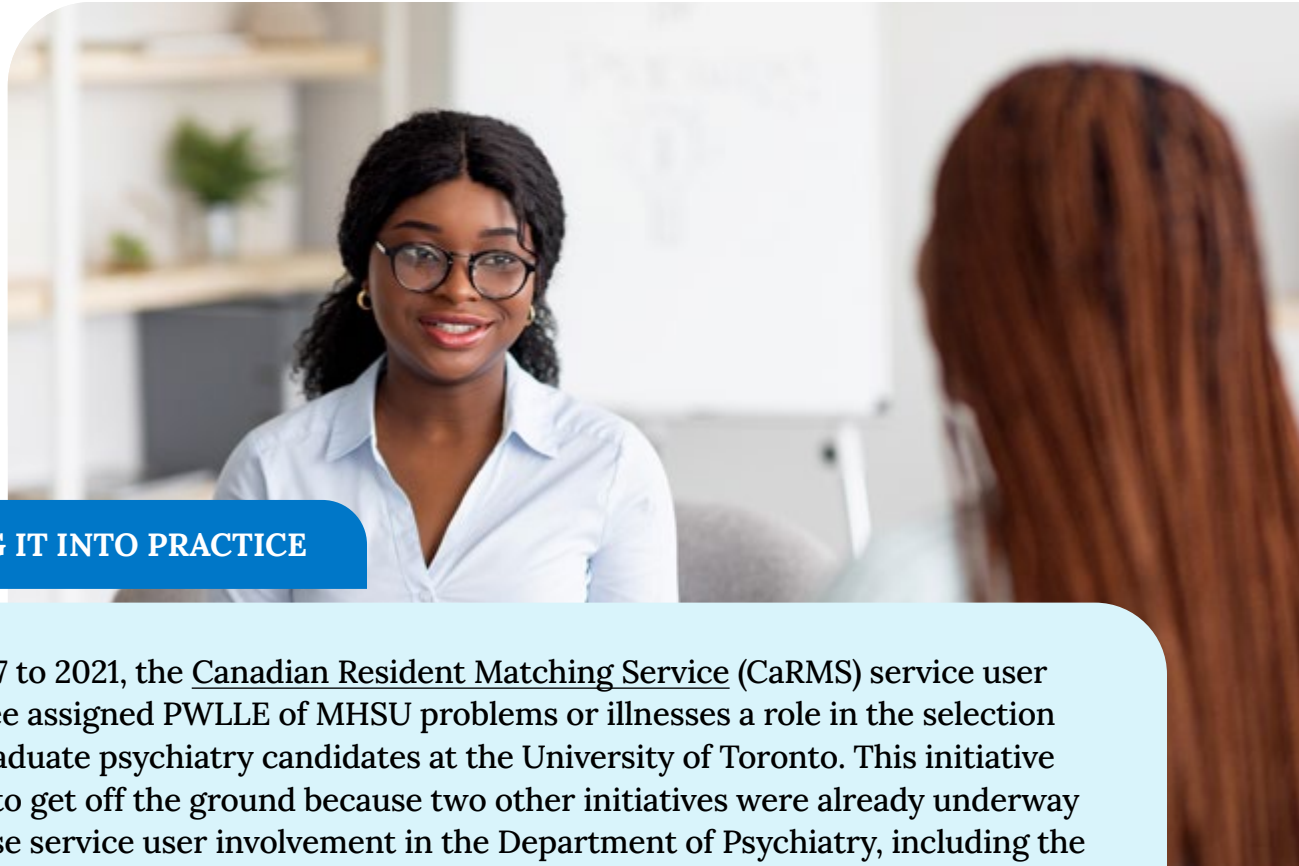




PUTTING IT INTO PRACTICE

To achieve the anti-stigma objectives set out in its 2012 strategic plan, the Department of Psychiatry at the University of Toronto partnered with the Empowerment Council to co-create InSight: a committee of representatives from community organizations with a history of working for and with mental health service users. The committee developed a series of guiding value statements, such as “People with psycho-social disabilities have the right to determine their own priorities” and “Empowering the community is facilitated from an anti-oppression, anti-racist/anti-colonialist, disability-positive framework.”

In addition to communicating these values through workshops and events, including a mental health and wellness fair, InSight created the Centering Madness course to teach first-year psychiatry residents about the history of mental health care, the lived experiences of people with mental health problems or illnesses, and the body of knowledge created by service users and mental health advocates over the past 40 years. Since 2017, the course curriculum has looked at mental illness through the lens of mad studies, intersectionality theory, and social justice, while also drawing from academic and activist work on equity, disability, critical race theory, and queer theory to advance students’ understanding of mental illness and the voices and experiences of service users.



PUTTING IT INTO PRACTICE

From 2017 to 2021, the Canadian Resident Matching Service (CaRMS) service user committee assigned PWLLE of MHSU problems or illnesses a role in the selection of postgraduate psychiatry candidates at the University of Toronto. This initiative was able to get off the ground because two other initiatives were already underway to increase service user involvement in the Department of Psychiatry, including the Centering Madness course – an indication that strong momentum existed to elevate the voice and role of PWLLE of MHSU problems or illnesses.

To define the vision for the service user committee, the initiative's co-leads first held informal consultations with service users to see if they even had an appetite to get involved in the CaRMS process and to discuss how they might be involved. (With these consultations, the perspectives of service users were embedded in the initiative from the start.) Later, the committee's initial members spent a lot of time whiteboarding the values, principles, and beliefs they wanted to see in psychiatry residents, such as a commitment to equity and looking at the social determinants of health. Having these values clearly defined not only influenced resident selections but also made it easier to recruit and onboard new members as people left the committee.



Reflection and discussion questions

- Are there any institutional and/or financial barriers that might limit the scope of the visioning process and prevent your organization from thinking in big and bold terms? If so, how might those barriers be overcome?
- How will your organization bring service users and PWLLE of MHSU problems or illnesses into the visioning process? Do you have a system in place for paying them for their time and expertise?
- What is your organization's plan for addressing different or competing visions for change?
- Are you able to present some real-life examples of the impacts of MHSU-related structural stigma on service users to clearly demonstrate why change is needed? If not, who might be able to help you collect those examples?
- Is there any education or training you need to provide to reinforce your vision for change (e.g., on the latest evidence-informed care practices for people living with MHSU problems or illnesses)? If so, do you know where to get this information?
- Can your organization's vision for change be easily broken into smaller, more manageable steps?

Tools and resources

More than Paint Colours: Dialogue about Power and Process in Patient Engagement

This report from the Empowerment Council details the collaborative engagement process that led to creation of the InSight committee and Centering Madness course.

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

The MHCC launched a research program to better understand MHSU-related structural stigma, leading to seven priorities for dismantling and disrupting structural stigma in health-care environments.

Mental Health Structural Stigma in Healthcare eLearning Course

This free online training from the MHCC and CHA Learning covers the impacts of MHSU-related structural stigma in health care and how to dismantle it. The course is for health-care leaders at any level, health-care professionals seeking to improve quality of care, and anyone interested in learning about structural stigma.

ADKAR model

This model by Prosci advocates for a bottom-up approach to change that begins with the individual employee and ends with organizational change.

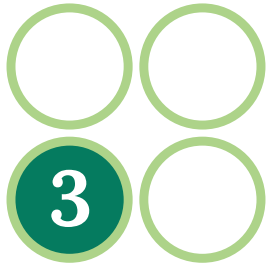
7-S framework

This model by McKinsey and Company focuses on the interrelationships among structure, systems, style, staff, skills, strategy, and shared values.

8 Steps for Leading Change

Dr. John Kotter developed this model focusing on creating urgency to make a change happen.





PART 1.3

Align values across diverse partners

Structural stigma cannot be addressed by one unit or department alone. It requires a team effort involving many different partners, both within your own institution and among agencies of all types and sizes throughout the community, all learning from and supporting each other in pursuit of shared values and goals. Getting everybody to agree to the same set of values can be challenging – but by committing to collaborative and creative problem solving, you can help them see past competing priorities and embrace one vision for change.

Key principles for health-care organizations

Explore synergies and outliers

What are the most important values for each partner in your change initiative? During your initial meetings, having participants name their core values can help reveal synergies across your many different partners. What value statements would no one disagree with? Those may be the ones to put at the heart of your change initiative. At the same time, pay attention to the outliers: take a close look at any uniquely named values and try to understand why they stand out and what they can teach you about the group's goals.

Consider working with different partners on small-scale pilot projects first (perhaps a single unit or department in your organization) to see how their values align with yours. If they are successful, the small wins from those pilots can then be scaled into something bigger.

Focus on equity rather than equality

Not all values can be prioritized at all times. Project partners must be willing to concede influence and power to people who have been marginalized. To understand their values, meet with community members who may have been harmed or silenced because of MHSU-related structural stigma. Be willing to hear their stories and to meaningfully involve PWLLE of MHSU problems or illnesses in the change initiative, without tokenism and in a culturally safe and appropriate way.

Be sure to provide psychologically safe and brave spaces where people can feel comfortable sharing their thoughts, opinions, and experiences. (For information on how to create such spaces, see [Identify and ensure a shared understanding of the problem](#) earlier in this section.)

Follow patients' lead

Dismantling MHSU-related structural stigma in health care is about improving access to and quality of care for PWLLE of MHSU problems or illnesses – so always remember to keep your patients' values and priorities at the forefront of any discussions with partners. From securing a family doctor to getting help with housing or income support, patients' goals should always come first, and all partners should be aligned in wanting to meet those goals.

Speak plainly

No matter how technical or academic a partner might be, speak in clear, simple terms about the desired change, your plan to achieve it, and your terms for working together. How you describe and disseminate knowledge will play a big role in your ability to remove inequities and realize change.

Meet with smaller teams as needed

In large hospitals and other institutions, it can be next to impossible to get every partner into the same room for a presentation on the values driving your organization's change initiative. Instead, host smaller sessions with specific groups to communicate the values in a way that resonates with them. This will help more teams see themselves in the change initiative.



Always be open to discussion

Be willing to have difficult conversations at any time to help partners understand your organization's values and what you're trying to achieve. Listen to their perspective and the questions, concerns, assumptions, and fears they might have. Demonstrating a caring and understanding attitude helps show that you're leading by example.

Ensure explicit buy-in and support from your organization's leaders

It can be hard to shift power to individuals who experience multiple levels of stigma and marginalization – and to shift resources to MHSU services – if the organization itself isn't ready to do so. Even with full alignment at the program level, any amount of resistance from higher up can threaten the change initiative's long-term sustainability. Supportive leadership and passionate champions who share the same values are crucial to lasting change.

Don't start from scratch if you don't need to

If your organization has a long history of working with a particular partner, there's a good chance your values are already well aligned. A practical starting point in such cases may be to contrast this change initiative with the usual processes and requirements of your partnership.

Reinforce your organization's values on an ongoing basis

Daily reports or hand-offs can help people from various teams in your organization – from physicians to peer support workers to substance use counsellors – keep track of what each person is working on and prioritizing. That way, they can help ensure consistency in the values being brought to their work. Having those shared values as a foundation can also help get you and your partners through challenging points in the change journey.

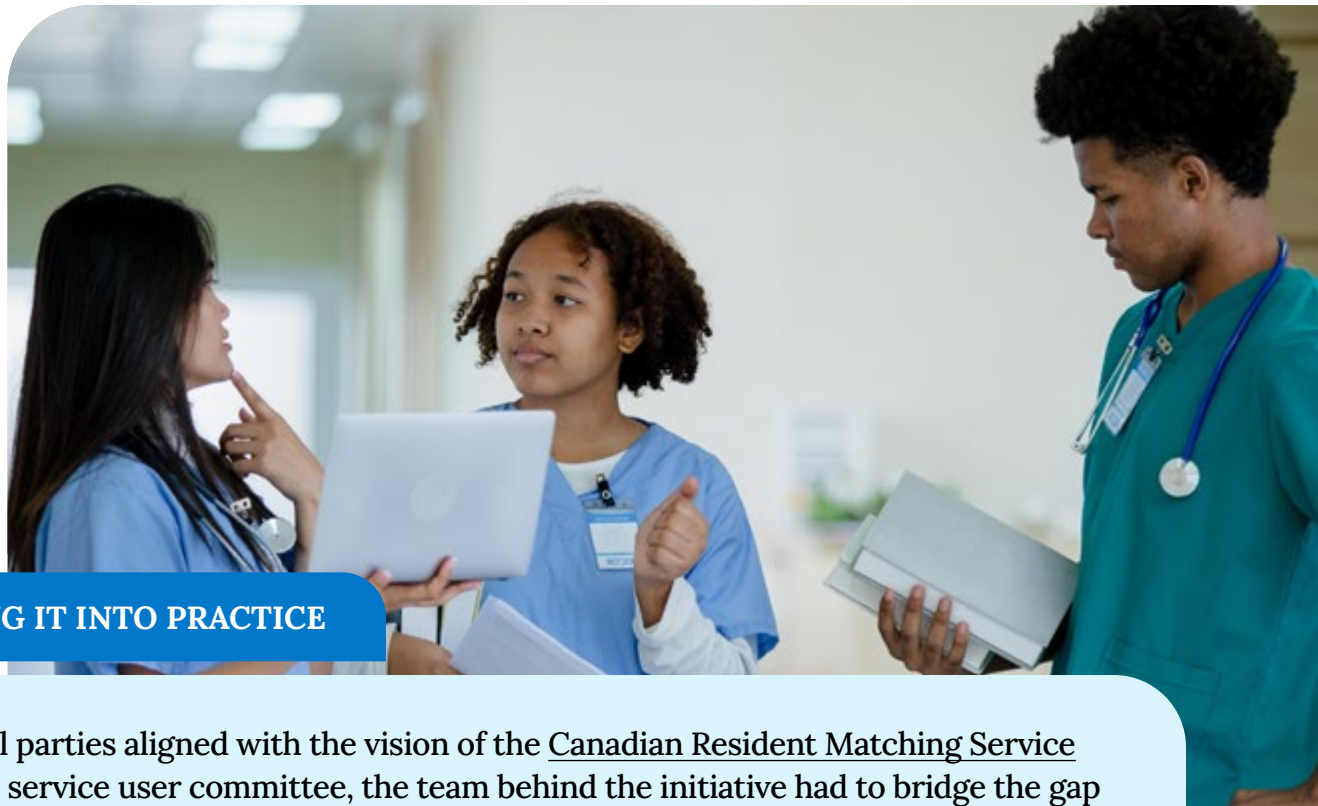




PUTTING IT INTO PRACTICE

Alberta Health Services' Addiction Recovery and Community Health (ARCH) program is located in Edmonton's Royal Alexandra Hospital, a large institution with many units and teams. It therefore took a significant effort to build the relationships required to ensure alignment with the program's vision and goals. The ARCH team used a mix of large group meetings and smaller focus groups to communicate its vision to clinicians, nurse educators, facilities staff, and others in the hospital. Nurses and physicians with direct service roles were also invited to share their thoughts through formal research programs.

That work paid off. As more teams in the hospital came to recognize the value of ARCH, they began to refer greater numbers of patients to the program for consultation, from 111 consults in 2016 to 4,575 in 2021. When ARCH started in 2014, it had a rotating team of one physician per day plus one nurse practitioner, one social worker, and one clinical nurse specialist. It has since grown to a team of two physicians per day plus four nurse practitioners, three social workers, three addiction counsellors, three peer support workers, two clinical nurse educators, one pharmacist, and 20 nurses on rotation, as well as multiple managers and administrative staff.



PUTTING IT INTO PRACTICE

To get all parties aligned with the vision of the Canadian Resident Matching Service (CaRMS) service user committee, the team behind the initiative had to bridge the gap between two different worlds. First, it had to ensure that service users understood what was at stake with their involvement in the selection of postgraduate psychiatry residents, including their role in the legally binding CaRMS hiring procedures and how they fit into the well-established processes of the University of Toronto's Department of Psychiatry. (After they receive their medical degree, trainee doctors enter a residency, where they work under supervision at a hospital or clinic to continue their training.) Second, the team had to help faculty who were used to doing things in a certain way – and may not have had any experience working directly with service users – to understand why and how things should be done differently.

Communication and leadership were critical to creating rapport with everybody at the table and facilitating discussions to explain the “why” of involving service users in the CaRMS process. If service users have a say in selecting the physicians who will one day treat them, the university is more likely to pick candidates who are sensitive and empathetic to the needs of PWLLE of MHSU problems or illnesses. As of 2023, the first wave of residents selected by the committee are more than halfway through their programs and are now supervising junior psychiatry resident physicians, fostering a culture change in the department with a stronger emphasis on equity and social justice.



Reflection and discussion questions

- Does everybody involved in the change initiative know what your organization's core values are? Have those values been formally documented anywhere?
- Does everybody involved in the initiative understand the rationale and need for change?
- What approaches can be taken to quickly but clearly communicate your organization's values to your partners?
- Is your team equipped to engage with partners and stakeholders in a way that aligns with your organizational values (e.g., by using culturally safe methods and practices)? Or will additional training and resources be required?
- Do you already know which partners are a better match with your organization's values? Or will some pilot projects and trials be needed to find the right fit?
- Is senior leadership aligned with the values at the heart of your organization's change initiative?

Tools and resources

Safewards: Including Service User Voices

This report by the Empowerment Council on the Safewards model of care discusses the importance of language and communications in building a culture of safety in health-care settings.

Cultural Safety and Humility

The First Nations Health Authority has produced guides, videos, and other resources to help organizations create health-care environments free of racism and discrimination.

ARCH Implementation Manual

This guide details how the ARCH program came to be, including an overview of its vision, how it built effective partnerships with the community, and how it implemented cultural change.



PART 1.4

4 Ensure shared governance and payment structures

The success of any transformative change depends on whose voices are heard from the start. Shared governance is an organizational commitment to empower staff, service users, and other stakeholders in making decisions on clinical practice. It's about declaring that the people who have traditionally held power, like board members and executives, will no longer have the *only* say in how programs are developed and managed. Ultimately, it's a model rooted in the principles of partnership, equity, and co-design – to deliver better, more relevant outcomes for the people most affected by MHSU-related stigma.

Key principles for health-care organizations

Put in place a formalized governance structure

Although people may agree with the general idea of shared governance, they might not know how to implement it. Having a formalized framework that defines how power will be shared among the many partners and participants in your initiative will help answer questions about who leads the discussions and how decisions are finalized. It will also help ensure that anti-stigma is built into the foundations of every decision rather than be an afterthought.

Consider replicating an already established model, such as the Community-Engagement Governance framework. Your governance structure can also be formalized as part of a memorandum of understanding (MoU) that details the responsibilities and accountabilities of each party. Be careful: if improperly designed, an MoU can reinforce structural stigma by codifying who has the power.

Do more than just give people with lived and living experience a seat at the table

Shared governance is more than just having PWLLE of MHSU problems or illnesses present at decision-making board meetings: they must be actively *involved in* and central to the decision-making process. That means, for example, giving peer support workers a seat at the table *and* a voice equal to that of clinicians and other medical professionals. Any working groups and committees should also have representation from patients and/or their families and caregivers.

PWLLE of MHSU problems or illnesses who have previously advised on a project and have had a negative experience (e.g., their involvement was tokenistic or their ideas were dismissed or not taken into account) may be less willing to participate in future initiatives. This kind of situation is compounded by the fact that PWLLE of MHSU problems or illnesses already experience oppression when engaging with the health-care system: they are often dismissed or lack autonomy over their own care. It is therefore critical to ensure that their involvement in your initiative acts to empower them rather than oppress them further.

Pay people for their time and expertise

Adequately recognizing and valuing different forms of expertise and experience through shared governance requires defining a process for payment and remuneration. If hospital staff get paid for attending meetings or sending project-related emails, for instance, so should the external PWLLE of MHSU problems or illnesses who have been invited into the process.

How you will pay PWLLE of MHSU problems or illnesses for their time must be considered early in the development of your change initiative. This is because, if not properly planned, payment and remuneration models can contribute to MHSU-related structural stigma by acting as barriers to the meaningful involvement of certain groups of people or organizations in decision-making processes.



For example, many participants from the community prefer cash payments, as they may not have bank accounts or could see their disability support payments reduced if they deposit a cheque. (A cheque might also take several weeks to get into the hands of a participant who could use that money right away.) However, agencies are not often set up to effectively handle cash disbursements. So if your organization pays using debit or cheque only, it may prevent or deter PWLLE of MHSU problems or illnesses from participating in your change initiative, meaning that they will be unable to contribute their perspectives to it. Note that gift cards should *not* be used as an honorarium, as they limit how people can use the payment and are also viewed as taxable income by the Canada Revenue Agency.

Also consider going beyond the ad-hoc involvement of PWLLE of MHSU problems or illnesses – and the one-time cash payments that come with it – by providing actual employment opportunities. If possible, create funded positions that give PWLLE a chance to be real leaders in your organization.

Don't mix expenses and honoraria

Organization will often lump together honoraria and the reimbursement of expenses (e.g., travel costs, hotel rooms) in a single payment. But if a T4A form needs to be generated, this means PWLLE of MHSU problems or illnesses will have to pay additional tax on their expense payments (even though they shouldn't have to). Separating honoraria from expense payments will save the people participating in your initiative financial headaches down the road.

Watch for potential barriers

True shared governance requires those who have traditionally held power to trust in and be comfortable with the idea of others making decisions or providing input into significant organizational decisions. That will require psychologically safe spaces to be developed and nurtured by those who currently hold power. (For more information on safe spaces, see [Identify and ensure a shared understanding of the problem](#) earlier in this section.) It might also involve shifting the role of the board of directors, for example, from steering decisions to holding the organization accountable for making progress toward change.

However, legal requirements, privacy regulations, or risk management considerations may prevent the board from fully sharing or ceding power. Creativity may be required to navigate these barriers and find alternative ways of bringing more voices into your governance structure. In this case, it may take additional time and effort to ensure PWLLE of MHSU problems or illnesses trust and feel safe participating in your initiative. Even without a fully shared governance framework, the involvement of PWLLE of MHSU problems or illnesses is what brings legitimacy to your change initiative and must be prioritized.

Take time to do things right

Even if it means spending several more months planning and getting the infrastructure in place, make sure the organization is fully ready to support a shared governance structure (rather than hastily bringing people to the decision-making table). No matter how long it takes, PWLLE of MHSU problems or illnesses should be involved in every step of the planning process.

Be transparent about governance, decision making, and finances

When creating your shared governance model, ensure that everyone understands the funding structures that affect your organization and where the money is coming from – along with the opportunities (and barriers) that come with it. This will also allow for greater transparency regarding anything financial, including budgets and funds put toward projects intended to drive transformative change. Be honest about the in-kind costs and time that different organizations are bringing to the table.





PUTTING IT INTO PRACTICE

Although the Biigajiiskan: Indigenous Pathways to Mental Wellness program is based out of St. Joseph's Health Care in London, one of its key principles was to make its much smaller health agency partner, Atlohsa Family Healing Services, the project lead – a role that would include handling the funding from the provincial government. While the government wanted the money to flow through the hospital (as was standard practice), St. Joseph's refused to proceed unless Atlohsa was recognized as the lead payment agency, deeming this necessary to symbolize the intent of the initiative to address historical power imbalances.

St. Joseph's handled the funding for the first two years of the program, working closely with Atlohsa and the province to navigate bureaucratic barriers and build Atlohsa's capacity to eventually take the lead. By the start of year three, all funding flowed directly to Atlohsa. In the end, the governance and funding structure – and the partners' commitment to change – was formalized by a hybrid Indigenous and Western memorandum of understanding (MoU) that embedded Indigenous storytelling approaches, including a wampum ceremony, into the typical MoU format. (Belts made of wampum, or tubular beads, have long been used to mark agreements, treaties, and commitments, with the patterns woven into the belts often symbolizing people and events. Also, when a wampum belt is held in a person's hand, they are said to be speaking truthfully.)



PUTTING IT INTO PRACTICE

Health Justice uses the Community-Engagement Governance framework to expressly share governance power across three groups: a Lived Experience Experts Group (LEEG), an Indigenous Leadership Group (ILG), and a traditional non-profit board of directors. The framework specifies how it is *not* the board that makes substantive decisions in terms of the organization's strategic direction; instead, that power rests in the other two groups.

This innovative way of governance moves beyond advisory models where PWLLE of MHSU problems or illnesses are subordinate to the board and avoids the pitfalls that can come with an advisory-based approach, such as tokenism. By moving beyond mere participation to true co-production, this framework has fundamentally changed Health Justice's advocacy work as it aims to improve British Columbia's mental health and substance use laws. PWLLE of MHSU problems or illnesses are making crucial decisions about the structure of the organization and the nature of its human rights advocacy, and staff now feel the same level of accountability to LEEG and ILG members as they do to directors and executives.



Reflection and discussion questions

- Which groups are currently not represented at your decision-making table? What would be the potential impact on your organization of having their voices at the table?
- Are there any legal or financial barriers that might hinder your organization's ability to implement a shared governance model? If so, how will you ensure that involvement of PWLLE of MHSU problems or illnesses is at the foundation of your change initiative?
- What resources might you be able to draw on to help draft your governance framework or MoU? How can PWLLE of MHSU problems or illnesses be involved in that process?
- What are the potential risks if organizations are not transparent about their finances or resource allocation? How could such a lack of transparency affect the success of the change initiative?

Tools and resources

The Participatory Revolution in Nonprofit Management

This article provides an in-depth discussion of stakeholder participation in organizational governance and decision making, reviewing the forms it can take as well as challenges and opportunities for non-profit organizations.

Community-Engagement Governance framework

The author of this article provides an overview of this governance framework, including its seven key principles, what it looks like in practice, and how it has been used by other organizations.

Peer Engagement Principles and Best Practices

The BC Centre for Disease Control offers this guide on how to enhance peer engagement and bring new voices to the decision-making table.

Peer Payment Standards for Short-Term Engagements

This guide from the BC Centre for Disease Control outlines how to equitably pay peers for short-term engagements, such as attending meetings as an expert or advising on policy documents.

Co-producing Psychiatric Education with Service User Educators: A Collective Autobiographical Case Study of the Meaning, Ethics, and Importance of Payment

Academic Psychiatry published this article on the dynamics involved in co-producing psychiatric education with service users and service providers, including the importance of paying service users for their contributions.

Shared Decision-making for Nonprofit Governance

Ignite NPS produced this guide to help non-profit leaders reimagine a more effective way to fulfil governance functions, including structure, practices, and processes.

Peering into the Future: Reimagining Governance in the Non-Profit Sector

This research paper from the Mowat Centre serves as the foundation for the Reimagining Governance initiative, which provides strategies to help non-profits fulfil governance roles more effectively.

Memorandum of Understanding (MoU) Template

Health-care organizations can use this template when creating an MoU with partners in their change initiative.



PART 2

Success Factors

Any successful change initiative involves many different factors. Among the most important are social interactions, relationships, and behaviours, such as teamwork and information sharing.

These are vital to breaking down and rebuilding health systems to better meet the needs of people living with MHSU problems or illnesses. Such processes, traits, and approaches are also how we bring about change. Embracing difficult conversations and challenging others to critically reflect on the assumptions that underpin existing models of care enables us to proactively manage disruption and resistance to change.

Strong relational processes make it easier to bend, break, and rebuild your organization's change initiative – and endure the cycles of “heating up” and “cooling down” that are necessary to forge lasting change over time. They help those involved acknowledge and address long-standing mistrust and tokenism in the health-care system and intentionally reach out and listen to the people suffering most from MHSU-related structural stigma.

“I lost 15 to 20 years of my life because of a misdiagnosis and ineffective treatment. I was labelled bipolar, and when that happens it may as well be tattooed right on your forehead. After 20 years of being unsuccessfully treated, I find out I have PTSD. The problem is, our health-care system is built to prioritize the speed of diagnosis rather than the value of achieving recovery... You can't imagine how desperate you can feel when no one will listen, when no one will believe you, when you're dismissed and disregarded time and time again. We need to build systems that see the person first and recognize their humanity.”

Samaria Nancy Cardinal, social worker, Patients for Patient Safety Canada

What health-care organizations need to do

2.1 Build and sustain trust

Acknowledge and then overcome fears and concerns about change by listening to and connecting with others.

2.2 Redistribute power in relationships

Address the power imbalances that reinforce MHSU-related structural stigma by elevating the voices of those who have traditionally been disempowered.

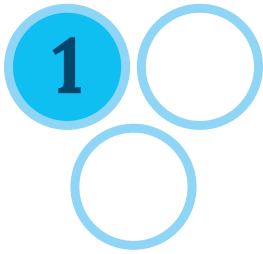
2.3 Measure and monitor outcomes

Evaluate your change initiative in a targeted way to maintain alignment with your initial goals and values.

Part 2 Success factors



- **Build** and sustain trust
- **Redistribute** power relationships
- **Measure** and monitor outcomes



PART 2.1

Build and sustain trust

Trust is integral to any project or partnership. That's especially true when tackling an issue as pervasive and complex as structural stigma. The fear and mistrust caused by MHSU-related structural stigma have caused countless people to avoid reaching out for help and engaging with the health-care system. Mistrust also makes it difficult for PWLLE of MHSU problems or illnesses to participate in shared governance and power structures. Earning and keeping trust – between patients and service providers, patients and institutions, and your organization's teams – must be a critical focus of your change initiative.

Key principles for health-care organizations

Provide a psychologically safe and brave environment

A psychologically safe and brave environment is one that allows all voices to be heard, valued, and respected. That means listening, understanding, and taking people's stories at face value. Trust is built by seeing and connecting with others as people first. Avoid assumptions. Take the time to ask people what they need and how you can help them get through their situations. Only then can you go on to discuss weightier topics such as power imbalances and historical injustices.

Seeing PWLLE of MHSU problems or illnesses as people first means recognizing that they do not have to “overcome” their symptoms to be credible or hold space. They may also have things to share about experiences beyond their own MHSU problems or illnesses that deserve to be heard, especially if they work in the health-care system as a nurse, as a caretaker, or in another role. Even without such experiences, their contributions are not any less valuable.

Share information freely and frequently

If your intervention involves a multidisciplinary team, make sure everybody is aware that they are part of the team and what the goals are. Share documentation and resources continuously to ensure that nobody is in the dark about what is going on.

Before implementing a dramatic, transformative change, communicate openly and regularly with everyone affected about what that change will look like, for both patients and your teams. Be sure to directly address (and not downplay) any concerns, referring back to your vision and values – the shared “why” behind your initiative – as a touchstone whenever needed.

Encourage collaboration

When designing your initiative, start with an open agenda that allows for and encourages collaboration and input from service users. Don’t develop detailed goals or objectives before engaging with all the appropriate stakeholders. Setting the direction for your work through collaboration is essential to establishing a sense of trust right from the beginning.

Bring in external help if needed

If there is significant historical mistrust between marginalized populations and your institution, consider hiring a third-party engagement specialist. Such specialists can observe meetings, host focus groups and listening tours, speak to individuals one to one, and help you determine the level of trust (or mistrust) among different groups before making recommendations for change.





Hire PWLLE of MHSU problems or illnesses as expert consultants or salaried employees

PWLLE with MHSU problems or illnesses, such as peer support workers, can connect with patients and service users in ways doctors and nurses cannot. The fact that they know what a person has gone through can help build and promote trust. When creating paid roles for PWLLE of MHSU problems or illnesses, keep in mind that minimal education requirements, which are standard for most health-care jobs, can inadvertently reinforce structural stigma by excluding certain people from applying for the job.

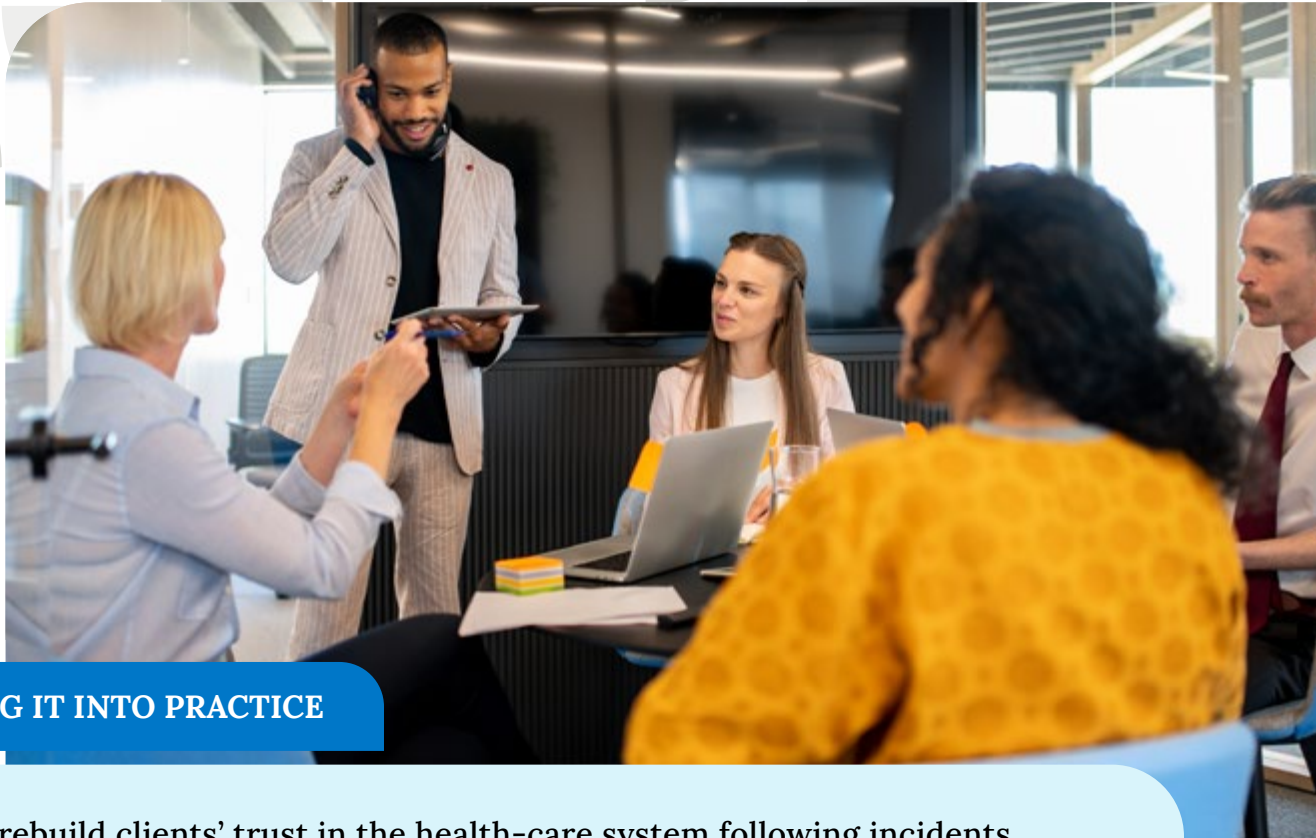
In addition to creating paid positions for PWLLE of MHSU problems or illnesses, consider incorporating anti-stigma values into your organization’s hiring process to ensure that any new employee is able to engage appropriately with service users. PWLLE of MHSU problems or illnesses should be involved in defining and developing those values.

Educate team members on the characteristics of a just culture

A just culture is a system of shared accountability that emphasizes faulty organizational cultures as the general cause of mistakes rather than the people directly involved. It’s a no-blame approach that focuses on exploring what went wrong instead of who caused the problem — which is also at the heart of dismantling structural stigma. A just culture is more effective when everybody thrives and feels comfortable working alongside each other, including organizational leaders.

Follow up on action items

Listening to others and taking action on what you heard helps build trust. If somebody raises a concern, don’t just pass it along and forget about it. Demonstrate your reliability by updating the person on how their concern is being addressed.



PUTTING IT INTO PRACTICE

To help rebuild clients' trust in the health-care system following incidents of seclusion and restraint, Nova Scotia Health's Adult Neurodevelopmental Stabilization Unit (ANSU) Dual Diagnosis Program revamped its approach to clinical care planning. In the past, staff and clinicians met to decide what would be best for their clients. Today, clients and/or their substitute decision makers (if needed) are also represented in these meetings, along with other stakeholders such as representatives from partner agencies in the community.

While it took some convincing to make that change, the results have been worth it. For example, partner agencies, such as those that provide housing and direct care support to clients after they are discharged from ANSU, are able to get advice and recommendations directly from ANSU clinicians and then work with ANSU to modify a client's care plans, as needed. Thanks to that collaborative approach, when a client is discharged, they are better able to trust in the supports and services available to them in the community.



PUTTING IT INTO PRACTICE

Alberta Health Services' Addiction Recovery and Community Health (ARCH) Program established a community advisory group to gather information, suggestions, and feedback from the people it serves, many of whom are Indigenous. This approach ensures that everything the program does goes through the community and reflects community members' needs – helping to build trust between the hospital and its patients.

Among teams and units in the Royal Alexandra Hospital, building trust comes through a focus on education, such as answering questions from staff in other departments on how ARCH provides care for opioid use disorder, manages its supervised consumption service (SCS), and other topics. The 2018 launch of the hospital-based SCS – the first of its kind in North America – was a clear indicator that hospital leadership trusted in the vision of the ARCH team to provide better access to quality care for people who use substances.



Reflection and discussion questions

- What is the current state of trust (or mistrust) between your organization and its service users? Would an external facilitator or engagement specialist be useful in building or rebuilding trust?
- What mechanisms are currently in place to facilitate stakeholder collaboration and input into program design? What might your organization need to do to encourage greater collaboration?
- Do PWLLE of MHSU problems or illnesses play a meaningful role in your organization's decision-making process? If not, what are the barriers to bringing them into that process? What can be done to ensure the empowerment of PWLLE of MHSU problems or illnesses regarding the services that affect them?
- Are anti-stigma values embedded in your organization's hiring processes? If not, how might the recruitment and interview steps be improved to ensure that the values of new employees align with those of your change initiative?

Tools and resources

Just Culture

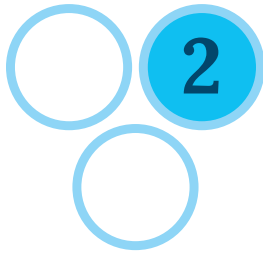
The Health Quality Council of Alberta provides a website with resources and information to help organizations establish a framework and actions to support a just culture.

Guidelines for Partnering with People with Lived and Living Experience of Substance Use and Their Families and Friends

This guide from the Canadian Centre on Substance Use and Addiction describes how to develop sustainable and successful partnerships with PWLLE of substance use and their family and friends.

Overcoming Stigma Through Language: A Primer

This guide from the Canadian Centre on Substance Use and Addiction discusses how to facilitate conversations and increase awareness about the stigma that surrounds people who use substances, their support networks, and service providers in the community.



PART 2.2

Redistribute power in relationships

Asymmetric power systems reinforce and perpetuate stigmatizing processes and policies. To dismantle structural stigma, organizations must mitigate or actively correct power differentials. That involves both recognizing the people who have been traditionally invalidated or had their expertise devalued because of their identities and lifting them up so they can hold power in the organization. Doing so requires a willingness in those who currently have power to embrace a shared distribution of power and resources.

Key principles for health-care organizations

Be honest about the power differentials that exist

Acknowledge up front how MHSU-related structural stigma has contributed to historical power imbalances and be intentional about *not* replicating them in your initiative. (In the process, also consider the role racism, ableism, homophobia, transphobia, classism, and other factors may have played in creating those power imbalances.) For people who have traditionally held power, that means practising humility by acknowledging that their experience is not the most important in the room. Not every organization will have the knowledge on cultural safety and humility to be able to do this. As a first step, you may need to explore ways to enhance culturally safe interactions, environments, and service delivery with your organization and in its partnerships.

When working with partners in the community, be honest about the fact that there are “have” and “have not” agencies. Some are favoured by funders or the media and have a voice and connections that others do not. If your organization has power but is unwilling to acknowledge this imbalance, your initiative will be starting on the wrong foot.

Construct a less hierarchal system

To make sure everyone's voices can be heard, construct a less hierarchal system that actively engages with people not currently in roles of authority. Power often presents itself in terms of how much time and space a person is provided. The politics of power can also mean silencing certain topics or voices entirely so that the organization may never talk about very important things.

To combat this, consider making it a requirement that service users or PWLLE of MHSU problems or illnesses co-facilitate all meetings and presentations (and are properly compensated for their time and labour). Avoid using titles such as *doctor* during meetings, as these can reinforce existing power imbalances. Address people by their first names, instead. Make sure all meetings take place in psychologically safe and brave spaces. (For more information on how to create such spaces, see [Build and sustain trust](#) earlier in this section.)

Hierarchies and power differentials can also show up in several other ways (some of which are quite subtle), such as the layout of meeting spaces and the heights of chairs for different types of people (e.g., doctors sitting in taller chairs than service users). Be aware of and work to overcome them.

Cement your approaches for sharing power by writing them in your organization's policies or governance model. That way, it will never be up to a single person to enforce or champion them, as they will be built into the fabric of your organization.





Balance power at the project level

In addition to the power relationships at the organizational level, carefully consider who the leads of any project will be. Step back from traditional roles and elevate PWLLE of MHSU problems or illnesses so they have a real voice in how individual projects in your larger change initiative are designed and run. Then support them with training and resources, as necessary, so they are as prepared as possible to make a real difference. Keep in mind that when power is redistributed, the ways work is done and decisions are made may end up looking quite different.

Reframe away from a zero-sum model

Those with power must be actively encouraged to bring others who have been historically disempowered into the conversation. That doesn't mean abandoning the power they hold but rather to leverage it so that everyone else is lifted up, pushing those often ignored to the forefront so they can be heard. For example, they could tie their support (and organizational resources) on a given initiative to having PWLLE of MHSU problems or illnesses in prominent decision-making roles. When having these conversations and getting buy-in from people in positions of power, emphasize that power is not a zero-sum situation (where an advantage for one side will mean an equivalent loss for the other) and how all sides can benefit from power sharing.

Move beyond tokenism

Allow service users the opportunity to provide solutions rather than merely serving in an advisory role, with others taking their input away and acting on it. Ensure that the “how” of any solution comes from those directly involved with and affected by the solution, and that PWLLE of MHSU problems or illnesses participate in making foundational decisions from the start. One way to achieve this is by formalizing processes to provide financial compensation for PWLLE of MHSU problems or illnesses, in recognition of the expertise they are bringing to the table.

Create funded roles for service users

Share power by creating funded co-leadership roles for service users and giving them a meaningful stake in your organization (such as in evaluation or teaching positions). Formally recruiting and hiring people for those positions – and by turning service users into active participants in running the services and institutions that provide care – can also help avoid “medical paternalism” (i.e., when a physician chooses not to honour a patient's choices because “they know best”).



PUTTING IT INTO PRACTICE

When Health Justice used to meet with ministers and other government officials as part of its advocacy work, the executive director would typically be the one to take those meetings. Decisions about what to discuss during a meeting would be made by the management team. That has since changed. Recognizing the power imbalance at play, Health Justice modified its processes to have members of its Lived Experience Experts Group develop the agenda and other materials for those meetings, supported by staff members as needed – and also attend those meetings.

“The biggest highlight for me was when the Lived Experience Experts Group and staff met with the minister of mental health and addictions. Sharing my experiences at that meeting made me feel seen, all of a sudden, after I have been made to feel invisible for so long. I felt validated and it made me feel hopeful that change can happen.”

– Sarah, Health Justice lived experience expert

Health Justice says that this approach has made its meetings much more effective, and that their submissions to government now resonate with more people. Overall, its work is stronger, more credible, and more respected than ever.



PUTTING IT INTO PRACTICE

St. Joseph's Health Care London successfully redistributed power relationships by making its much smaller Indigenous health agency partner, Atlohsa Family Healing Services, the lead agency for the Biigajiiskaan: Indigenous Pathways to Mental Wellness program. First, St. Joseph's had to formally recognize the existing power differential – the fact that, as a major hospital, it had the funding, departments, and staff that the provincial government expected a lead agency to have. It then used its power to elevate Atlohsa in the eyes of the government, constantly and intentionally putting the smaller agency at the forefront of all program-related discussions (by redirecting emails and phone calls to people at Atlohsa, for example).

With Atlohsa leading the way, the program has been able to launch effective community-driven initiatives such as a culturally relevant winter shelter for unhoused Indigenous people, which has helped reach people who would otherwise never set foot in a hospital because of the stigma they would face. Because power was purposefully redistributed, other institutions in the area are now calling Atlohsa – and not St. Joseph's – for advice on how to implement similar models and approaches.



Reflection and discussion questions

- How is power currently distributed in your organization?
Are there voices that are missing, silenced, or needing to be elevated?
- How might your organization's decision-making processes and other ways of working have to change to account for redistributed power relationships?
- Is your organization one of the “have” or “have not” agencies in your community?
How does the power you hold (or not hold) and the relationships you have with funders, government, the media, and others impact your work and your service users?
- What are some ways that power may be inadvertently hoarded?
How can organizations centre their perspectives and diminish those of others?





PART 2.3

Measure and monitor outcomes

How do you know if your work to dismantle structural stigma is leading to real change? It takes constant evaluation and measurement: everything from informal surveys to rigorous academic research. The challenge is ensuring that you're staying true to your initiative's vision and values when conducting those evaluations — and that those with power won't use the data to reinforce the status quo or shut down your change before it has a chance to get off the ground.

Key principles for health-care organizations

Ensure that your measures reflect diverse perspectives

From the outset, work collaboratively and have an open, honest discussion about what progress looks like and what outcomes will be most meaningful to your organization and service users. Keep in mind that different people will have different ideas about what is important to measure — and people in power should be mindful of not imposing their preferred measures on others. Consider implementing measures that have been co-designed with PWLLE of MHSU problems or illnesses.

Move on from approaches that don't align with your values

Be aware of the approaches your organization may have used in the past to measure progress and outcomes. Who was involved in developing those measures? Why were they selected? If they were imposed from the top down without input from patients and service users or designed solely to satisfy funding requirements, they may have perpetuated power imbalances. Make sure your evaluation approaches align with the values, vision, and frameworks driving your desired change.

Don't try to measure everything

Just as it is easier to boil a pot of water than boil the ocean, it is better to have one or two thoughtful outcome or progress measurements than try to evaluate every aspect of your initiative. When considering what to measure, ask yourself these questions: Why should we track that? Whose needs will the answers meet?



Go beyond the numbers

Asking if people are satisfied with your services is important, but it's the wrong question when evaluating transformative change. Focusing only on data like client satisfaction scores will make it difficult to truly assess the complexities of the power relationships in your organization and how they're evolving.

If you want to measure a paradigm shift, start by asking the following types of questions:

- Does your initiative address increasing inequality and the growing gap between the haves and have nots? If it doesn't, what must be done to start working in that direction?
- Does your initiative cater more to business models and funding applications, where people are thought of as consumers or statistics for services, goods, and research agendas? If the answer is yes, how might you do a better job of shifting focus to PWLLE of MHSU problems or illnesses and their experiences?
- Do marginalized groups and/or PWLLE of MHSU problems or illnesses own or govern the initiative? Or is it being driven by the institution? If the former, what are their experiences of how power is being shared? If the latter, how can you ensure that they don't just have a seat at the table but rather a powerful voice in how decisions are made?

Consider research ethics and quality improvement

Different types of evaluations will need different approval processes, especially in larger institutions like hospitals or universities. Quality improvement measurements, for example, will require a different kind of ethics-board approval than academic research. In some cases, ethics considerations need to be made six months or a year before any in-depth research or patient engagement can begin.

Assess and reassess regularly

Because disruptive change happens over a long period across many initiatives, build in regular checkpoints to monitor progress and determine whether adjustments are needed. Outline in advance who will be accountable for conducting these ongoing assessments and make room in your organization's budget for them. Consider bringing in a third-party expert to handle this work and eliminate potential bias in your assessments.

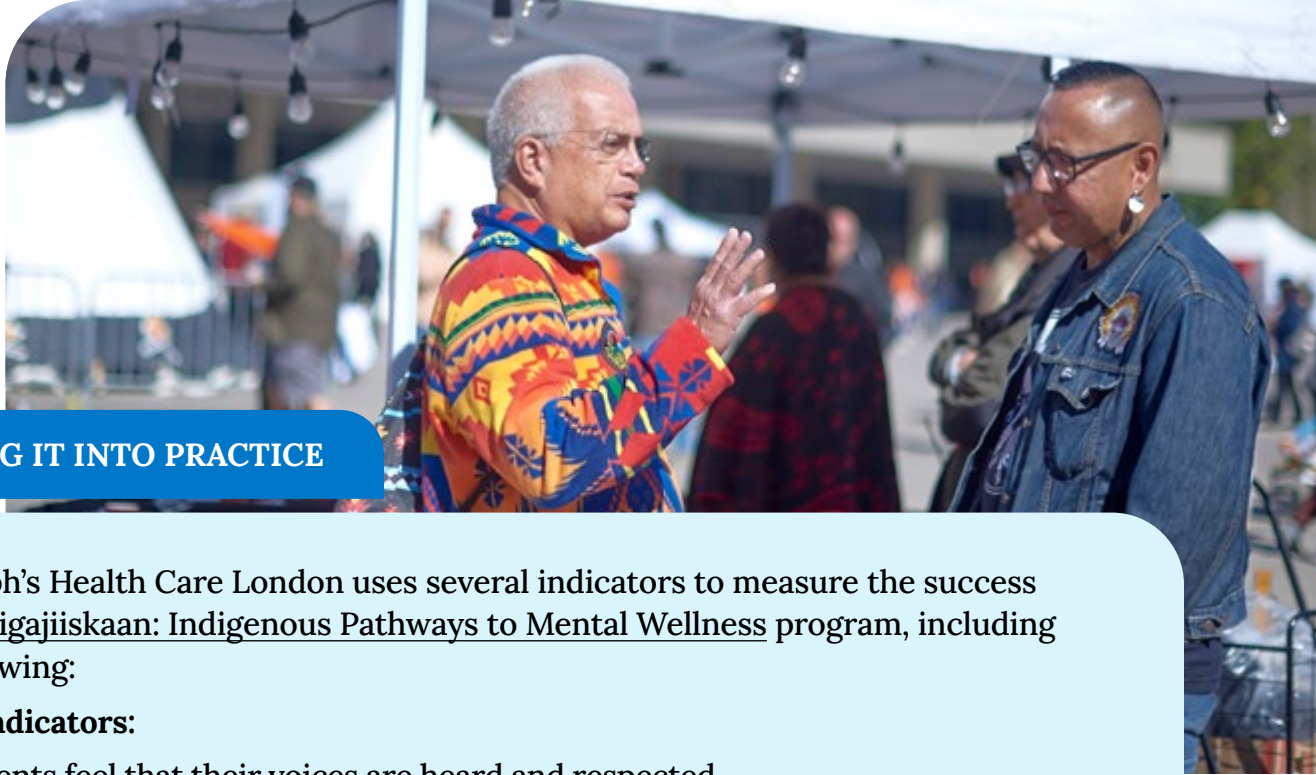
Track resistance

Resistance to change is natural, so one way to measure progress is to evaluate how others are reacting to your work. Is your initiative still making waves? Is it still making people in power uncomfortable? Tension and dissonance foster growth. If you're encountering no more resistance, it could mean that everybody in your organization is committed to change – or that people with power have co-opted your initiative and turned it into something different. Constantly assess the integrity of the initiative and whether it is staying true to its original vision.

Share your successes and your failures

Continuously communicate the findings of your evaluations – both the successes and failures. If you talk frequently about your work, the milestones you've reached, and what you've learned along the way, everyone in your organization can see how even small wins can lead to real change. Being open about the ups and downs can also help build trust in your initiative, internally and with your partners.





PUTTING IT INTO PRACTICE

St. Joseph's Health Care London uses several indicators to measure the success of the Biigajiiskaan: Indigenous Pathways to Mental Wellness program, including the following:

Client indicators:

- Clients feel that their voices are heard and respected.
- Clients begin to get involved with the Indigenous community and its resources and agencies.
- Clients have increased or rekindled an interest and pride in their culture.

Staff indicators:

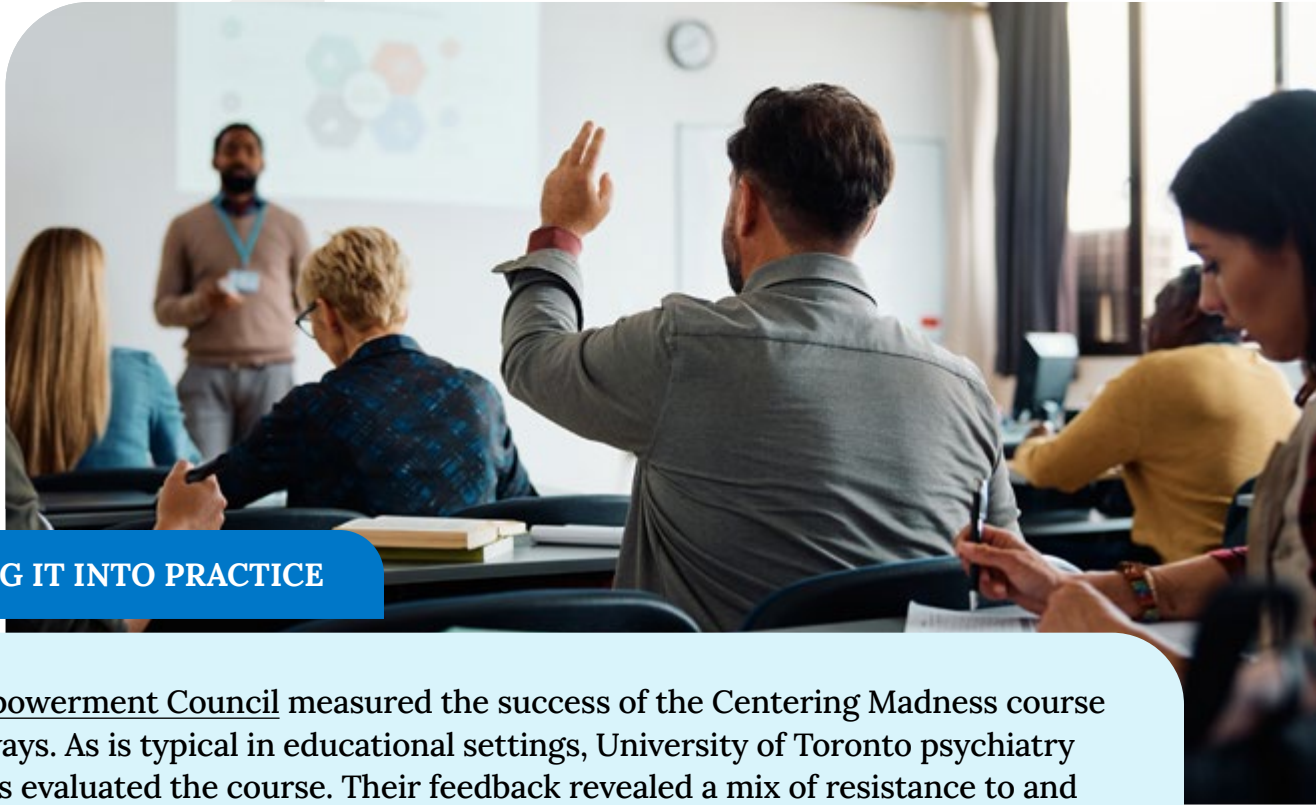
- Elders feel that they are an integral part of the program.
- Hospital staff and Indigenous agency staff have access to and are involved in ongoing training around culturally safe practice, historical issues, and intergenerational trauma.
- Staff feel that they can address both the Western and traditional aspects of the program.

Program indicators:

- Partnerships, pathways, and collaborations are developed or solidified through the project.
- The program has been shared with other hospitals and Indigenous service agencies.
- The program has significant client retention and program completion rates.

Organizational indicators:

- Other health-care agencies support, continue, and replicate the program.
- Policies are reviewed to ensure that they support the implementation, continuation, and possible expansion of the program.
- Success is measured by quantitative and qualitative data and feedback from the community (Elders, PWLLE of MHSU problems or illnesses, family members) and Atlohsa and St. Joseph's staff.



PUTTING IT INTO PRACTICE

The Empowerment Council measured the success of the Centering Madness course in two ways. As is typical in educational settings, University of Toronto psychiatry residents evaluated the course. Their feedback revealed a mix of resistance to and acceptance of the material. Of much greater importance was the service-user educators' evaluation of the residents, based on their contributions to in-class discussions and assignments. Not only did this yield valuable insights about resident learning, it offered a tangible route to making this initiative truly meaningful. Giving service-user educators the power to assign grades to residents and provide feedback through competency-based education mechanisms meant that residents' engagement with the course (or lack thereof) would have a real impact on their academic file.

Residents' response to and uptake of the course material served as a signal to the project team that they were indeed challenging previously held ideas and assumptions about mental health service users and the profession of psychiatry. The team then used these findings to continuously revise and strengthen its teaching approach, noting the possibilities in these moments of discomfort to offer an alternative approach to thinking about, understanding, and valuing the expertise of service users.



Reflection and discussion questions

Measuring and monitoring outcomes:

- What are the top one or two measures to best indicate the progress your change initiative is making?
- Who will be accountable for monitoring progress in your organization? What will they need to be effective in that role?
- How did your organization measure progress in the past? Who was involved in developing those measures? Who benefited from the findings?
- What are the ethics approval processes in your organization? How might those affect your approaches to monitoring and evaluation?
- What are some of the different ways you could use the information learned through your evaluation and monitoring activities to promote or advance your initiative's overall success or sustainability?



PART 3

Sustainability

Dismantling structural stigma won't happen overnight. It requires sustained, long-term efforts focused on changing your organization's culture, policies, practices, and relationships. You can help ensure the success and sustainability of any change initiative through leadership support and a commitment from passionate champions to continue engaging and collaborating now and into the future.

Ultimately, the most successful and sustainable interventions to address structural stigma have co-designed processes into which new norms and approaches to care are gradually embedded to build trust and support among all stakeholders, especially those who may be resisting the change. Organizations must also be intentional about formalizing new practices into existing structures (through policy) while constantly collecting feedback on how an intervention could be improved to better meet the needs of those affected by stigma.

“I didn't know where to access services and, because of the stigma associated with having a mental illness, I kept quiet about it. Then I got physically sick because of the anxiety I was experiencing, and I knew something had to be done... In mental health care, we need to shift the focus from diagnosis to recovery and person-centred care. In providing care, we need to realize that there isn't a one-size-fits-all model, and that every path is unique. People are so much more than their diagnosis.”

Amber May LeRoy, former employee, CHANNAL

What health-care organizations need to do

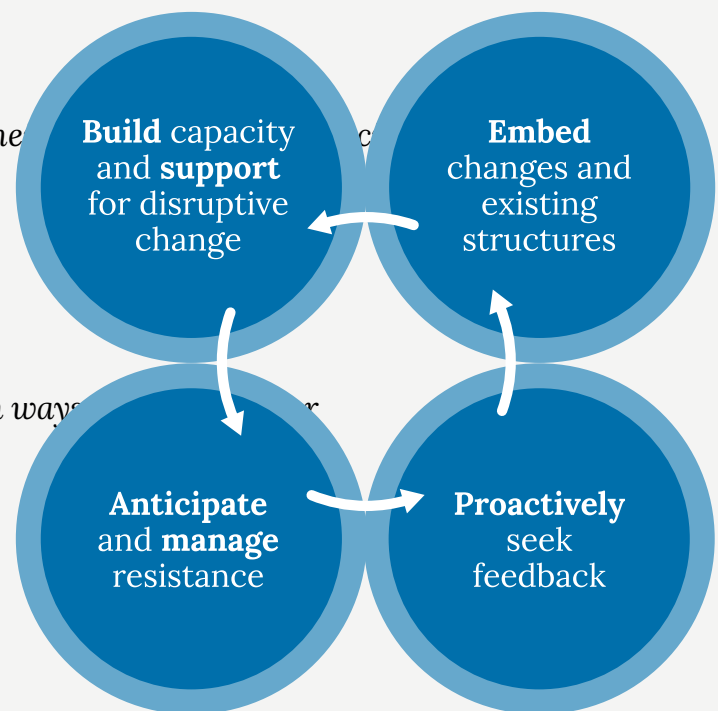
3.1 Build capacity and support for potentially disruptive change
Maintain organizational buy-in and support for your initiative by reinforcing why change is needed.

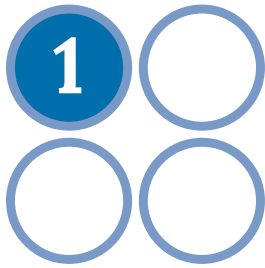
3.2 Anticipate and manage resistance
Win over those most likely to oppose change by recognizing the conversations.

3.3 Seek and respond to feedback in a proactive way
Be humble and open to suggestions from all stakeholders on ways to improve an anti-stigma initiative.

3.4 Embed change in existing structures
Get your change to “stick” by codifying it into your policies, processes, and systems.

Part 3 Sustainability





PART 3.1

Build capacity and support for potentially disruptive change

In the mental health and substance use care system, everybody strives toward the same goal: to help others. Yet difficult conversations may occur when those eager to help realize that they may be inadvertently causing harm and there may be better ways of doing things. While building up the institutional capacity for change (and maintaining support for it) can be a shared learning process that involves acknowledging people's unique strengths, challenges can arise when people feel defensive or challenged about the nature of MHSU-related structural stigma and their role in perpetuating it.

Key principles for health-care organizations

Reinforce your vision and values

To build internal support for your change initiative, communicate continuously. Be sure everybody in your organization understands the problem being addressed, why it matters, and knows that they can ask questions as necessary. Getting there may mean talking about the issue in different ways and formats with different groups to reinforce the guiding “why” behind your vision and values.

If necessary, train or recruit people with the right skills (such as cultural safety) to communicate your vision effectively and make change stick over time.

Use storytelling to make the case for change

Personal stories and experiences can help illustrate why change is needed – and how it can happen via new methods of thinking – in a way hard data cannot. First-person storytelling and advocacy can also help relieve the guilt that drives individuals' defensiveness and helps everybody move forward together. A storytelling approach is especially important for organizations that work with Indigenous communities. In Indigenous health research, storytelling has emerged as an approach that acknowledges Indigenous oral traditions, creates spaces to share wholistic knowledge about health and illness experiences, and invites community involvement.



Co-design the path forward

MHSU interventions and policies are more likely to succeed if they are co-designed with the people they will impact. Provide multiple opportunities for service users, PWLLE of MHSU problems or illnesses, staff who deliver care, and others to participate in the process to design solutions, including interacting with outside consultants (if they're involved). This will help alleviate concerns and gain support for the initiative.

Ensure that every aspect of co-design happens in a psychologically safe and brave environment that allows all voices to be heard, valued, and respected. (For more information on how to create such spaces, see [Identify and ensure a shared understanding of the problem](#) in Part 1.)

Speak to the individual; focus on the structural

Helping people to identify “What’s in it for me?” is important to getting them to support the change initiative. Find out what they may be personally concerned about so those issues can be addressed proactively.

At the same time, keep the discussion at the structural level rather than the individual. Remember, structural stigma is caused by a failure in systems and policies, not the actions of a single health-care worker. Approach the topic with empathy and kindness. The intent is not to shame a person for their behaviour but to invite them to reflect critically on their role in a system that perpetuates stigma.

Obtain and sustain buy-in and support from senior leadership

If your initiative is to be successful, people in power must actively support and engage in it – and more importantly, be truly willing to change. Leaders often express support for change but relate to it as something that applies to others and not themselves. This can be avoided in part by using real examples from leaders' own work areas to talk about MHSU-related structural stigma and how decision making can be shared effectively.

Depending on the community you serve, you may also want to get buy-in and support from the community's senior leadership (e.g., Elders when working with Indigenous populations).

Encourage disagreement and constructive criticism

Change is supposed to be uncomfortable, especially when disrupting established systems and processes, so lean into the discomfort and difficult conversations that come with it. Talk openly about why discomfort is natural and to be expected. That includes leaving space for “negative” emotions. For example, in race and/or gender training, one technique is to provide facts and evidence, then leave room for self-questioning and guilt and/or sadness so people can come to terms with what they've learned (or unlearned).

Use ‘stress inoculation’ to confront the magnitude of the proposed change

Building up the internal capacity for transformative change requires an environment that is accepting of the change. Take the time to understand your particular environment; if it has a low tolerance for change, people may be more likely to dig in and resist.

To nurture support for your initiative, try “stress inoculation,” a technique that involves directly introducing the goal of the change, and then pointing out the gaps between that end state and where you are now. Putting it all out there from the start like this can push people's thinking toward the long-term perspective. When it comes time to return to tactical planning, the first steps in the process should feel more achievable and less scary, leading more people to get on board.

Build change into your strategic priorities

Your organizational capacity for change can be improved by embedding the goals and vision of your change initiative – as well as any funding and resource requirements – directly in your governance model, strategic plan, or change management framework.



PUTTING IT INTO PRACTICE

With a focus on systemic advocacy, Health Justice strives to build support for transformative change both internally and across the broader mental health system as well as among the people with power to change mental health and substance use laws. How does Health Justice take those people through the process of redistributing power, questioning how things could be done differently, and having difficult conversations about MHSU-related structural stigma in health care?

It has gained significant support for its work by demonstrating what shared power can look like and how its own organization is working to dismantle MHSU-related structural stigma. As an example, British Columbia amended a law to standardize the availability of independent human rights advisers for people detained in psychiatric units without consent. Through Health Justice's advocacy, the government became much more willing to share power and engage with PWLLE of MHSU problems or illnesses in a more nuanced way on this issue, leading to real change.



PUTTING IT INTO PRACTICE

Delivering the Centering Madness course for first-year psychiatry residents would not have been possible if support from the University of Toronto had not first been gained. To do so, the Empowerment Council leveraged its existing relationship with the university to pitch the course to the psychiatry residency director and secure teaching time, first as a pilot with a subset of residents and then as a recurring component in the full curriculum. It was also important that allies in the department of psychiatry were willing to advocate for the continued inclusion of this course, even when it faced scrutiny from some residents and faculty. Where people from the Empowerment Council might be dismissed, those with institutional positions could use their power to speak up for the course and its benefits. This type of relationship building takes time, as well as humility and a commitment to the activism of service users.

By building internal capacity and support for the course, the Empowerment Council was able to have content developed and taught by service users included in the mandatory curriculum for psychiatry residents, a remarkable achievement given that it situates the scholarship of service users as valuable knowledge for learners.



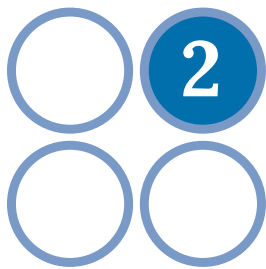
Reflection and discussion questions

- How will your vision for change be communicated to multiple groups inside and outside your organization? Will new skills and expertise be required to do so effectively?
- How might personal stories and experiences be collected by your organization to illustrate the need for transformative change?
- How will you go about securing leadership buy-in and support for your change initiative?
- What is your organization's tolerance for change? If it is low, how might you overcome that?

Tools and resources

Indigenous Storywork

Based on the work of Dr. Jo-Ann Archibald, this website provides information on the structure and framework of Indigenous stories and discusses considerations for using storytelling in teaching and learning.



PART 3.2

Anticipate and manage resistance

When it comes to major, system-level change like dismantling MHSU-related structural stigma in health care, resistance and defensiveness are inevitable. Even people who agree that change is needed often dig in when they see *what* has to change and *what* the implications are for them (especially when it comes to sharing power). They may rationalize their resistance by coming up with reasons why change isn't possible or else adopt the mindset that the initiative is not going to work. Change will uncover many different feelings among the people in your organization. Knowing where resistance is likely to come from – and how to manage it effectively – is critical to the success of any anti-stigma initiative.

Key principles for health-care organizations

Acknowledge the resistance

It's not a question of *if* there will be resistance to change, but how much. By acknowledging that it will happen from the start, you'll be better equipped to explore its causes and then build ways to address it into your plans.

In many cases, resistance comes from people in power who feel unmoored or even threatened when their perspectives are no longer the top (or only) priority. Recognize and respect that this is a valid reaction, then work to support those people through conversations rooted in empathy and curiosity.

Resistance can come from unexpected places as well. PWLLE of MHSU problems or illnesses who have been continuously oppressed in the past – and would benefit the most from your change initiative – may have seen previous attempts to address MHSU-related structural stigma fail or been involved in those efforts in a tokenistic way. As a result, they may be reluctant to commit more time and energy to a project that, in their mind, has no chance of succeeding.

Anticipate the possible reactions, then respond tactically and tactfully

When planning your change initiative, take time to imagine some of the reactions and issues that might arise. Where is resistance likely to happen? Where might the friction be with your organization's existing policies and systems? Anticipating such reactions will help you be more prepared for your initial conversations with different stakeholders. Similarly, prior to a given stakeholder meeting, think about who might be most likely to oppose the change, who will be allies, and who might require extra effort to overcome their concerns. Do as much advance homework as you can so that you are as prepared as possible going into the meeting.

You may want to proactively address resistance by sending an email to the people you'll be meeting with, explaining what your organization is trying to achieve and answering some of the questions you think they're likely to raise. If you prime people in this way, they are less likely to be defensive or hostile during the meeting.

Reframe from individual to structural

When addressing systems of structural oppression, it's easy for people to hear, "You are a bad person." We can't shy away from the historical harms of racist or ableist policies, so part of managing resistance is to move into a more reflective space and remind people they are not personally responsible for those issues — but because of their profession, they are implicated in perpetuating stigmatizing structures and systems.

Physicians and other health-care professionals may feel challenged by that statement. Remind them that *they currently have the power in the system* — and will continuously gain power as they advance in their careers — so they have a responsibility to use that power to make change for the better.

Foster relationships and gather allies

Having allies in your organization who can speak the same language as the people who are resisting — and share some of the emotional labour involved in addressing resistance — is vital to keeping everybody moving forward together.

Communicate constantly

Resistance can occur if staff are suddenly told that change is happening rather than being involved in the process from the start. Being transparent and open every step of the way, including about the areas of resistance that arise, can help avoid the feelings of alienation that can cause people to dig in and resist change.

As part of this effort, share stories that contextualize resistance as a natural, expected part of the process rather than a failing of the project.





Bring in people with strong interpersonal skills

Navigating resistance requires people with high emotional intelligence and strong interpersonal skills. Rather than considering those attributes and skills to be “nice to haves” when hiring staff, build them into your organization’s hiring approach: ask about them during the job interview and evaluate them just as you evaluate education or experience.

Also consider bringing in a third-party specialist in change management theory. This person can facilitate discussions related to resistance, using approaches like the Five Whys to help uncover the root causes of problems and concerns and ensure your organization’s leaders are participating in those conversations rather than steering them.

Know when to walk away (for now)

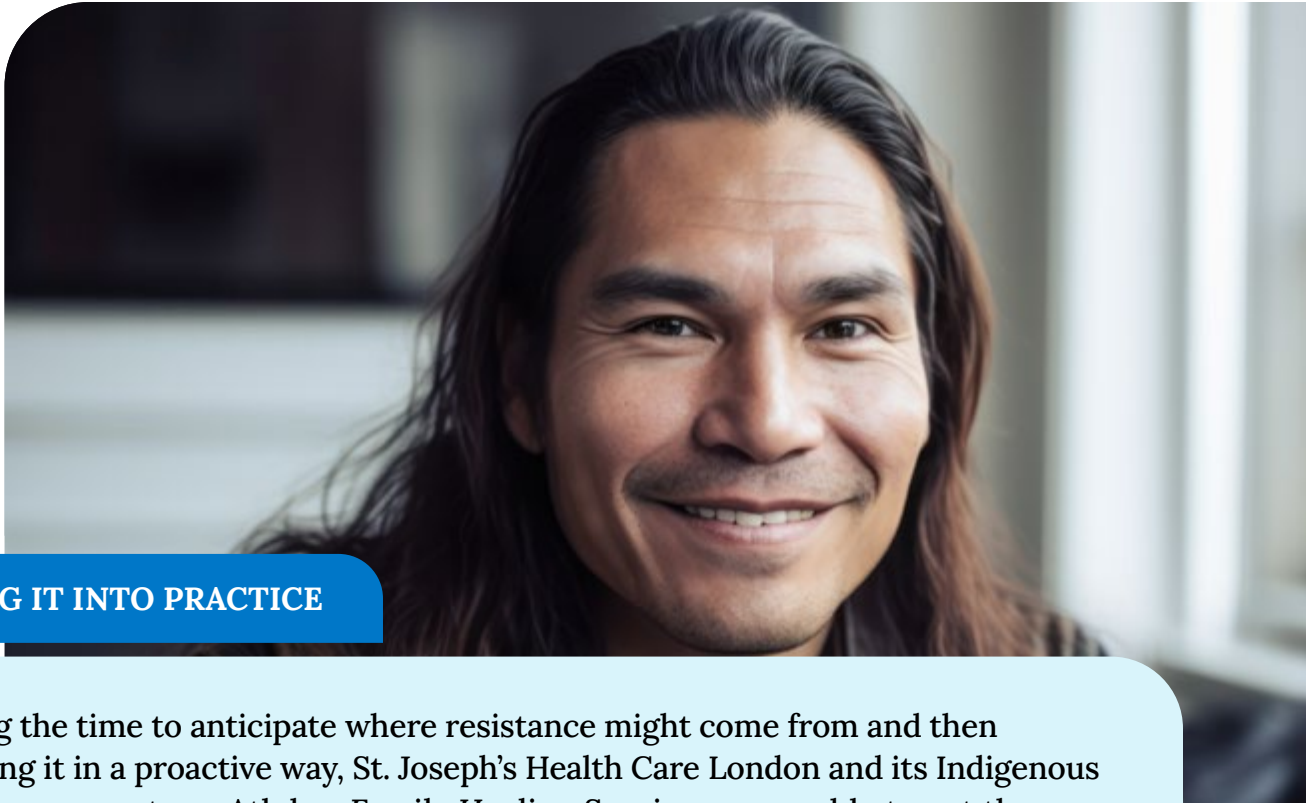
If the resistance becomes too great and it becomes clear that your organization isn’t actually ready for disruptive change – or if there has been a dramatic shift in vision and direction from senior leadership – you may have to decide whether it’s still possible to maintain the integrity of the initiative’s vision. If not, it may be time to walk away. But remember, doing so doesn’t necessarily mean abandoning the work entirely. You could still use this as an opportunity to better understand what is preventing change and look at possible new ways of addressing MHSU-related structural stigma, so that when the organization is truly ready to take action you can hit the ground running.



PUTTING IT INTO PRACTICE

Developed by the University of Toronto and the [Empowerment Council](#), the Centering Madness course for first-year psychiatry residents aims to identify how power and privilege play a role in psychiatric practice and explore opportunities for engagement and solidarity work with mental health service users. Designed and delivered by service users, it challenges entrenched psychiatric beliefs in a way that is both emotionally uncomfortable and intellectually challenging for many residents. This initially prompted resistance from students and faculty alike, some of whom felt that it was a waste of time to have non-psychiatrists teaching residents.

An external review of the course in 2018 to better understand where and how students were experiencing difficulties provided suggestions on how it could be adjusted to address some of the concerns. Two years later, the resistance to the course changed direction entirely, with many students expressing an interest in having more modules and classes delivered from a service user's perspective.



PUTTING IT INTO PRACTICE

By taking the time to anticipate where resistance might come from and then addressing it in a proactive way, St. Joseph's Health Care London and its Indigenous health agency partner, Atlohsa Family Healing Services, were able to get the Biigajiisakaan: Indigenous Pathways to Mental Wellness program up and running even as the hospital was focused on the COVID-19 pandemic.

Before any stakeholder meeting, representatives from St. Joseph's and Atlohsa would sit down to discuss issues that were likely to come up, such as concerns related to a proposal to give Atlohsa access to the clinical information on a patient's chart. They would consider the questions a stakeholder might ask, the roadblocks they could present to the initiative, and what it would take to convince the stakeholder of the proposal's benefits. The answers would then be sent by email or discussed with the stakeholder in a pre-meeting session. This tactical, proactive approach has made meetings far more productive, with the team encountering less resistance because people come into each session with a better understanding of the program.



Reflection and discussion questions

- Where is resistance to change likely to come from in your organization?
How might you work to overcome that resistance?
- Who are the potential allies among your partner agencies who could assist in addressing resistance to your change initiative?
- What is your backup plan for addressing MHSU-related structural stigma if the resistance to your change initiative is too great?
- What are the root causes of MHSU-related structural stigma in your organization?
How can they be addressed?

Tools and resources

Five Whys Root-Cause Analysis Tool

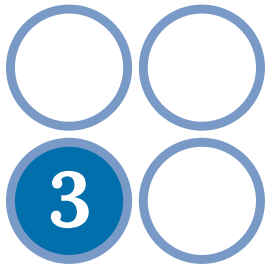
This Lean management tool enables users to quickly dissect a problem and reveal its underlying causes.

PDSA Cycle

The Plan-Do-Study-Act cycle can help users to implement a major change by breaking it into incremental chunks: planning it, trying it, and observing the results.

More than Paint Colours: Dialogue About Power and Process in Patient Engagement

This report from the Empowerment Council details the collaborative engagement process that led to the creation of the InSight committee and Centering Madness course.



PART 3.3

Seek and respond to feedback in a proactive way

Great ideas can come from anywhere, which makes collecting feedback vital to sustaining your efforts to dismantle structural stigma. It's about being humble and open to suggestions, reassessing and readjusting your approach as needed on the basis of that feedback, while keeping in mind the ultimate goal of knocking down barriers and delivering better care to those who face MHSU-related structural stigma in health care.

Key principles for health-care organizations

Get feedback from all stakeholders

Seek feedback from internal *and* external stakeholders, and give as many people as possible the opportunity to provide input. This will help you gain buy-in, reach compromises, and access the best ideas available. When people feel engaged in an initiative, they are more likely to support it and help make it happen.

Town halls are an effective model for gathering feedback, as they encourage multiple communication styles for more complete, authentic comments and participation. They also demonstrate a broader organizational commitment to change. That said, they are better suited for larger organizations like hospitals and may not be applicable or effective in other settings. Also, not everyone is comfortable speaking publicly at a town-hall meeting, so providing multiple ways for individuals to give feedback helps make the process more accessible and inclusive. For most organizations, surveys are simple but effective tools for collecting feedback. Talking circles led by Elders are a safe, brave, and efficient way of accessing Indigenous voices. (For more information on creating safe spaces, see [Identify and ensure a shared understanding of the problem](#) in Part 1.)

Keep in mind that there may be biases in the feedback you receive, including those that reinforce systems of oppression.

Listen to the communities most affected by stigma

If there are barriers or needs related to specific communities or population groups, get feedback and input from those communities directly. For example, if stigma is being directed primarily toward Indigenous service users, seek responses from the Indigenous community specifically.

Establish a dedicated team to oversee the change process

Having a team dedicated to this process will enable you to collect feedback on a more timely and consistent basis and may ensure that follow-ups to let people know their feedback is valued are sent promptly. Provide staff, clients, and other stakeholders with the team's email address or phone number, and implement an open-door policy so they know they can submit questions and feedback at any time.

Don't wait for feedback to come to you

In larger institutions such as hospitals, each unit, program, and department will be preoccupied with its own projects, issues, and emergencies. To get feedback from all parts of your organization, you will probably need to connect with the people in each unit to ask what they think about the change initiative and what could be improved.

Consider safety and anonymity when needed

Adapt your approaches to accommodate those who don't feel safe participating in traditional ways. Owing to the power dynamics at play, some people may feel uncomfortable pointing out mistakes or areas for improvement, or they may fear consequences for speaking up about a certain issue. People from marginalized communities may also be reluctant to share their thoughts because of the negative ways knowledge has been extracted from them and used against them historically.

When doing a survey, make sure people can answer anonymously. This will help you to gather more open and honest feedback. Also, limiting the number of questions asked — two really strong questions might be all you need — can lead to more complete and useful answers by ensuring respondents don't get overwhelmed.



Look for actions and not just words

Actions often speak louder than words, especially when you are seeking feedback from historically marginalized patients or clients. If asked how they are feeling, they will often say they're fine even when they're not. Look for visual cues to determine if something might be wrong in terms of their health outcomes, service access, and other important topics. Asking indirect questions may make it easier for them to elaborate on their experiences.

Establish continuous feedback loops

Continuous feedback loops are critical to any change initiative. Build intentional checkpoints, work collaboratively to identify what is important to receive feedback on, and set timelines for receiving and reviewing comments. Dedicate time to having conversations about the feedback and what it means for your organization. Share what you've heard at meetings to ensure that everybody knows what stakeholders are saying or recommending.

As part of this process, be sure to regularly review the feedback mechanism itself. Are you still asking the right questions? Are you asking the right number of questions? What might need to change to get the data needed to sustain and improve your organization's change initiative?

Act on the feedback in a transparent way

Make sure any changes that happen as a result of the feedback received are transparently linked back to specific comments. That way, participants can see that their input truly is valued and being used to make a difference.





PUTTING IT INTO PRACTICE

Nova Scotia Health's Adult Neurodevelopmental Stabilization Unit (ANSU) Dual Diagnosis Program uses a variety of tools to collect feedback from patients and/or their families or caregivers (if a patient is non-verbal, for example). Twice a year, it conducts an anonymous survey that asks two simple questions: "What was your experience with us?" and "What would you like to see changed?" This approach makes it easy to quickly gather a lot of useful responses. A gift card is used as an incentive for participating in the survey.

Comment cards are also available at the unit's entrance so people can, in the spur of the moment, write in their kudos or concerns for the ANSU team.



PUTTING IT INTO PRACTICE

Alberta Health Services' Addiction Recovery and Community Health (ARCH) Program has implemented quarterly grand rounds (large-group sessions to discuss clinical cases at a high level) as well as frequent polls and surveys to ask what physicians in the Royal Alexandra Hospital would like to know about the program.

It was through those surveys that the ARCH team learned that it needed to be much more proactive in providing education and awareness about its program, as many in the hospital had no knowledge of ARCH. The team acted on that feedback to broaden its awareness-raising efforts. Now more people on teams throughout the hospital, from physiotherapy to nursing, are reaching out to ARCH for advice on supporting different types of patients with substance use concerns.



Reflection and discussion questions

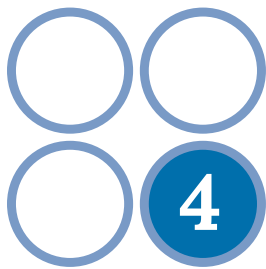
- What kinds of feedback mechanisms would work best for your organization?
- What types of questions will help your organization effectively measure outcomes and progress?
- What is your organization's capacity for collecting and analyzing feedback? Will new tools or software be required to do so effectively?

Tools and resources

Grand Rounds

Grand rounds are a methodology of medical education where groups of physicians, residents, medical students, and others get together at a formal meeting to discuss the clinical case of one or more patients. Unlike daily rounds, grand rounds are typically focused on the bigger picture, including experiences with patients over many years.





PART 3.4

Embed change in existing structures

Any sort of change can be difficult to accomplish. Getting that change to stick by having it embedded in your organization's way of thinking and doing is even more challenging. It requires a commitment to codifying the change through new policies, processes, systems, and positions, all co-designed with diverse partners for maximum impact and staying power. It also requires being open to a long-term process and recognizing that it will take time for small changes to add up to something everyone can see.

Key principles for health-care organizations

Identify your fit in existing structures

It's important to identify two things when designing your change initiative. First, where can you attach or embed the desired system-level change in your organization's existing frameworks and practices – and what might the impact of the change be for them? Any level of change can be overwhelming. Working it into your organization's existing structures can help reduce how many new tools and policies staff will have to learn and use on an ongoing basis.

Second, determine the changes that will *not* fit into your organization's existing structures and/or identify the barriers in those structures that might prevent change from happening. This will help clarify where entirely new policies or practices may be needed to realize your vision for change.

Don't make change contingent on a single person

For change to be sustainable, it must be formally embedded in the organization itself and not tied to a commitment made by a single person in a leadership position. If that person leaves, the desire for change may leave with them, forcing you to restart the process if their replacement brings different values and priorities.

Structural stigma must be met with systematic changes. Articulate the commitment to dismantling MHSU-related structural stigma directly in your organization’s mission statement, strategic plan, policies, or governance structure. Make sure representatives from across your organization’s various departments support and are knowledgeable about your change initiative. That way, it will continue to be put into practice no matter who is in charge.

Engage with the community

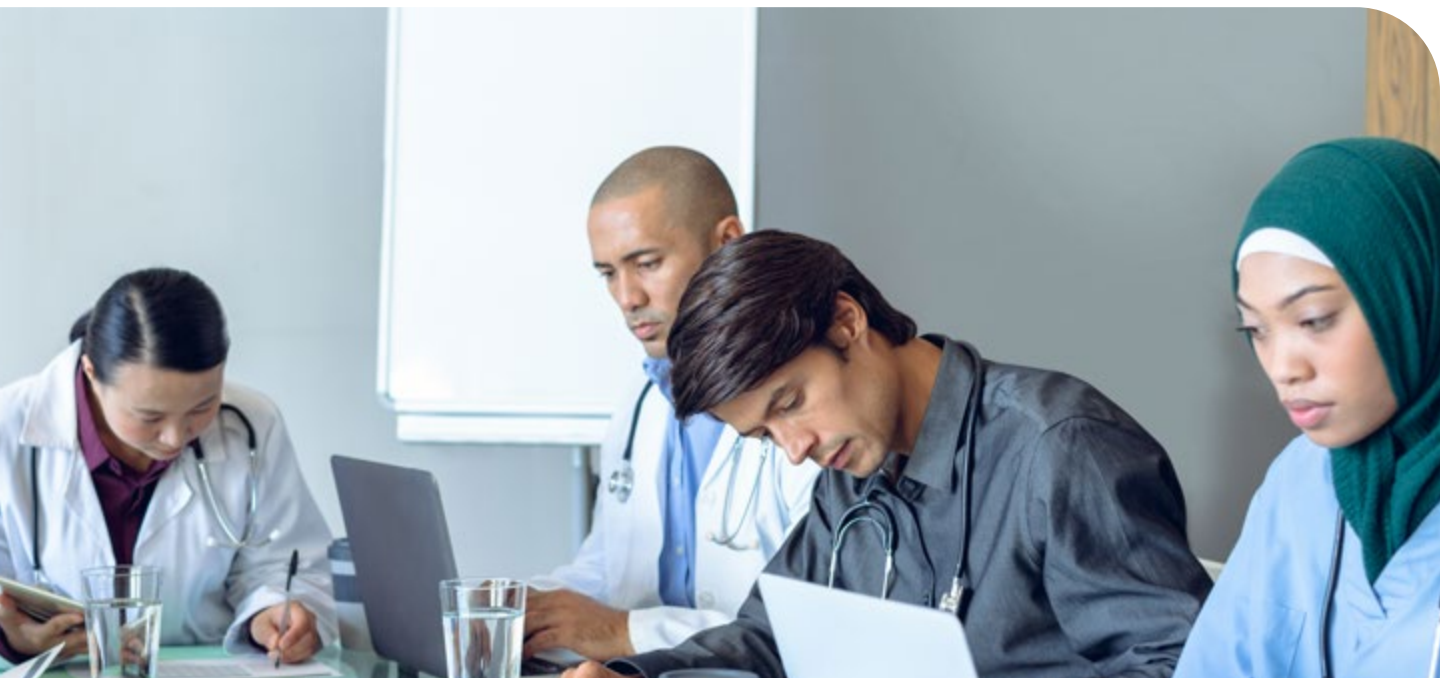
Change won’t last unless you continuously engage with those it affects. Build and maintain relationships with members of your community and always consider how your efforts are relating to and responding to their needs.

Start small and remember that change is a long-term process

Structural stigma won’t be dismantled in a week, a month, or even a year, so don’t get discouraged if you don’t see immediate, large-scale results. To make change stick, it pays to start small with a single pilot initiative, focusing on a specific priority area in a single unit or department, then expand and scale up your efforts over time. Appreciate and celebrate the little wins as they happen and recognize that many successful smaller changes will eventually add up to one big change.

Show your homework

People will need to be convinced of the value and outcomes of your work. By researching and presenting data on the real-world impacts of your initiative to address structural stigma, you’ll be more likely to find supporters who will help embed change in your organization’s policies, practices, and frameworks.





PUTTING IT INTO PRACTICE

Alberta Health Services' Addiction Recovery and Community Health (ARCH) Program was able to launch the first hospital-based supervised consumption service (SCS) in North America because it prioritized sharing data and making the case for why an SCS was needed and would lead to better outcomes for patients with substance use issues.

To alleviate concerns and generate buy-in across the many different units in the Royal Alexandra Hospital, the ARCH team had to raise awareness on how the SCS could support patients' needs, dispel the myths of an SCS, and explain how the SCS process would work. They repeated this process several times over the following months, providing numerous opportunities for questions and feedback. When the SCS finally opened to service users, the ARCH team offered tours to staff from the other units to keep the dialogue going and further make the case for its positive impacts.

The ARCH team has since shared its policy and guideline documents with other hospitals across Canada wanting to start their own SCS and overdose-prevention programs, along with guidance on how to measure the severity of a patient's opioid withdrawal symptoms.



PUTTING IT INTO PRACTICE

Although the Canadian Resident Matching Service (CaRMS) Service User Committee wound down in 2021 (largely as a result of changes in leadership), the project team is still proud of how it was able to embed the perspectives of service users in the highly standardized, national process for selecting psychiatry residents. Some of the initiative's success came from the University of Toronto psychiatry department's larger strategy to share decision-making power and shift the culture of residency training so it would more significantly incorporate the knowledge, views, and experiences of PWLLE of MHSU problems or illnesses.

By giving PWLLE of MHSU problems or illnesses a formal voice in the selection process, this initiative helped set expectations for psychiatry residents by communicating an important, institutional-level message about the values that matter in the practice of psychiatry. Feedback from residents suggested that the involvement of service users in the selection process was quite meaningful in shaping and supporting how they intend to practise in the future.



Reflection and discussion questions

- How easy would it be to embed change in your organization's existing policies, practices, and processes? Will new policies, practices, and processes have to be developed to implement and sustain the desired change?
- What are the barriers to change across your organization?
- Are you dependent on a single champion to support the change initiative? What might happen if a new person stepped into their position? How will you ensure continuity of the initiative's vision if there is a change in leadership?
- What is your organization's capacity for conducting research and demonstrating the value and impacts of the change initiative?

Tools and resources

Supervised Consumption Service (SCS) at the Royal Alexandra Hospital: Information Sheet

This two-pager raises awareness among hospital staff about the SCS site managed by the ARCH program, explaining how the program works, who is eligible for the program, and more.



MHCC LIBRARY OF **Structural Stigma Resources**

“Access Denied” – How Mental Health/Substance Use-Related Structural Stigma Impacts Health-Care Access

A video where people share their stories about how MHSU-related structural stigma impacts their access to health-care services.

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

A report with six concrete steps for documenting the nature and severity of MHSU-related structural stigma in health-care contexts.

A Way Forward – How We Can Dismantle Mental Health- and/or Substance Use-Related Structural Stigma

A video where people share their insights on how MHSU-related structural stigma can be dismantled in health-care settings.

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

A report on the lessons, insights, approaches, and strategies for successfully tackling MHSU-related structural stigma in health-care environments, based on the experiences of six champion and changemaker organizations.

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

A report on a research program designed to better understand MHSU-related structural stigma, leading to seven priorities for dismantling and disrupting structural stigma in health-care environments.

Design Prototypes for Measuring Structural Stigma in Health-Care Settings

A report on potential quality measurement indicators or audit tools that standards creators, regulators, and policy and decision makers could use to assess structural stigma.

Ghost in the Machine: Tackling Structural Stigma in Health-Care

A webinar about the MHCC's multi-year project to better understand and address MHSU-related structural stigma in health care.

“Less Than” – How Mental Health and/or Substance Use-Related Structural Stigma Impacts Quality Of Care

A video where people share their stories about how MHSU-related structural stigma impacts the quality of the health care they receive.

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

A report on measurement approaches that could be used to monitor the extent to which health-care settings offer caring cultures, person-centred care, or recovery-oriented care.

Mental Health Structural Stigma in Healthcare

Free MHCC and CHA Learning online training about the impacts of MHSU-related structural stigma in health care and how to dismantle it. This course is for health-care leaders at any level, health-care professionals seeking to improve quality of care, and anyone interested in learning about structural stigma.

Silent Barriers: How We Can Dismantle Mental Health- and Substance Use- Related Structural Stigma in Health Care

A short, animated video on how MHSU-related structural stigma causes real harm, both to people trying to access care and health-care workers seeking to provide it.

Structural Stigma: Personal Experience Stories

This resource with educational narratives of personal stories told by individuals with direct experience of structural stigma in health-care settings.



Mental Health
Commission
of Canada

Commission de
la santé mentale
du Canada

Financial contribution from



Health
Canada

Santé
Canada

Mental Health Commission of Canada, 2023

Suite 1210, 350 Albert Street
Ottawa, ON K1R 1A4
Tel: 613-683-3755
Fax: 613-798-2989

mhccinfo@mentalhealthcommission.ca
www.mentalhealthcommission.ca



[@MHCC_](https://twitter.com/MHCC_)



[/theMHCC](https://www.facebook.com/theMHCC)



[/Mental
Health
Commission
of Canada](https://www.linkedin.com/company/Mental-Health-Commission-of-Canada)



[@theMHCC](https://www.instagram.com/theMHCC)



[/1MHCC](https://www.youtube.com/channel/UC1MHCC)



[@theMHCC](https://www.pinterest.com/theMHCC)