

# Champions and Changemakers

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

Stephanie Knaak, PhD  
Javeed Sukhera, MD, PhD

Mental Health Commission of Canada  
[mentalhealthcommission.ca](http://mentalhealthcommission.ca)

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### **Addiction Recovery and Community Health (ARCH) Program**

- Chris Cardinal, Kathryn Dong, Parabhdeep Lail, Eliza Lo, Beatrix Masee, Karine Meador

### **Adult Neurodevelopmental Stabilization Unit (ANSU) Dual Diagnosis Program**

- Adeola Adebayo, Oluseye Akinkunmi, Nabiha Atallah, Rachel Boehm, Nicole Robinson, Mutiat Sulyman, Olugbenga Alaba Williams

### **Biigajiisakaan: Indigenous Pathways to Mental Wellness**

- Deb Gibson, Bill Hill, Lynn Hinds, Arlene MacDougall, Melissa Preece, Renee Sweeney, Jodi Younger

### **Canadian Resident Matching Service (CaRMS): Service User Committee Initiative**

- Sacha Agrawal, Rachel Carr, Rachel Cooper, Mark Fefergrad, Mark Hanson, Lauren Munro, Gina Nicoll

### **Centering Madness Course: Building Capacities for Community Engagement**

- Kathryn Church, Lucy Costa, Mark Fefergrad, Christina Foisy, Lauren Munro

### **Health Justice**

- Anita David, Kendra Milne, Renea Mohammed, Shareen Nimmo, Sara Quill, Aman Sharma

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# Contents

- Executive Summary ..... i**
- Introduction and Background ..... 3**
- Project Description ..... 4**
- Addiction Recovery and Community Health (ARCH) Program..... 4**
- Health Justice..... 7**
- Biigajiiskaan: Indigenous Pathways to Mental Wellness ..... 10**
- Canadian Resident Matching Service (CaRMS) Service User Committee Initiative..... 13**
- Centering Madness Course: Building Capacities for Community Engagement ..... 15**
- Adult Neurodevelopmental Stabilization Unit (ANSU) Dual Diagnosis Program ..... 18**
- Summary and Conclusions ..... 21**
- References ..... 25**

# Executive Summary

Structural stigma refers to the accumulated activities of organizations that create and maintain social inequalities for people with lived and living experience of mental health and substance use problems. Structural stigma is also embedded within the formal and informal rules and practices of organizations and society at large. Mental illness- and substance use-related structural stigma remains a significant problem that adversely impacts the quality of Canadian health care.

In August 2020, the Mental Health Commission of Canada (MHCC) distributed 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, those that showed promise or effectiveness by improving access and the quality of health care and/or outcomes for people with lived and living experience of mental health problems or illnesses and/or substance use.\* The MHCC was seeking to identify case studies to help raise awareness and illustrate the problem of mental illness- and substance use-related structural stigma in Canada’s health-care system. The aim was to leverage what was learned from these real-world examples to inform key ingredients, features, strategies, and considerations and assist other organizations, departments, or work units who have an interest in combating and addressing such structural stigma.

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

- The Addiction Recovery and Community Health (ARCH) initiative, which tackles structural stigma by providing a patient-centred, trauma-informed, recovery-oriented model of care for people with substance use problems within a hospital setting. It offers services such as peer support, reproductive health, ID procurement, an in-hospital safe consumption site, pain management, as well as treatment and referral services.
- Health Justice, 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.
- Biigajiiskan: Indigenous Pathways to Mental Wellness (bee-GAH-jees-khan), a partnership between Atlohsa Family Healing Services and St. Joseph’s Health Care London. The program provides culturally safe, specialized care for Indigenous people with serious mental illness, addiction, and concurrent disorders by combining traditional healing medicine, Indigenous elder-guided care, and ceremony with hospital-based health-care practices and psychiatric treatment in a hospital setting.
- The Canadian Resident Matching Service (CaRMS): Service User Committee initiative, which gives a concretized role to people with lived experience of a mental illness or substance use problem in recruiting and selecting candidates for psychiatry postgraduate training in Canada’s largest psychiatric residency program.
- Centering Madness: Building Capacities for Community Engagement, a mandatory, embedded, and graded educational module for first year University of Toronto psychiatry residents. The course applies a social justice-informed critical lens to dominant paradigms and understandings of mental health and illness and is fully designed and delivered by service users.

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\* This request was embedded within a larger project focused on the topic of structural stigma.

- Adult Neurodevelopmental Stabilization Unit (ANSU) dual diagnosis restructuring, 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 behavioural care.

From these real-world examples, we learned several important lessons, insights, approaches, and strategies for successfully tackling structural stigma in health-care environments.

1. Prioritize the meaningful participation of service users and community members/stakeholders in the design, delivery, and/or governance of any initiative for change and to formalize any established models of co-design and shared leadership.
2. Focus on embedded and ongoing education and training approaches that prioritize the voices and perspectives of people with lived experience.
3. Implement models that provide high-quality, evidence-based, holistic, culturally safe, client-centred, and recovery-oriented care, which are guided by the perspectives and input of people with lived and living experience of mental health and/or substance use problems, and which incorporate ongoing education, training, and engagement — as well as role modelling and leading by example — to help facilitate and support wider cultural buy-in.
4. Work to change inequitable and unjust laws and policies that negatively impact the experiences of care for people with mental health and substance use problems and (in many cases) violate their human rights. Advocacy efforts can be enhanced through service user-led outreach, engagement, and education activities.
5. Focus on the intersecting nature of structural stigma by addressing the needs of population groups that face multiple levels of stigma and experiences of marginalization.
6. Ensure the success and sustainability of any initiative for change by drawing on supportive leadership and passionate champions.
7. Commit to making collaborative and creative problem solving part of the structural change process to meet administrative and other system-level challenges that will occur along the way.
8. Be aware that concerns about long-term sustainability, especially with respect to funding, are common and can pose real threats to long-lasting structural change.
9. Know the importance of undertaking evaluation and research, setting targets or goals, and monitoring progress. The design of evaluation and other research should involve input and direction from people with lived experience.

For more information on these initiatives, please contact [access@mentalhealthcommission.ca](mailto:access@mentalhealthcommission.ca).

# Introduction and Background

Since its inception, stigma reduction has been central to the Mental Health Commission of Canada's (MHCC's) mandate. [Opening Minds](#), the commission's first major stigma initiative, focused on identifying, evaluating, then sharing, promoting, and scaling up effective interventions and approaches. The MHCC has since expanded its mandate twice more to include [substance and opioid use-related stigma](#) (2017) and [structural stigma](#) in health care (2019).

Structural stigma is distinct from other kinds of stigma (e.g., at the individual or interpersonal level). It operates in our institutions, organizations, policies, laws, and other formalized or entrenched practices through the accumulated activities that create and maintain social inequalities. Structural stigma is also embedded within the formal and informal rules and practices of organizations and society at large. It tends to be "reinforced in laws, the internal policies and procedures of private or public institutions and systems, and the practices of professionals and decision makers" (p. 4).<sup>1</sup>

While structural stigma against people with mental illnesses and/or substance use problems exists across all social domains — for example, housing, employment and income, education, criminal justice, privacy, public and civic participation, travel and immigration, media, and reproduction and parenting — the MHCC's work focuses on the manifestations of structural stigma in the health-care sector.

In 2019, the MHCC's Access to Quality Mental Health Services\* team launched a new structural stigma initiative. Research findings from its first year were summarized and integrated into an expanded version of the [Action Framework for Building an Inclusive Health System](#) from [The Chief Public Health Officer's Report on the State of Public Health in Canada](#).<sup>2</sup> This MHCC's [summary report](#) highlighted key evidence-informed priorities, interventions, approaches, strategies, and models of care for reducing mental illness- and substance use-related structural stigma. It was intended to help guide health leaders, researchers, and other individuals who are interested in tackling structural stigma and stigma-related barriers to access and quality care for people living with mental health and substance use problems.

Building on the research from Year 1, a key activity for Year 2 was to identify, describe, and highlight real-world examples of approaches that address structural stigma in Canada's health-care system. The purpose of identifying and describing various real-world examples was to

- raise awareness about the problem of mental illness- and substance use-related structural stigma
- help illustrate the problem of structural stigma using real-world cases
- describe innovative initiatives that are actively challenging, disrupting, or dismantling structural stigma
- leverage what was learned from these real-world examples to inform key ingredients, features, strategies, and considerations and assist other organizations, departments, or work units who have an interest in combating and addressing structural stigma.

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\* Which includes substance use and addiction services.

# Project Description

In August 2020, the MHCC put out 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, those that showed promise or effectiveness by improving access and the quality of health care and/or outcomes for people with lived and living experience of mental health problems or illnesses and/or substance use. A total of 62 completed submissions were received by the September 15 deadline.

Expressions of interest were categorized into five broad themes according to initiative type (while recognizing that many initiatives fell into more than one category): (1) innovations in service design, (2) innovations in training and education, (3) policy and advocacy initiatives, (4) shared leadership initiatives, and (5) initiatives to address the needs of special populations within mental health and substance use. Due to the large number of submissions, two independent reviewers scored and ranked them according to the following criteria:

- the strength and clarity of the initiative’s connection with structural stigma
- the extent to which the initiative contributes to innovative and promising approaches in addressing structural stigma
- whether the initiative has demonstrated some effectiveness at reducing structural stigma (e.g., a shift in organizational culture, attitudes, or care practices; improved retention in care, client satisfaction, or client outcomes; enhanced performance monitoring)

After the review, six initiatives were jointly identified as strongly meeting these criteria and were selected for inclusion.

To gain a more thorough understanding of each initiative, the authors completed online interviews with each program lead and/or team and reviewed program documents. Interviews were also conducted with other stakeholders (e.g., program participants, organizational leadership, members of governance boards or advisory committees, and others involved in program design or delivery), who were identified through the initial interviews and program reviews.

This report provides an overview and description of all six initiatives. While the descriptions cannot express everything we learned, they nevertheless present some of the key features that make each program an important approach for tackling structural stigma. The report concludes by identifying common themes that stood out as key barriers and facilitators for the success of these initiatives.

## Addiction Recovery and Community Health (ARCH) Program

As is shown in this [video enactment](#), the Addiction Recovery and Community Health (ARCH) program tackles structural stigma by providing a patient-centred, trauma-informed, recovery-oriented model of care within a hospital setting — to help build trust and improve the quality of care provided to patients

living with substance use problems. More specifically, ARCH embeds interdisciplinary addiction-medicine consult teams within the hospital to serve the needs of inpatient and emergency department patients living with problematic substance use.

The program started after the hospital organization noticed high levels of substance use-related problems and frustration within the medical teams. One interviewee mentioned that, before building the program, they asked patients: “What do you hope for when you come here and what do you expect? How could we do better?” In response, patients told them that they would be willing to access more services if they were offered.

ARCH began at the [Royal Alexandra Hospital](#) in Edmonton, and now it also operates at the [Peter Lougheed Centre](#) in Calgary. These are Alberta’s two busiest hospitals for substance use-related presentations.

ARCH offers a full spectrum of evidence-based harm reduction, treatment, and recovery options to better support patients across the care continuum, facilitate their pathway into treatment, and reduce the immediate risks of ongoing substance use. ARCH teams are multidisciplinary, patient centred, trauma informed, and recovery oriented. Their aim is to make patients feel safe, listened to, well cared for, and to ensure that they receive high-quality evidence-based care. According to program documentation, patients appreciate access to an interdisciplinary team. One person using ARCH described the experience this way: “I walked into a room and there’s a nurse, there’s a social worker . . . there’s four people all there talking about me and my situation and all brainstorming about how to move forward . . . and you don’t get that anywhere else” (p. 3).<sup>3</sup>

While the specific suite of services offered through ARCH is tailored to the needs of each site, they generally include the following:

- harm reduction services, including an in-hospital supervised consumption service<sup>4</sup>
- opioid agonist treatment
- relapse prevention pharmacotherapy for alcohol use disorder
- complex pain and withdrawal management
- motivational interviewing, addiction counselling, and psychosocial supports
- referral to treatment programs
- a managed alcohol program
- connections to income support, low-income health benefits, medication coverage, and housing services
- access to government-issued identification and a secure identification storage bank
- sexually-transmitted and blood-borne infection screening
- sexual and reproductive health services (e.g., Pap smears, contraception counselling, and immunizations)
- linkages to community and primary care with bridging through a transitional clinic, as needed

In addition to providing services, ARCH focuses on stigma-informed education for staff, as well as research and evaluation. All clinical, educational, and research initiatives the ARCH team undertakes are informed by a community advisory group consisting of individuals with lived or living experience of

substance use, hospitalization, and/or homelessness. ARCH was started with funding from the Royal Alexandra Hospital Foundation and is now predominantly funded by grants from Alberta Health.

## Key features that help make ARCH an innovative example for addressing structural stigma

### **Meaningful involvement by people with lived experience in the design and delivery of services**

Trust building is central to ARCH's aims. Its teams include peer support workers as core members, since peer support relationships can help engage clients in care who have historically avoided services out of fear or mistrust.



ARCH team peer support workers Chris Cardinal and Beatrix Masee, Royal Alexandra Hospital. Photo: Ken Dalton, Royal Alexandra Hospital medical photographer.

ARCH also relies on a community advisory group to provide direction in all areas of its program, including service delivery, research and evaluation, and education and training. The advisory group comprises individuals with lived or living experience of substance use, hospitalization and/or homelessness. The ARCH team regularly receives input from this group and the information they provide helps shape the direction of all facets of the program. One interviewee said that the group has “driven

the innovation” for the program. The group meets quarterly, and members are compensated for their contributions.

### **Research prioritizes the experience of service users and is used to inform program successes and needed improvements**

In addition to tracking and monitoring metrics such as number of patient consultations, number of unique patients, types of services received, etc., ARCH has prioritized research that focuses on understanding the experiences of its clients. In 2019, researchers published the [results of a qualitative study](#) that examined the main facilitators, barriers, and impacts of ARCH from the perspectives of the clients themselves, who

*We try to show them a different way just by talking to them. Try to show them that we actually care here. We try to stop them from leaving. Starts by just talking with them as people — not talking at them. We talk to them. We don't talk at them. It just starts simple.*

— interviewee

reported that the [program] had a positive impact on them overall. Several participants reported improved pain and withdrawal management. . . . Many participants also described . . . improvements in their mental and emotional health. [Some] also reported improvements in their socio-economic circumstances. (p. 4)<sup>5</sup>

Findings from the study were used to inform the program’s successes and make further improvements.

### **Education and role modelling to work toward culture change**

In terms of education and training, ARCH has largely adopted an ongoing continuing education approach. Its aim is to slowly shift the broader culture of caring so it more closely resembles ARCH’s holistic and patient-centred model of care. Ongoing educational activities include education/site orientation for new hospital staff, training for residents and medical students, an ARCH clinical nurse educator who touches base with units on a regular basis, and holding regular education days, grand rounds, and symposiums.

In addition to ongoing teaching and education, team members emphasized the importance of being ambassadors within the hospital and described how *leading by example* with a patient-centred, trauma-informed, and recovery-oriented approach was inspiring positive shifts in the larger culture of caring at the hospital. The team emphasized that they are role models for others and have noticed how other staff member’s behaviours and attitudes shift through role modeling of the ARCH approach.

## Health Justice

Structural stigma operates at all levels of society, including its enactment through laws. Mental health legislation is one of the most powerful mechanisms for shaping the behaviours of organizations and individuals.

[Health Justice](#) is a non-profit human rights organization, established in 2020, whose mandate is to research, educate, and advocate to improve the laws and policies in British Columbia that govern coercive health care (i.e., care that involves the use of authority to restrain another’s autonomy).<sup>6</sup> Its core mission is to reduce structural stigma by advocating to eliminate discriminatory practices, implement stigma-informed legislation and policies, and improve human rights monitoring and enforcement mechanisms. The organization’s current focus is advocating for reform of the province’s

*Mental Health Act (MHA)* to help address the disparity found in B.C.'s high rates of involuntary mental health hospitalization.

Health Justice was started by two passionate champions who identified the need for an independent advocacy organization to prioritize the fight for mental health legal reform. The existing advocacy and community mental health organizations tend to be underfunded, stretched for resources, and faced with multiple competing priorities. Health Justice is funded by a three-year open innovation grant provided by The Law Foundation of BC.

Their workplan includes:

- Year 1: Building an education and engagement structure and strategy
- Year 2: Bringing stakeholders together through the engagement process and deciding on the key priorities for change
- Year 3: Working to mobilize change, while recognizing that specific strategies and approaches will depend on what comes out of the engagement process

## Key features that help make Health Justice an innovative example for addressing structural stigma

### **Prioritizing legislative reform to protect human rights and ensure best practice standards**

The MHA is one of the main pieces of legislation that sets out when and how people can be detained and involuntarily treated for mental health problems. Health Justice believes that the current act falls short of many human rights protections and standards and causes considerable harms to people who have been subject to detention under the act. This initiative therefore seeks to reform the MHA to bring it in line with national and international human rights protections and best practice care standards. For one of the team's members, Health Justice is about

restoring the MHA to a framework in which a patient going in with a voluntary or involuntary or extended leave [for a mental health or substance use problem] can be assured that the system will care for them and will not harm them. And that the human rights code will not be violated while we are not within a so-called healthcare facility.

*There are many ways that the B.C. Mental Health Act falls short of the rights guaranteed by the Charter of Rights and Freedoms, international human rights laws, and evidence-based best practices. For example, the Act:*

- *authorizes detaining facilities to “discipline” patients in detention with no limits on disciplinary measures and no review process.*
- *has no criteria governing the use of restraints and seclusion, so patients are tied to their beds using mechanical restraints and solitarily confined in small, locked rooms with no limits on when it can be used and how long it can last.*
- *provides no patient rights to access counsel, to receive visitors, to same sex clothing removal, or to access means of communication with people outside detaining facilities.*
- *overrides the right to have family members or other personal supporters involved in health care decisions when you are unable to consent. (para. 5)<sup>7</sup>*

### **Employing a participatory engagement governance model**

Health Justice uses an organizational model called participatory engagement governance. Under this model, the board expressly shares governance power with two groups: (1) a lived experience experts group (LEEG), made up of people with lived or living experience (PWLE) of involuntary treatment under B.C.'s MHA, and (2) an Indigenous leadership group (ILG), made up of experts in cultural safety and trauma-informed care in the context of mental health and substance use crisis treatment.

This innovative way of governance moves beyond advisory models where PWLE are subordinate to the board, and pitfalls such as tokenism can more readily occur. In adopting it, Health Justice seeks to balance power across the organization and empower and value PWLE contributions by embedding those principles into its organizational structure. One interviewee said that their goal is to “move beyond fostering participation and instead focus on co-production and meaningful power sharing.”

Also embedded into the model are explicit assumptions that PWLE hold expertise of equal value to staff members. Such equivalence applies to legal/human rights/policy expertise in terms of creating stigma-informed legislation, making crucial decisions about the structure of the organization, and contributing to legal and human rights advocacy.

Financial and staffing support is provided to all LEEG and ILG members, in accordance with peer-developed best practices, to reflect the value of their expertise in the organization.

### **Building stakeholder engagement and buy-in through contact-based education**

Health Justice views education as foundational to building stakeholder engagement. It's efforts revolve around two identified learning needs: (1) a generally low level of awareness about the ways structural stigma and the MHA affect real people, and (2) a resistance to change among some health professionals, stemming from a belief that conversations about human rights, autonomy, and choice are at odds with conversations about providing good care:

When there is conversation surrounding human rights and choice, it is often viewed as a hindrance to care and something that gets in the way of providing care. . . . Because this conversation is so polarized in B.C., when we talk about autonomy, part of our project is not to polarize the conversation further. That is why we are starting at the grassroots level and pairing legal research with mobilization. (interviewee)

Health Justice's education and engagement strategy is PWLE and Indigenous centred and is a key activity of the LEEG and ILG. It uses the principles of intergroup contact (also known as social contact or contact-based education), where PWLE share personal experiences and perspectives of involuntary treatment and interactions with the MHA to educate people about the act and the need for change.

Key target groups identified for education and engagement include social justice organizations, legal organizations and people in the legal profession, government policy/decision makers, nursing associations, labour associations, mental health service providers (who are interacting with the legislation), clinicians, educators (post-secondary), and family and caregivers. Their strategy is to engage allies to help support MHA reform and government decision makers who may be able to help instigate a call for change.

We are really trying to be thoughtful in how we go about [education], targeting institutions like health and social service workers, and also going right to the source by educating people right within government — elected officials and policy makers who have the power to influence health system culture, policies, legislation, and funding. (interviewee)

# Biigajiiskaan: Indigenous Pathways to Mental Wellness

[Biigajiiskaan: Indigenous Pathways to Mental Wellness](#) is a referral-based mental [wellness program](#) that aims to provide accessible, culturally safe, specialized care for Indigenous people with serious mental illness, addictions, and concurrent disorders. Biigajiiskaan (bee-GAH-jees-khan) is a co-led partnership initiative between Atlohsa Family Healing Services and St. Joseph’s Health Care London (St. Joseph’s) in Ontario.

The name Biigajiiskaan (bee-GAH-jees-khan) is an Ojibway concept that describes how a broken and rotting tree stump feeds new life. It acknowledges the importance of all living things working together in harmony for the greater good. (program documentation)



A healing ceremony takes place in the dedicated Indigenous healing space located at St. Joseph’s Parkwood Institute.

Health system-related stigmatization toward Indigenous people is widespread, significant, and compounded even further in the context of substance use and/or mental illness. A history of colonialism has negatively impacted health equity and led to barriers in accessing care. As a consequence, many

Indigenous individuals lack cultural safety and anticipate harm. One interviewee from the program described this response in the following way: “When we walk into a western institution, we walk in with layers and layers of trauma that causes our guard to be up. We are on high alert, ready for all types of discrimination that we or others before us have suffered.”

Biigajiisakaan combines traditional healing medicine, Indigenous elder-guided care, and ceremony with hospital-based health-care practices and psychiatric treatment. The goal is to provide a culturally safe environment that includes Indigenous-led services that are focused on meeting the cultural and health-care needs of each client.

Its services include

- an Indigenous-led multidisciplinary team working in-hospital and in the community that provides consultation, assessment, treatment planning and management, discharge and care transition planning, and ambulatory services
- a dedicated Indigenous healing space at Parkwood Institute's mental health care building
- Indigenous elder-guided care and teachings from knowledge keepers
- traditional Indigenous practices such as healing circles, ceremony, smudging, and drumming circles
- educational and mentoring opportunities for health-care professionals and students.

The program, situated on-site at St. Joseph’s Parkwood Institute, is the only one of its kind in Canada in a faith-based hospital.

Biigajiisakaan has been funded for the last three years by the Ontario government through The Journey Together: Ontario’s Commitment to Reconciliation with Indigenous Peoples initiative. Program funding is held and directed by Atlohosa Family Healing Services.

## Key features that help make Biigajiisakaan an innovative example for addressing structural stigma

### **Integrating an Indigenous-led model of care within a western institution**

Biigajiisakaan’s model of care is focused on creating culturally safe, holistic, accessible, recovery-oriented care for Indigenous clients with mental health and substance use problems. This model is guided by the Thunderbird Partnership Foundation’s [First Nations Mental Wellness Continuum Framework](#), a strengths-based approach in which wellness is understood as the achievement of a healthy level of hope, belonging, meaning, and purpose. It also recognizes the foundational importance that culture, language, creation, Elders, families, and community have for mental wellness.

By providing culturally safe and accessible mental health care to Indigenous peoples through an Indigenous lens, Biigajiisakaan creates connections with and beyond the Western notion of mental wellness, and seeks ways to support community through relationships with the self, land and all of creation. (program information)

What makes Biigajiisakaan’s model unique is that it adapts the current health-care system by combining traditional healing medicine and knowledges with hospital-based health care and practices. For one interviewee, the “voice of the Indigenous community is, for the first time, taking the lead in its own care within the hospital setting.”

Biigajiisakaan has identified several success indicators for its program:

- 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 and feel a sense of connection or reconnection.
  - Clients have increased or rekindled an interest and pride in their culture.
  - Clients feel that they have transitioned into next phase of care and are taking more of an interest in their cultural identity and in their lives.
- 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 are mutually comfortable and feel 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 was implemented and shared with other hospitals and Indigenous service agencies.
  - The program has significant client retention and program completion rates.
- Organizational indicators —
  - The Indigenous health advisory committee (governance circle) continues in its capacity as a collaborative network.
  - 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, people with lived experience, family members) and Atlohsa and St. Joseph's staff.

### **Attending to stigma related to physical space**

Physical space is a well-recognized component of structural stigma. As the design and feel of physical spaces impact the extent to which people feel welcome, safe, and comfortable, they may either hinder or facilitate healing. According to an interviewee, all too often

Indigenous people do not see themselves reflected in the majority of society. Being able to create a mutual space, in partnership with St. Joseph's, where Indigenous individuals are free to be themselves and experience care and services that are being led by their own community, creates a sense of hope.

A central feature of the Biigajiisakaan program is its in-hospital, land-based Okwari:kowa (ohg-wally go-wah) healing space, located within St. Joseph's Parkwood Institute. This is a dedicated space for patients to engage in traditional healing practices and ceremony, traditional teachings, traditional ceremonial activities, and traditional medicines.

*Something so seemingly simple as murals or artwork or other indicators of an Indigenous presence makes a world of difference for an Indigenous person walking into an institution. The fact that there is space, and that it is very identifiable, and that you see people from your own community working within that space, it has such an impact . . . where it lets you let some of that guard down.*

— interviewee

This attention to the physical space environment has also been described as helping to build and support a larger “culture as care” environment within the hospital.

### **A commitment to co-leadership and co-design**

Central to Biigajiisakaan’s approach is a commitment to co-leadership and co-design, in which Atlohosa and St. Joseph’s are equal partners in the design and delivery of services.

Biigajiisakaan is pushing us to truly work side-by-side, respecting both streams of care, and acknowledging the history of bias and cultural barriers for Indigenous peoples in our system. (program information)

A central element of this shared leadership is that Atlohosa receives funding for the program directly, rather than having the hospital act as a transfer payment agency. This model represents a significant structural shift, as Althosa had been funded previously through social services only. While establishing this new structure took more than a year of work and advocacy, it was seen as essential for achieving true shared leadership — both in name and in structure.

Through this partnership . . . to the best of our ability we are attempting to embody the true spirit and intent of the treaties and historical relationships that were originally intended to form a brotherhood and sisterhood between our Indigenous nations and the settler nations. . . . What’s beautiful about this program approach is that neither partner is greater than the other. We each have gifts to offer to this service, but the Indigenous community is where the strengths lie to address Indigenous wellness overall. (interviewee)

The Biigajiisakaan program is overseen by an Indigenous governance circle. This model is seen as a key ingredient for addressing structural inequities in care for Indigenous patients, including historical experiences of harm and trauma.

## Canadian Resident Matching Service (CaRMS) Service User Committee Initiative

Meaningfully involving people with lived experience in decision-making roles has been identified as an important priority for addressing mental illness- and substance use-related structural stigma in the health-care system. The CaRMS service user committee initiative seeks to do so by recruiting and selecting candidates for postgraduate training at Canada’s largest residency program (the University of Toronto psychiatry department). It is part of a larger strategy within the department to shift the culture of residency training so that it more significantly incorporates the knowledge, views, experiences, and perspectives of people with lived experience of a mental illness or substance use problem.

For one interviewee, the ultimate goal is improving the recruitment process “so we can select better residents.” Ideally, they want residents who are

holistic in their thinking, not dogmatic in terms of a medical model or biomedical conceptualization of mental illness. Residents who are really committed to walking with their patients . . . really finding ways to work collaboratively as opposed to a coercive or a paternalistic model of care. And also doing so with a real emphasis on culture, . . . race, and other elements of one’s identity that fundamentally shape their experience of mental illness as well as how they receive care. (interviewee)

Since the program began in 2016, the service users on the committee has consisted of a lead and a co-lead which were added in 2019, a core group of five to 10 people, the residency program director, and a

small group of interested faculty members and residents. Its core responsibilities are to define a guiding set of desirable attributes for prospective residents and then work to align them with recruitment and selection activities.

The committee currently has three key roles in the recruitment and selection process:

- developing and scoring pre-interview personal statement questions
- developing and scoring interview-day reflective writing prompts
- developing and delivering an interactive orientation presentation for newly selected residents

*Some attributes generated by the committee:*

- *advocate*
- *compassionate*
- *aware of power/privilege*
- *non-judgmental*
- *reflective*

The Committee's future goals include participating in the interviews of residency candidates and in educational interactions with residents throughout their training.

## Key features that make CaRMS service user committee initiative an innovative example for addressing structural stigma

### **Giving service users a formal voice in the selection process signals a message about the values that are important for the practice of psychiatry**

While the role played by service user committee members is only one part of a larger selection process, grading residents' writing assignments does carry weight in terms of the overall selection process. The committee also plays a role in determining and shaping the interview questions. These involvements — along with a service user-led orientation session for new residents — do more than just give service users a voice in the selection process. They also communicate an important institutional-level message about the values that are important to the department, which helps set the tone on expectations and direction for the residents:

For a resident that comes in, knowing that . . . part of their selection was due to the service users is powerful . . . knowing that a lot of things that were valued about them as a candidate come from things that were important to service users. I think this knowledge helps them carry those strengths throughout their training. (interviewee)

Feedback solicited from residents suggests that the involvement of service users in the selection process can be meaningful for students in terms of shaping and supporting how they intend to practise. It is also one of the reasons some students seek out the University of Toronto, specifically: "We need to continue to challenge stigma and systemic barriers despite the inevitable future pressures that may push us towards cynicism/losing hope" (resident comment, 2019; program documentation).

### **Concretizing processes and roles to ensure the sustainability of structural changes**

The formalization of committee member roles, leadership positions, and remuneration agreements and processes has been described as key for the success of this initiative — both for ensuring the program's sustainability and, again, signalling its value, importance, and legitimacy within the larger institutional structure. Organizers emphasized the importance of having formalized structures, paid positions, and

involvement that follows the same rigour as other traditional university jobs and processes — which are also seen as central to the program’s sustainability.

Formalizing service user committee leadership roles was considered particularly important in this regard, as was formalizing payment processes and remuneration agreements:

By building this collaboration with careful consideration of such issues as paying honoraria to service user collaborators to support and acknowledge their work . . . and sharing power by creating a service user lead and co-lead role within the collaboration, we aim to create a model that can serve to catalyze other forms of meaningful involvement of service users in education, research, and mental health services at the University of Toronto and elsewhere. (program information)

### **A commitment from leadership toward meaningful engagement and co-design**

To a certain extent, the creation of the service user committee stemmed from the desire among department leadership to more meaningfully involve people with lived experience in psychiatric resident training. In fact, from its early stages building and sustaining the initiative has been helped by a combination of leadership support and a commitment among champion leaders toward such engagement and collaboration:

The last thing people want is you creating a program without their input and then going to them and telling them they should adopt it or buy into it. Its all about co-creating from the very very beginning. I love the story about the CaRMS initiative because we held a town hall and just let people talk . . . that’s my number one piece of advice — involve stakeholders early. From the very beginning, they need to be involved. (interviewee)

Interviewees emphasized the importance of having a strong leadership commitment to collaboration and meaningful engagement — and to avoiding tokenism — for the program’s success:

If collaboration is not done in a genuine way, it’s nothing more than virtue signalling. If it’s done really well, it can signal the potentialities for people, not just service users, but also people who want to be residents in the department. (interviewee)

## Centering Madness Course: Building Capacities for Community Engagement

Initiated in 2017, Centering Madness: Building Capacities for Community Engagement is a mandatory course for first-year University of Toronto psychiatry residents. The course was designed and developed — and is [taught](#) — by mental health service users. It is the result of a partnership between the [Empowerment Council](#) at the Centre for Addiction and Mental Health (CAMH), the University of Toronto’s department of psychiatry, and the school of disability studies at Ryerson University (Toronto).

The curriculum for Centering Madness builds on the expanding field of scholarship known as “Mad Studies,” which applies a social justice-informed critical lens to the dominant paradigms and ways of understanding mental health and illness. The course also draws from academic and activist work on disability, critical race, and queer theory, and uses the theory of intersectionality to more deeply engage the complex ways service users experience injustice across varying identity categories. As such, it exposes students to frameworks linked to both patient experience and service-user scholarship, which provides them with skills and perspectives they are likely to have never encountered in previous medical training.

Residents take Centering Madness during the “transition to discipline” month of first-year psychiatric education, where they attend up to four classes each day while also spending time at their home sites. Centering Madness is co-taught by two instructors and includes a series of guest speakers. More important than their individual experiences with the mental health system, the instructors have strong backgrounds in service user advocacy, inclusion movements, and mad studies scholarship. This lens is important because it emphasizes the rich history of service-user organizing and theory building. It also challenges the assumptions that prioritize clinician expertise over lived experience (including knowledge stemming from scholarship). Taught over four three-hour classes, the learning objectives of Centering Madness are to

- introduce the perspectives, knowledge and community organizing of mental health service users;
- identify how power and privilege play a role in the mental health system and psychiatric practice;
- address the impact of gender, race, class, ability, and sexual orientation and how each has affected the experiences of people with mental health issues;
- explore opportunities for engagement and solidarity work with service users;
- centre service user voice and epistemology. (course syllabus; program documentation)

Classes are designed to be interactive, and students are required to complete a series of reflection exercises (as homework) as well as a final (graded) assignment. That assignment gives instructors an opportunity to offer feedback, both on how well each resident engaged with the material and where their capacity for engaging with service users has room to grow (from a perspective that is equity seeking and acknowledges power dynamics).

## Key features that make Centering Madness an innovative example for addressing structural stigma

### **A commitment to teaching ‘difficult knowledge’**

The curriculum of Centering Madness is considered a form of “difficult knowledge,”<sup>8</sup> as it challenges entrenched, dominant beliefs and paradigms while privileging theoretical and epistemological frameworks that may be emotionally uncomfortable and intellectually challenging for residents:

You have this beautiful kind of rubbing up of two different starting points of knowing, and two different bodies of knowledge and how to begin to integrate and make sense of how those things come together. The course is designed to advance an understanding of that terrain through reading, writing and reflection, but it’s an uncomfortable terrain, I think. (interviewee)

To note one example, the curriculum confronts the ways in which foundational medical training and the field of psychiatry have historically contributed to a legacy of harm and mistrust among service users, including how power dynamics tend to disadvantage more marginalized people during clinical encounters.

### **Leveraging disruption for growth and learning**

Given the difficulty and discomfort of the content, the course can (and has) prompted resistance from both students and faculty. Departmental leadership has, however, remained committed to the course and its delivery model, even in the face of such push-back:

The course is designed to make people feel uncomfortable [and] early on, the feedback we got was essentially, “This is not psychiatry. We don’t need to know this. This is a waste of time, why are you having non-psychiatrists teach us?” . . . The course was under a lot of heat and pressure. (interviewee)

To better understand where and how residents were experiencing difficulties, the department commissioned an external course review in 2018. The results confirmed the course’s importance to resident training, recommending that the department “maintain or increase institutional support for the course and course instructors as a way to authorize the importance of thinking critically about psychiatry” (program documentation). The report also provided suggestions for how the course could be adjusted to address students’ concerns.

Interestingly, in its most recent year (2020), there was a noticeable shift in receptivity: resistance not only disappeared, residents expressed an interest in having more modules and classes. Such a change provides an opportunity to expand the Centering Madness curriculum:

Every year there was some version of “I like this but its too much or we don’t want or don’t need it.” This year was the first year where we heard, “Why do we only have four sessions?” Now they want more. . . . So now we are wanting to find a way to expand . . . to weave it throughout their residency. The trick is to really find a way to make it a lived practice. That they can keep working over and over. Make it part of the fabric as opposed to some side thing we made them do. (interviewee)

Broader generational and societal shifts were highlighted as possible reasons why students’ reactions were so different in 2020. The increased receptivity was not generally believed to be the result of improvements to the course\* but rather to shifts in the students themselves.

Although there have been different iterations over the years, the iterations don’t explain the change in acceptance for the Centering Madness course. My best guess is that it is connected to larger societal shifts. . . . People are just ready to think about those issues differently. And to appreciate that . . . we have a broader societal need to destigmatize mental illness within the country. And also destigmatize it within the department. (interviewee)

### **Embedding service-user epistemology and knowledge in formal education and training processes**

A key strength of the course is that it tackles many problems that characterize efforts to include people with lived experience in education and training — problems such as tokenism, power imbalances, lack of compensation for time and expertise, and “after the fact” consultation and input.

For one, both the design and delivery of Centering Madness is fully service-user led. The course is also a mandatory part of residency training. As such, instructors are given formal employment contracts for teaching and administration, and guest speakers receive honorariums. In addition, each student’s course grade goes into their residency file, contributing to their overall evaluation within the program:

Unlike other initiatives that aim to “include” service users, this course moves beyond mere insubstantial inclusion of service-user perspectives. Our goal has been to consistently push medical education to foster and drive legitimate leadership by service users (as opposed to service users being led by clinician agendas) and, in so doing, push for more critical thinking and commitment to improving practice, policy, and ethics surrounding the engagement of service users. (program documentation)

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\* Although it was thought that delivering the course virtually (due to COVID-19) may have offered students a “safer” way to engage with the content.

Significantly, the strength and work of the Empowerment Council was identified as an important ingredient in setting the foundation for this model and approach:

The teaching we are doing at the U of T initially has come through the Empowerment Council. . . . When speaking of structural stigma, it is important to recognize that work to address institutional discrimination/prejudice has been going on for a very long time by service users, and our work at the Empowerment Council has done things like develop a bill of rights at the hospital, intervened in court cases, conducted research, and worked to challenge institutional or community practices that discriminate against people with psychiatric disabilities, for example. (interviewee)

As such, Centering Madness is always connected to community stakeholders and service users outside of the university.

## Adult Neurodevelopmental Stabilization Unit (ANSU) Dual Diagnosis Program

The adult neurodevelopmental stabilization unit (ANSU), formerly Emerald Hall, is a nine-bed unit at the Nova Scotia Hospital in Dartmouth that provides in-patient care and community transition support to patients living with a dual diagnosis of intellectual disability and mental illness. In 2016, ANSU Emerald Hall underwent what has been described as a “wholesale transformation” of their model of care when it shifted from a primarily custodial approach to one that prioritizes recovery-oriented principles and positive behavioural care.

The structural improvements implemented were instigated by an identified need for change, including quality care concerns and dissatisfaction among family members and staff. According to an interviewee, there were “signals that our [old] care model was failing our patients. . . . This led our senior leadership to look at the structures, and it was recognized that things needed to change.”

The new model emphasizes alternative behaviour management practices to

- reduce the frequency and duration of restraint and restrictive practices
- develop functional behaviour assessments and treatment plans
- increase collaboration with health and community agencies (to support a positive and holistic approach to care)
- put more emphasis on the engagement with family members.

The restructuring and model change has led to an overall improvement in the quality of care. This includes dramatic reductions in the use of restraints and restrictive practices, more interdisciplinary activities for patients (e.g., swimming, community outings, camps, patient and family barbecues), improvement in quality of life metrics (e.g., access to the community, improved structure and routine), and shorter lengths of in-patient stays. Also improved were collaborations with substitute decision makers (e.g., a patient's family member), staff morale, and co-operation among staff and with community partners.

## Key features that make the dual diagnosis program an innovative example for addressing structural stigma

### A commitment to making large-scale structural changes

In adopting its new model of care, the program had to undertake several staffing and organizational changes, which required a commitment from leadership, along with passion and perseverance to navigate the change process.

The main structural changes included the following:

- Staff changes that involved a switch in direct care provision from developmental workers and licensed practical nurses to registered nurses and therapeutic assistants. A board-certified behaviour analyst, an occupational therapist, and a recreational therapist were also added.
- Modifications to patient individualized care plans that included identification and modification strategies for early intervention, individualized pro re nata (PRN) (i.e., when required) medication protocols (alongside behavioural strategies), positive behaviour support plans, post-incident team debriefs, and additional team meetings to address emerging concerns.
- The establishment of front-line and clinical “core teams” to improve and promote consistency in practice.
- Ongoing staff training to build knowledge, capacity, and accountability; reduce the use of restraint and restrictive practices; and increase the understanding of policies and procedures.
- The implementation of regular practice and policy reviews and meetings, including reviews of relevant policies at staff meetings.
- The inclusion of patients and family members/substitute decision makers (SDMs), i.e., the people making decisions for patients) in regular care-planning meetings.
- Increased education to, and collaboration with, governmental and residential agencies.
- Increased educational opportunities for medical students, psychiatry residents, nursing students, and allied health students.
- Improved use of space such as having multiple rooms available for patients with autism spectrum disorder, a strategy that helps reduce stimulation and sensory feedback (lighting, noise, etc.) and reduce the likelihood that a behaviour of concern will occur.
- The implementation of a “kudos” program for staff to help change from a culture of negativity to one of mutual support and positive acknowledgement.

*[Family members/SDMs] are given a voice. [Including them in care-planning meetings] has also helped reduce the self-stigma that existed with the dual diagnosis population. More SDMs and family members are participating in care planning and other social events that are jointly organized for the patients and families. This has fostered better trusting relationships between our program and the SDMs.*

*— interviewee*

In describing the response to the kudos program, one interviewee noted that “the staff are very excited to see the cards, and it is motivating and inspiring. We also check in with staff to see how they are doing and to see if they need support. It has really changed morale.”

Early engagement from staff and family members was central to setting the direction of these systemic changes and the overall success of the process. An experience-based co-design project was initiated in 2016, which involved interviewing front-line staff, management, and family members/SDMs to learn about their experiences, expectations, and the changes they would like to see. A steering committee was then put in place, consisting of SDMs/family members, allied health staff, physicians, and management, to review reports and provide direction and recommendations.

### **Taking a thorough approach to education and engagement**

Ongoing education across multiple stakeholder groups — including program staff, other hospital staff, community partners, and family members — has been crucial for the success and buy-in of the new model of care. It remains a central strategy for ensuring the model's wider adoption and the culture shift in caring for people with a dual diagnosis of intellectual disability and mental illness.

To build capacity and scale up their work, the team also expanded this new model to other organizations and settings such as residential treatment centres.

Medical students and psychiatry residents have also benefited from educational opportunities provided by the unit's psychiatrists:

We've been doing clinical trainings which include classroom teaching and clinical placement for psychiatry residents, who have now shown more interest in working with this population, and so we have better outcomes now when our patients present at the ER. There is more of a collaboration now due to this capacity building. (interviewee)

### **Ongoing performance measurement and tracking**

Tracking and measurement provide important feedback for ongoing quality improvement and evaluating the impact of the structural and cultural changes undertaken in the dual diagnosis program. Key metrics include the use of restrictive practices, the rate of self-injurious behaviour by patients, and incidents of aggression to staff/others — all of which have shown substantial reduction since the new model's implementation. Patient transition to community living is another success indicator, as is improvement in staff morale. The following observations reflect some of the improvements from the new model of care:

Prior to the commencement of this initiative in 2016, four of the patients at Emerald Hall required 2:1 constant observation for 12 to 24 hours daily. Among these four, two have been completely weaned off their 2:1 constant observation and one has been successfully placed in the community within the first year. As of today, all patients have been taken off 2:1 constant and three of them have been successfully placed in the community. (program information)

Reviews of the use of restrictive practices . . . over a period of six months to 24 months show significant downward trends in the frequency of use. The use of ERC [emergency restraint chair] and Pinel restraints have declined to zero for several months, and the use of all forms of seclusion very rare. (program information)

ANSU Emerald Hall had a certain reputation and it was not a place where RNs wanted to work. . . . So much of this has changed due to the team and developing pride in their speciality . . . staff have reported feeling proud about working at on the unit. (interviewee)

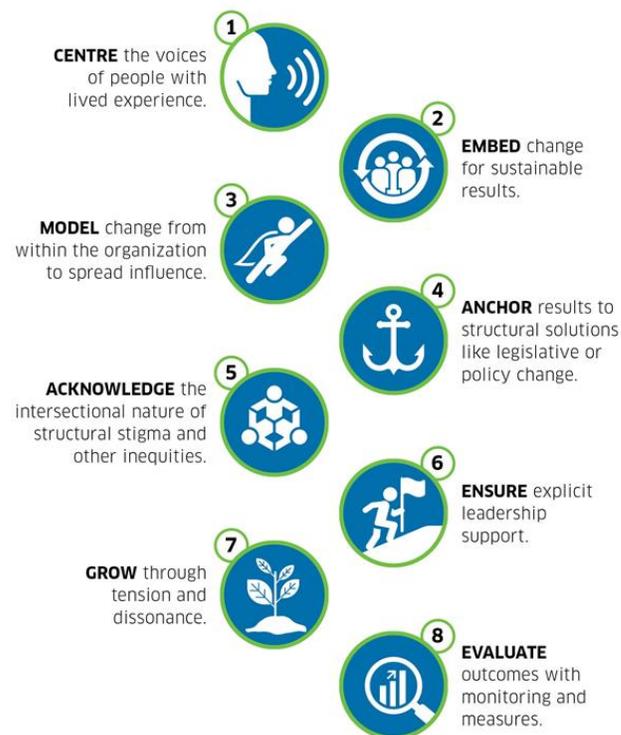
# Summary and Conclusions

The initiatives described in this report illustrate how combating mental illness- and substance use-related structural stigma in health care is a complex and multilayered endeavour, which can be targeted through multiple intersecting avenues and approaches. These include:

- focusing on education and training approaches that are embedded and ongoing, and which prioritize the voices and perspectives of people with lived experience
- implementing approaches to care — that provide high-quality evidence-based care that is holistic, culturally safe, client centred, and recovery oriented — which are guided by the perspectives and input of people with lived and living experience of mental health and substance use problems
- working to change laws and policies that are inequitable and unjust, and that negatively impact the experiences of care for people with mental health and substance use problems and, in many cases, violate their human rights
- building and formalizing models of shared leadership to ensure that the people the organization is meant to serve have a meaningful role in influencing its decisions, outcomes, and direction
- focusing on the intersecting nature of structural stigma by addressing the needs of population groups that face multiple stigmas and intersecting experiences of marginalization.

In addition to these approaches, several common themes emerged from these initiatives both in terms of key enablers or ingredients for success and barriers and challenges.

**Figure 1. Keys to Combating Mental Illness- and Substance Use-Related Structural Stigma**



First, all selected programs strongly emphasized how important supportive leadership and passionate champions were to their success and sustainability of their initiative. Recognition that leaders have structural power and are key ingredients for addressing structural stigma is crucial. Some interviewees said their initiative would simply not have even been possible without these two key ingredients:

[Name] is the heart and soul of this project and has been challenging our systems. We have run into bumps and hurdles, but with [name's] passion, we are challenging the status quo. . . . And we also could not have done it without strong support from [name] from hospital leadership. (Biigajiisakaan interviewee)

From my experience, the site must be willing, and the front-line staff have to have identified a need. To implement this in a site that wasn't willing would be very difficult. Must be a clinical need and support from leadership. . . . Kudos to our hospital leadership. (ARCH interviewee)

Second, all programs prioritized the meaningful participation of service users, community members, and stakeholders in the design, delivery, and/or governance of their initiative. Many indicated that committing to shared leadership models and meaningful involvement was itself an act that challenged structural stigma because it represents a fundamental shift in how to think about the design, delivery, and management of health care for people with mental health or substance use problems. It was also commonly recognized that models of shared leadership or other models of meaningful engagement are not without their challenges. In this context, initiatives stressed the importance of a commitment to working through those issues and tensions as they arise:

We figure out the roadblocks along the way and are trusting of the parties we are working with and brave enough to address any barriers that come up along the way. And where there is friction, remember that there a common goal we are all working towards here. Add that the achievement of reconciling differences isn't going to be easy by any means. (Biigajiisakaan interviewee)

It takes a lot of time and a lot of effort to build that rapport. There are good reasons why people are angry and mistrustful and scared. There really has to be active committed attempts to reconciliation. You have to do that slowly to do it properly; there are no shortcuts. (CaRMS interviewee)

Our course is designed, taught, and controlled by service users and is supported by people who have resources, which is the department of psychiatry. That's what is unique about this course. But when speaking of structural stigma, which is a new phrase, it is important to recognize that the work to address institutional discrimination/prejudice has been going on for a very long time by service users. (Centering Madness interviewee)

Third, programs emphasized the importance of incorporating ongoing education, training, and engagement — as well as role modelling and leading by example — to help facilitate and support wider cultural buy-in to the new model or initiative. They also stressed the importance of education and engagement with stakeholders outside their own walls. In this context they spoke about seeing positive shifts in the larger “culture of caring” in their institutions, organizations, or among their identified stakeholders. They also stressed, however, that culture change requires patience, perseverance, and time, and many acknowledged that there was still a considerable way to go:

Structural stigma is the way that the structures in place reinforce bias. . . . Legislation changes might not change culture but will disrupt the cycle. [That's why we are] working on the cultural piece through education and working on advocacy through legislative changes. We need those key groups, that cultural piece, to be successful. (Health Justice interviewee)

Education, education, education. The education of the management, of the staff, of the community so they have the buy-in. Once they have the ownership of what you want to do. You have to address their fears, their anxieties. And show them where it has worked and why it works and then you will be very successful. (ANSU interviewee)

We have come so far, but we still have such a long way to go, you know, to change the hearts of people. To change the minds of people. (ARCH interviewee)

Fourth, most initiatives described encountering various structural challenges in implementing their programs or models of care. More than one program described their experience as “building the plane while flying it,” suggesting that many challenges they encountered could not have been foreseen given the innovative nature of what they were doing. In this context, initiatives recommended that others “dive in” but also to expect challenges; namely, that the system will get in the way, and you will have to find ways around those situations:

This was a difficult change for the organization because we did end up having to replace a whole category of employees. No one likes to see employees lose positions. . . . A lot of stakeholders had to get to the place where they saw that this change was necessary. Had to go through a lot of hoops. (ANSU interviewee)

One of the trickiest things to figure out is payment. You cannot recruit assistance from an underserved community by recruiting them to co-create and then not pay them. But it is difficult to get money into their hands. Working within existing institutional structures, this is not an easy thing to figure out. There’s structural barriers — the university system is not set up to pay them. It is literally hard to get money into their hands. (CaRMs interviewee)

Many initiatives also expressed concerns about long-term sustainability, as their funding was grant based and limited. The uncertainty of being able to secure long-term, stable, sufficient levels of funding was a reality most initiatives had to contend with:

I get operating funds from the department [but there is] never enough money. [Service users] aren’t paid enough for the work they do and the time they put in. . . . I’ve done a combination of penny pinching and saving and siphoning off and collaborating with the people to whom the money will go to help decide how they want it dispensed. (CaRMS and Centering Madness interviewee)

We have funding for three years in the amount of \$1 million. This is not enough. The need is growing for this work, and the work will not be completed after three years. (Health Justice interviewee)

Finally, the importance of undertaking evaluation and other research, setting targets or goals, and monitoring progress was emphasized by the various initiatives. They stressed that the design of evaluations and other research should be done with the input and direction from their various advisory or governance committees. Also commonly noted was that securing funding, and building the capacity to undertake thorough, longitudinal evaluation and research, could be a challenge:

We track process outcomes that we need to report on for our grant (for example, how many consults completed in a year). Longer-term outcomes require more time, investment, and/or effort and require administrative data for finding people that are hard to find after they leave care. (ARCH interviewee)

Future plans are to continue this work and eventually find the time to write a journal paper. We want to connect with researchers who are looking at the impacts [of the course], connect back with service users themselves for knowledge exchange and input. (Centering Madness interviewee)

Overall, the diverse group of champions and changemakers highlighted in this report have gone above and beyond expectations in addressing and responding to structural stigma against individuals with mental illness and substance use challenges in health care. Each initiative provides an example of

innovation that can inspire other organizations toward their own form of change. The case descriptions highlight that leadership support, meaningful engagement with people who have lived experience, structural change complemented with ongoing training, growth through tension, and attention to long-term sustainability and evaluation are key features to consider.

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la santé mentale  
du Canada



## Mental Health Commission of Canada

Suite 1210, 350 Albert Street  
Ottawa, ON K1R 1A4

Tel: 613.683.3755  
Fax: 613.798.2989

[mhccinfo@mentalhealthcommission.ca](mailto:mhccinfo@mentalhealthcommission.ca)  
[www.mentalhealthcommission.ca](http://www.mentalhealthcommission.ca)

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