



Mental Health
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Commission de
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Structural Stigma

Personal Experience Stories

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Access Denied

How structural stigma prevents people with mental health problems or illnesses and/or substance use concerns from accessing the care they need.

Imagine being told to sleep on the hospital floor because no beds are available or seeking a treatment for your illness that's both proven and recommended but unavailable because of a lack of funding and training. People living with mental health problems or illnesses and/or substance use concerns have greater difficulty accessing services compared to the general population, due in large part to resource maldistribution, denial of care, and fragmented care.* To get a better understanding of the topic we explore in [Access Denied – interview-based video](#), we also spoke with Karen Shin and Javeed Sukhera about their first-hand experiences with this issue.

Karen Shin is the deputy chief and medical director of ambulatory mental health services at St. Michael's Hospital in Toronto. Karen told us one of the most disappointing experiences she had last year was telling a service user experiencing treatment-refractory depression that they couldn't access repetitive transcranial stimulation (rTMS), a Health Canada-approved therapy, because it was not publicly funded.

MHCC: *You mentioned how this made you see "with fresh eyes how structural stigma extends implicit barriers and prevents robust mental health services."*

Karen: Well, I've had several service users who've tried to access rTMS. Sometimes

working in an academic centre in Toronto, you can more easily access specific types of care for service users. This itself presents inequities in care in our system, and places smaller communities at a disadvantage. My ability to refer service users to rTMS is generally funded through research clinics. However, my service user did not qualify for a research study, and they do not have money for private access.

MHCC: *What are some of the other ways you've seen inequity in health care?*

Karen: Foundations often get money to pay for devices that have capital expenditure. But people who might feel very comfortable donating money and having their name attached to a magnetic resonance imaging (MRI) machine may not necessarily have the same comfort donating money for some sort of mental health infrastructure or equipment.

Many people are experiencing depression or anxiety, but some might not want medications because of the side effects, and others might need additional treatment beyond medication. When we have another therapy, it's frustrating when the option becomes limited, even though it is something that's shown to be beneficial. I wonder, if other types of physical health treatments were unavailable, would there be such a delay in getting them funded properly?

* Livingston, J. D. (2020). *Structural stigma in health-care contexts for people with mental health and substance use issues: A literature review*. <https://www.mentalhealthcommission.ca/English/media/4348>

Javeed Sukhera is a physician, educator, and activist conducting research in stigma, bias, and equity within the health-care system.

MHCC: *You said you were struck by the systemic prejudice within the health-care system toward people living with mental health problems or illnesses and/or substance use concerns. When did this become clear to you?*

Javeed: I can't say that it was specifically a moment. It's more a gradual accumulation of 1,001 moments over the course of my career. As a Canadian, who has trained and lived outside of Canada, and someone who's revered our health-care system and held it up on a pedestal, I think it was the realization that our system simply isn't fulfilling its promise to people with mental health problems or illnesses and/or substance use concerns. There are systemic issues at play.

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 dehumanization ... that lack of welcoming, I think, is considerably worse within

the systems designed for people with mental health problems or illnesses and/or substance use concerns. 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.

MHCC: *How does this dehumanizing approach affect health-care professionals?*

Javeed: There's this culture of perfection where people are expected to be a fantasy version of themselves. That makes it harder to be vulnerable, and that's a huge problem. So, what we found through our research was that people who work in a system, with high expectations of themselves and one another, were struggling at an emotional level. Their training (and the culture in which they work) didn't really create space and time to honour their humanity and penalizes health-care providers from seeking help. Part of the problem, too, is that people in health care are encouraged to compartmentalize themselves as a means of self-protection. In that effort to armour up to protect ourselves, we're not only potentially causing harm to our own well-being, but also creating problems for equity and access.

Less Than

How people with mental health problems or illnesses and/or substance use concerns systematically receive a lower quality of care.

Structural stigma is expressed when people with mental health problems or illnesses and/or substance use concerns systematically receive a lower quality of care. Three key areas of poor health-care quality are practitioner practices, negative experiences, and coercive approaches.[†] For service users, a lack of meaningful, timely care, centred around the needs of the individual, is a pervasive problem. To get a better understanding of the topic we explore in [Less Than – interview-based video](#), we also spoke with Samaria Nancy Cardinal and Don Mahleka about what quality care means to them, and what progress can look like.

Samaria Nancy Cardinal is a social worker and member of CPSI’s Patients for Patient Safety Canada (PFPSO). She’s spoken with groups of health-care professionals, sharing her experiences of stigma within the health-care system.

MHCC: *You’ve mentioned how, for years, you felt like you didn’t have a voice in how you were being treated. Why is that?*

Samaria: 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. This is one of the many ways the very structure of care needs to change. 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.

MHCC: *Why do you think it’s so important that you share your misdiagnosis and experiences with stigma with health-care professionals?*

Samaria: With the added pressures and impacts of COVID-19, mental health is really failing in this country. People that maybe would have had mild symptoms of mental health problems or illnesses are really suffering right now, and health-care providers lack the necessary resources to manage this crisis. In Alberta, doctors now have 10-minute appointments, unless you are a specialist and can have longer appointments. Doctors are stressed. They want to get in there, write a prescription and move on to the next service user. They don’t want somebody that they have to sit and talk to for a long time because they have multiple issues. If you are referred for mental health care, you could be waiting months to see someone. If you require special therapy, you may be out of luck if you don’t have money to pay for it.

[†] Livingston, J. D. (2020). *Structural stigma in health-care contexts for people with mental health and substance use issues: A literature review*. <https://www.mentalhealthcommission.ca/English/media/4348>

The only way to change that is for people to fight back and say, “This is not working.” Our health-care system needs more resources to provide the quality care that is needed for recovery.

MHCC: *What are some of the ways you still experience structural stigma over your diagnosis?*

Samaria: Within the system, you cease to be a person and are defined solely by your illness. Once, I went to emergency because my heart was palpitating. The first thing the doctor said to me was, “Did you take your medication today?” And I just looked at him and I said, “Now, what is that referring to?” And he says, “Oh, well, I see you have mental health issues.” And I said, “How do my mental health issues connect with the palpitations unless it’s extreme anxiety?” I said, “You never took my pulse or listened to my heart. You are just interested in my mental health?” This can be known as diagnostic or treatment overshadowing: the process by which a person with a mental health or substance use disorder receives inadequate or delayed treatment for a physical condition because it is misattributed to an underlying mental health or substance use disorder. The health-care system’s twin crises of unconscious bias and discrimination need to be named and remedied — with no time to waste.

MHCC: *How do you want this environment to change for the better, so those seeking help don’t go through the same experience you had?*

Samaria: I want to be part of rebuilding a system that puts recovery-oriented practice at its centre. Social workers are taught to look at a person’s upbringing. We understand that recovery is personal and occurs in the context of one’s life. We look at how they developmentally came to the point where they are now, we look at how they were raised in their environment, everything that they’ve gone through in their life. When I see someone sit

down across from me, I will see the person first. Period. I will give them what I was denied: recognition of their humanity. And in that small way, I will be working to rebuild something that’s broken.

Don Mahleka is a community support counsellor at St Joseph’s Healthcare Hamilton’s youth wellness centre. Through his experience of moving from Zimbabwe to Canada and becoming a mental health advocate, Don has seen a lack of understanding within health care as to how racism and colonialism impacts the mental health of Black, Indigenous, and racialized populations.

MHCC: *How has racism impacted your mental health, and what was your experience navigating the health-care system?*

Don: I remember the first couple of times that I experienced racism or discrimination when I had just arrived in Toronto as a refugee in Grade 9. Racism didn’t instantly affect me since it was a new experience I was starting to process and navigate, but it was the increasing amount of time and exposure to it that started to compound my anxiety and depressive symptoms. My single mother and I weren’t ever made aware of mental health/wellness supports despite the high prevalence of trauma and other health indicators in refugees. When you’re in survival mode and navigating your legal rights, you’re pressured to be silent about systemic racism so as not to be seen as a burden. It can look like you have more to lose if you report or stand up for your own rights. At the time, I didn’t have the terminology to really explain it to anybody. I think being disconnected from my culture also took a big toll, especially on my single parent. I also began to internalize a lot of the things that I was being told — the perceptions and assumptions of being a Black male. There can be a lot of toxic stress and constant anticipatory vigilance of racial discrimination.

MHCC: *In your work as a mental health advocate, what have you heard from others?*

Don: Over time, a lot of youth would say things like, “I experience racism on the daily, whether it’s people that are physically aggressive towards me or even threatening to kill me. But I don’t report it because I’ve reported in the past to police or to school administration, and they don’t do anything about it. And quite frankly, a lot of times, I end up being blamed for even reporting it.” Youth have also shared their experiences [with] various systemic racial barriers to accessing mental health supports, over/underdiagnosing, and the coercive practices they’ve endured in trying to navigate the system.

MHCC: *In your opinion, what is missing from the current approach to how people are receiving care?*

Don: There’s a lack of understanding of the intersectional needs of, for example, African, Caribbean, Black youth and diverse Black populations, and systems not being able to recognize or address the impacts of racism. Racism exists in instances of not being able to find good employment or by experiencing discrimination at work and at school. It creates the scenario of not feeling like you belong in these places — for myself as well. It feels like constantly having this imposter syndrome, where you feel like, no matter what you do, you’re never going to be good enough because of the way that you’re perceived and treated. Racism needs to truly be a social determinant of health, especially when it comes to having

appropriate screeners and interventions. We need to have mandated standards of disaggregated race-based data collection and dissemination to better understand racial health disparities. This will also help with making concrete and transparent change management plans. We really need to prioritize and value the cultural knowledge and perspectives of Indigenous, Black and racialized communities, so there’s a paradigm shift in addressing structural racism by having culturally informed practice and collective leadership.

MHCC: *What do you think health-care professionals can do to be a part of the solution?*

Don: Anti-racism work needs to be at the core of health-care organizations and personal development for practitioners. Sometimes diversity, equity, and inclusion (DEI) initiatives are not incorporated as the core of the mission and long-term strategic directions of organizations, and that needs to change. There’s been some positive frameworks to give anti-racism a more equitable focus, so that it doesn’t get lost in the term, DEI. I think it’s also understanding that it’s going to be a journey, that cultural competency isn’t really a thing, it’s more of an ongoing process where we’re always going to be learning and unlearning. For example, for myself, even if I meet someone else from Zimbabwe, I don’t know their story, I don’t know their whole identity. It’s about listening and learning about where they’re coming from, where they are, where they’re going. That’s what’s really important.

A Way Forward

Opportunities to address and dismantle structural stigma.

As important as it is to understand how structural stigma surfaces in healthcare environments, it's equally as important to explore the ways in which structural stigma can be addressed and dismantled. To get a better understanding of the topic we explore in [A Way Forward – interview-based video](#), we also spoke with Rachel Boehm and Amber May LeRoy to hear their experiences and learn more about ongoing efforts to address structural stigma.

Amber May LeRoy is a former employee of CHANNAL (Consumers' Health Awareness Network Newfoundland and Labrador), a non-profit organization created by and for individuals living with mental health and addiction issues.

***MHCC:** What comes to mind when you think of structural stigma?*

Amber: Stigma kind of eats away at you. It takes away your freedom, it takes away your life, it takes away your identity. It just makes you that one thing the stigma says you are. Multiple people that I work with at CHANNAL have also experienced the impacts of stigma and have said, "I got fired from my job because I had to go on sick leave because of my depression," or "Some of my sister's teachers pegged her as that sensitive, overreacting child, when really it was just her anxiety." So, it happens every day, in various settings and at multiple levels. It's a terrible thing.

I also experienced the difficulties of navigating the health-care system. I knew about Kids Help Phone but didn't know about other organizations, such as CHANNAL. I didn't know about walk-in clinics. I didn't know that you could get grants for counselling. I didn't know any of that. 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.

***MHCC:** What changes would you like to see?*

Amber: More resources need to be available for youth, and we need to educate people that are working with youth, whether it be teachers or people in preschool, after school programs, coaches, sports, etc. They need to be taught the right way to see the signs and symptoms of mental illness, how to ask the right questions, and how to offer the right resources and support.

I was so happy to learn about CHANNAL when I did, but also thought, "Well, why didn't I hear about this before? Where were they a few years ago when I needed that help?" I remember getting home that day and calling my mom, being like, "Guess what? There's this place called CHANNAL. Everyone that works there has a mental illness. Everyone is welcome. It's an open-door policy, and you just go there to talk about what it's like to live with mental illness and get help, and there's no judgment." I didn't think it was possible to get help and to be so open about a mental illness. I know lots of people that haven't found an organization like CHANNAL and have died by suicide or have attempted suicide, or have gone to drugs, or still just live at home sleeping all the time because of their depression. There are so many people that have not gotten the help they need like I have, or who don't have the confidence and the motivation to speak about it and reach out. We have to ensure people who need access to services know where to get help. We need to create safe spaces for people to share. I think that would make a big difference.

MHCC: *What can health-care providers do to address structural stigma?*

Amber: There's a lot of pressure on health-care professionals to be problem solvers, and they are trying to do that. 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 and health-care providers should work with service users to develop a recovery plan that aligns with their goals and aspirations.

Rachel Boehm is the director of mental health and addictions at the Nova Scotia Health Authority's central zone.

MHCC: *What is dual diagnosis?*

Rachel: Dual diagnosis refers to having both a mental illness and intellectual disability. If you have Down syndrome or autism or another intellectual disability, you're actually more likely to develop mental illness as an adult.

We have a service in Nova Scotia called [the] Adult Neurodevelopmental Stabilization Unit Dual Diagnosis Program that is available to service users living with dual diagnoses, whether they live at home, with family care providers, or in residential settings such as group homes. We offer accessible services to assist service users with mental illness and often challenging behaviours that are putting themselves, their caregivers, and housing at risk. Sometimes service users can receive the treatment they need in the community, while others need to be admitted to hospital for stabilization. Our approach prioritizes recovery-oriented principles and positive behavioural care.

MHCC: *I understand you've been working on a project to transform the acute care unit serving people with dual diagnoses in your area. How has it changed?*

Rachel: There was a lot of family dissatisfaction with care, and there were a lot of safety incidents happening. I think that really caused everyone to stop and say, "Something is not right." We weren't seeing the positive indicators that you should see when you're working with people with a dual diagnosis, which would be people getting admitted quickly when they need to receive treatment to address illness and/or symptoms and return to their place in the community.

The team went through 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. For example, the team made a lot of changes in the way they work with families. So they really brought the families on board starting from the beginning. We needed more registered nurses involved in leading the care of each service user, and we needed a support role that was highly trained, specifically in therapeutic interventions. Everything we do with a service user now is therapeutic. And the goal is to build their capacity and independence. A psychiatric hospital is not a place to live because everyone deserves to live in the community, and that's our goal for every person. It's probably been the highlight of my career just to see how different the care is now and the impacts of that care.

MHCC: *What advice would you share with other decision makers in the mental health space?*

Rachel: When I started this work, it was not an area that was talked about — this particular unit. And I think what I learned was, it's often the areas that nobody's talking about that you probably need to look at the most. Silence on any topic can be a sign of stigma. It could mean that everything's fine, but it could also be a warning that nobody's paying attention or that the needs are so unmet that nobody even knows they exist.



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

Tel: 613.683.3755
Fax: 613.798.2989

mhccinfo@mentalhealthcommission.ca
www.mentalhealthcommission.ca

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