CANADA AWARDS FOR EXCELLENCE
PRIX CANADA POUR L'EXCELLENCE
2020
ORDER OF EXCELLENCE RECIPIENT MENTAL HEALTH AT WORK
RÉCIPIENDAIRE ORDRE DE L'EXCELLENCE SANTÉ MENTALE AU TRAVAIL

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

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

James D. Livingston, PhD
Associate Professor, Department of Criminology
Saint Mary's University, Halifax, Nova Scotia

Mental Health Commission of Canada
mentalhealthcommission.ca

Ce document est disponible en français

Citation information

Suggested citation: Livingston, J. D. (2021). *A framework for assessing structural stigma in health-care contexts for people with mental health and substance use issues.* Ottawa, Canada: Mental Health Commission of Canada.

ISBN: 978-1-77318-208-7

Legal deposit National Library of Canada

Health Canada Santé Canada

The views represented herein solely represent the views of the Mental Health Commission of Canada. Production of this material is made possible through a financial contribution from Health Canada.

Contents

Executive Summary

Research consistently identifies the health-care system as a significant contributor to stigma for people living with mental health and substance use issues. Structural stigma surfaces for them when policies and practices produce inequitable access and lower quality of care they experience. A necessary first step for addressing structural stigma is to assess its severity, which entails determining how it materializes, how it varies between populations and sites, and how it changes over time.

The framework presented in this report outlines concrete steps for documenting the nature and severity of structural stigma in health-care contexts for people with mental health and substance use issues. Drawing from a review of existing literature, the report summarizes the assessment domains, methodological considerations, and data sources.

The framework includes six major components:

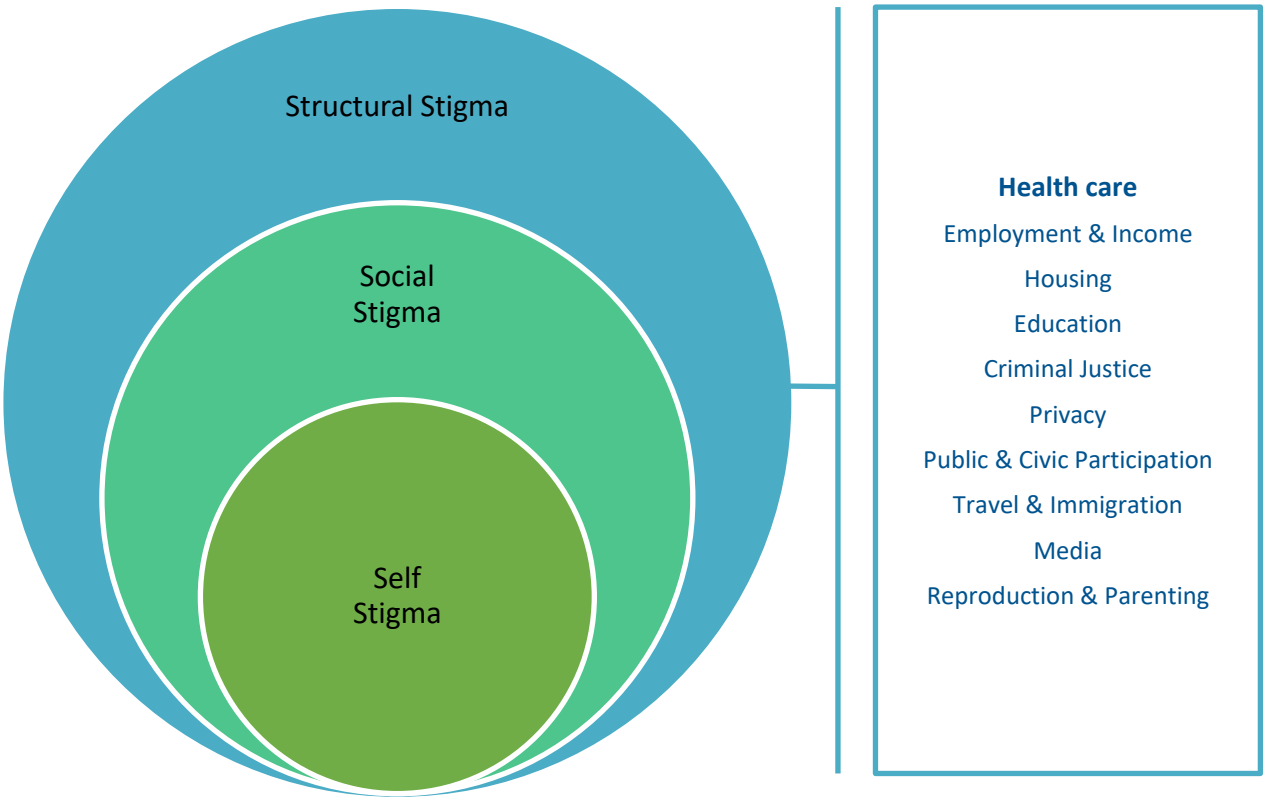
- assessing and monitoring health care-related structural stigma across multiple domains, such as inequitable resource distribution, the denial of care, fragmented and poorly integrated care, negative practitioner practices, adverse health-care interactions and experiences, and an overrreliance on coercive approaches
- using methodological approaches that are participatory, multi-method, and longitudinal
- attending to intersectional stigma, multiple levels of the health-care context, and the effect of structural stigma on health outcomes
- gathering information about structural stigma from major data sources, including people with lived experience, health-care providers, health-care institutions, health insurers, governments, and legislation and legal systems
- learning from existing projects, programs, and initiatives already developed that have implemented methods, tools, and approaches to assessing elements of structural stigma
- embedding structural stigma assessment initiatives within a broader strategy that is working toward transforming systems, thereby ensuring that assessment processes are linked to action

Tangible efforts must be made to reduce the stigma-driven barriers and inequities that interrupt people's access to quality health care. Accurately assessing the problem will ensure that anti-stigma efforts and resources address the most urgent and serious problems.

Structural stigma

Structural stigma refers to the inequity and injustice rooted in the rules, policies, and procedures of social institutions. Negative stereotypes and discrimination are enshrined and reinforced in laws, the internal policies and procedures of private or public institutions and systems, and the practices of professionals and decision makers. Across multiple life domains, people with mental health and substance use issues must contend with arbitrary restrictions on their rights and opportunities — even in countries with advanced legal protections against discrimination, such as Canada. Structural stigma manifests in health care, employment and income, housing, education, criminal justice, privacy, public and civic participation, travel and immigration, the media, and reproduction and parenting.[1] Stigma cannot be eradicated without addressing structural stigma.

Figure 1. Levels of Stigma



Introduction

Structural stigma in health-care contexts

Research consistently identifies the health-care system as a significant contributor to stigma for people with mental health and substance use issues. This system contributes through its production of structural stigma, which worsens health outcomes and is a fundamental cause of population health inequity. Among people living with mental health and substance use issues, structural stigma fosters unmet needs, delayed help seeking, and treatment withdrawal. Consequently, scholars recommend that the health-care system be given high priority in any effort to reduce structural stigma.

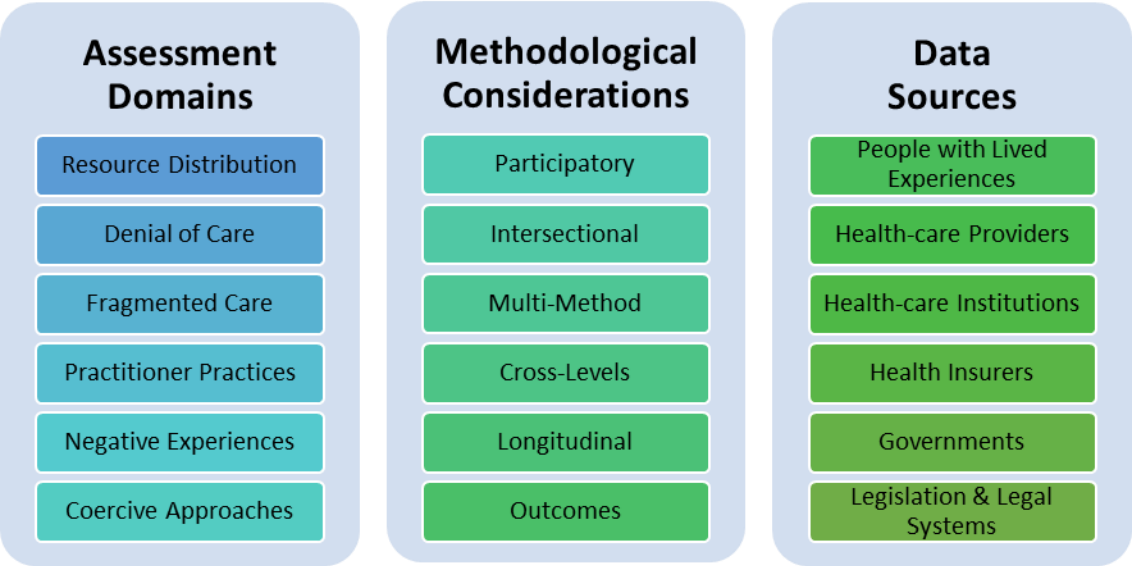
As an earlier report discusses in detail,[2] structural stigma in health-care contexts focuses on two key issues: access and quality. For people living with mental health and substance use issues, such stigma surfaces when policies and practices lead to inequitable access and a lower quality of care. Both issues therefore inform the assessment framework described in this report.

Assessing structural stigma

The current report summarizes the methodological options and approaches for documenting structural stigma while assessing how it changes over time and varies between groups and health-care contexts. It extends the ideas presented in three 2020 reports developed in partnership with the Mental Health Commission of Canada.[3-5] In particular, it extracts pertinent information gathered and synthesized from the literature for *Structural Stigma in Health-Care Contexts for People with Mental Health and Substance Use Issues: A Literature Review*.[6]

Figure 2 provides an overview of the assessment domains, methodological considerations, and data sources for assessing structural stigma in health-care contexts while showing the complexity with which it weaves its way through the system.

Figure 2. Structural Stigma Assessment Framework for Health-Care Contexts



Numerous tensions exist within this assessment framework, which tries to bring together knowledge from different epistemologies, multiple disciplines, and diverse communities. The topic also spans different fields (e.g., stigma, health-care quality, health equity, disability rights) and involves people from distinct roles (e.g., researchers, administrators, advocates/activists, persons with lived experience), who view structural stigma through unique lenses. Consequently, divergent perspectives exist about the purpose and goal of assessing structural stigma (e.g., advocating for rights, improving health outcomes).

Why assessment matters

A necessary first step toward addressing structural stigma is to document it, "thereby exposing the prevalence and perniciousness of the phenomenon" (p. 32).[7] Assessing and monitoring structural stigma are required to understand its severity, how it materializes, how it varies between populations and sites, and how it changes over time, as Knaak and Ungar (2017) succinctly articulate: "The main purpose . . . would be to make visible the aspects of structural stigma that are often hidden in health care, allowing them to be identified, addressed, and corrected" (para. 3).[8] Routine monitoring of structural stigma may promote a cultural shift whereby health-care organizations become more aware of the structural barriers facing people with mental health and substance use issues, a process that connects to the concept of structural competency.[9]

Stuart and colleagues (2012) argued that the paradigm for anti-stigma projects had moved beyond the goal of improving knowledge and attitudes through public awareness and education initiatives (i.e., social stigma) and into the process of removing structural barriers and inequities (i.e., structural stigma).[10] Accurately diagnosing the problem ensures that the efforts and resources aimed at reducing structural stigma address the most urgent and serious problems, which in turn helps health-care administrators find and prioritize the policy areas needing improvement. Assessing and documenting structural stigma also builds evidence that can help communities advocate for change and garner support from policy makers. Assessment without action achieves little. So initiatives to address structural stigma must be part of a broader strategy with sufficient resources and authority to transform systems.

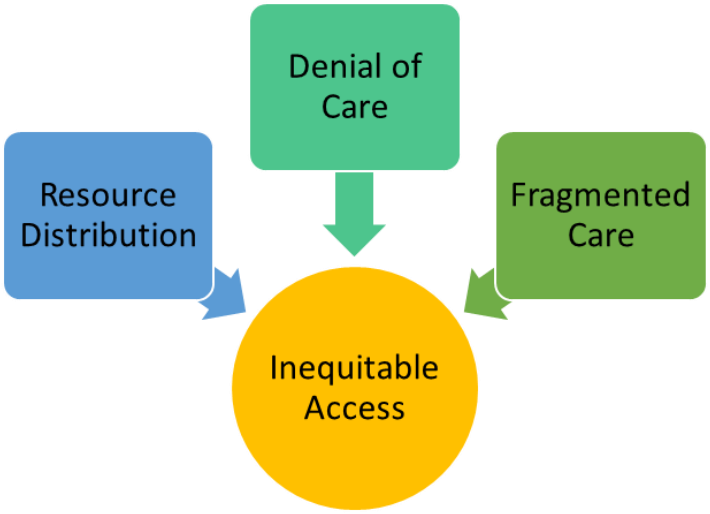
Assessment domains

As mentioned, for people with mental health and substance use issues, structural stigma in health-care contexts relates to two key issues: their access to and quality of health care. These in turn supply the recommended domains for assessing structural stigma.

Inequitable access

People living with mental health and substance use issues have greater difficulty accessing health-care services, compared to the general population. In part, this difficulty occurs due to practitioner- and system-related matters, which discourage them from accessing the care they need. A previous report[11] identified the three major areas of inequitable access depicted in Figure 3a.

Figure 3a. Assessment Domain: Inequitable Access to Health Care



Assessment efforts must incorporate indicators of resource distribution that measure the nature and severity of under-resourcing for mental health and substance use services as well as issues with health insurance coverage. This would include evaluating how governments, health insurers, health research funders, and health-care institutions distribute funding.

Structural stigma assessment efforts must also incorporate indicators that measure how people with lived experience are deprioritized, undertreated, and otherwise denied access to health care. This kind of treatment often manifests during interactions with health-care practitioners (e.g., through diagnostic and treatment overshadowing[*]). But it arises as well when people with mental health and substance use issues are denied access to preventive and routine care (e.g., vaccinations, cancer screening) or are rejected or excluded from health-care services. Systemic inequities can also be seen in the absence of mental health and substance use indicators in health-care quality performance measures. In fact, the degree to which health-care systems fail to include and involve people with lived experience in governance processes, service delivery, and care planning can itself be thought of as an indicator of structural stigma.

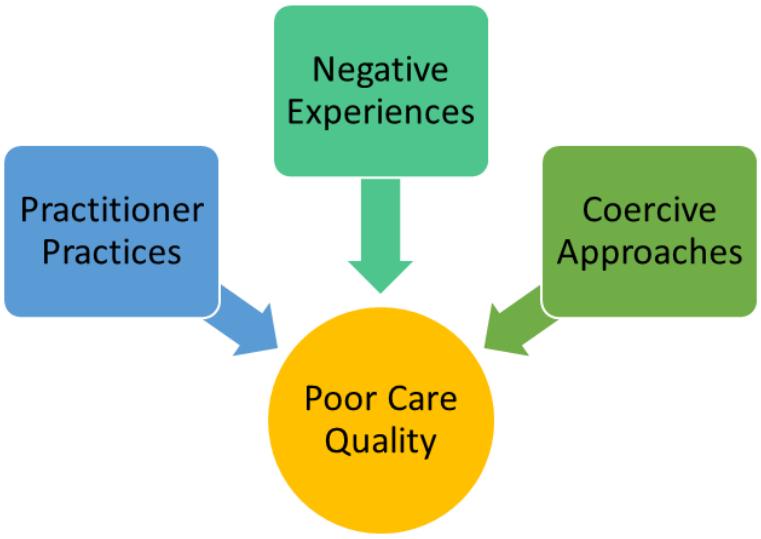
[*] That is, practitioners' failure to identify and diagnose health issues for people living with mental health and substance use issues as a result of ignoring and overlooking physical health concerns.

The third subdomain under inequitable access pertains to the systemic separation of mental health, substance use, and physical health services. Assessment efforts should incorporate measures to reveal the structural issues that contribute to fragmented and poorly integrated health care for people with mental health and substance use issues. This includes the structural separation of mental health, substance use, and physical health-care services as well as inadequate professional competencies among health-care providers to meet the holistic health needs of people with mental health and substance use issues.

Poor quality

Structural stigma is expressed when people with mental health and substance use issues systematically receive a lower quality of care. The stigma associated with these issues has a detrimental impact on the quality of health-care services people with lived experience receive. This influence has been referred to as one of the most pernicious and powerful forms of structural stigma. A previous report[12] identified three key areas of poor health-care quality, depicted in Figure 3b.

Figure 3b. Assessment Domain: Poor Quality of Health Care



In the health-care context, structural stigma most commonly manifests in the realm of professional practice, including the unwritten procedures and practices of health-care practitioners and administrators that express organizational culture, resources, and policies. It is recommended that efforts to assess structural stigma incorporate indicators for the attitudes of health-care providers and administrators as well as for stigma-producing practices. These include:

- diagnostic and treatment overshadowing
- non-caring and unhelpful behaviours
- paternalistic and non-collaborative approaches
- withholding information and services
- using task-oriented and depersonalized practices
- excluding or rejecting people from services

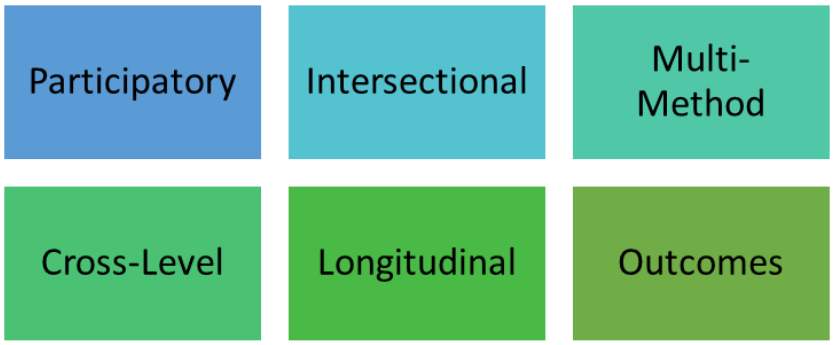
Adverse interactions and experiences are a second key subdomain for assessing poor quality health care for people with mental health and substance use issues. This includes situations in which, as a result of stigma, people have been disrespected, uncared for, devalued, disregarded, excluded, infantilized, insufficiently informed, and overhastily diagnosed and medicated in (a range of) health-care settings. Such experiences discourage help seeking and undermine the effectiveness of the care people receive.

The third subdomain of poor quality health care pertains to the health-care system's overreliance on coercive approaches. It is recommended that assessment efforts monitor the frequency with which involuntary and compulsory forms of care, such as involuntary hospitalization and community treatment orders, are supported and used. Policies and resources that promote the interaction between people with lived experience and criminal justice authorities or security officers — including hospital security staff, police-involved crisis response teams, mental health and drug courts, prison-based mental health care, and forensic mental health programs — should be conceptualized and tracked as indicators of structural stigma. Other important indicators in this subdomain include the provision and availability of rights-based information, policies enshrining individual rights (e.g., patient charters), legal and advocacy services, grievance processes, and recovery-oriented/person-centred care.

Methodological considerations

The literature highlights a number of important methodological considerations for assessing health care-related structural stigma for people with mental health and substance use issues. A significant resource for this section (and elsewhere in this report) was the comprehensive and insightful guidelines developed by Mitchell and van den Hof (2018)[13] to measure tuberculosis-related stigma. As depicted in Figure 4, an assessment framework's methodological approaches must be participatory, multi-method, and longitudinal and must also attend to intersectional stigma, multiple levels of the health-care context, and health outcomes.

Figure 4. Methodological Considerations for Assessing Structural Stigma



Participatory

A key ingredient of any stigma-related initiative is ensuring that people with lived experience are integral to its design and implementation. Assessing structural stigma is no different. People with lived experience, and the groups and agencies they lead, must be meaningfully involved in efforts to document and track structural stigma in health-care contexts. Such initiatives will include selecting meaningful indicators, choosing appropriate methods, gathering and analyzing data, interpreting and reporting findings, monitoring change, and making and implementing recommendations.[14] Ideally,

existing advocacy agencies, peer support teams and organizations, and patient empowerment or advisory committees led by people with lived experience should be funded and supported to drive structural stigma assessment efforts.[*]

Intersectional

Across multiple social contexts and life domains, structural stigma specific to mental health and substance use issues conspires with other forms of oppression, such as racism, classism, sexism, 2SLGBTQ+-phobia, and colonialism, to shape people's lives, resources, and opportunities — including their access to and experiences with the health-care system. When assessing structural stigma, it is essential that active and focused efforts examine how inequities (e.g., barriers to care) disproportionally affect people with mental health and substance use disorders, who face intersecting forms of stigma. Assessment efforts should draw from current methods for documenting and analyzing health-related intersectional stigma;[15] for example, the strong intersectional analysis of structural stigma in the investigation of anti-Indigenous racism and discrimination in British Columbia's health-care system.[16]

Multi-Method

Given the complexity of structural stigma, assessing it through multiple research methods and data collection approaches is recommended.[17] Doing so would include using a range of quantitative, qualitative, and mixed method designs. Quantitative methods are suitable for examining patterns in large data sets, analyzing change over time, making comparisons between groups and settings, identifying factors that moderate and mediate structural stigma, and empirically linking structural stigma to health outcomes. Qualitative methods are appropriate for gaining a deeper understanding of people's experiences, exploring the cultural context that contributes to processes that reinforce structural stigma, and documenting phenomena that may be challenging to measure quantitatively (e.g., clinical practices, intersectional stigma). Smaller-scale surveys (e.g., patient experiences of care in a hospital), larger-scale surveys (e.g., national experiences of discrimination), interviews and focus groups involving people with lived experience and practitioners, and naturalistic observation of clinical settings and practices should be used to produce diverse types and levels of information pertaining to structural stigma in health-care contexts.

Cross-Level

Structural stigma is located at the macro-level. It differs from self-stigma and social stigma, which are located at the micro- and meso-levels, respectively. Fracturing the macro-level into multiple sublevels, as is depicted in Figure 5, helps expose the unique structural elements (i.e., policies/laws, models, practices) that contribute to structural stigma in distinct ways. Structural stigma assessment efforts should measure and monitor how inequitable access and poor health-care quality are both shaped by stigma located at different levels of the health-care system.

[*] Community-based participatory research approaches are well suited to meaningfully involve people with lived experience in assessing structural stigma.

Figure 5. Assessing Structural Stigma Across Levels [18]

From "Improving the Quality of Health Care in the United Kingdom and the United States: A Framework for Change," by E. B. Ferlie and S. M. Shortell, 2001, *Milbank Quarterly, 79*(2), p. 284 (https://doi.org/10.1111/1468-0009.00206). Copyright 2001 by John Wiley and Sons, Inc.

Indicators should identify how structural stigma manifests in the attitudes, knowledge, skills, practices, and composition of health-care practitioners and teams. The organizational structures and processes that shape the governance, resourcing, and operation of health-care facilities (e.g., hospitals, clinics) and systems (e.g., regional health authorities) are another level for assessing structural stigma in health-care contexts. More broadly, the regulatory, political, and economic context has relevance for understanding the drivers of structural stigma in health-care systems. A multilevel approach for assessing structural stigma would measure and track how it operates within and across each level.

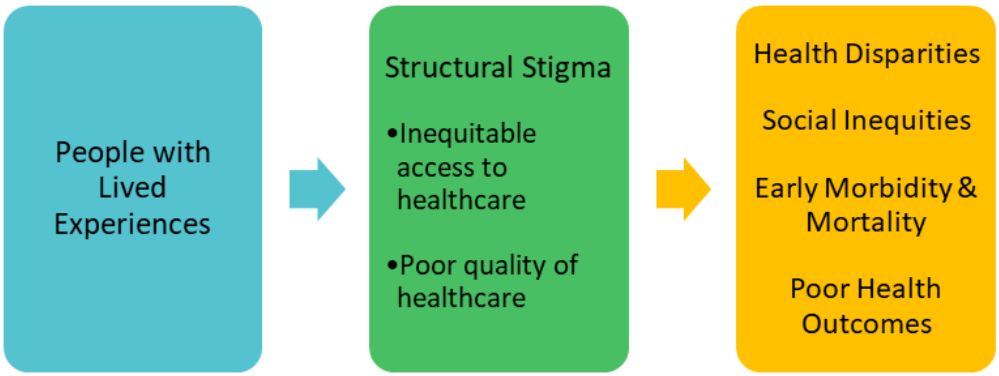
Longitudinal

A principal reason for assessing structural stigma is that doing so provides the opportunity to monitor changes that result from interventions (e.g., initiatives undertaken to reduce it). So longitudinal study designs that incorporate repeated observations over time are the cornerstone of these assessments. Such studies would involve following cohorts or systems to identify structural barriers impeding their access to and engagement with the health-care system. They would also involve routine monitoring of quality indicators to track the performance of a health facility or system in relation to structural stigma. Such longitudinal designs are vital for assessing interventions focused on structural stigma.

Outcomes

An understudied question is how, and to what degree, structural stigma contributes to health disparities, social inequities, morbidity and mortality, treatment avoidance and disengagement, and poor health outcomes among people with mental health and substance use issues (see Figure 6).

Figure 6. Linking Structural Stigma to Health and Social Impacts



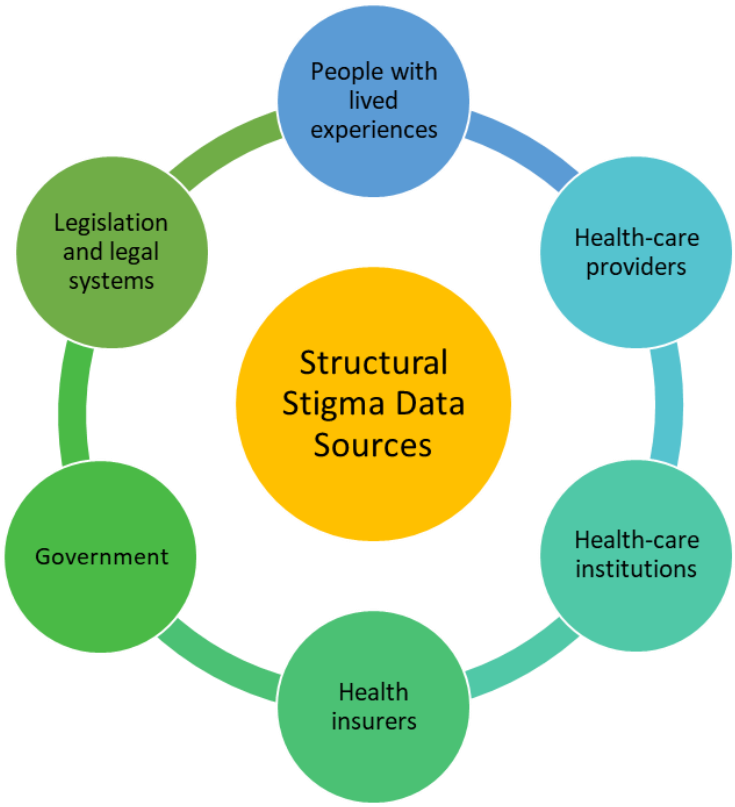
Understanding how structural stigma impacts people's health should be prioritized in assessment efforts. This involves comparing exposure to structural stigma and analyzing health indicators between stigmatized and non-stigmatized groups. Additionally, identifying the factors that moderate the connection between structural stigma and health is important for developing effective health-care promotion, disease prevention, and equity-oriented initiatives.[19]

Data sources

When assessing structural stigma, where should one look? What relevant data and information already exist? What new possibilities are there for documenting structural stigma? This section identifies and describes the major data sources for assessing structural stigma (represented in Figure 7).[*]

[*] This report treats these data sources as discrete, but they overlap and intersect.

Figure 7. Major Data Sources for Assessing Structural Stigma



People with lived experience

The most effective and sensible way to document structural stigma is to ask people who live with mental health and substance use issues about their experiences seeking and using health-care services and supports. Engaging people with lived experiences in the process as peer researchers (e.g., designing questionnaires, conducting interviews) is strongly recommended. Family members also hold valuable information on issues affecting quality and access in relation to health-care services, since they often play a vital role with navigating the health-care system and advocating on behalf of their loved ones.

Focus groups and interviews involving people with lived experience have often been employed (especially in research) to generate information about stigmatizing experiences in health-care contexts. Such an approach can also be incorporated into quality improvement processes to routinely identify and track structural stigma. Surveys documenting people's health-care experiences and satisfaction levels across a range of health-care contexts also produce relevant information for examining structural stigma. Commonly, such surveys are administered as part of accreditation and quality improvement processes and upon the completion of treatment or hospital discharge. Additionally, population surveys, such as those administered by Statistics Canada and other agencies (e.g., Australia's National Stigma Report Card in the next section), that focus on people's health needs and health-care experiences hold valuable data to help identify issues of health inequity and discrimination. Such surveys reveal valuable information about the structural barriers that prevent people with mental health and substance use needs from accessing and engaging with the health-care system.

Health-care providers

Health-care providers' attitudes and practices shape the quality of health-care interactions for people living with mental health and substance use issues. Consequently, structural stigma can be assessed by examining the beliefs, attitudes, and implicit or unconscious biases that health-care providers (e.g., emergency department staff, nurses, primary care doctors, pharmacists) have toward people with mental health and substance use issues. Several scales have been established to measure health-care providers' attitudes, including the *Opening Minds Scale for Health Care Providers*[20] and the *Opening Minds Provider Attitudes Toward Opioid Use Scale*.[21] Such scales are typically administered to evaluate the effectiveness of anti-stigma interventions that aim to improve the knowledge and attitudes of health-care providers. Assessing organizational culture would involve administering such scales at regular intervals over longer periods of time.

It is imperative that behavioural manifestations of structural stigma also be assessed, including the nature of patient-provider interactions as well as the clinical quality of care delivered by health-care providers. These can be measured indirectly by asking providers about their behavioural intentions; that is, how they plan to treat people who have mental health and substance use issues in the future, including how they intend to clinically manage health issues.[22] Another approach is to ask health-care providers about their past clinical practices to ascertain whether inferior services and supports were provided to people with mental health and substance use issues.[23]

Another way structural stigma manifests among health-care providers (e.g., nurses, doctors, social workers) is through undertraining and poor preparation with respect to managing and treating mental health and substance use issues appropriately. The systematic exclusion and depriortization of these issues from medical and nursing (and other) curriculums contribute to health-care providers' discomfort and lack of capacity in managing them. Since this undertraining negatively affects access and quality of care, a review of these curriculums, including deficiencies in covering essential mental health and substance use issues (e.g., harm reduction), is a further avenue for documenting structural stigma.

Health-care providers also have rich information about the systemic deficits observed across multiple components of the health-care system and can provide important insights into structural stigma. In one study, health-care provider interviews were used to uncover stigma-related inequities and gaps associated with managing endocarditis.[24] Several similar studies involving interviews with front-line health practitioners, including peer workers, are present in the literature.[25]

Observing how health-care providers interact with people living with mental health and substance use issues can supply useful information. The types of behaviours indicative of structural stigma might include breaches of confidentiality, diagnostic and treatment overshadowing, the denial of care, disparaging or rude behaviours, the use of stigmatizing language, exaggerations of danger or risk, or using coercive, threatening, or paternalistic approaches.[26] Direct observation of the physical environment in clinical spaces can also reveal visible expressions of structural stigma (e.g., disrepair, paternalistic signage, a lack of privacy, extensive security measures). For example, one study examining stigmatizing practices toward people with HIV observed instances in which health-care providers overused barrier protections when interacting with HIV-positive patients and publicly identified HIV-positive patients (e.g., signs on beds indicating HIV status).[27] Another technique involves having someone pose as a mystery client or surrogate patient to measure the quality of health-care encounters (e.g., with administrative personnel or clinical staff) in a naturalistic setting.[28]

Health-care institutions

Health-care institutions, health authorities, accreditation organizations, and health-care data warehouses (e.g., the Canadian Institute for Health Information) routinely gather information about the performance of health-care systems. This includes administrative health databases and health quality dashboards that capture information about resource allocation, health service use, health outcomes, patient experiences, and population health. Such databases have enormous potential for assessing and monitoring treatment inequities and health disparities.

Potential indicators, some of which were highlighted by Ungar and Moothathamby (2020),[29] are listed below and can be compared between people with and without mental health and/or substance use issues:

- How long do people wait for necessary health-care services (e.g., seeing a specialist)?
- What is the accuracy of emergency department triage?
- How do people rate the quality of their health-care experiences?
- What are the rates of health screening and assessment (e.g., weight, blood pressure, lipids, immunization status, mammography, pap test, colorectal cancer)?
- How often is preventive care and routine treatment provided (e.g., influenza immunizations, dental checkups, cardiovascular procedures, hip fracture surgery within 48 hours, pain management)?
- How often is followup care provided after hospital discharge or other medical procedures?
- What is the rate of patient safety and adverse events?
- What is the rate of involuntary services (e.g., involuntary hospitalization, involuntary treatment, compulsory community treatment)?
- What are the morbidity and mortality rates for a range of health conditions (e.g., obesity, hyper-tension, congestive heart failure, chronic obstructive pulmonary disease, cancer, hepatitis, HIV)?

Comparing how people with and without mental health and substance use issues fare across these and other indicators will reveal inequities and disparities that may indicate structural stigma.

Because structural stigma is also embedded in the written policies and procedures of health-care institutions, these too should be assessed for stigmatizing language, rights protections, and discriminatory practices (e.g., unnecessary surveillance) — including admission and discharge criteria that systematically prevent people with mental health and substance use issues from accessing care. In addition, health-care institutions have processes in place to receive and manage patient complaints and grievances about the quality of care that should be included in assessment efforts, since they are likely to reveal systemic inequities and injustices. Reviews should also be undertaken on whether orientation programs for new staff and continuing education for existing staff promote negative stereotypes and stigmatizing practices toward people with mental health and substance use issues.

The proactive steps taken by health-care institutions to reduce structural stigma are also important to assess. This process may include

- providing anti-stigma and equity workshops
- taking targeted action to address stigma and inequities
- supporting and funding meaningful engagement with people who have mental health and substance use issues

- offering ready access to peer support and advocacy services
- educating people about their rights and helping them seek redress
- incorporating stigma and equity indicators in performance measurement frameworks.

Structural stigma assessment efforts should also measure the degree to which health-care institutions align with person-centred, shared decision-making, and recovery-oriented frameworks.[30-32]

Health insurers

Structural stigma is expressed when public and private insurers do not supply fair coverage and reimbursements for mental health and substance use services.[33,34] As a result, people have greater difficulty accessing appropriate care for mental health and substance use needs than they do for needs related to physical health. It is therefore recommended that assessment efforts review the policies, plans, and practices of public and private health insurers to document and track inequities in the coverage of mental health and substance use services. These inequities may manifest in several ways:[35]

- covering hospital-based, institutional care but not community- or home-based care
- covering emergency or crisis services but not services needed for supporting stability, recovery, and wellness
- covering physician-based care but not services delivered by other health-care providers
- omitting mental health and substance use services from the definition of universal health care
- excluding evidence-based mental health and substance use services from coverage (e.g., medications, psychological therapies, harm reduction interventions)
- employing restrictive formularies that prevent people from accessing the most effective medications to treat their mental health and substance use issues
- establishing high deductibles and unaffordable copayments for mental health and substance use services
- requiring that people's mental health status deteriorate before treatment coverage is allowed
- reimbursing health-care providers at lower rates for mental health and substance use services compared to reimbursements for other medical services

Parity legislation, such as the *Mental Health Parity and Addiction Equity Act* in the United States (enacted in 2008), aims to rectify such health-care inequities through multiple avenues. These include requiring insurance companies to cover mental health and substance use services at the same level as physical health services, eliminating or reducing coverage restrictions, and removing misguided clauses related to mental health and substance use issues from insurance policy documents.[36] Tracking progress, or lack thereof, in this area is key for assessing structural stigma in health-care contexts.

Legislation and legal systems

Because structural stigma is embedded within the legislative and regulatory framework of health-care systems, laws should also be included in assessment efforts. Doing so could reveal their positive and negative effects on equity and justice in health-care contexts for people with mental health and substance use issues.[37,38] By analyzing the laws of a particular jurisdiction, the strength of protections offered to people with lived experience and the ways their rights are restricted can both be brought to light.[39,40] Legal epidemiology, a growing research method for studying the direct and indirect effects of

the law on population health outcomes (e.g., policy surveillance), holds great promise for measuring and mapping structural stigma in legislation and regulation.[41-43]

The legal system is another key source of information about structural stigma. Litigation, class actions, inquires, hearings, and investigations pertaining to human rights violations, discrimination, medical malpractice and errors, professional misconduct, health-care deficiencies and noncompliance with regulations, and preventable deaths can all reveal important information about the nature of structural stigma in health-care systems.[44] Decisions and recommendations made by the courts, human rights tribunals and commissions, coroners' juries, government-appointed ombudspersons and advocacy offices, and regulatory bodies hold vital information relevant to assessing and tracking structural stigma.

Governments

Governments play a key role in shaping health-care institutions, health insurance coverage, and legislation, so they are already present in other data sources and indicators. However, governments also have distinct obligations and commitments that are important for structural stigma assessment efforts to capture. These include the degree to which they

- prioritize and invest in mental health and substance use issues
- uphold their human rights obligations (e.g., the UN Convention on the Rights of Persons with Disabilities)
- respond swiftly to public health emergencies (e.g., the overdose/drug poisoning crisis)
- adhere to the federal and provincial/territorial mental health and substance use strategies (e.g., Canada's mental health strategy)[45] and other recommendations (e.g., resulting from government reviews and public inquiries)
- ensure access to a broad continuum of mental health and substance use services (including a range of harm reduction services) and adherence to evidence-based guidelines
- establish, enforce, and comply with mental health and substance use parity legislation
- establish accountability and oversight mechanisms to monitor compliance with the above obligations.

The level of government resources distributed specifically to public mental health and substance use services, such as the percentage of health-care budget, health research budget, and international funds committed to addressing mental health and substance use issues, is another key indicator of structural stigma. It is recommended that government investments in inpatient and residential care (e.g., psychiatric hospital beds, detoxification, residential treatment, supported housing) and community-based services and supports (e.g., supervised consumption sites, partial hospitalization programs) be tracked to show how structural stigma manifests in the insufficient and unequal resource capacity of mental health and substance use services.

Notable initiatives

During the literature review undertaken for this report, several notable projects, programs, and initiatives emerged relevant to assessing structural stigma. Although the list of initiatives (briefly described below) is not comprehensive or complete, it highlights examples of methods and tools that have been used to measure elements of structural stigma.

Mental health indicators for Canada [46]
This initiative created a comprehensive set of 63 indicators to measure and monitor the performance of mental health systems throughout Canada. Assessing each indicator involved drawing information from a range of existing data sets maintained by the Canadian Institute for Health Information, Statistics Canada, and Accreditation Canada. Many indicators tap into issues of equitable access and quality of health care for people with mental health issues, which can be extended to include people with substance use issues. The indicators most relevant to documenting structural stigma include readmissions to hospital within 30 days, one-year rate of repeat hospitalizations, unmet mental health-care needs, unmet physical health-care needs, self-reported experiences of discrimination or unfair treatment, and number of mental health programs satisfying accreditation standards.

Stigma Index 2.0 for people living with HIV [47]
The Stigma Index 2.0 is a survey to assess how stigma is experienced by people living with HIV, including access to (and stigma within) HIV-specific and non-HIV health-care services. The survey asks people to report whether they have experienced discrimination in the past year across several domains, such as staff disclosure of HIV status without consent, staff talking badly about a person due to HIV status, being denied services due to HIV status, being verbally or physically abused due to HIV status, and health-care staff taking extra precautions (e.g., double gloves, avoiding physical contact) due to HIV status. The Stigma Index 2.0 has been administered on a national scale, including by lived-experience service organizations in the Dominican Republic in 2019.[48]

Health Equity Impact Assessment Tool and Workbook [49]
This Health Equity Impact Assessment tool and workbook was developed by the Ontario Ministry of Health and Long-Term Care, in partnership with other organizations. It is intended to help organizations inside and outside the health-care system identify, assess, address, and monitor the unintended negative effects of policies and programs on vulnerable or marginalized populations, including people with disabilities related to mental health and substance use. In informing planning and decision making in health-care contexts, it aims to reduce inequities that result from barriers in access to quality health-care services, thereby improving health outcomes. The tool has been applied to the community mental health system in Ontario.

Example questions guiding the health equity assessment process:

- How will the policy, program, or initiative affect access to care for specific populations?
- Is it likely to have negative effects that contribute to, maintain, or strengthen health disparities?
- Will the program benefit some people or communities more than others, and why?
- How can the organization reduce or remove barriers and other inequitable effects?
- What specific changes does the organization need to make to the initiative, so that it meets the needs of each vulnerable or marginalized community that has been identified?
- Could the organization engage the specific population in designing and planning these changes?

Mental Health and Human Rights Evaluation Instrument [50]
This Canadian framework was developed in 2011 to help provincial and territorial governments assess the degree to which their mental health legislation, policies, and standards advanced human rights and were consistent with the UN Convention on the Rights of Persons with Disabilities. The instrument was

based on a review of existing evaluation instruments, domestic legislation, policies and standards, and consultations with stakeholders and people with lived experience. It was pilot tested in Nova Scotia, Manitoba, and British Columbia with the intention of administering it in all provinces and territories. A lived-experience steering committee was involved in its development and testing.

National Stigma Report Card [51]

This Australian survey was designed to assess people's experiences of stigma related to their mental health issues. It incorporated several existing stigma measures (e.g., Discrimination and Stigma Scales-12) and has indicators across 14 life domains, including services for both mental and physical health care. In each domain, people are asked to self-report on whether they experienced stigmatizing situations in the past year, whether they anticipated stigma experiences, and whether they withdrew from particular situations or opportunities. The survey, administered to 1,912 adults with mental health issues (between October 2019 and March 2020), found that stigma was experienced by 84 per cent of respondents who received health-care services and 72 per cent of respondents who received mental health care services. Almost one-third of respondents reported "frequent" or "very frequent" stigma in health-care services. The survey items have direct relevance for assessing structural stigma in health-care contexts. An interactive and accessible website provides a detailed and visually appealing summary of the results.

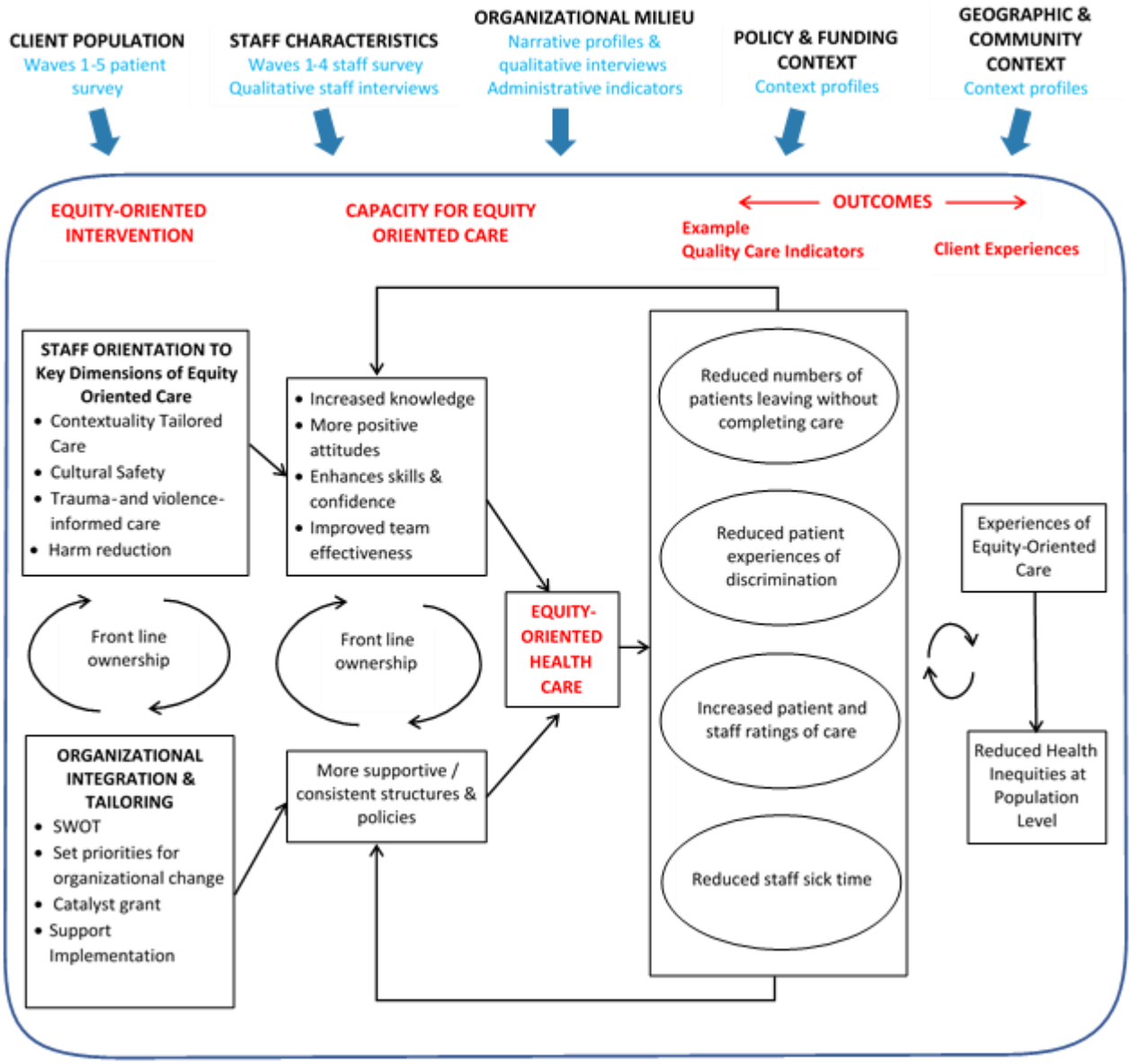
Canadian Alcohol Policy Evaluation [52]

This project evaluates the implementation of evidence-based alcohol policies in the provinces and territories across several policy domains (e.g., liquor law enforcement, pricing, and taxation). Each jurisdiction is assigned a score that reflects the degree to which they have implemented policies known to reduce alcohol-related harms. Although not specifically focused on structural stigma, the approach this evaluation uses could be adapted to assess and compare Canadian jurisdictions regarding their efforts to reduce structural stigma in health-care contexts.

Equipping Primary Health Care for Equity [53,54]

This Canadian initiative was established to enhance equity and reduce institutional discrimination in primary health care and was later extended to emergency departments. It is an organizational-level intervention to improve the quality of health care for people who experience inequities. The aims are to improve population health, enhance health-care experiences, improve health outcomes, reduce health-care costs, and improve the worklife of health-care staff. The evaluation framework, shown in Figure 8, identifies several health equity indicators (e.g., ratings of care, self-reported discrimination experiences, incomplete care) that can be adapted to examine structural stigma for people with mental health and substance use issues. EQUIP has also developed several tools to assess equity-oriented health care.

Figure 8. Evaluation Framework for Equity-Oriented Health Care [55]



Reprinted from "EQUIP emergency: Study protocol for an organizational intervention to promote equity in health care," by C. Varcoe, V. Bungay, A. J. Browne, E. Wilson, C. N. Wathen, K. Kolar, N. Perrin, S. Combar, A. Blanchet Garneau, D. Byrnes, A. Black, and E. R. Price, 2019, *BMC Health Services Research, 19*, Article 687, p. 7 (https://doi.org/10.1186/s12913-019-4494-2). Copyright The Author(s) 2019 Open Access.

Closing

This report summarized the assessment domains, methodological considerations, and data sources for assessing structural stigma in health-care contexts and tracking how it changes over time. Clearly, there are many options and issues to address when considering a structural stigma assessment framework. These include:

- assessing and monitoring health care-related structural stigma across multiple domains, such as resource distribution, the denial of care, fragmented care, practitioner practices, negative experiences, and coercive approaches
- using methodological approaches that are participatory, multi-method, and longitudinal
- attending to intersectional stigma, multiple levels of the health-care context, and health outcomes
- gathering information from major data sources, including people with lived experience, health-care providers, health-care institutions, health insurers, governments, and legislation and legal systems
- learning from existing projects, programs, and initiatives that have already developed and implemented methods, tools, and approaches to assess structural stigma.

The detrimental effects of structural stigma on the lives of people with mental health and substance use issues is well documented in the literature. Tangible efforts must be made to reduce the stigma-driven barriers and inequities that interrupt people's access to quality health care. Part of the solution includes accurately assessing the problem to ensure that structural stigma reduction efforts address the most urgent and serious problems. But, to reiterate a crucial point, since assessment without action achieves little, initiatives to assess structural stigma must be embedded within a broader strategy that works toward transforming systems.

References

[1] Livingston, J. D. (2013). *Mental illness-related structural stigma: The downward spiral of systemic exclusion.* https://www.mentalhealthcommission.ca/sites/default/files/MHCC_OpeningMinds_MentalIllness-RelatedSructuralStigmaReport_ENG_0_0.pdf

[2] 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/sites/default/files/2020-07/structural_stigma_in_healthcare_eng.pdf

[3] Livingston, J. D. (2013). *Mental illness-related structural stigma: The downward spiral of systemic exclusion.*

[4] Livingston, J. D. (2020). *Structural stigma in health-care contexts for people with mental health and substance use issues: A literature review.*

[5] Ungar, T., & Moothathamby, N. (2020). *Structural stigma in health care for mental health and substance use: Networking for the design, development, and implementation of an audit tool.* https://www.mentalhealthcommission.ca/sites/default/files/2020-07/structural_stigma_in_health_care_for_mental_health_and_substance_use_eng.pdf

[6] Livingston. (2020).

[7] Livingston. (2013).

[8] Knaak, S., & Ungar, T. (2017). Towards a mental health inequity audit [Correspondence]. *Lancet Psychiatry, 4*(8), 583. https://doi.org/10.1016/S2215-0366(17)30281-X

[9] Metzl, J. M., & Hansen, H. (2014). Structural competency: Theorizing a new medical engagement with stigma and inequality. *Social Science and Medicine, 103*, 126-133. https://doi.org/10.1016/j.socscimed.2013.06.032

[10] Stuart, H., Arboleda-Florez, J., & Satorius, N. (2012). *Paradigms lost: Fighting stigma and the lessons learned*. Oxford University Press.

[11] Livingston. (2020).

[12] Livingston. (2020).

[13] Mitchell, E. M. H., & van den Hof, S. (2018). *TB Stigma measurement guidance*. Challenge TB. https://www.mcgill.ca/tb/files/tb/tb_stigma_measurement_guidance.pdf

[14] Mitchell, E. M. H., & van den Hof, S. (2018). *TB Stigma measurement guidance*. Challenge TB.

[15] Turan, J. M., Elafros, M. A., Logie, C. H., Banik, S., Turan, B., Crockett, K. B., Pescosolido, B., & Murray, S. M. (2019). Challenges and opportunities in examining and addressing intersectional stigma and health. *BMC Medicine, 17*, Article 7. https://doi.org/10.1186/s12916-018-1246-9

[16] Turpel-Lafond, M. E. (2020). In plain sight: Addressing Indigenous-specific racism and discrimination in B.C. health care. https://engage.gov.bc.ca/app/uploads/sites/613/2020/11/In-Plain-Sight-Full-Report.pdf

[17] Hatzenbuehler, M. L. (2017). Advancing research on structural stigma and sexual orientation disparities in mental health among youth. *Journal of Clinical Child and Adolescent Psychology, 46*(3), 463-475. https://doi.org/10.1080/15374416.2016.1247360

[18] Ferlie, E. B., & Shortell, S. M. (2001). Improving the quality of health care in the United Kingdom and the United States: A framework for change. *Milbank Quarterly, 79*(2), 281-315. https://doi.org/10.1111/1468-0009.00206

[19] Hatzenbuehler, M. L. (2017). Advancing research on structural stigma and sexual orientation disparities in mental health among youth.

[20] Kassam, A., Papish, A., Modgill, G., & Patten, S. (2012). The development and psychometric properties of a new scale to measure mental illness related stigma by health care providers: The Opening Minds Scale for Health Care Providers (OMS-HC). *BMC Psychiatry, 12*, Article 62. https://doi.org/10.1186/1471-244X-12-62

[21] Mental Health Commission of Canada. (2020). *Opening Minds Provider Attitudes Toward Opioid Use Scale (OM-PATOS)*. https://www.mentalhealthcommission.ca/sites/default/files/2020-09/om_patos_eng.pdf

[22] Bamgbade, B. A., Barner, J. C., & Ford, K. H. (2017). Evaluating the impact of an anti-stigma intervention on pharmacy students' willingness to counsel people living with mental illness. *Community Mental Health Journal, 53*(5), 525-533. https://doi.org/10.1007/s10597-016-0075-6

[23] Wakeman, S. E., Pham-Kanter, G., & Donelan, K. (2016). Attitudes, practices, and preparedness to care for patients with substance use disorder: Results from a survey of general internists. *Substance Abuse, 37*(4), 635-641. https://doi.org/10.1080/08897077.2016.1187240

[24] Bearnot, B., Mitton, J. A., Hayden, M., & Park, E. R. (2019). Experiences of care among individuals with opioid use disorder-associated endocarditis and their healthcare providers: Results from a qualitative study. *Journal of Substance Abuse Treatment, 102*, 16-22. https://doi.org/10.1016/j.jsat.2019.04.008

[25] Murney, M. A., Sapag, J. C., Bobbili, S. J., & Khenti, A. (2020). Stigma and discrimination related to mental health and substance use issues in primary health care in Toronto, Canada: A qualitative study. *International Journal of Qualitative Studies on Health and Well-Being, 15*, Article 1744926. https://doi.org/10.1080/17482631.2020.1744926

[26] Mitchell & van den Hof. (2018).

[27] Pulerwitz, J., Oanh, K. T. H., Akinwolemiwa, D., Ashburn, K., & Nyblade, L. (2015). Improving hospital-based quality of care by reducing HIV-related stigma: Evaluation results from Vietnam. *AIDS and Behavior, 19*(2), 246-256. https://doi.org/10.1007/s10461-014-0935-4

[28] Mitchell & van den Hof. (2018).

[29] Ungar, T., & Moothathamby, N. (2020). *Structural stigma in health care for mental health and substance use: Networking for the design, development, and implementation of an audit tool.*

[30] Livingston, J. D., Nijdam-Jones, A., & Brink, J. (2012). A tale of two cultures: Examining patient-centered care in a forensic mental health hospital. *Journal of Forensic Psychiatry and Psychology, 23*(3), 345-360. https://doi.org/10.1080/14789949.2012.668214

[31] Marchand, K., Beaumont, S., Westfall, J., MacDonald, S., Harrison, S., Marsh, D. C., Schechter, M. T., & Oviedo-Joekes, E. (2018). Patient-centred care for addiction treatment: A scoping review protocol. *BMJ Open, 8*(12), Article e024588. https://doi.org/10.1136/bmjopen-2018-024588

[32] Mental Health Commission of Canada. (2015). *Guidelines for recovery-oriented practice.* https://www.mentalhealthcommission.ca/sites/default/files/2016-07/MHCC_Recovery_Guidelines_2016_ENG.PDF

[33] Pugh, T., Hatzenbuehler, M., & Link, B. (2015). *Structural stigma and mental illness*. https://sites.nationalacademies.org/cs/groups/dbassesite/documents/webpage/dbasse_170045.pdf

[34] Wiktorowicz, M. E., Di Pierdomenico, K., Buckley, N. J., Lurie, S., & Czukar, G. (2020). Governance of mental healthcare: Fragmented accountability. *Social Science and Medicine, 256*, Article 113007. https://doi.org/10.1016/j.socscimed.2020.113007

[35] Canadian Mental Health Association. (2018). *Mental health in the balance: Ending the health care disparity in Canada*. https://cmha.ca/wp-content/uploads/2018/09/CMHA-Parity-Paper-Full-Report-EN.pdf

[36] Livingston. (2020).

[37] Blake, V. K., & Hatzenbuehler, M. L. (2019). Legal remedies to address stigma-based health inequalities in the United States: Challenges and opportunities. *Milbank Quarterly, 97*(2), 480-504. https://doi.org/10.1111/1468-0009.12391

[38] Mitchell & van den Hof. (2018).

[39] Corrigan, P. W., Watson, A. C., Heyrman, M. L., Warpinski, A., Gracia, G., Slopen, N., & Hall, L. L. (2005). Structural stigma in state legislation. *Psychiatric Services, 56*(5), 557-563. https://doi.org/10.1176/appi.ps.56.5.557

[40] Hatzenbuehler. (2017).

[41] Burris, S., Cloud, L. K., & Penn, M. (2020). The growing field of legal epidemiology. *Journal of Public Health Management and Practice, 26*, S4-S9. https://doi.org/10.1097/phh.0000000000001133

[42] Burris, S., Hitchcock, L., Ibrahim, J., Penn, M., & Ramanathan, T. (2016). Policy surveillance: A vital public health practice comes of age. *Journal of Health Politics, Policy and Law, 41*(6), 1151-1173. https://doi.org/10.1215/03616878-3665931

[43] Goldberg, D. S. (2020). Structural stigma, legal epidemiology, and COVID-19: The ethical imperitive to act upstream. *Kennedy Institute of Ethics Journal, 30*(3-4), 339-359. https://doi.org/10.1353/ken.2020.0018

[44] Mitchell & van den Hof. (2018).

[45] Mental Health Commission of Canada. (2012). *Changing directions, changing lives: The mental health strategy for Canada*. http://strategy.mentalhealthcommission.ca/pdf/strategy-images-en.pdf

[46] Mental Health Commission of Canada. (2015). *Informing the future: Mental health indicators for Canada.* https://www.mentalhealthcommission.ca/sites/default/files/Informing%252520the%252520Future%252520-%252520Mental%252520Health%252520Indicators%252520for%252520Canada_0.pdf

[47] Friedland, B. A., Gottert, A., Hows, J., Baral, S. D., Sprague, L., Nyblade, L., McClair, T. L., Anam, F., Geibel, S. Kentutsi, S., Ubald, T., Diof, D., Amenyeiwe, U., Mallouris, C., Pulerwitz, J., & PLHIV Stigma Index 2.0 Study Group. (2020). The People Living with HIV Stigma Index 2.0: Generating critical evidence for change worldwide [Editorial]. *Aids, 34*(Suppl. 1), S5-S18. https://doi.org/10.1097/qad.0000000000002602

[48] Red Dominicana de Personas que Viven con VIH/SIDA. (2019). *People living with HIV Stigma Index 2.0 Domincan Republic Country Assessment*. http://www.projsoar.org/resources/dr-stigma-index-rprt/

[49] Ontario Ministry of Health and Long-Term Care. (2012). *Health equity impact assessment (HEIA) workbook*. http://www.health.gov.on.ca/en/pro/programs/heia/docs/workbook.pdf

[50] Chammartin, N., Ogaranko, C., & Froese, B. (2011). *Equality, dignity and inclusion: Legislation that enhances human rights for people living with mental illness*. Canadian Mental Health Association (Winnipeg), & Public Interest Law Centre. http://www.mentalhealthcommission.ca/English/document/5201/equality-dignity-and-inclusion-legislation-enhances-human-rights-people-living-mental-?terminitial=24

[51] Groot, C., Rehm, I., Andrews, C., Hobern, B., Morgan, R., Green, H., Sweeney, L., & Blanchard, M. (2020). *Report on findings from the Our Turn to Speak Survey: Understanding the impact of stigma and discrimination on people living with complex mental health issues*. Anne Daveson Research Centre, & SANE Australia. https://nationalstigmareportcard.com.au/sites/default/files/2020-10/NSRC_Full_Report.pdf

[52] Wettlaufer, A., Vallance, K., Chow, C., Stockwell, T., Giesbrecht, N., April, N., Ashbridge, M., Callaghan, R., Cukier, S., Hynes, G., Mann, R., Solomon, R., Thomas, G., & Thompson, K. (2019). *Strategies to reduce alcohol-related harms and costs in Canada: A review of federal policies*. https://www.uvic.ca/research/centres/cisur/assets/docs/report-cape-fed-en.pdf

[53] Browne, A. J., Varcoe, C., Ford-Gilboe, M., Wathen, C. N., & EQUIP Research Team. (2015). EQUIP healthcare: An overview of a multi-component intervention to enhance equity-oriented care in primary healt care settings. *International Journal for Equity in Health, 14*, Article 152. https://doi.org/10.1186/s12939-015-0271-y

[54] Varcoe, C., Bungay, V., Browne, A. J., Wilson, E., Wathen, C. N., Kolar, K., Perrin, N., Combar, S., Blanchet Garneau, A., Byrnes, D., Black, A., & Price, E. R. (2019). EQUIP emergency: Study protocol for an organizational intervention to promote equity in health care*. BMC Health Services Research, 19*, Article 687. https://doi.org/10.1186/s12913-019-4494-2

[55] Varcoe, et al. (2019). EQUIP emergency: Study protocol for an organizational intervention to promote equity in health care*.*

Mental Health Commission of Canada
Commission de 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
www.mentalhealthcommission.ca

@MHCC_ /theMHCC /1MHCC @theMHCC
/Mental Health Commission of Canada