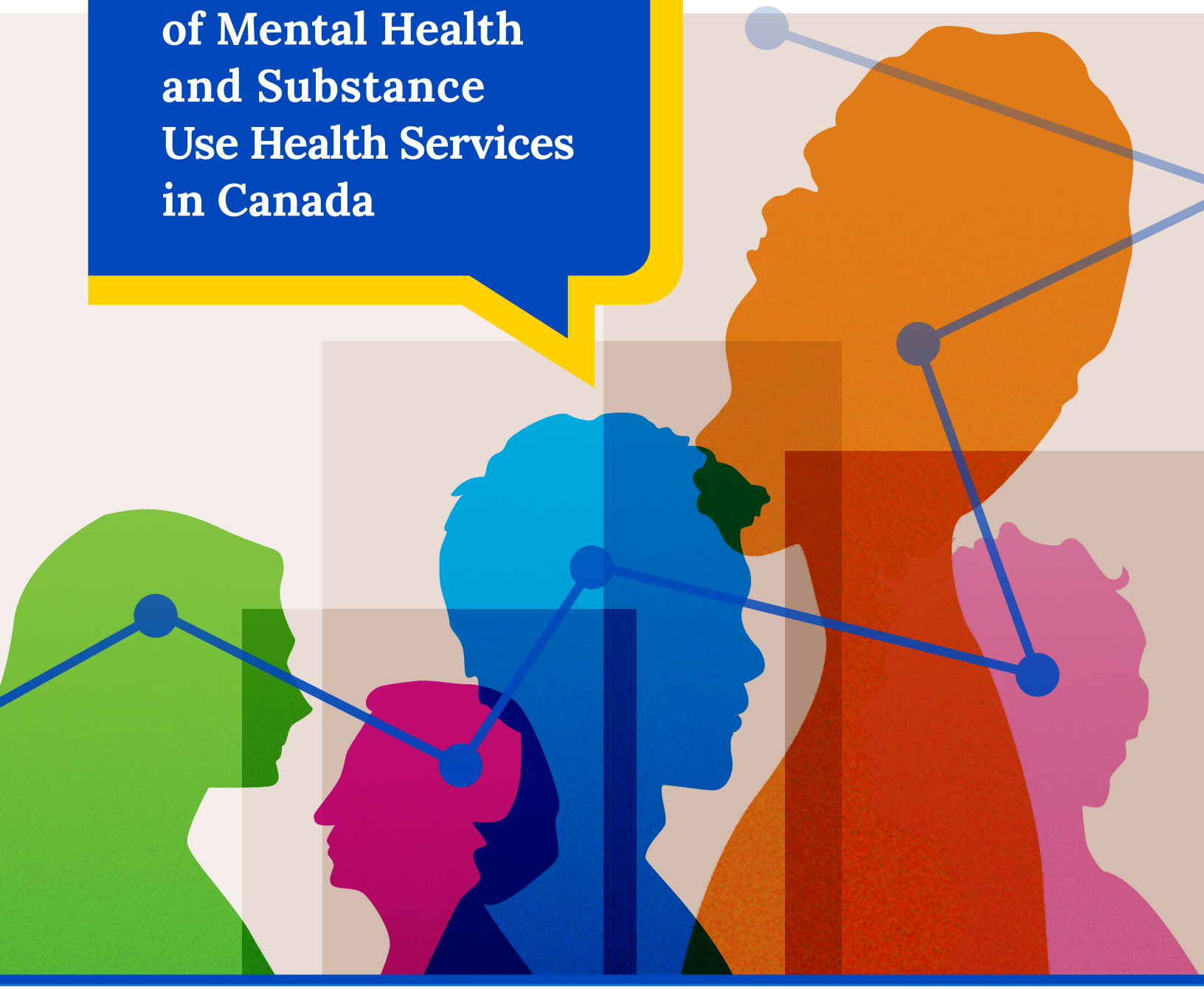
# Summary Report: Experience and Expertise of People with Lived and Living Experience on the Integration of Mental Health and Substance Use Health Services in Canada



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

Canadian Centre on Substance Use and Addiction

CAPSA ACEPA

# Acknowledgments

This study was conducted by research team members from the Community Addictions Peer Support Association (CAPSA):

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## CONTRIBUTORS

This report is focused on how people in Canada experience formal integrated services when they have questions or concerns about their mental health and substance use health. An equally important theme that emerged during its interviews and focus groups were the expressions of "service" study participants give to friends, families, and strangers, which complement or make up for formal services. These daily expressions are central to integrated wellness and could have been the subject of their own study. We thank the participants for sharing these with us and hope they can see their important contributions in this report.

*Ce document est disponible en français.*

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The authors have incorporated the diverse views of the participants in this study, which are not necessarily the views of CAPSA, the Canadian Centre on Substance Use and Addiction, or the Mental Health Commission of Canada. The full report is available on request at **mhccinfo@mentalhealthcommission.ca**

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# Contents

# Executive Summary

## INTRODUCTION

While integrated services for mental health and substance use health have been studied for more than two decades,[1,2,3,4,5,6,7,8] no recent or comprehensive reviews exist — particularly with a peer research methodology — on how the people who use these services experience integration.[9-10]

To address this need, this study explores (1) how people with lived and living experience (PWLLE) define service integration, (2) what gaps and demands exist in mental health and/or substance use health services, (3) why participants do or do not support further service integration, (4) which systemic bottlenecks prevent meaningful integration, and (5) what characteristics participants considered important for effective service delivery.

At a time when Canada is establishing its first national standards of care on mental health and substance use health services, this report examines wide-ranging PWLLE experiences to inform its policy and practice recommendations for improving delivery, matching needs to services, and developing systemic incentives.

## METHOD

This study was led and written by a research team of five subject matter experts living well with substance use and mental health disorders at CAPSA (Community Addictions Peer Support Association), an organization that works to dismantle systemic stigma and improve the health of people who use substances. Consistent with Braun and Clarke,[11] it used a mixed method approach, employing a reflexive thematic analysis of semi-structured, open-ended focus groups and key informant interviews (see Appendix A). Demographic information and opinions on service integration were collected through a brief survey to all participants (see Appendix B).

Eligible participants were residents of Canada, 18 or older, who had accessed a mental health and/or substance use health service ($n$ = 102). The research team used an open social media call to recruit participants for online focus groups ($n$ = 77) and personal invitations to staff at an overdose prevention clinic to recruit for in-person focus groups ($n$ = 11). It then selected key informants for individual interviews ($n$ = 14) based on convenience and snowball sampling, targeting a diversity of demographic representation and experience. Once accepted into the study, all participants were invited to complete the survey ($n$ = 63; 62% response rate).

Results were independently and thematically analyzed by each CAPSA research team member and were only considered valid if triangulated. The team presented a preliminary analysis of the findings at a workshop with study participants, who confirmed the results.

## FINDINGS

The analysis revealed four main themes: (1) how participants defined integrated services, (2) what the most common reasons were for seeking mental health and/or substance use health services, (3) how participants felt about integrated services, and (4) what the systemic barriers to meaningful integration were. A fifth, overarching theme also emerged on the characteristics of effective providers for integrated, mental health, substance use health, or any other services.

### Defining integrated services

Participants defined integrated services broadly. Their experiences included mental health and substance use health services but also focused on other areas:

- economic and social well-being
- family and community supports
- organizations that "integrated" multiple pathways into care (e.g., harm reduction and abstinence)
- services that supported wellness (e.g., fitness centres and faith-based organizations)
- physical health

### Common reasons for seeking services

Participant survey data indicated that alcohol and stimulant use were the most common substance use health concern, while anxiety and mood disorders (e.g., depression and bipolar disorder) were prevalent for mental health.

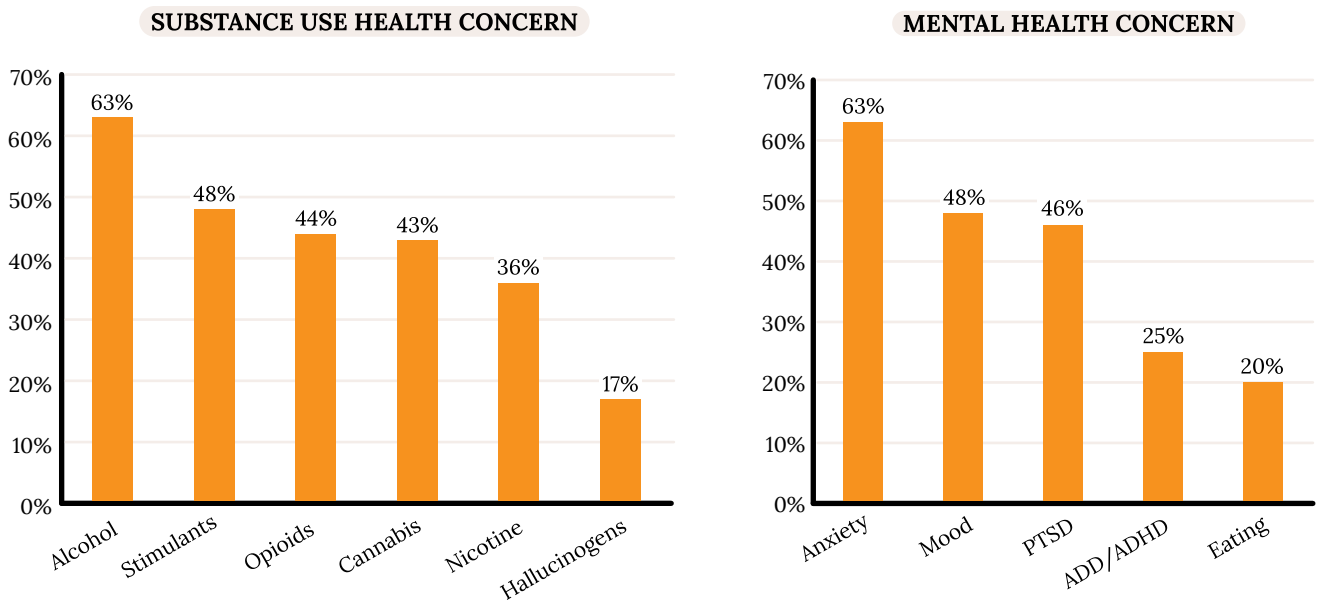



***Figure 1:*** *Most reported Substance Use Health and Mental Health concerns*

Based on focus group interviews, the most frequent *concurrent* concerns were (1) alcohol and anxiety, and (2) cocaine and ADHD. Trauma (childhood, adult, intergenerational) was the most common underlying cause: Survey data showed that 77 per cent of participants had gone through at least one adverse childhood experience, while focus group and key informant interviews indicated that many had experienced more than one.

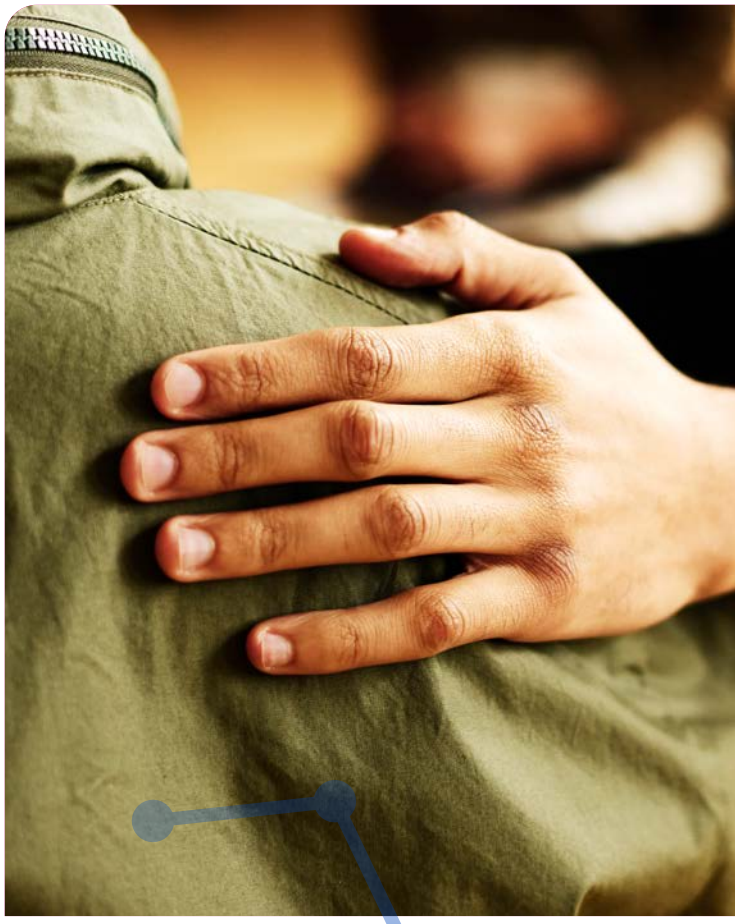
## Support for integrated services

There was overwhelming support for further integrating mental health and substance use health services. A strong majority (89%) of survey respondents were in favour of doing so, with 70 per cent saying that it would improve access and the quality of services. Focus group responses pointed to three main reasons for preferring integrated services: their ability to (1) secure the diversity and depth of expertise required for complex issues, (2) coordinate and simplify the logistics of care, and (3) ensure that concurrent issues were dealt with at the same time (or as simultaneously as possible).

## Concerns about integrated services

In a small number of cases, support for integrated services was less robust. Some participants feared, or had experienced, cumbersome intake processes, a loss of specialization in their treatment, or longer wait times if their concerns were not "complex enough." There was also some historical resentment for being "forced" to work with service providers who had previously turned them away. A common example was being excluded from mental health supports until substance use was under control:

> **"It would have been eight to 10 years ago that my daughter went to a psychiatrist for help with anxiety and depression. The psychiatrist basically said, 'Until you deal with your addiction, I'm not going to help you.' Now, that's changed."** (*Focus group participant and parent of a person with lived and living experience*)



## Mutual stigma is a barrier to service integration

Survey data showed that, while 21 per cent of participants with a mental health concern (unrelated to a substance use disorder) felt uncomfortable using services that included substance use health care, 11 per cent with substance use health concerns (only) felt uncomfortable using services that included mental health care.

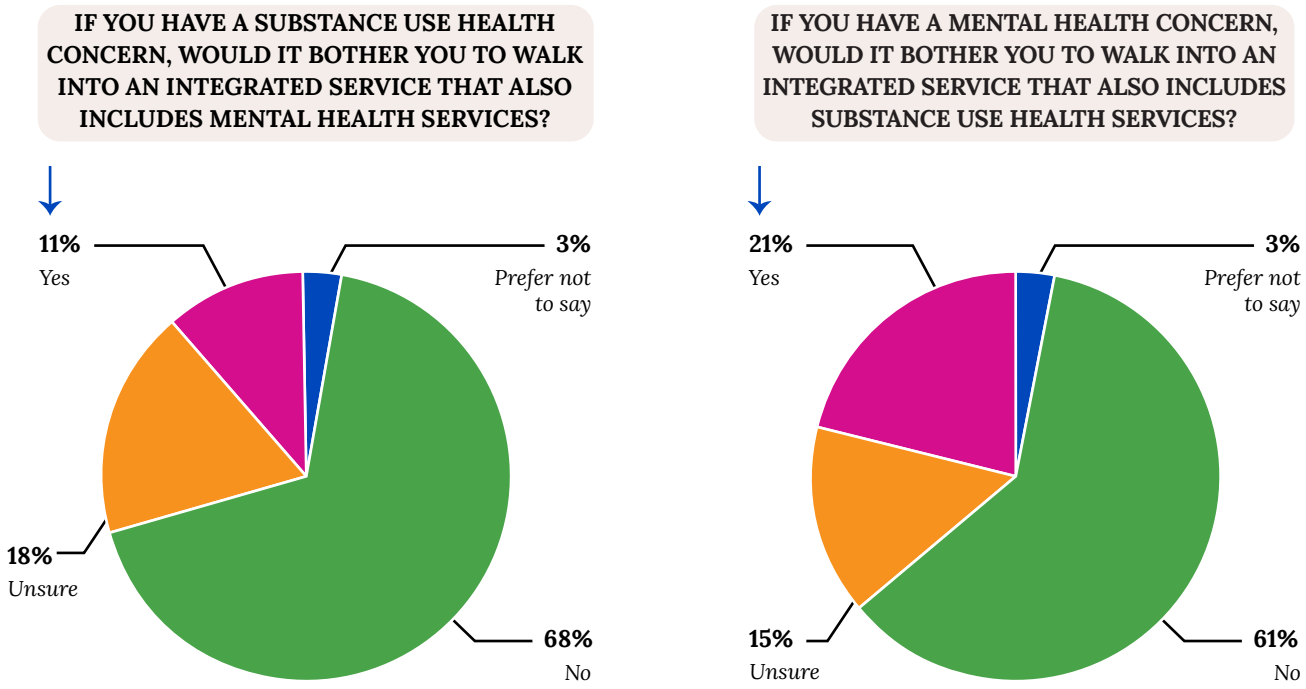



***Figure 2:*** *Survey Responses About Stigma*

This mutual stigma, albeit more pronounced toward people who use substances, resulted in a preference among some participants for "separate doors" for mental health and substance use health services.

## Systemic bottlenecks

Some study participants were seasoned health service providers. From their dual perspective as a service user and provider, they observed the following barriers to meaningful integration:

- A reticence to share patients with other agencies because it also meant shared billing
- Inconsistent measuring, reporting, and compensation for interagency communication, coordination, and referrals
- A culture of professional "gatekeeping," i.e., the territorial environment in certain health-care specializations
- A lack of expertise about mental health, substance use health and concurrent disorders, particularly in the area of prevention (e.g., screening and assessment, knowledge of how to have basic conversations with patients)

One key informant's comment emphasized the effects of such barriers for service users and providers:

> **"When I say 'screening,' all I really mean is asking the question, 'How's your physical health? How's your mental health? How's your substance use health?' No one asks these things."**

### 'Best service experiences' are about more than integration

When asked about the service experiences that made the most difference, participants rarely discussed expertise in both mental health and substance use health or location first. Rather, they noted the disposition and competence of an individual caregiver — often by name. The characteristics of exceptional caregivers were consistent with the principles underpinning trauma- and violence-informed care and other patient-centred approaches (e.g., compassion, empathy, having reasonable expectations, competence, patience). Also important was their ability to tailor care to a specific context (e.g., being able to draw on evidence and experience that related to differences in gender, sexuality, race, income, and culture). In addition, service users appreciated providers who took a strengths-based orientation to care and did not focus solely on patients as "problems to be solved." One focus group member put it as follows:

> **"Here's what worked for me. My doctor said, 'It might not work the first time, and if not, that's okay, come back. We're going to try a new thing, and that's okay.' So, then there's the expectation, or else the person feels like, 'I'm for sure going to come back if it doesn't work because it's not all my fault.' And they're not going to be surprised when I show up because they've already said, 'Listen, it might take a while to figure this out. We'll figure this out together, but you're not alone.'"**

Best experiences were also linked to therapists, doctors, nurses, and counsellors with their own lived and living experience of substance use and mental illness. They were preferred because they (1) prioritized patient involvement, (2) had a more practical focus, (3) showed that wellness was possible, (4) were more forthcoming with follow-up and ongoing care, (5) understood stigma and were sensitive to trauma, and (6) could get "to the heart of the matter" quickly and authentically by "reading between the lines." According to one focus group participant:

> **"Service providers who have the technical expertise *and* the lived experience — that's what worked for me. There is something about empathy experience. It's almost like you're a code breaker. There are certain markers, and that comes from 'experience intuition.' It's not only a skill but almost an intuition. It's all the underlying things not said that speak volumes."**

## PRACTICE AND POLICY IMPLICATIONS

In making recommendations, the research team's analyses thematically categorized the data into three areas:

1. Immediate and practical issues related to direct service delivery
2. More accurate matching of needs to services along the entire spectrum of wellness to illness (not only during periods of acute need)
3. Systemic incentives for improving interagency communication, coordination, and referrals

### Service delivery

1. **Update knowledge and expertise on concurrent disorders.** Participants suggested a need for more clinical expertise on concurrent disorders generally and more particular expertise on "lesser known" eating disorders and autism, including their connections with substance use disorders.
2. **Review and evaluate continuing education opportunities for the mental health and substance use health workforce.** These reviews could evaluate whether (1) skills development matches current need and demand from PWLLE, (2) there is enough focus on implementation, action, and knowledge sharing with colleagues, (3) approaches to learning should include an interdisciplinary, team-based, collaborative focus.
3. **Integrate overarching principles of care into service delivery.** These include trauma- and violence-informed care (and other patient-centred or led approaches), an intersectional lens, and a strengths-based orientation.
4. **Continue offering services that prioritize autonomy and self-defined wellness without judgment.** Participants valued the growing recognition of the range of wellness options and outcomes over the last decade, especially harm reduction and pharmacological approaches for people with substance use disorders. Participants recommended integrating these into care, building more expertise around them, and addressing the stigma associated with non-abstinence-based approaches.
5. **Incorporate professionals with lived and living experience as service providers.** While participants are not suggesting that experience of a disorder is necessary to be an effective service provider (or that PWLLE universally have these competencies), integrating their expertise can bring significant value in terms of humanizing service delivery, reducing stigma, and providing more current, compassionate, and practical care.

### Matching needs to services

6. **Review needs for services along the entire spectrum of wellness to ensure their accurate and cost-effective distribution.** Participants suggested a need for (1) more regular "conversations" about mental health and substance use health early on (e.g. during routine checkups as is done with physical health), (2) more education about how and when to use brief interventions (e.g., screening and assessment tools), and (3) more knowledge of referral options to community-based peer supports as a preventive measure or for ongoing wellness.

**"You shouldn't have to qualify to get help. There's a real truth there. [Right now] people must be at their worst [to get care], particularly in terms of their mental health. They must have acute or chronic symptomology to knock those doors open."**
*(Key informant)*

## STUDY LIMITATIONS

The levels of concurrent concerns and disorders among the study population were significantly higher than the average population in Canada. It will therefore be important to explore the experiences of people with more moderate health concerns before generalizing the need for integrated services. There were also no participants from Canada's territories in this study.

### Systemic incentives

7. **Create mechanisms to measure, financially incentivize, and compensate interagency communication, coordination, and referrals.** These should be consistently written into job descriptions, work plans, performance evaluations, and institutional reporting requirements — and compensated accordingly.
8. **Establish a centralized and coordinated assessment and referral agency.** An umbrella organization whose primary purpose is to make interagency connections (and whose value is measured on their ability to do so) could act as a "gapping" mechanism with built-in accountability checks for offering services for mental health, substance use health, and physical health.

# Conclusion

> **"Transforming our health-care system is tough because we are trying to fix the tires on a moving vehicle."**
> (*Key informant*).

The full report lays out a comprehensive list of "tire patches" and systemic suggestions to improve integrated service delivery in Canada. While scientists and PWLLE have made many of these recommendations before, today policy makers and the public have a cautious political optimism and a sense of widespread urgency regarding mental health and substance use health. As the report was being finalized, the Standards Council of Canada had established nationwide committees to make practice and policy recommendations that will feed into the first national standards of care on mental health and substance use health services. Central to these standards are the contributions of PWLLE, which have not been historically easy to capture in a comprehensive way. This study — in both its community-driven methods and results — is an attempt to fill this gap. The research team believes that integrating these findings into future work will improve the mental health and substance use health of people throughout the country.

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