

Access to PRIMARY CARE

*Access to Primary Care
for people living with
mental health and
substance use issues:
A qualitative study*



RECOMMENDATIONS:

Empowerment and Advocacy for Clients:

WHAT'S THE PROBLEM?

Participants were interviewed for our research project anonymously (we keep their identity private), and were able to be open about the mistreatment they've received in primary care. This might not be so easy for others to do in a clinical setting, because of reasons like power imbalances, fear of losing care, etc.

WHAT WE RECOMMEND:

1. Developing a patient advocacy system for primary care.

This would be a system set up so that clients could safely report any mistreatment by primary health care providers. This system could work under a semi independent body like the Psychiatric Patient Advocate Office or Ontario's LHINs. We understand that relationships between clients and providers are complicated, so we recommend a model that would focus on building understanding and solutions to try to prevent the situation from happening again (restorative justice style), instead of just disciplining the provider.

2. Continuing to support existing, and promote the development of new client-directed independent advocacy organizations.

These organizations can be a voice for clients on all matters that affect them in the healthcare system. For example, they can help to encourage open communication between service providers and service users, and support clients in moving through the often complicated and confusing healthcare system. In addition to supporting organizations that already exist, we recommend

supporting the development of any new independent client-directed advocacy organizations in primary care settings.

3. Developing a Public Awareness Campaign to Empower People Living with Mental Health and/or Substance Use Issues to be Active Partners in their own Health Care.

This campaign would take place in partnership with clients, and could focus on lots of different areas related to client empowerment. For example, a campaign could:

- Promote the knowledge that *clients have certain rights*.
- Empower people to know that they *deserve the best possible care*, and that they can complain without fear of consequences if they don't get it.
- Encourage clients to *request limits to disclosure*. This could include requests like not having to repeat your story over and over again, or to see just one doctor instead of different residents when addressing an uncomfortable health issue.
- Raise awareness that *clients have a choice* when it comes to healthcare providers. For example, if you aren't receiving the treatment you deserve, you can change doctors.
- Promote an understanding of *informed consent*. This means that doctors must get their client's permission before beginning a treatment, and make sure that clients have a good understanding of the risks, benefits, side effects, and other available options before beginning a treatment.

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- Suggest ways to make sure that clients make the *best use of the time* they have with primary care providers (e.g., coming to appointments prepared with notes).

Taken together, empowerment initiatives would aim to actively engage service users in their primary health care.

Service Provider Education:

WHAT'S THE PROBLEM?

Participants shared their experiences with providers who have judgmental values and negative attitudes about people living with mental health and/or substance use issues. Some doctors couldn't or wouldn't address mental health or substance issues, and didn't see these issues as part of their job. Both client and service provider participants agreed that in some cases, the lack of engagement with mental health and substance use is because of poor understanding about these issues.

WHAT WE RECOMMEND:

4. **In partnership with clients, providing educational opportunities for primary care providers on the lived realities and self-identified needs of clients living with mental health and/or substance use issues.**

Service providers must be educated about the way that different issues in participants' lives impact their experience of health and healthcare. Education would include training about anti-oppression (recognizing the different ways that sexism, racism, classism, etc. may impact clients' lives and the provider/client relationship) and social determinants of health (factors influenced by our environment and social and economic status, like access to healthy food, etc.). For example, education programs could be developed for providers and intake and reception staff on the impacts of living in poverty for people with mental health and/or substance use issues. Better knowledge of culture and mental health care is also needed, especially for doctors who serve newcomers to Canada.

Above all we believe more education for primary care physicians is needed to address the discriminatory attitudes and values experienced by our participants. For doctors to provide the best possible care, it is crucial for them to understand what it's like for people to live with mental health and/or substance use issues.

WHAT'S THE PROBLEM?

Many participants felt frustrated that their primary care providers often didn't seem to know about what mental health and/or substance use resources were available to them. Service provider participants also talked about how they didn't have a big enough or appropriate pool of referral resources.

WHAT WE RECOMMEND:

5. **Sharing information about how primary care providers can find referral resources and education related to mental health and/or substance use issues.**

Providers need better access to mental health referral/resource information for clients, as well as information about ongoing mental health and substance use training opportunities for providers. This could include, for example, education on issues like appropriate pain management for clients with a history of substance use.

WHAT'S THE PROBLEM?

Many interviewees talked about how primary care providers may be unwilling to take on patients who were viewed as having more than one, or more intensive (complex care) needs. This was often because doctors didn't feel they had enough knowledge of, or comfort with, mental health and/or substance use issues. Some service providers also talked about feeling like they didn't have enough training on these issues.

WHAT WE RECOMMEND:

6. **Expanding opportunities for physicians to network with and be mentored by mental health and/or substance use specialists.**

Networking and mentoring could increase provider knowledge, confidence, and comfort with mental health and substance use issues. Networks that

already exist, like the Ontario College of Family Physician’s Mental Health Care Network and Medical Monitoring for Addictions and Pain program, should be supported and/or expanded, and more opportunities for networking and mentorship should be explored.

Systems Level:

WHAT’S THE PROBLEM?

This report shows how systems level barriers like waitlists, a lack of services or too many steps to access them, and poor provider communication prevent access to care for people living with mental health and/or substance use issues. These issues, along with barriers related to clients’ mental health experiences (e.g., anxiety) or practical barriers (e.g., transportation), point to the need for coordinated services to help people with mental health and/or substance use issues access health care.

WHAT WE RECOMMEND:

7. Increasing access to collaborative and interdisciplinary models of care.

Because people living with mental health and/or substance use issues often have more complex healthcare needs and face more barriers to accessing care, we recommend increased access to collaborative care. By collaborative care, we mean enabling people to access the different kinds of health services that they need in one location (e.g., primary health care, mental health care, social supports, case managers, etc.). Addressing all aspects of a client’s wellbeing, these models could provide services that address social needs, like supporting access to social assistance (e.g., ODSP), providing second language and culturally appropriate services, and providing transportation tokens for clients who need to travel to access healthcare. We think that collaborative care models may be the best way to address unmet care needs of people living with mental health and/or substance use issues by increasing access to primary care and providing other mental health and social supports.

WHAT’S THE PROBLEM?

Both clients and service providers talked about the difficulties in accessing mental health services. Many

participants wanted support other than medication for their mental health and/or substance use issues, but doctors often weren’t helpful in finding these services. Even with supportive doctors, mental health services often weren’t available, had long waitlists, or the costs involved in accessing them was a barrier for our participants.

WHAT WE RECOMMEND:

8. Providing more access to free mental health support services.

This could both help improve the health of people living with mental health and/or substance use issues, and may help to provide more cost-effective mental health supports than traditional psychiatry services. These supports include, but aren’t limited to, services like psychotherapy, trauma therapy, warm lines, crisis lines, and other ongoing and immediate supports.

WHAT’S THE PROBLEM?

Participants faced a number of barriers that made it hard to access and maintain primary care. These difficulties were made worse by providers who were judgmental and didn’t give clients respectful or proper care. Participants talked about how these negative experiences made it especially important to have good advocacy and support to increase both their ability and comfort in accessing healthcare services.

WHAT WE RECOMMEND:

9. Increasing availability of case managers, system navigators, advocates, peer support workers, outreach workers or other intermediaries between clients living with mental health and/or substance use issues and the healthcare system.

These supports can help clients navigate the system, access and maintain counseling and other mental health supports, and go with clients as needed to both physical and mental health appointments.

In addition to increasing these supports for people within the healthcare system, we also recommend an increase in outreach services to help people who, because of other factors in their lives (e.g., homelessness) may not access primary health care services. An increase in peer support workers could



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help provide outreach both outside of and within the system, to help people living with mental health and substance use issues feel more comfortable accessing health services.

WHAT'S THE PROBLEM?

Participants showed how poor communication between services providers meant that they didn't receive the right care to meet their needs. Participants were frustrated about being referred back and forth between providers, and they were confused about referral processes as well as the different roles that service providers play in their lives. A lack of communication between providers sometimes led to 'disclosure exhaustion.' This means that for participants, having to tell providers their history over and over again led to emotional and mental stress, and made them less willing to access care or share their story with providers.

Service providers also talked about how poor communication made it hard to provide clients with the best possible care. They described poor communication between hospitals and community organizations, as well as between different professions (e.g., doctor/psychiatrist/social worker).

WHAT WE RECOMMEND:

10. Exploring strategies to improve communication between health care providers working with individuals with mental health and/or substance use issues.

Collaborative models of care may help to increase communication between mental and physical health care providers. Having providers in the same location and working on teams may increase the chances that clients will have more well-rounded and appropriate care. Communication strategies could also include shared (electronic) charting, and discharge practices that include communication with all involved service providers.

Communication strategies must be open, clear, and protect the privacy of people living with mental health and/or substance use issues, as there may be parts of their medical record they don't want shared between providers. Clients should be educated about their privacy rights in relation to primary care and medical records.

WHAT'S THE PROBLEM?

Participants talked about how healthcare funding is set up so that doctors aren't able to spend very much time with each client. This also makes doctors less willing to take on clients who may need more care or have more complicated health issues, as these clients may need longer or more frequent appointments.

WHAT WE RECOMMEND:

11. Investigating the impacts of primary health care funding models on access and outcomes for clients living with mental health and/or substance use issues.

Very little research exists which looks at different funding models (e.g., the different ways that doctors are paid) and how they affect access and health outcomes for people living with mental health and/or substance use issues. We recommend more research be done to explore these issues so that the funding model used in Ontario increases access to primary care for people living with mental health and/or substance use issues.

CONCLUSION

Recent research in Ontario has shown that people with mental health and substance use issues experience a greater lifelong negative effect on their quality and length of life than all the chronic diseases combined¹. The voices of clients heard in this project illuminate some of the factors that may be contributing to this state, and what might be done to facilitate better healthcare for all.

For more information about this project, please visit our webpage at:

www.camh.ca/primary-care-study

¹ Ratnasingham S, Cairney J, Rehm J, Manson H, Kurdyak PA. *Opening Eyes, Opening Minds: The Ontario Burden of Mental Illness and Addictions Report. An ICES/PHO Report.* Toronto: Institute for Clinical Evaluative Sciences and Public Health Ontario; 2012.