

EXPERIENCE EXCHANGE

Our voice is being lost: What people with lived experience are saying about equity & human rights responses to COVID-19

Experience Exchanges capture and share diverse stakeholder experiences as a part of efforts to bring evidence to bear on Ontario's mental health and addictions system. Evidence includes research, professional expertise, the lived experience of people and families, and cultural and traditional knowledge. In this Experience Exchange, we facilitated a discussion with a diverse panel of People with Lived Experience on their experiences with the COVID-19 pandemic. The information is a reflection of panel members' views and opinions and is intended to help inform equitable, system-level pandemic response planning and service delivery. It does not necessarily reflect the opinions of the Centre for Addiction and Mental Health (CAMH).

BACKGROUND

Advocacy groups across the province and beyond have highlighted increased risk of COVID-19 related harms for people who experience systemic oppression and exclusion. These include Black and Indigenous communities, people living on low incomes such as those receiving Ontario Works (OW) and Ontario Disability Support Program (ODSP), people living with disabilities, people who use substances, people who are incarcerated, psychiatric survivors, psychiatric in-patients, sex workers, members of 2SLGBTQ communities, Francophones, youth and people experiencing homelessness.^{1, 2, 3, 4, 5, 6, 7, 8, 9}

This resource is intended to inform Ontario service providers and policy makers in the mental health and addictions sector about the experience of people with mental health and addiction issues and their families during COVID-19 and to provide considerations for how system responses might include an equity focus. The need for this resource was suggested by members of the Persons with Lived Experience and Family Advisory Panel of the Provincial System Support Program (PSSP) at CAMH.

WHAT WE DID

One of PSSP's roles is knowledge exchange, bringing together evidence from research, practice, personal lived experience and Indigenous cultural knowledge to inform system-level action in the mental health and addictions sector.

As part of this work, we regularly convene the Persons with

WHAT YOU NEED TO KNOW

- People with mental health, substance use and addiction issues, disabilities, and others experiencing systemic oppression and exclusion, have short and long-term heightened risk of harms from COVID-19.¹⁰
- COVID-19 has worsened mental health, substance use and addiction issues for many people, while at the same time making it harder to access care and supports.¹⁰
- The lived realities and analysis of people with mental health, substance use, addiction, disability issues, and people who experience systemic and intersectional forms of oppression (ex: anti-Black racism, anti-Indigenous racism, generational poverty, sexism, able-ism, homophobia, transphobia etc.) need to be central in pandemic planning and response strategies.
- The current COVID-19 response plan has failed to meet the needs of people with lived experience, creating further disparity between those who have privilege and those who are disadvantaged.

Lived Experience and Family Advisory Panel to inform our provincial projects and internal initiatives. The panel currently has 13 active members from across the province representing diverse communities and perspectives. At the Panel's request, we convened a virtual meeting to learn more about what people and their communities are experiencing during COVID-19, with the intention of sharing this information back to system stakeholders.

The conversation was facilitated using the following guiding questions and conversation starters:

- We know that several inequities exist in accessing mental health and addictions services at this time (during COVID-19). Name one inequity that is missing from the conversation.
- What are the access barriers to virtual care (phone and internet access, home, privacy) and in-patient care?
- What would the ideal equity and human rights approach to COVID-19 look like in the Ontario mental health and addictions system?
- We know that discrimination and systemic oppression were problems long before the pandemic. What is something that should not go back to "normal"?

PSSP synthesized and summarized the information and recommendations from this dialogue, and Panel members reviewed the summary and recommendations for accuracy and additional considerations. The information that follows represents the opinions and experiences shared by Panel members during this consultation. It does not necessarily reflect the opinions of the Centre for Addiction and Mental Health. We recognize that this summary does not capture the extensive nuanced conversation that we had with panelists about equity and human rights issues during COVID-19. It is meant to be a starting point, not an exhaustive account. Please refer to the resources shared at the end of this document for more information on concrete actions and advocacy by service-users, people with lived experience, family and community allies.

WHAT WE HEARD

Pre-existing inequities and human rights issues exacerbated by the pandemic

- COVID-19 is increasing experiences of systemic oppression and exclusion of people with mental health, substance use and addictions issues, but these inequities are not new. Rather, COVID-19 is exacerbating already-existing systemic and intersecting inequities (this might refer to people experiencing racism, sexism, gender-discrimination, homophobia, transphobia, economic-discrimination, geographic-discrimination, cultural-discrimination, language-discrimination, ageism and ableism etc.)
- Social isolation can negatively impact people's mental health, substance use and addiction challenges.
- The opioid crisis represents a second ongoing public health pandemic that is being overshadowed by COVID-19.

Prioritizing lived experience analysis and knowledge in planning

- Voices and experiences are being lost in pandemic planning and response. The way in which COVID-19 responses have been designed and implemented has resulted in a failure to engage people with lived experience.
- The data formalization process creates a lag which is problematic, as people on our panel know that they are seeing increased suicide attempts, addiction relapse to alcohol and other drugs, overdoses and overdose deaths in their communities, but the formal data may not yet be showing these things.
- People with lived experience are not being included in decision-making processes around pandemic equity planning.
- Human rights must be embedded in all COVID-19 protocols and responses. Early drafts of Ontario's proposed COVID-19 triage measures included measures that disregarded the human rights of people with disabilities, such as deprioritizing patients with neurodiversity and those who require supports for daily living.⁴ Panelists described how there has been lack of PPE for people living and working in congregate living settings for people with mental health issues.

Types of support: environmental, economic, social, mental, physical, cultural

- Safe and dignified space needs to be created so that people experiencing homelessness can comply with public health recommendations. Physical distancing guidelines require access to proper space, access to hand washing, access to PPE, etc. Panelists also described how people living in crowded or unsafe housing is a risk. Many panelists discussed not having enough money to purchase groceries for a two-week period, and many do not have the means to purchase reusable masks or sufficient hand sanitizers and cleaning products.
- Trauma-informed care and approaches are largely missing. COVID-19 has had profound psychological effects even for those who are not physically affected, including feelings of anxiety, confusion, hypervigilance and disempowerment. The pandemic itself may be experienced as a type of trauma, in the way that its effects have transformed people's lives and affected their ability to cope. For individuals with a history of trauma, including systemic oppression and marginalization, COVID-19 may be especially triggering, distressing or even re-traumatizing.
- People providing peer support, whether formal or informal, are overwhelmed by requests that are not necessarily within the realm of peer support. People are reaching out for help in accessing services, both sector-specific and outside mental health and addictions, and peers often do not have the resources to help with these matters.
- Material supports are needed, in addition to psychological supports. People experiencing disability, intimate partner and family violence, and other issues require concrete supports. Financial stress exacerbates mental health and substance use problems, as well as oftentimes co-occurring physical health issues. Food security services were noted to be difficult to access in some communities. Many panelists worry that the situation will only get worse as austerity measures continue to prioritize business over people and force already marginalized and impoverished individuals and communities to work harder to address basic needs as well as needs related to mental health and addiction problems.
- The Canadian Emergency Response Benefit* (CERB) (and now the Canadian Recovery Benefit CRB) is limited and discriminates against people already living in poverty. People who were not working, working as a volunteer, or were working cash jobs, do not have access to CERB/CRB or other supports meant to enable people to support themselves. OW and ODSP top-ups in Ontario are low, can be subject to case worker discretion, and the amount received by social assistance recipients when compared to CERB/CRB continues to imply that the needs of this group are below the needs of others when they are in fact greater. This is reinforced by requiring ODSP claimants to ask and qualify for inadequate COVID-19 funds despite living far below the poverty line.

System navigation

- Disruptions in mental health and addictions services are affecting people in need of support. People are often experiencing inconsistencies in service provision, for example, not being able to speak consistently with the same provider, who has knowledge of their background. It is important to be able to maintain a routine with the same mental health professional. Wait lists and intake processes have been halted, with sometimes no direction to alternative services in the meantime.
- People who are new to the mental health and addictions system, who may be experiencing new or significantly increased mental health challenges due to COVID-19, are struggling to find help. Web-based assessments can be overwhelming, and the supports that people are routed to by web-based assessment processes are often experienced as not relevant to their needs.

Virtual care

Virtual and Telehealth care for mental health presents a number of challenges. Panelists shared the following observations:

- A person may appear more “well” than they actually are on a virtual platform, because clinicians cannot directly observe changes in mannerisms, hygiene, etc.
- Some panelists expressed concern that post-COVID-19, the tendency will be to maintain people on virtual care as a cost-saving measure, when in their experience it is not as effective as in-person care. Additionally, it was noted that people who lack a safe space for a virtual or phone conversation are limited in their ability to benefit from virtual care or access it at all.

* We recognize that The Canadian Emergency Response Benefit (CERB) has now been replaced with the Canadian Recovery Benefit (CRB). At the time of our discussion, CERB was still in place. <https://www.canada.ca/en/services/benefits/ei/cerb-application/transition.html>.

- Access to technology such as Wifi and devices is a challenge for many, including people who are economically disadvantaged, people in rural and remote communities, older adults, people with a range of sensory processing issues or disabilities, people who have vision impairments, are Deaf, deafened or hard of hearing, have communication disabilities, including speech and developmental disabilities. It is easy to lose these people when trying to transition them to virtual care. Additionally, different providers utilize different virtual care platforms and it can be overwhelming to have to learn multiple new programs very quickly.

Information sharing

- Credible COVID-19 information was recognized as a need, but also that it is hard amidst a flood of information to determine what is credible. People noted that the flood of information and the difficulty in distinguishing what to believe can have negative impacts on mental health.

PANEL RECOMMENDATIONS

“Right now capitalism is the priority: it is usually folks who are working class who are the ones risking their lives.”

Throughout the dialogue, panel members suggested that incremental change may not be enough to produce a truly equity-focused pandemic response system. They voiced the desire for justice-oriented system transformation and a new economic paradigm that fosters mutual aid, care, and community capital instead of solely prioritizing private profit.

Panelists also recommended a number of concrete steps for service providers and system-level stakeholders in the short term to understand how existing inequities are worsened by COVID-19 and current responses

and to move towards reducing the disproportionate harm on people who are experiencing systemic inequity.

- More deliberate inclusion and meaningful engagement of people with lived experience analysis in equity and human rights planning related to COVID-19. **Now is the time to bring people back to the table.**
- Service providers should engage in **increased outreach** to connect with individual and family service recipients, and be careful not to place the burden on the client to work harder to access services during this time.
- Service providers should provide **safe and dignified** space for all service -users accessing virtual and remote mental health and addictions services, allowing people to access Internet without cost in a way that provides suitable privacy and complies with COVID-19 recommendations. The burden of accessing the space and technology to access the service should not be on the service-user. People with lived experience analysis need to be immediately integrated into the virtual and telephone support groups that are now blossoming.

“Decisions were made by people in positions of power without consulting us. There were no considerations about whether these decisions were realistic for those of us who live in the real world.”

“This was a lost opportunity to work WITH us to design a response plan that can better meet the needs of everyone.”

- Holistic, equitable, and integrated approaches to mental health and addictions services are needed. Panelists noted that one-size-fits-all supports are not relevant to a wide variety of people. Generic resources on coping with COVID-19 assume that everyone has access to the same material and social resources and are not only often not helpful, but may actually be harmful in reinforcing existing inequities.

“The intersection of disability identities and mental health and addition challenges are often overlooked in institutional settings, for example care facilities are not adequately accessible for people with physical and cognitive disabilities in addition to mental health issues.”

“We know that overdoses are up, but it is not included in the data.”

“We’ve been doing this work for decades, but our voices are being reduced to an anecdotal picture.”

- Integrated responses and solutions should recognize the intersectionality of experiences of oppression (experiences of racism, ableism, gender-discrimination, economic-discrimination, etc).
- Approaches to data collection and analysis should include experiential knowledge and histories of systemic oppression. The recommendation is that current COVID-19 data collection and analysis be combined and contextualized with decades of existing experiential evidence. This is essential to understanding and presenting data in a way that reflects the real experiences Ontario’s diverse populations.
- In addition, the system should engage in systematic and vigilant tracking of inequities within the mental health and addictions system and build this data into planning and mitigation strategies for the next wave of COVID-19 as well as other future public health crises.

WHAT DOES AN INTEGRATED APPROACH TO EQUITY-FOCUSED RESEARCH, DECISION MAKING, AND PLANNING LOOK LIKE?

A reoccurring theme in this dialogue was that pandemic planning has been disconnected from people’s lived realities of inequities, without meaningful engagement of diverse populations at all levels. Embedding an anti-racism and decolonizing analysis into planning and research is essential.

The intersectionality of people with lived experience of mental health issues, addiction and disabilities needs to be central to equity research, analysis, and planning. Race-based data should be collected to address the disproportionate impact of COVID-19 on people from racialized communities, particularly Black and Indigenous people.

Real life narratives need to be incorporated to humanize the picture.

Further, people from racialized and other diverse communities need to be meaningfully engaged in every step of pandemic processes to avoid perpetuating the status quo and harms.

“Get out of silos: need to include Social Determinants of Health, Racism, Sexism, Ableism, Classism etc.”

“Show the inequities in a human way, bring the articulate picture to them – decision-makers, policy analysts.”

FURTHER CONSIDERATIONS

During the review process of this Experience Exchange, several panelists highlighted the impact of Anti-Black and Anti-Indigenous racism on people with lived experience and families. Racism can lead to anxiety, depression, hypervigilance, chronic stress, chronic fatigue, internalized racism and symptoms similar to post traumatic stress disorder. This is called racial trauma.* Panelists highlighted the need to transform the justice and mental health systems to affirm the lives and futures of Black, Indigenous and People of Colour in our society. They recommended reallocating funds away from policing Black, Indigenous and People of Colour communities, removing police from wellness checks, and investing in economic and social supports, especially community-based mental health, addiction and disability services that are culturally relevant and affirming for people experiencing crisis.

*“Racial Trauma” is a term developed by Sheila Wise Rowe in her book Healing Racial Trauma: <https://www.psychologytoday.com/ca/blog/hope-resilience/202005/healing-racial-trauma>

ADDITIONAL RESOURCES

The following resources may be useful for centering equity and human rights in pandemic planning and service delivery:

- [Virtual Learning Hour Special Series: Centering Equity in the Response to COVID-19](#) from the Institute for Healthcare Improvement.
- [Radical Health Advocacy](#) from the Studio for Media Activism & Critical Thought.
- [Mad Covid Launches COVID-19 Recommendations for Mental Health Services](#) from Mad COVID.

NOTES

1. Alliance for Healthier Communities (2 April 2020). [Statement from Black Health Leaders on COVID-19's Impact on Black Communities in Ontario](#).
2. Toronto Star (4 April 2020). [Indigenous Communities, Systemic Racism, and COVID-19](#) (podcast).
3. Human Rights Watch (16 March 2020). [Protect Rights of People with Disabilities during COVID-19](#).
4. Arch Disability Law Centre (16 June 2020). [COVID-19 Related Updates and Resources](#).
5. CBC Radio (2 April 2020). [Voices from Inside: COVID-19 in Canada's Prisons](#).
6. European Monitoring Centre for Drugs and Drug Addiction (25 March 2020). [COVID-19 and People who Use Drugs](#).
7. Yao, H., Chen, J.-H., & Xu, Y.-F. (2020). Patients with mental health disorders in the COVID-19 epidemic. *The Lancet* 7(4). [https://doi.org/10.1016/S2215-0366\(20\)30090-0](https://doi.org/10.1016/S2215-0366(20)30090-0)
8. Egale (6 April 2020). [Impact of COVID-19: Canada's LGBTQI2S Community in Focus](#).
9. UNICEF Canada (17 April 2020). [The Impact of COVID-19 on Children in Canada: Short-, Medium- and Long-Term Mitigation Strategies](#).
10. Centre for Addiction and Mental Health (July 2020). [Mental Health in Canada: COVID-19 and Beyond](#).

The Provincial System Support Program (PSSP) at the Centre for Addiction and Mental Health works with communities, service providers and other partners across Ontario to move evidence to action to create sustainable, system-level change. With offices in Toronto and across the province, PSSP is on the ground collaborating with stakeholders to build a better system through our work in implementation, knowledge exchange, evaluation, data management, health equity and engagement.

Visit www.camh.ca/pssp to learn more.

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