



"BE BOLD. MAKE CHANGES."

Perspectives from Lived Experience Advisors and Partners (LEAP) on unmet needs of individuals with complex mental health and substance use issues

ACKNOWLEDGEMENTS

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Members of the core Lived Experience Advisors and Partners (LEAP) team



Anita David (Co-Chair)



Chris Lamoureux



Mark Brady



Mo Korchinski



Pam Young



Shirley Paulsen

BCMHSUS also acknowledges the coordination, leadership and expertise of the members of the Network's project team (listed below). The team was critical to facilitating the needs assessment activities and discussions that are reflected in this report. The team also extends its appreciation to April Furlong, who supported the development of this report.

Provincial Mental Health and Substance Use Network project team



**Krista English, Sr. Network Lead,
Co-chair of LEAP Team**



**Anita David, Lived Experience
Strategic Advisor,
Co-chair of LEAP Team**



**Deborah Ross, Provincial
Provincial Director, Strategic
Initiatives (BCMHSUS)**



**Ashok Krishnamoorthy,
Physician Lead**

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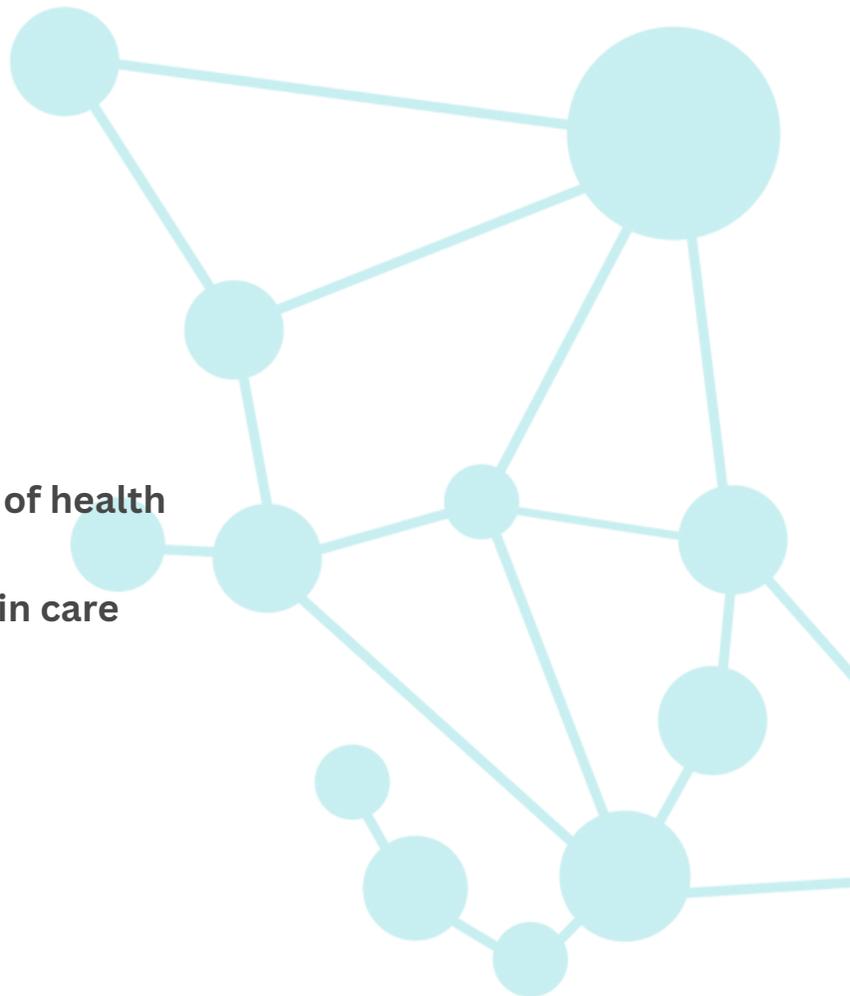
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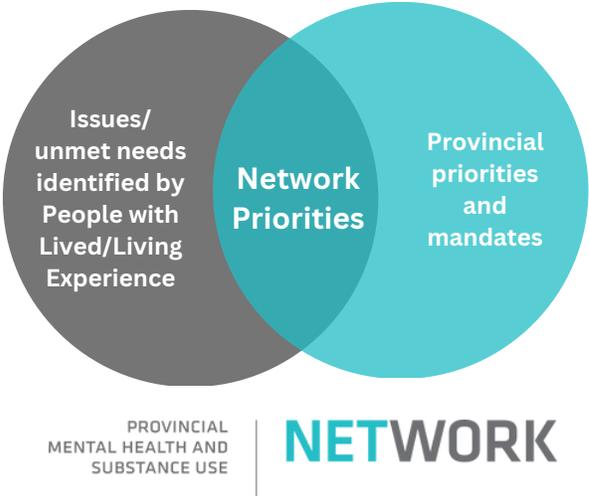
BACKGROUND

B.C. Auditor General Review of Tertiary Mental Health and Substance Use Services

In 2016, the B.C. Office of the Auditor General conducted an audit of adult tertiary mental health and substance use services. The resulting report, *Access to Adult Tertiary Mental Health and Substance Use Services*, outlined ten recommendations to enhance stewardship of services, planning, access, flow and public performance reporting. The provincial response to the audit identified key strategic actions focused on populations whose complex mental health and substance use go beyond the threshold of services currently available, including people who may also have:

- developmental/ intellectual disabilities;
- acquired brain injury;
- histories of extreme violence and/or current aggression and;
- involvement with criminal justice system

In 2021, the Provincial Mental Health and Substance Use Network (or Network for short) was launched as an evidence-informed way to advance the province's response to the Auditor General's recommendations. Hosted by BC Mental Health and Substance Use Services (BCMHSUS), the Network brings together diverse groups of partners, including people with lived and living experience of mental health and substance use issues (PWLLE); service and support providers; and other partners across various sectors, regions and programs, to better serve British Columbians with complex mental health and substance use needs. Network priorities are identified based on the intersection of issues/unmet needs identified by PWLLE and provincial priorities and mandates.



Provincial Needs Assessment

Reflecting the **strong evidence that incorporating the priorities of clients* and families leads to better outcomes**, the Network has focused its early efforts on engaging and empowering PWLLE to provide their unique perspective on the provincial response to the audit, as well as to identify any additional unmet needs, existing gaps and relevant context that may hinder access to appropriate services. This report provides a summary of the perspectives gathered from some of these needs assessment activities. The results from these and future needs assessment activities with LEAP will help identify Network priorities and initiatives for system improvement.

* Based on the recommendation and preferences of Lived Experience Advisors and Partners (LEAP), the term "client" is generally used throughout this report. The term "patient" is only used when reflected in the names of specific organizational and/or advisory groups, when included in direct LEAP quotations, and in content for which LEAP felt the term was more applicable.

APPROACH

Who participated

This report reflects the perspectives of Lived Experience Advisors and Partners (LEAP), who are wise, dedicated and passionate PWLLE (including family members; see also Figure below).

The majority of insights highlighted in this report are from the Network's core LEAP team. The core team is self-named and comprised of five members who meet monthly, based on the recommendation of its members. The team is tasked with ensuring that the experiences and perspectives of PWLLE are recognized, prioritized and enacted by the Network. The core LEAP team is co-chaired by the Senior Network Lead and Lived Experience Strategic Advisor, whose roles include facilitating 'Dialogue + Perspective' sessions with the core LEAP team to identify and discuss unmet needs of individuals with complex mental health and substance use. A summary of these sessions are shared with BCMHSUS leaders and other partners in a variety of ways, so that they can be used to inform system planning and decision making.

To enhance the depth and breadth of perspectives shared by the members of the core LEAP team, the co-chairs engaged additional LEAP to participate in targeted Dialogue + Perspective sessions. These sessions were also facilitated by the Lived Experience Strategic Advisor and engaged participants from:

- Patient and Family Experience Council (PFEC) – comprised of Patient and Family Partners as well as staff from across BCMHSUS, the PFEC advises the BCMHSUS Senior Operations Committee on policies, practices, planning and delivery of patient- and family-centered care across BCMHSUS.
- Patient and Family Partners Network – a provincial network of PWLLE of mental health and substance use and/or criminal justice involvement focused on helping health care leaders and providers design a better way forward, together.



What we asked

To guide discussions aimed at identifying the unmet needs of individuals with multiple and complex mental health and substance use issues, LEAP was asked to respond to a series of questions, listed below, to get their feedback on Key Actions identified as part of the response to the B.C. Office of the Auditor General audit and by other provincial priorities. Detailed notes were taken of all consultations and Dialogue + Perspective sessions were recorded. A member of the Network project team coded data using qualitative software (NVivo) to identify themes and the analysis was validated by members of the core LEAP team.

- **What does person-centered care mean to you?**
- **What do you need to feel safe in care?**
- **What kinds of housing and other supports would you benefit from in the community?**
- **What kinds of services/supports would be helpful when moving between services?**
- **What qualities or skills are most important in your care provider?**
- **In the context of the toxic drug supply, what is needed to better support people that use substances?**
- **In what settings do you experience the most stigma?**
- **What helps and/or prevents family involvement in care?**
- **How would you like your culture, religion, and values to be a part of your care?**

LEAP PERSPECTIVES

This section presents a summary of LEAP perspectives, organized by the different areas of focus. As much as possible, the actual words of LEAP are provided to help ground and give context to their perspectives, and to illustrate the ways in which these areas interrelate.



"Be bold. Make changes."

"Take politics out of it. Be bold. Make changes. Take our voices and do something."

LEAP emphasized that in order for changes to be effective, clients and families must be engaged as partners – beginning at the earliest stages of setting priorities, and at all aspects of planning, implementation, and evaluation.

"The Network has great potential for understanding the problems and building up from there. Let's make sure it does something different than the other networks."

Finally, LEAP highlighted that efforts to introduce system change must be evidence-based, properly resourced, supported by policy and championed by leadership.

LEAP identified many significant system challenges, including the fact that hospitals are one of the most stigmatizing settings for clients and families, and the general need for more services and better access to them. A range of perspectives were offered to address these challenges. Central to all of them was the importance of making bold, innovative changes.

"No one is listening to the experts [with lived/living experience]."

"Develop more educational opportunities with patients and staff to increase collaborative learning opportunities."

"Broaden the lens of participation."

LEAP expressed optimism that the new Provincial Mental Health and Substance Use Network will be an important mechanism to engage clients, families, and other partners differently and more effectively; to identify and prioritize what needs changing; and to develop an approach that has a lasting impact.

"Don't just put it all on staff and say 'Go do this!'"

"Follow the science."

Provider qualities

LEAP identified a range of qualities, beyond clinical and technical skills, that mental health and substance use service providers need in order to effectively deliver person-centred care and, more specifically, to meaningfully engage and work with clients as partners. These qualities are summarized below.

"Short conversations have a significant impact on people's lives."

"Ask them - what do you need to be successful?"

"If you meet people where they are at, you have a better chance that they will follow through."

"Patients should be involved as equal partners and be considered a healthcare team member."

"Empower them. Give them dignity. Don't use a one-size-fits-all approach. Let them know: 'You matter. Your voice matters.' Be a champion for them."

"Show respect and humility. There is a power imbalance - and the minute you remind me of the power you have over me, I shut down."

Works in partnership

Empowers **Cheerleader** Instills hope
 Recovery-focused Practical experience
 Caring **Good communicator**
Compassionate Champion **Respectful**
 De-escalation skills **Holistic** Insightful
Trauma-informed
Non-judgmental Good listener Kind
 Passionate and committed Humble
 Trustworthy **Empathic**

Access

LEAP emphasized the importance of improving **timely access to services** to meet the needs of individuals with multiple and complex mental health and substance use concerns (see right). In particular, they strongly emphasized **the importance of elevating the role of peer support** as part of the service continuum (including for families).

"Peers change your life."

To help service providers better understand the role and value of peer support and to better integrate peers as equal members of the care team, it was identified that service provider training was also needed across all levels.

Peer support was also seen as an important mechanism to support **service navigation**. LEAP also emphasized the need for **easily accessible** service inventories and dedicated navigation supports (for clients, families and providers).



Services Needed

LEAP identified the need for improved access to the following services, beginning with the most commonly identified.

- Service navigation and access supports
- Peer support
- Supportive housing
- Home-based services
- Crisis supports
- Supports for brain injury/cognitive issues
- Safe supply
- Substance use programming
- Life skills programming
- Self-management resources
- Case management services
- Community-based services
- Drop-in services
- Medication
- Trauma services
- Relapse prevention programming

The importance of **direct access to services**, without the need for a doctor or specialist referral was also commonly emphasized.

"When you are in a crisis situation, you don't have time to wait a week or two weeks to get in somewhere."

LEAP also highlighted the need for more **equitable** access to treatment, particularly for rural and remote communities and for specific population groups.

"Smaller communities throughout the province are suffering."

Quality and Safety



Standards and Accountability

LEAP emphasized the importance of developing, implementing and enforcing standards to monitor the quality and safety of mental health and substance use services and supports – at the organizational, community, regional and provincial levels.

"[Patient-centered care] is a nice slogan and based on my experience I see the statement often but would like to have facts to back that up, with examples of what does that look like to the treatment facility/organization. Otherwise it's just words on a page."

"I would like to see cultural safety in care for those who identify as Indigenous."



Input from Clients and Families

Input from clients and families was identified as a foundational source of data to support quality improvement and LEAP offered a number of concrete mechanisms to facilitate their input:

- **Look at what others are doing** – Conduct an environmental scan of organizational processes to identify best practices.
- **Make it easy** – Provide multiple ways for clients and families to share feedback, make those ways obvious, and remove barriers.
- **Shift the language and culture** –The focus should shift away from “a complaint process” to developing a culture where clients and families are supported as change agents.



Staff Wellness

LEAP highlighted that in addition to ensuring that service providers have the right competencies to deliver quality care, organizations have a responsibility to support their health and wellness. Some LEAP have observed a “trickle down” effect, whereby stressful and demanding workplaces, professional burnout, and reluctance to disclose mental health and substance use issues due to stigma, seem to keep providers from providing the best care and support to clients and families.

"Often staff are experiencing burnout which affects the level of attention and care patients are receiving. It gives an impression that everyone has given up on them, which is an awful feeling."



Built Environment

The physical spaces in which services are offered need to be designed to ensure the safety and security of clients and families, while at the same time being welcoming and inviting. Some examples offered to enhance client and family experience include private rooms with home-like settings and quiet spaces.

"It's important to create a good impression at the door, so it feels like a safe place to go into — an impression that is welcoming and personable for patients/clients."

Continuity of Care

LEAP emphasized how critical it is for individuals with complex mental health and substance use needs to have access to continuous and integrated care and supports, particularly during periods of transition along their recovery journey (such as when an individual is experiencing a relapse of symptoms or when individuals are transitioning from inpatient or correctional facilities to the community). Specific suggestions for strategies to support continuity of care provided below.

Full Continuum of Services

- Accessible services for all stages of the care journey and tailored to meet individual needs and preferences
- More services available for clients experiencing a relapse

"When we think of mental health services currently, you either get a bed or you don't get a bed, but there is nothing in between."

Accessible Information

- Better information sharing between services.
- Advertising services in community settings (e.g., medical clinics)

Integrated

- Agency collaboration to offer embedded services (e.g., educational programs in correctional settings)
- Use of case managers as a "go-between" for clinical and social service providers

"People are passed around and must keep repeating their stories over and over."

Seamless Transitions

- Proactive discharge planning
- Leveraging peer navigators to support transitions
- Attention to vulnerable populations (e.g., criminal justice involvement, drug use issues)

"As soon as someone comes into jail, start applications [for housing]."

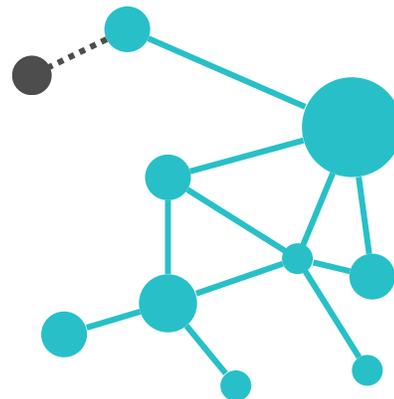
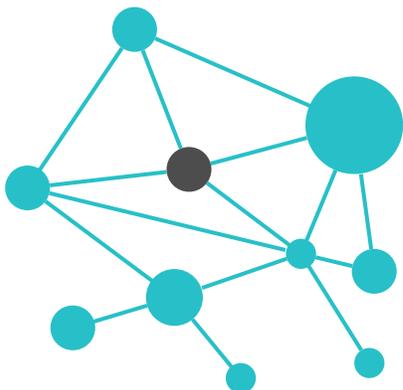
Stigma

Hospitals are consistently identified as the setting where people feel the most stigma.

Stigma was identified as a significant barrier to accessing high quality services and supports. LEAP shared several examples of how long-past mental health and substance use issues continue to surface as "red flags" that negatively shape the services that are offered. There was also a perception that some health service providers with mental health and substance use issues of their own are hesitant to seek help due to stigmatizing work cultures.

LEAP also discussed how stigma acts as a **barrier to accessing social services and supports**, including housing, employment, and education – particularly for individuals with a history of problematic drug use and/or criminal justice involvement.

"Stories and storytelling are a legacy and are a powerful way to help shift stigma."



"People coming out of prison should not be dying, but they are, and this is directly related to stigma."

"Even when you decide to change, you feel like an imposter because you don't feel like you belong."

LEAP offered a number of recommendations for addressing stigma. Central to all of them was **the need to facilitate dialogue about stigma and its impacts** on people with complex mental health and substance use issues, and on the people who support them, including health service providers and families and caregivers.

LEAP also highlighted that **health and social service organizations have a responsibility** to act as a catalyst to raise public awareness about stigma and to identify and address structural practices that perpetuate stigma (e.g., screening practices designed to exclude people with complex mental health and substance use issues from services).

Social Determinants of Health

LEAP emphasized the fundamental importance of ensuring that individuals with complex mental health and substance use needs have access to healthy food, safe and supportive housing, opportunities for employment and education, and communities that foster connection and wellbeing.

LEAP discussed how individuals with complex needs are often "**fighting an uphill battle**" in which poverty and isolation are not only significant barriers to accessing services and supports, but can place already vulnerable individuals at risk for developing more health problems, like substance use disorders.

These challenges are compounded by the overlay of stigma faced by individuals with mental health, substance use, and criminal justice involvement.



"A lot needs to happen on the education/ regulation/ policy side. It's slow moving and almost closes doors for patient input. There's lots of patient input in community work, but the education system and government/ policy lens are limited and exclusive."

"There is often a 'ghettoization' of things recommended to people coming out of mental health programs, and often patients don't want to be stuck in the mental health community for the rest of their lives."

"Housing is about more than a building and a manager."

"Professional environments are not open minded about people with serious mental illness."

LEAP offered the following recommendations to better address the social determinants of health:

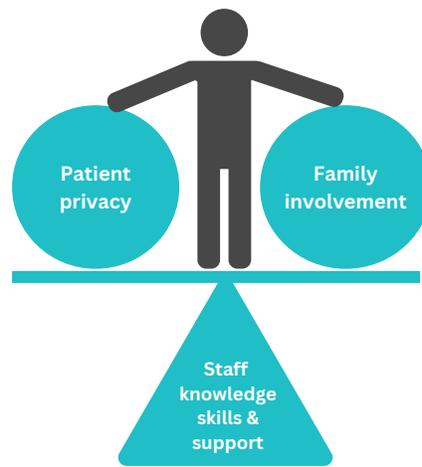
- Help individuals navigate the supports that are available
- Invest more in housing and social services
- Leverage peer support
- Advocate for culture change in the employment and education sectors to address stigma and discrimination
- Engage people with lived/living experience as partners in planning for system change

"Think outside the medical model and look at the social determinants of health."

Family involvement in care

LEAP discussed the importance of family and caregiver involvement in care - both in terms of their role as members of the care team, and in terms of their own need for support. While LEAP acknowledged examples of positive organizational changes (for example within BCMHSUS), lack of family involvement in patient care was still felt to be a systemic issue.

On one hand, LEAP acknowledged the complexities of identifying and protecting patients' needs for privacy – including how their needs can shift over time and at different points along the care journey; and how ethical and legal considerations often constraint the extent to which patients' needs and preferences can be respected.



On the other hand, LEAP described the barriers families face when trying to share and receive information about patient care.

"Most families fold up and leave the arena. You need a strong backbone to fight through the system."

In particular, LEAP highlighted how difficult it is for families to access, understand and navigate information about their rights to involvement in care.

Providers are challenged to facilitate an effective balance between these complexities, and often in the context of high workloads and insufficient capacity. LEAP emphasized the importance of staff having enough knowledge, skills, and organizational support to achieve this balance. Otherwise, the needs of families are not prioritized.

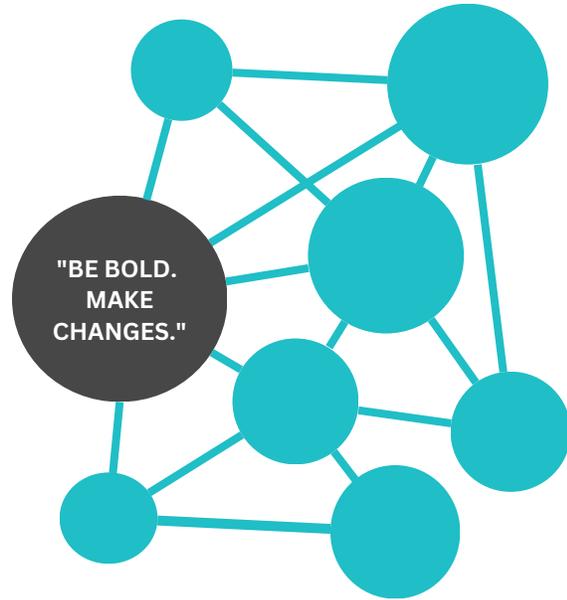
"Many staff used the Privacy Act as an excuse to disengage."

LEAP offered the following perspectives to address these complexities:

- **Leverage the support of peers** - Peer support workers can be an important resource and ally to both staff and families, for example, by helping to "translate" policies and information in ways that families can understand.
- **Develop and enforce standards and policies** - Patients and families have a right to expect consistent standards and approaches throughout the system of care.
- **Give providers enough time, training, and support** - Effectively involving families in patient care is an important provider competency that requires sufficient time, training and organizational support.
- **Use patient and family voices and stories** - These can be important tools for helping to share information about the rights and limits of client privacy and family information needs.

SUMMARY

This document summarizes a range of important LEAP perspectives on the long-standing unmet needs of individuals with complex mental health and substance use issues. Central to all of them was an emphasis on **the importance of making bold, innovative, system-level improvements, in partnership with PWLLE and their families.**



"I like that we have a direction, a set purpose. The topics are all dear to my heart. Organizations need to understand the real challenges. This is a really focused group, which is what I love."

Reflecting the strong evidence that incorporating the priorities of clients and families leads to better outcomes, LEAP also expressed optimism that the new Provincial Mental Health and Substance Use Network can be a driving force for these improvements by engaging and collaborating with clients, families, and other partners **differently and more effectively.** This was reinforced by members of the Network's core LEAP team, who recently shared, as part of an evaluation of the new group, that one of the things that keeps them coming back is the opportunity to provide input on important system issues.

NEXT STEPS

Most of the issues identified in this report are not new. They represent long-standing unmet needs that have been repeatedly identified by clients and families, and by the people who support them. What *is* new is the broad and collective commitment of the members of the Provincial Mental Health and Substance Use Network to address these issues through diverse engagement and collaboration; knowledge translation and exchange; and innovative, evidence-based, system-level solutions.

Reflecting the fact that complex issues often call for complex solutions, the Network will continue to engage LEAP (and other partners) to better understand the ways in which these common challenges may be experienced differently – for different communities and regions across the province, and for different groups of people. Examples of upcoming LEAP opportunities include:

- Focus groups with diverse partners, including PWLLE, to ensure adequate representation of perspectives and needs of underserved groups with complex mental health and substance use issues are captured (including those with co-occurring developmental/intellectual disability, acquired brain injury; histories of extreme violence and/or current aggression and; involvement with criminal justice system)
- Regional Dialogue + Action sessions involving a broad cross section of PWLLE, care/service providers along the continuum of care, and other partners
- An online, interactive, and anonymous exchange of ideas (through *ThoughtExchange*)

Interested in participating in any of these opportunities, have ideas for other ways to engage current and future LEAP, and/or want to join the Provincial Mental Health and Substance Use Network?

Get in touch



