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LIVED EXPERTISE IS QUALITY SERVICE

HOW TO BUILD THE YOUTH MENTAL HEALTH AND SUBSTANCE USE SYSTEM OF TODAY

May 2023

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ACKNOWLEDGEMENTS

As an organization that values connecting and convening, Frayme consistently engages in conversations with various stakeholders from across the Canadian youth mental health and substance use (YMHSU) sector, and analyzes the knowledge gathered for insights and opportunities for sharing to create a more connected system. Our stakeholders are both knowledge sources and knowledge users, and we acknowledge and tremendously appreciate their contributions to the knowledge products Frayme develops and disseminates to the system, including this document.

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LIVED EXPERTISE IN OUR SECTOR: WE'VE COME A LONG WAY, BUT NOT FAR ENOUGH

Lived expertise (LE) is critical to a system that can adequately meet the needs of young people, their families, and communities across Canada. Although we've seen greater efforts to include those with lived and living experience in research and service design, there is still a lot of work to be done. Our sector faces challenges around knowledge to practice gaps, the current value attributed to certain types of knowledge and evidence over others, and the limited and often tokenistic engagement of lived experts.

However, our sector has seen major improvement in recent years in terms of the level that we integrate peers into the continuum of service. This has been a success of the LE movement, as it has allowed us to enter into new conversations and challenge oppressive systems and structures that have historically created barriers for young people to access timely and appropriate care.

But this is only the start of the LE movement— there are still many elements within our continuum that require national conversations and an aligned vision for persistent sectoral growth. Having authentic conversations, taking accountability as organizations, leading with humility, and changing policies and standards to reflect the needs of young people in Canada can improve the state of both LE and the continuum of service in our sector.

#LEKS2022 - FRAYME'S LIVED EXPERTISE KNOWLEDGE SERIES

In November 2022, Frayme hosted *The Lived Expertise Knowledge Series*, an event that gathered over 200 attendees and panelists from across Canada and beyond to discuss what is working, what isn't, and what's next for LE in our sector. Over the course of 2 days, #LEKS2022 participants explored topics surrounding the current state of peer support programs and research, training and supervision considerations in relation to developing a LE workforce, integrating peer support into treatments for Serious Mental Illness's (SMIs) and concurrent disorders, and large and small changes we need to make to respond to existing issues and gaps of LE in our sector. Breakout room conversations took place at the end of each day to provide participants with the opportunity to fulsomely participate in knowledge sharing.

The cumulative content from the panel sessions and breakout room conversations informed the recommendations found in this document. Our hope is for these recommendations to be referenced and leveraged in future decision-making, program development, sector conversations, knowledge mobilization and research.

Learn more about #LEKS2022

Stream #LEKS2022 panel sessions

LIVED EXPERTISE IS QUALITY SERVICE

SYSTEM RECOMMENDATIONS OVERVIEW

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1. Dismantle oppressive systems and expand the continuum of service to more fulsomely integrate peers and lived expertise at all levels

2. Invest in and amplify peer support as a valid part of the continuum of service

3. Work to create standards of service for peer support and peer support workers

SYSTEM RECOMMENDATIONS

RECOMMENDATION #1

Dismantle oppressive systems and expand the continuum of service to more fulsomely integrate peers and lived expertise at all levels

- The way we value certain forms of knowledge over others is harmful and inherently excludes individuals from moving into organizations/systems. For example, we place more value on credentials than we do on lived experience. We respect those with credentials more, and have more trust that they can do their job. In order to address this issue, we need to work to **dismantle these oppressive systems by establishing non-academic qualifications as valuable** and necessary assets in job descriptions. We need to **accept and embrace LE** in the same capacity that previous work experience is accepted.
- The current care continuum is inappropriate and potentially harmful for many populations, especially those made marginalized (see Canadian Mental Health Association, 2018, Lin, 2023). Care for mental health and substance can be a stigmatized and dehumanizing experience that restricts service providers from authentically connecting and building relationships with their patients (see Knaak, Mantler, & Szeto, 2017). **We need to lead with equity-first frameworks to address harmful practices and consider the needs of underserved communities and populations** (rural, BIPOC youth, etc.). This includes embedding equity in service delivery and design, engaging those with LE in co-design/research/evaluation/etc., and ensuring all service delivery uses a trauma-informed approach. Youth from marginalized populations should be actively engaged in all steps of service design, such as the ideation and development phases, to be given appropriate decision-making power to ensure services reflect and implement the needs of diverse people in their communities.

- Individuals experiencing SMI's face stigma at all levels of care: internalized stigma within the individual seeking support, those offering support who often lack adequate training, and systems whose clinical services for SMIs are notoriously under-resourced (see Corrigan & Watson, 2022; Knaak, Mantler, & Szeto, 2017). This stigmatization is further heightened for populations that face systemic racism and marginalization, which prevents them from accessing trauma-informed care. Peer support has proven itself as a helpful asset in community care models servicing SMIs - it provides a unique context for young people to interact with services that are culturally/trauma informed, and take a strengths-based approach to healing. Moreover, peer support provides a culture of care that centers clients and their family/caregivers, and can be a way to improve communication in family systems, limit isolation and educate caregivers on the youths' experiences. **Thus we need to expand the current continuum of care to include peer support, especially for SMIs**.

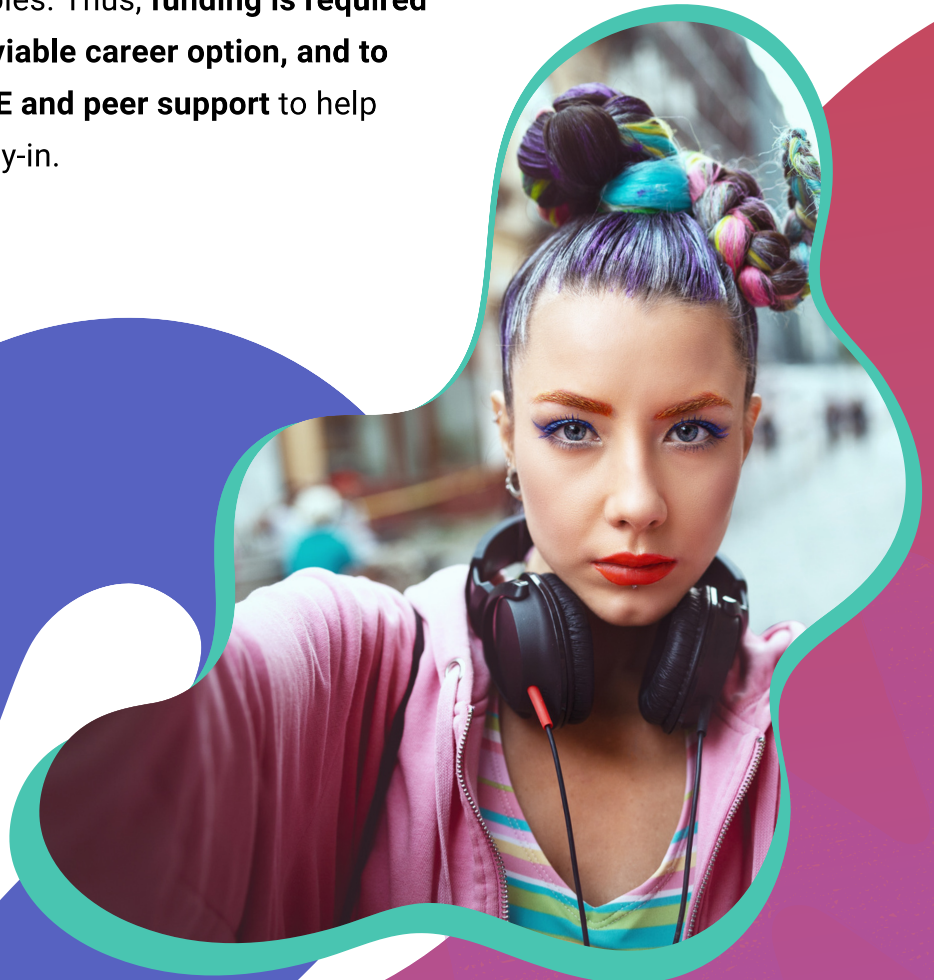
RECOMMENDATION #2

Invest in and amplify peer support as a valid part of the continuum of service

- Unsustainable funds affect several moving parts of our sector, including: workers (capacity, job security, QOL, etc.); programs (longevity, growth, refinement, etc.); and youth (losing access to programs that actually work for them and having to start all over elsewhere, trust in the healthcare system). Thus, **adequate, sustainable funding is needed to support programs that integrate peer support and LE**. As well, improved efforts should be made by system leaders to engage young people with LE who have not previously been engaged through refined outreach strategies (co-developed with youth) that offer long-term engagement opportunities to invest in future capacity. Re-investment in current projects allows for scale-up of services, program redesign, evaluation, permanent jobs, and new services if necessary.

- The role of peer support holds great potential for our sector, but lacks research evidence. This has impacted buy-in from service providers and hospitals, inhibiting the growth of peer support. Greater research is needed in several areas of peer support, including: feasibility, sustainability, recovery outcomes, safety, and required training. Therefore, **national funding programs are needed that examine peer support and the impact of LE across various settings** (clinical, community, organizational and university). This research should be co-designed with those with LE, and findings should be accessible, presented in plain language, and scaled up to serve as implementation and evaluation guides for current and future programs.

- Service providers may lack the knowledge and resources to implement peer support. Greater awareness of peer support and the role of LE in mental health care is required to overcome hesitancy. Those invested in peer support need to participate in and prioritize cross-sector knowledge sharing of training/evaluation/best practices. Moreover, awareness and advocacy campaigns need to be leveraged to address the stigma and hesitancy of many clinical professionals and support efforts addressing issues of equity and diversity in peer support roles. Thus, **funding is required to promote peer support as a viable career option, and to share 'stories of success' of LE and peer support** to help reduce stigma and increase buy-in.



RECOMMENDATION #3

Work to create standards of service for peer support and peer support workers

- Despite the promise of peer support, we have yet to establish agreed upon standards for peer support workers. Creating standardized peer support positions will help to make it a viable career option for those with LE. **Standardization would include role clarity both internally and externally to support those interested in becoming peer support workers, and support stakeholders interested in developing these positions within their organization**. Training of workers could also be standardized, ensuring workers have easy access to Peer Service Canada's certification program or other forms of training. Additionally, standardization of training could include requirements around culturally relevant care and culturally-specific supports. Importantly, peer support workers should have access to funding assistance for those facing financial barriers.
- Conversely, over-standardizing peer support can lead to decreased adaptability, decreased responsiveness to different needs and populations, increased risk of peer support being co-opted by other clinical approaches, and may limit the overall benefits of service delivery (see Marcu, Dey, Kiesler & Reddy, 2016; Stratford et al., 2019). To limit the potential risk of over-standardization, **standardization should be carried out at an organizational level, not an individual level**. Thus, organizations should be accountable for safety promotion, wellness support, training, and supervision.

- Current working conditions for peer support workers and lived experts are unsuitable due to lack of funding, regulations and research. Investment in employment positions will also allow for local individuals to fulfill mentor roles, which will increase emotional and social connection between mentors and those accessing services. In order to promote peer support workers as a viable career, **we need to establish standard work benefits associated with peer support roles, including a liveable wage, holistic benefits, vacation time, and personal development opportunities**.

ABOUT FRAYME

Frayme leads a national knowledge mobilization network of over 400 partner organizations that connects mental health, health and social services working with youth and young adults to accelerate the integration and implementation of youth care in Canada.

With our network made up of youth, families, caregivers, clinicians, researchers, policy makers, and service providers, Frayme acts as an intermediary between youth mental health and substance use organizations to promote collaboration and knowledge sharing.

By focusing on knowledge exchange to promote the use of youth-centered integrated services, Frayme serves as a needed bridge between lived expertise, research, policy, practice, and experience to improve services by facilitating local action, national collaboration, and knowledge mobilization.

Learn more about Frayme's impact

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frayme.ca

frayme.info@theroyal.ca

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