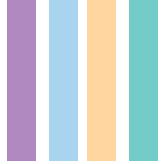camh

Fostering Meaningful Engagement

of Persons with Lived Experience at the System-level

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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, information management, health equity and engagement.
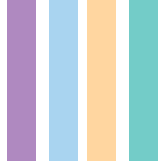
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Acknowledgements

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Summary

The purpose of this summary report is to describe the context, purpose and benefits of meaningfully engaging persons with lived experience of mental health and addiction issues in system-level work. "System-level engagement" refers to engagement that happens at the highest tier of decision-making (governmental, institutional, and organizational) to promote change in culture, policies, and procedures across organizations and services. This summary report outlines common barriers and facilitators to meaningful engagement at the system level, as well as outcomes related to this work. It also highlights examples of engagement frameworks from Canada, the United Kingdom, and the United States. There are many successful practices to draw from; the evidence does not point to a one-size-fits-all approach. Rather, the literature outlines the importance of creating a "receptive context" that combines individual, organizational, structural, political and cultural conditions for meaningful engagement (1). That said; engagement frameworks are most meaningful when they meet the needs of all stakeholders involved.

Three key findings:

- Meaningful engagement refers to genuine, equitable, and affirming processes to integrate the perspectives and expertise of people with lived experience within the mental health and addiction system, from policy development to point-of-care (2).

- Through their expertise, persons with lived experience can enhance how the mental health and addiction system works.

- Shifts in organizational culture and practices, as well as practitioner beliefs are required to facilitate meaningful engagement of persons with lived experience in improving the mental health and addiction system.

What is Lived Experience?

Lived experience refers to someone's experiential knowledge of a subject or topic. The term originated in phenomenology, a branch of 20th century continental philosophy that focuses on human experience and perception as a way of understanding and investigating phenomena (social, environmental, political etc.) (3). It was used primarily to reinsert "the human" into scientific research methods; for example, qualitative research methods like interviews and participant observation come from treating lived experience as valuable

evidence. Lived experience can be understood as an "intermediary category coming between ways of being and ways of knowing" (3). However, it's not enough to present experience as raw data; experience needs to be framed and interpreted within a social context in order to have meaning:
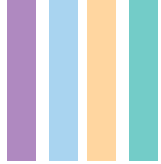
> We talk of 'lived' experience, but experience always involves interpretation of what happens in life, of what makes our perceptions, feelings, and actions meaningful. This depends on how they come into expression and are conceptualised, organised and given temporal identity, or, in other words, how experience is given the quality of narrative. (3)

The term also stems from social justice movements, namely the civil rights and feminist movements of the 1960s-1990s (4). Marginalized groups utilized their experiences of everyday discrimination as a source of power to speak out and incite social change; such practices continue to inform current social movements.

Today, almost every field within the social sciences and humanities engages with lived experience to validate and illustrate the impact of research, or to strengthen a theoretical claim. "Grounded-research", "participatory-action research," and "auto/ethnography" are social science research methods that seek to engage lived experience in an ethical and meaningful way. The resulting knowledge is thus co-created, reflexive, and geared towards a useful impact for everyone involved (not just researchers or funders).

In the context of the mental health and addiction system, lived experience refers to a person's personal experience with mental health and / or addiction issues. Persons with lived experience may or may not have a formal psychiatric diagnosis. Their experience of living with mental health and / or addiction issues is considered a form of expertise and evidence (5). Several terms or labels exist in relation to lived experience; the social context of this language is aptly summarized by the Faculty of Public Health and Mental Health Foundation (2016):

> There has been a move within the field of mental health, largely led by people with lived experience, to avoid the term 'patient' and use instead alternatives including 'survivor, 'service user' and person with lived experience / experts by experience. This language draws on the social model of disability, which moves away from defining people by a clinical diagnosis or service use to focus on people's individual and collective everyday realities. Seventy five per cent of people with a mental health problem of a severity to warrant diagnosis, do not

receive secondary mental health services, and thus may never regard themselves as a 'patient' or 'service user' (6).

When valued and meaningfully engaged, these diverse lived experiences can be used to inform research methodology, political advocacy, service and system planning, and knowledge exchange initiatives.

What's the issue?

Persons with lived experience of mental health and addiction issues have spent over 40 years advocating for system change and improvement (7). The core values underlying their work have included human rights, equity, choice, self-help, self-definition, and self-determination (7). This advocacy has spawned a new era of mental health system decision-making, one that is now actively seeking the input, advice, and expertise of persons with lived experience. *Changing Directions, Changing Lives: The Mental Health Strategy for Canada* (8) recommends the inclusion and active involvement of persons living with mental health challenges in areas such as program planning and delivery, evaluation and monitoring, program and policy research, leadership development, and addressing stigma and discrimination.

In recent years, several important Ontario documents have identified "patient engagement" as a quality improvement driver (9-10) for population health and wellness. In the mental health and addictions system, a similar wave has taken place. In 2011, Ontario released a comprehensive mental health and addictions strategy entitled, *Open Minds, Healthy Minds*. Part of that strategy involved engaging persons with lived experience in initiatives aimed at transforming the system.

In 2019, the Ministry of Health and Long-Term Care (MOHLTC) announced the formation of the Minister's Patient and Family Advisory Council. According to the Ministry's website, The Council was formed "to advise government on key health care priorities, to drive meaningful changes to provincial programs and policies, and to help inform health care plans in Ontario" (11). These commitments and actions demonstrate that lived experience is increasingly recognized as an important aspect of health care improvement and planning.

Establishing advisory bodies demonstrates commitment, yet setting up these structures does not guarantee meaningful engagement or system impact. In 2010, the Minister's

Advisory Group on the 10 Year Mental Health and Addictions Strategy articulated a system vision specific to meaningful engagement of persons with lived experience as:

> A system which is accountable to people with lived experience and values them as integral and expert partners in system design, governance, policy development, program and service provision, as well as decision making about their own care. Sustainable mechanisms are in place at all levels to facilitate their meaningful involvement and participation and gain their insights. This partnership also includes their families or caregivers, where appropriate. (5)

In short, engagement efforts must take into account the importance of ensuring that persons with lived experience play a central role in creating the system that will best serve them. This Summary Report was developed to explore the context, benefits and outcomes of meaningful engagement, as well as barriers and facilitators. Examples of engagement frameworks will also be shared.

What did we do?

A team of knowledge brokers with the Evidence Exchange Network (in the Provincial System Support Program at the Centre for Addiction and Mental Health) set out to identify the most meaningful ways to engage persons with lived experience at the system level within the mental health and addiction sector. The team worked with a CAMH librarian to conduct multiple searches of the evidence and used surveys, single studies, guidelines, policies, and grey literature produced between 1999 and 2018. Evidence produced in Canada, the United Kingdom, Australia, New Zealand, and the United States was used to inform this report.

Psych INFO was primarily used in the literature search. Please see Appendix 1 for details of the search terms used, as well as limitations of this Summary Report.

What did we find?

There is a growing body of literature exploring all aspects of lived experience engagement in the mental health and addiction system. Our findings cover the definition and context of meaningful engagement, barriers and facilitators, engagement outcomes, as well as frameworks to support meaningful engagement practices.

Defining meaningful engagement

Research shows that the meaningful engagement of persons with lived experience can improve the ability of the system to respond to people's needs (8); foster greater public knowledge and awareness about the mental health and addiction system; and decrease the stigma associated with mental health services at every level of policy and practice (8).

Engagement exists on a continuum between meaningful and symbolic (or "tokenistic") engagement. Since Arstein's "Ladder of Citizen Participation" was published in 1969 (2), there has been critical reflection on the different ways in which health and social service systems conduct engagement. Engagement can range from passive involvement, like attending an information session, to an active partnership or leadership role (12, 13), like creating and leading workshops or conducting research. Engagement practices must be aligned with the goals, readiness, and capacity of all stakeholders involved (14).
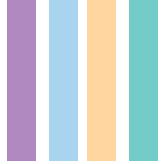
Meaningful engagement refers to genuine, equitable, and affirming processes to integrate the perspectives and expertise of people with lived experience within the mental health and addictions system, from policy development to point-of-care (15). Ensuring that engagement is "meaningful" for everyone involved, especially for persons with lived experience, is important.

Tokenism, on the other hand, refers to the perfunctory or symbolic engagement of people with lived experience (16). Tokenistic engagement still happens despite efforts to meaningfully engage, and tokenistic dynamics can occur when people are:

- not included early enough to meaningfully contribute to a project;

- not properly informed of what is being asked of them;

- not paid equitably for their time and skills;

- silenced when they have critical reflections to share.

Engagement for the sake of engagement can be very harmful and can lead to situations where people feel used and devalued (16). Persons with lived experience need to be engaged based on their specific skills and expertise, not their identities alone nor for the system's "convenience" (17).

The evidence defines meaningful engagement as a *human relationship* (17, 18, 19) characterized by its core *values*, including: equity, trust, respect of human rights, balance of

power, recognition of unconscious bias and privilege, accountability, collaboration/co-creation, transparent decision-making, and valuing lived experience as evidence and expertise (17). Asking 'What is meaningful—and to whom?' can be useful for viewing meaningful engagement as a "receptive context" (1) which we must negotiate with others. "Meaning" should be "made" by all stakeholders, instead of imposed by some (12).

Evidence points to the need for a *revamping of current system structures and mechanisms* in place to support meaningful engagement. As Treichler says, "it is not enough to merely create organizational involvement opportunities; the structure of the system must change in congruence" (20). It also shows that hierarchical structures and the ideological dominance of the medical professions are major barriers to the meaningful engagement of persons with lived experience (21). In order for persons with lived experience to have genuine influence at the system level, there needs to be a redress of hierarchical power, transparent governance and resourcing structures, mechanisms for *allyship,* clear and defined leadership roles for persons with lived experience (with direct channels to high-ranking system decision-makers), and consistency in the "believing and breathing the vision" of meaningful engagement (13, 21).

Meaningful engagement needs to focus on "what matters most to stakeholders" (22). Although every stakeholder will have different needs, the basis of coming together and sharing such differences should be founded on transparent, equitable, and accountable partnerships (22). Ultimately, the way engagement is understood and executed should be a shared, co-created process that benefits all involved. Meaningful engagement cannot be something people do off the "side of their desk" (23). It requires a significant amount of commitment and dedicated work hours (13).

Another important consideration for defining meaningful engagement is power differentials (7, 18, 19, 20, 21, 23). Despite having diverse stakeholders from all levels within the system participate in a partnership, teams must transform divisive dynamics "to move away from the managerial/consumerist approach" (21) and find a way for projects to be defined or led by those with lived experience who have the skills and capabilities to do the work "rather than those who hold power" (21). There is "talk of empowerment of the service user, but there is little evidence that this leads to a shift in control over the process or that the balance of power has changed" (21). To counter this imbalance, the emergence of "peer research" or research produced by the consumer/survivor/ex-patient movement is focused on the "reclamation" of lived experience as knowledge (24) that can significantly improve the mental health and addiction field (24).

Barriers and Facilitators to Meaningful Engagement

Conceptually, barriers and facilitators to meaningful engagement can be understood as stemming from **organizational and systemic cultures, as well as processes** related to the involvement of people with lived experience. Both culture and process form an interdependent relationship and must be understood in dialogue with one another to truly understand what gets in the way of, and what can facilitate meaningful engagement at the system-level; conditions must be ripe in both.

Under this set of definitions, organizational or system *culture* refers to a set of shared assumptions, values and beliefs that guide what happens in organizations or social systems by defining appropriate behavior for various situations (25). Organizational culture affects the way people and groups interact with each other, with service users, and with other stakeholders. In general, it relates to overall climate. Therefore, culture in and of itself, is not something we can see or touch, but is felt. This intangible fabric functions to keep certain values in place and others at bay. This environment may be favorable or unfavorable for persons with lived experience to thrive as leaders, to share their knowledge and expertise, and be system change-makers or innovators.

Process, on the other hand, refers to *the way* in which meaningful engagement is operationalized. Although process is more concrete than culture, it is also intertwined within culture and hard to change without intentional efforts to disrupt the status quo. Process involves methodology, the steps and actions we take to manifest an idea or project. It reflects the way in which a project or initiative is planned, funded, resourced, and sustained. Process can also refer to the pathways that individuals can take to grow within an organization or system. For example, having processes that create opportunities for persons with lived experience to gain power and legitimacy, either through leadership or employment, is important. Processes need to align with values in order for coherent and ethical outcomes to occur.

Barriers

Despite longstanding advocacy efforts on the part of people with lived experience to change the mental health and addiction system, formal engagement within system-level contexts remains relatively new. Many organizations and system tables have learned about meaningful engagement through trial and error, and many of the lessons learned along the way have been captured in the literature. Below are some of the key barriers to meaningful engagement, both within culture and processes.

Culture

Research indicates that the expertise of persons with lived experience is often undervalued due to stigma, discrimination, and power differentials (4, 5, 15, 18, 21, 24, 26, 27, 28, 29). The insidious nature of stigma related to mental health and addictions challenges has created conditions in which many organizations and systems do not value lived experience as a form of evidence and expertise. Often times, organizations and systems lack safe spaces for critical reflection and thinking about power. This makes it challenging to address the dynamics that exclude the perspectives of people with lived experience. More specifically, "professional defensiveness" refers to when those in power feel uncomfortable with persons with lived experience's views and "sanitize" their expression (26).

As they struggle to be seen as equals, persons with lived experience do not routinely access leadership opportunities within the system, nor are there sufficient mechanisms for mentorship and growth of persons with lived experience to advance in their system contributions (24, 30). At the same time, some individuals with lived experience who are in leadership roles are not "out" in their workplace due to fear of negative consequences.

Process

Organizations that do not have a value statement or guidelines that prioritize "lived experience" as a form of knowledge and expertise run the risk of overlooking the potential contributions of people with lived experience within their projects and initiatives.

Persons with lived experience of mental health and/or addictions challenges lack meaningful roles, as they are often overlooked as key contributors in the development and provision of services or in the creation of knowledge, analysis, and research. Also, they are sometimes treated as token examples of service users, instead of as individuals who can contribute to the strategic direction and improvement of system planning, research, and design.

Unrealistic timelines were another recurring barrier; as Nelson says, (23) "on a short timeline it was impossible to overcome decades of discrimination, abuse, suspicion and mistrust" (23). Engagement that happens too late, or after decisions have already been made—effectively asking people with lived experience to "rubber stamp" a decision or project—is tokenistic (23, 26) and a waste of time. Meaningful engagement takes time. Expecting staff to perform high-level co-production or engagement activities without the proper resourcing or time is setting them up to fail (23).
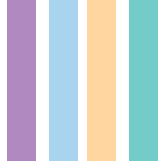
In some cases, persons with lived experience are not adequately compensated or recognized for their expertise, and not included at the outset of project planning (12, 24, 30). Further to this, engagement can take place, and the perspectives of persons with lived experience are collected, however their feedback is not incorporated. This can lead to significant frustrations for those who are engaged.

Figure 1: Cultural and Process Barriers to Meaningful Engagement

Culture

Stigma and discrimination

Lack of space and time to reflect and address power differentials

"Professional defensiveness"

Invisibility of PWLE in leadership roles

"Lonevoice"

Stagnation

Cooptation

Tokenization

Process

Lack of meaningful roles for PWLE

No value statement

Lack of engagement frameworks

Inadequate compensation

Unrealistic timelines

Failure to incorporate feedback

Ultimately, these barriers perpetuate negative experiences for those engaged, and results in overall poor engagement. In some cases, these barriers can lead to project stagnation, whereby progress on a given project or initiative slows to a halt due to lack of role clarity or direction for those engaged. Another common challenge in system-level engagement resulting from these barriers is the 'lone voice' phenomenon, which refers to the expectation that a small group of 'hand-picked' persons with lived experience should represent the diverse experiences of all service users (12, 29, 31). This is a vicious cycle because there are not enough opportunities for persons with lived experience to build the skills necessary to participate in such initiatives (30). In addition there is a lack of intentional recruitment strategies to bring in new and diverse voices (30).
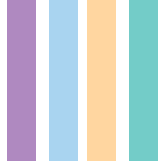
The barriers described above can also result in negative experiences for those that are engaged. For example, engagement that lacks clarity, purpose, and ability to influence decisions can lead to people feeling tokenized, or in other words, used and devalued (16). Under such conditions, participants can also experience a sense of commodification and cooptation of their lived experiences for the benefit of those in charge of engagement efforts.

Facilitators

To qualify engagement as "meaningful," there are a series of core components that must go into the process and planning, as well as the culture of the organization, or system carrying out engagement. The following practices, drawn from the literature, can all contribute to creating the conditions for meaningful engagement. As with the barriers, they are organized within the categories of organizational or system culture, as well as processes that can foster meaningful engagement.
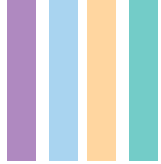
Culture

Create a "receptive context" (1) founded on the values of procedural justice, equity, and human rights. Persons with lived experience are integrated as legitimate and respected experts (1, 23, 26).

Foster strong organizational or system leadership and buy-in at the outset (1, 23, 30). Identify and work with champions in leadership roles, and encourage engagement to be considered at the earliest stage within a project or initiative.

Achieving meaningful engagement means going beyond participation (activities with minimal influence). Doing so requires the creation of engagement opportunities that allow persons with lived experience to take on leadership roles and have greater influence on the work in which they are involved (5, 21, 27, 30). Encourage a critical mass of persons with lived experience in leadership roles (18, 23).

Redress hierarchical power within organizations throughout the system (6, 13, 16, 21, 24) by creating processes and mechanisms allowing persons with lived experience to have direct influence in decision-making, hiring, governance, management, and budgeting (6, 15, 23).

Create space to reflect on power and privilege (18, 23, 26). Have a deliberative process in place to promote critical dialogue (14).

Process

Include an articulated engagement framework with guiding principles that explicitly value lived experience as expertise and evidence, to ensure engagement is not a fringe activity.

Have an accountability and governance structure in place, including working groups as appropriate, with strong leadership allies to keep progress on track (5, 15, 22, 27).

Measure outcomes of engagement at the system-level. Research relevant outcome measures to determine impact and effectiveness of engagement in system projects (12).

Create appropriate policies and hiring practices to recruit qualified and skilled persons with lived experience (27, 30).

Compensate persons with lived experience appropriately in order for their skills and labour (10, 30, 32) to be valued and acted upon. As a result, funding proposals need to build in requirements for compensating and hiring persons with lived experience.

Provide training and mentorship founded on principles of *allyship* that challenge medical hierarchical norms and professionalism more broadly (5, 23, 26, 30).

Articulate the level of engagement of persons with lived experience in any given project or initiative, to ensure that everyone has clear roles and responsibilities, in addition to understanding their level of influence. A ladder or continuum can be useful as a framing tool (2). Have all stakeholders involved define what "meaningful engagement" means in the context of the project, and seek their input in determining the desired outcomes (13, 23).

At the outset, include generous timelines to be able to complete the work in equitable and meaningful ways. The planning stages need to factor in the time it takes to build relationships suited for genuine collaboration (23).

In the context of skills-based endeavors (like research or intensive review processes), hold pre and post engagement events where conceptual and/or technical questions and concerns can be voiced and answered, openly (14, 23).

Ensure the application of a feedback loop following any engagement initiative (32).

Figure 2 illustrates elements of organizational and system culture, as well as processes that help foster meaningful engagement.

Figure 2: Fostering Meaningful Engagement

Venn diagram with two overlapping circles.

Culture
- "Receptive context"
- Leadership buy-in
- PWLE in leadership roles and influence
- Redress hierarchical power
- Create space to reflect
- Encourage critical dialogue
- Allyship

Overlap: Higher quality projects, research and evaluation

Process
- Value statement and framework
- Accountability structures
- Measure outcomes
- Hiring practices
- Fair compensation
- Training and mentorship
- Articulate level of engagement
- Generous timelines
- Pre and post events
- Feedback loop

With these facilitators in place with regards to organizational or system culture, as well as specific processes, engagement efforts are more likely to be meaningful for everyone involved. This stands to have positive impacts such as higher quality projects, research and evaluation.

Outcomes of meaningful engagement within the mental health and addiction system

The evaluation of meaningful engagement is an emerging field, and there is more to learn about how to effectively measure system impact (27, 33). Most of the evaluation research that exists is tied to process, not outcome (27, 33). Nonetheless, several positive outcomes have been identified in areas including: research and knowledge production, public and professional attitudes, organizational culture, and community planning and collaboration.

One of the most pronounced impacts identified was improved quality of research in the mental health and addictions field. Several authors noted how meaningfully engaging and

involving persons with lived experience in traditional science-based academic research projects led to the development of more complex research questions that "pushed science forward more quickly" (27, 28). Persons with lived experience's expertise also contributed to more credible research results (24, 27, 28) and improved consent procedures, creating more ethical research design (27). Creating research roles for persons with lived experience was also identified as important for building their capacity. Creating opportunities for mutual learning contexts between academics and persons with lived experience can break down systemic barriers (27, 28). However, equity and power differentials still create barriers to engaging within large academic research institutions, including widespread stigma and a belittling of lived experience expertise within academia (24). The evidence demonstrates the need for more opportunities for persons with lived experience to lead research and evaluation projects (31, 32, 33).

Empowerment and strengthening of the service user voice within system dialogue (27) has also been observed to challenge professional and public perspectives (34). Changes in public perception can lead to reduced stigma and discrimination (34). Often, changes in perceptions were observed to be stepping stones to more concrete changes in areas such as public policy, service planning and delivery, and funding allocations (34). Another major win for meaningful engagement has been the increased acceptance of peer support as critical component of treatment and care for people recovering from mental health and addiction challenges (24, 34).

Frameworks for Meaningful Engagement

A number of frameworks have been developed to provide guidance to groups seeking to meaningfully engage people with lived experience. The below examples are not intended to provide a comprehensive directory of frameworks, but represent some examples that may be useful to organizations in developing engagement strategies.

Walking the Talk: A Toolkit for Engaging Youth in Mental Health. Ontario Centre of Excellence for Child and Youth Mental Health (2016). Centered on youth engagement, this toolkit brings together the latest evidence, tools and templates to help get individuals or organizations started. http://www.yetoolkit.ca/

Peer Positive Toolbook. Provincial System Support Program, Centre for Addiction and Mental Health (2016). This is a step-by-step implementation guide for organizations to prepare themselves on becoming more "Peer Positive". Three core components make up what being "peer positive" entails: 1) peer involvement, 2) spaces to reflect on power, and

equity 3) accountable mechanisms of feedback and response.
http://improvingsystems.ca/img/Peer-Positive-Toolbook-Final-November-24.pdf

Community Engagement Framework. Centre for Addiction and Mental Health (2015).
Although this framework is not particularly about people with lived experience, it outlines
what "engagement at the system-level" looks like—practically, on the ground, and in
institutional environments.
https://camh.ca/-/media/files/camhcommunityengagementframework-pdf.pdf

**4PI Framework for Involvement. National Involvement Partnership and National
Survivor User Network (2015) UK**. This framework is founded upon 5 pillars: "Principles,
Purpose, Presence, Process and Impact" and is meant to help organizations meaningfully
engage lived experience and measure the impact effectively.
https://www.nationalvoices.org.uk/sites/default/files/public/4pinationalinvolvementstandar
dsfullreport20152.pdf

**Tools to Enhance the Engagement of People with Mental Health Conditions and
Addictive Behaviours. Canadian Mental Health Association, British Columbia (2014).**
This tool kit begins with a self-assessment test for organizations to "check" their
assumptions about persons lived experience. By clearly listing "things to consider" before
attempting to implement engagement strategies, organizations can mitigate potential
equity issues, and ensure that engagement practices are self-reflexive, circular, and
continuous. https://cmha.bc.ca/wp-content/uploads/2016/07/CMHA-engagement-report-
2014.pdf

Collaborative Autonomy Framework (Nothing About Us Without Us) (1998). *Nothing
About Us Without Us* (1998), written by James I Charlton, is the first book in the area of
disability literature to provide a theoretical overview of disability oppression that shows its
similarities to, and differences from, racism, sexism, and colonialism. The important
concept 'nothing about us without us' refers to the process of consulting with the people or
groups who will be impacted by a particular policy or project. The concept posits
fundamental systemic restructuring as integral to forming, developing, and sustaining
equitable, inter-professional partnerships between people with lived experience of
addiction and mental health issues and the larger health care system.
https://umbcassistivetech.files.wordpress.com/2014/08/nothing-without-us-12.pdf

Conclusions

The meaningful engagement of persons with lived experience at the system level is an ongoing process, one that requires consistent prioritization and evaluation. There is a strong case for the involvement of persons with lived experience in the mental health and addictions system. Persons with lived experience face many barriers, which may prevent them from engaging with planners, providers and system-leaders. Changes in organizational structures and practices, as well as cultural beliefs are necessary to fully utilize the expertise of persons with lived experience. Several frameworks exist to guide meaningful engagement; a focus on strengthening organizational and system culture towards valuing the contributions of people with lived experience, as well as thoughtful engagement processes and practices, can ensure the system moves towards better integration of lived experience perspectives. If we are to be successful, our journey to creating a more responsive, high quality mental health and addictions system must centre the people it intends to serve.

"Nothing about us without us."
**- James I Charlton, Disability Rights Activist**

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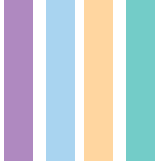
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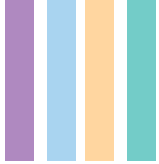
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Appendix 1: Methodology

Search Terms

The following terms and exclusion criteria were applied in the literature search:

People with lived experience/ service users/ substance users/ clients/ patients/ consumers/ survivors/ family members/ people with */ people experiencing *

Mental health/ mental illness/psychiatric diagnoses/ mental disorders/psychiatric disorders + addictions/ substance use + mood disorders/ depression/ anxiety/ psychosis/ PTSD/ schizophrenia/ personality disorders/ bipolar

Research/ planning/ design/ decisions/decision making/ development/production/delivery committees/ (advisory) boards/ guidelines/ implementation/ community collaboration/ policy/ healthcare improvement/ service improvement

Outcome/ impact/ effect/ buy-in/ uptake/ success

Level: System/ sector/ meso/ macro

Limitations

There is a lack of academic research focused specifically on the **meaningful engagement** of persons with lived experience at the **system level**. Most studies focus on point-of-care outcomes. Many studies identify this as a limitation and call for more research on and evaluation of system impacts.

Given the scope of this report, we were not able to include the following topics but would like to acknowledge their importance and relevance within this field. A more robust evidence synthesis would have included the following:

- Youth engagement, or engagement of any specific populations, within the mental health & addictions sphere (e.g. First Nations, Métis and Inuit, Francophone)

- Consumer-led or peer-operated mental health/addiction services

- Consumer involvement in the development, delivery, and evaluation of professional activities (i.e. general agency operations)
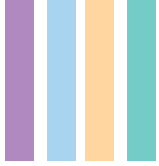
- Community-based (participatory action) research

- Intellectual/cognitive disabilities

- Service user impressions/satisfaction, family member satisfaction perceptions, etc. (Engagement in evaluation/performance outcome measurement)