

## **Bibliography: Best Practices for Engaging People with Lived Experience of Mental Illness of Addiction.**

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### **1. Toward the Heart program. (2017). [How to Involve People Who Use Drugs.](#)**

This resource provides a list of Do's and Don'ts for engaging people who use drugs in committee work. It was adapted from the Canadian HIV/AIDS Legal Network resource "Nothing About Us Without Us" (2005) and modified with extensive peer input (2017).

Five categories of Do's and Don't provide recommendations to committees about how to respectfully engage and remove barriers for people who use drugs. The categories include: diversity of perspectives; style of meetings; mobility and compensation; privacy; and travel.

### **2. PeerNet BC. (2017). [Allyship zine](#)**

This zine seeks to clarify the role of 'being an ally' and provides concrete ideas on how to practice allyship daily. According to the peer-led group who developed the zine, allyship begins when a person of privilege seeks to support a marginalized individual or group. It is a practice of unlearning and relearning, and is a life-long process of building relationships (as opposed to isolated, short term actions).

The responsibilities of being an ally are listed and include: actively acknowledge privilege; listen more and speak less; work with integrity and direct communication; do not expect to be educated by others; build capacity to receive criticism; embrace the emotions that come out of the process of allyship; do not expect awards or special recognition. According to the group, when allyship is practiced in this way it can be a powerful tool in challenging oppression.

### **3. Northwest Toronto Service Collaborative (no date). [Peer Positive Toolkit: Preparing organizations to better engage people with lived experience through equitable processes.](#) Centre for Addiction and Mental Health.**

This resource aims to prepare organizations for change by encouraging equitable processes of engagement that value lived experience. It was created by the Northwest Toronto Service Collaborative, a community-led process sponsored by the Provincial System Support Program at the Centre for Addiction and Mental Health (CAMH).

Peer are defined as people who have lived difficulties associated with issues such as mental health, addictions, substance use, HIV/AIDS, violence against women, and chronic illness, and who demand valuing this experience as a form of expertise that can help improve services. Three peer positive Core Components are identified, 1) Peer Involvement, 2) Space to Reflect on Power and Equity, and 3) Accountable Mechanisms of Feedback and Response. Practice standards and practical tools to encourage equitable processes of engagement are included for each of the Core Components.

**4. Saini, B., and Cramp, J. (2017). [\*Engaging People with Lived Experience of Mental Health and Addictions at the System Level – A literature Review.\*](#) Addictions and Mental Health Ontario.**

This paper compiles relevant literature on the benefits and challenges of engaging people with lived experience of mental health and addictions at the system level, including political advocacy and community planning. The paper describes different roles where ‘service users’ can be involved in decision-making and the organizational conditions/structures needed to support these roles. A spectrum of service user leadership is presented, ranging from no involvement to service user led.

Four frameworks for engagement of PWLE in committee work are summarized. Different decision-making opportunities are depicted in each of the models, ranging from treatment decisions (direct care), to service delivery design, to policy making. The benefits of engaging PWLE at the system level include opportunities to correct power imbalances between public and professional power; increase accountability of healthcare to user; and improve the quality and responsiveness of the services. On the side of the service user, benefits include building self-worth and empowerment, mobilizing positive change, and increasing understanding of changes that will affect them.

Facilitators and barriers to PWLE involvement are categorized under Individual, Organizational/Procedural and System Level. Evaluation of PWLE involved is discussed and proposed outcome measures are listed (e.g., % of mental health and addictions organizations with PWLE-led orientation or staff training sessions). Recommendations from the literature are presented under 5 categories: Training and preparation; Adequate and appropriate resources; Building self-confidence and trust; Inclusive structure and processes; and Eliminating stigma and discrimination.

**5. Cramp, J., Indrakumar., A., & Sani., B. (2017). [\*Best Practices in Peer Support.\*](#) Addictions and Mental Health Ontario.**

This report aims to address the confusion over the dimensions and goals of engaging people with lived experience (PWLE) in the mental health and addiction sector. Peer support role are listed and defined, ranging from peer support workers to peer navigators to peer advisors. Three key areas are explored – capacity building, public speaking and training.

Building capacity refers to meaningfully engaging PWLE at the system level. A literature review explores the benefits and barriers (at the individual, organizational and system level) of engaging PWLE at the system level. Two case studies identify activities and strategies that can be used to ensure that PWLE are 1) Informed, 2) Consulted, 3) Involved, 4) Collaborative with, and 5) Empowered. Factors for meaningful engagement are also outlined and include: 1) Plan for participation, 2) Invest in sustainability, 3) Address power differentials, 4) Establish legitimacy, 5) Assign resources.

Public Speaking refers to when a PWLE becomes a spokesperson and is in a position to alter attitudes and stigma associated with mental health and addictions. An environmental scan of existing resources revealed that there are limited resources available for people with lived experience of mental illness and/or substance use to help them share their story.

Training refers to opportunities for PWLE to obtain skills and knowledge to effectively provide peer support. The report identifies six key areas of training needs, 1) Self-assessment/evaluation, 2)

Interpersonal skills, 3) Working with Changes/Transitions, 4) Supervision, 5) Personal Development & Learning, 6) Information Toolkit.

**6. Centre for Addiction and Mental Health. (2013). [\*Strengthening Your Voice: A public speaking guide for people with lived experience of problems with prescription pain medication.\*](#)**

The purpose of this guide is to train people with lived experience of prescription opioid problems to tell their stories publicly. Material in the guide is based on the individual experiences of people in stigmatized groups (e.g., substance use problems, HIV/AIDS) and on the accounts of the support workers who help them and have seen the results of their efforts. The guide outlines several goals for speaking out publicly, including raising awareness, reducing negative attitudes, humanizing the issues, preventing others from developing problems with medication, and reinforcing a message of hope.

The guide provides practical advice and tools for PWLE who are preparing to tell their story publicly. The first section of the guide outlines some of the benefits to sharing one's story. An accompanying checklist identifies potential gains and risks. The first section also offers a self-assessment to gauge readiness, tips for developing the story and checklist on knowing your presentation style.

The second section focuses on presentation skills, managing the audience questions and planning the presentation. The guide emphasized the importance of addressing stigma as well as the importance of self-care.

**7. Greater Victoria Coalition to End Homelessness. (2017). [\*Engagement Toolkit: People with lived experience in BC's Capital Region.\*](#)**

This Toolkit was prepared for staff members of organizations in the Capital Region of Victoria, BC who have frequent contact with people who have experienced homelessness. The Toolkit is organized according to five levels of engagement, derived from materials developed by the International Association of Participation (IAP2), one of the most frequently cited sources for stakeholder and public engagement best practices. The five levels are, 1) Inform, 2) Consult, 3) Involve, 4) Collaborate, and 5) Empower. Practical tools and examples for each of the levels are provided.

**8. Homer, A. (2019). [\*Engaging People with Lived/Living Experience: A guide for including people in poverty reduction.\*](#) Tamarack Institute.**

This guide was written primarily for collaboratives working to reduce poverty, but is applicable to all collaboratives interested in reflecting on their current processes. The introduction identifies the benefits and challenges of engaging people with lived/living experience in poverty reduction work - "Their stories and experiences serve as powerful tools for building compassion and for disrupting and clarifying a community's understanding of its root causes and scope. The recognition of people with lived/living experience as context experts alongside government, business, and non-profit counterparts challenges power imbalances and counters the tendency for practitioners in leadership positions to dominate agendas, discussions, and ultimately, decisions".

Section 1 presents a self-assessment consisting of 10 key questions that can help collaboratives understand the groups' readiness for meaningfully engaging people with lived/living experience. Section 2 presents high-impact ideas for meaningfully engaging PWL/LE.

1. Commit to engaging people with lived/living experience
2. Create a culture of inclusion
3. Host accessible meetings
4. Create opportunities for engagement
5. Eliminate financial barriers to participation
6. Consider paying people with lived/living experience for their time
7. Take the time to build trust
8. Share power by opening up decision-making processes
9. Provide training and mentoring opportunities
10. Diversify representation and deepen engagement

Section 3 provides examples of how groups from across Canada are championing the 10 ideas. Section 4 offers useful resources and Section 5 outlines 10 ways to get started.