

2021



# Lived Experience Leadership

LITERATURE REVIEW AND RECOMMENDATIONS  
M.A.P.S. ALBERTA CAPITAL REGION



# Lived Experience Leadership

Literature Review and Recommendations

By

MAPS Alberta Capital Region

July 2021

## Introduction

*What is “Lived Experience Leadership”*

Definitions and abbreviations

**Lived experience (LEx):** Direct, firsthand experiences, past or present, of a social issue(s) and/or experience.

**People with lived experience (PWLEx)**

**Lived expertise:** Knowledge, perspectives, insights and understanding gathered through lived experience.

**Lived experience Leader (LEx leader):** Change makers, innovators and leaders who have activated their lived expertise to inform, shape and lead their social purpose work, (often in combination with their learned and practice experience) to directly benefit the communities they share those experiences with.

**Leader without lived experience: (Non-LEx leader):** a leader using learned knowledge, technical expertise and practice experience.

We’re living in a divided world. Divided by backgrounds, experiences, cultures, behaviours and world views. Rising inequalities threaten our society and a sense of hopelessness pervades social sector discussions about the future. At the same time, optimism for the future is flourishing across communities directly impacted by social inequities and a call of connected wisdom and visions of shared leadership is emerging. Sandhu (pg 5)

Lived experience leadership spans everything from perspective, to understanding, to wisdom and knowledge, to avoiding tokenism and essentialism, to respect, to empathy, to inclusivity, to survival, to honesty, to courage, to power, to support, to love, to self-reflection, to accountability, and responsibility. Clan Mothers Healing Village 2017

Although work in the social sector has achieved significant victories in giving agency to people with lived experience in society, recognition, celebration and investment in lived experience leaders has been long neglected. Technical expertise and learned knowledge continue to dominate social sector thinking, behaviour and activities. Many lived experience leaders feel isolated and disenfranchised, forced to operate outside of existing support structures designed

by this dominant culture – feeling side-lined, even rejected, as modern -day social leaders in the social sector. Sandhu (pg 5)

“We believe healing is only possible when we return to our Indigenous models and methodologies of healing. There is a recently renewed movement and respect for the important role and invaluable leadership of persons with lived experience, Grandmothers, and women. They are restoring teachings, values, and practices that were lost as a result of colonization and residential schools. Clan Mothers Healing Village

### *Where is Lived Experience Leadership Showing Up*

- Mental Health
- Disability/learning difficulties
- Long term Care
- Criminal Justice
- Migrant and Refugee rights
- Caregivers
- Homelessness/social housing
- Substance Misuse
- Gang affiliation
- Domestic Violence and Abuse
- Sexual Violence
- Multiple and Complex Needs
- LGBTQ2S+
- Race Equality
- Gender Equality

LEx leaders are engaged in the social sector as peer workers, practitioners, innovators, entrepreneurs, educators, artists, policy strategists, public servants, philanthropists and advisors.

**Nothing About Us Without Us**; *7 principles for leadership and inclusion of people with lived experience of homelessness identified by the Lived Experience Advisory Council of Canada*

**1. Bring the perspective of our lived experience to the forefront**

**2. Include people with lived experience at all levels of the organization**

**3. Value time and provide appropriate supports**

**4. Challenge stigma, confront oppression and promote dignity**

**5. Recognize LEx expertise and engage LEx leadership in decision-making**

## **6. Work together towards equitable representation**

## **7. Build authentic relationships between people with and without lived experience**

### **The Value of Lived Experience Leadership**

Unique strengths and competencies

- Courage, resiliency and adaptability
- Purpose, passion and drive
- Empathy and compassion
- Equity and justice
- Vulnerability
- Love and generosity

Benefits of Lived Experience Leadership

- Connecting to community
- Building community collaborations and partnerships
- Understanding problems
- Authenticity and accountability
- Strengthening organizations – building connected staff teams, bringing human essence into the work
- Mission focus vs mission drift
- Intersectionality
- Systems understanding and value
- Innovation skills and insights

Challenges Faced by Lived Experience Leaders

- Isolation
- Playing catch up with learned knowledge
- Imposter Syndrome
- Heart over Matter
- The emotive story marketplace; more than storytelling is needed to create change
- Keeping the ego in check; sharing your experience can inflate one's sense of self
- Going it alone
- Burn out
- Institutionalization; the system needs to change, needs a heart, instead PWLE are under pressure to conform to the system

## Structural, Systemic, and Cultural Disadvantages

Significant structural, systemic and cultural barriers hinder, or block or inadequately support LEx leaders capacity to thrive. Sandhu (pg 5)

- Legitimacy and credibility
- Power and control
- Lack of transparency and accountability
- Stigma, bias and discrimination

## **Development Needs of Lived Experience Leaders**

Reports from North America, Canada, New Zealand, Australia, and the United Kingdom demonstrate common issues regarding LEx work force development needs, including:

- Remuneration
- Role clarity
- Career trajectory
- Reduced risk of cooptation
- Access to training, supervision and support.

Limited time frames for lived experience initiatives and limited funding and resources for research inhibit the development of a robust evidence base. Byrne, Stratford, Davidson 2018

## **Recommendations for the Inclusion of Lived Experience Leadership**

Stand beside LEx , not behind or in front.

Ensure that your organization’s communications, fundraising, research, and programs do not reinforce the misconceptions that experiences are caused by individual problems or can be solved by charity.

Hire LEx leaders in positions at all levels – front-line, administration, and management.

Include lived experience as a dimension in your organization’s equity and diversity policies.

Create a liaison within municipal and provincial government bodies.

Work towards sustainability and advancement for “peer” positions, so that those hired on as “peer counsellors,” “peer researchers,” etc., can advance to permanent positions.

Anticipate the compensation and supports that will be required to properly include people with lived experience, and include those costs in funding applications.

Compensate well for the time spent in consultation, not only with token gift cards or minimal honorariums.

Remember that these issues have a huge impact for PWLEx because they can relate to the experience. Create a welcoming environment in which it is safe to express emotions.

Develop new ways of doing business - long meetings and bureaucratic procedures can be very draining and alienating, not only for people with lived experience!

Provide training and capacity-building to all members of the organization, including those with and without direct experience.

Ensure that the timeframe for an initiative includes the time required to form a good working relationship and do things at a reasonable pace.

Create a common ground to work from by providing Anti-Oppression 101 training to all members of the organization, from participants to volunteers to front-line staff and management.

Confront oppression through the use of anti-oppression models, which are inclusive.

Educate around intersectionality – that is, the ways that oppressions such as racism, sexism, classism and ableism work together and reinforce each other.

Review organizational policies and practices to ensure they promote equity, dignity, and rights of people facing social exclusion.

Include equitable representation as a goal in the organization's strategic planning process.

Set concrete objectives and specific timeframes, and work towards them.

Identify other organizations that have successfully implemented equitable representation and get their advice and mentorship.

Evaluate the organization's progress, seeking input from people with lived experience in the process.

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