

FRAMEWORK CHAPTER 8



VOICES of Lived Experience Dufferin is a community-based advocacy group composed of people with lived experience, and a facilitator /coordinator.

A community-based group of people with lived experience (PWLE) is a diverse and inclusive collective made up of individuals who have personally navigated a wide range of life circumstances. Members may include those who have experienced mental health challenges, substance use, homelessness, incarceration, domestic violence, poverty, trauma, chronic illness, disability, or systemic discrimination. Others may come from backgrounds of refugee or immigrant status, involvement in the child welfare system, or have lived through marginalization due to race, gender identity, or sexual orientation. This rich diversity of experience fosters a supportive environment rooted in empathy, peer connection, and shared resilience.

The VOICES Framework is a dynamic tool designed to guide organizations and communities in working more effectively with people with lived experience (PWLE). Each of the twelve chapters within the framework represents a distinct lens or tool that can be applied to shape programs, policies, and services that engage and support individuals and families.



*This document is one of 12 chapters from **The VOICES Framework**. The full framework and additional materials, as well as references and works consulted on this topic, can be found on the VOICES website.*



8 SHARING POWER AND CREATING LEADERSHIP ROLES FOR PWLE

GROUP DISCUSSION QUESTION PROMPTS

The VOICES process involves question prompts that guide the group discussion. These are the question prompts for this chapter's group discussion.



I think it is essential that PWLE are at the table when decisions are being made that impact them because...



When I am empowered, I feel...



I want to have more peer-to-peer support because...



Good ways for organizations, community groups, and governments to share power with PWLE like me would be...



What I want people to know who are in places of privilege and who are making the decisions about PWLE is...



INTRODUCTION

Sharing power and leadership with vulnerable people in decisions that impact them means active and intentional involvement of marginalized individuals or groups in decision-making processes that affect their lives. We feel that nothing is more important than involving those that decisions are being made for in the process. Doing so will ensure that our perspectives, needs, and interests are represented and considered. It involves recognizing and addressing power imbalances that may exist within an organization and seeking to create more equitable and inclusive decision-making spaces. Sharing power in this context promotes social justice, participation, and empowerment for PWLE of poverty, enabling us to have a say in shaping policies, programs, and practices that directly affect us.

PERSONAL AND COLLECTIVE INSIGHTS

At VOICES, we understand that sharing power and creating leadership roles for PWLE involves recognizing the value of lived experience first. If we are not valued, then our knowledge will not be seen as needed. If our knowledge is not seen as needed, people like us will not get the help they need. Recognizing the value of lived experience can transform organizations, making them more responsive and effective. Research supports this approach, highlighting how integrating lived experience into professional roles can enhance empathy, rapport-building, and advocacy skills (Mackay, 2023).



"Integrating our lived experiences into professional roles not only validates our struggles but also improves the services provided to others facing similar challenges." – **VOICES Member**





"Being part of the decision-making process empowers us and ensures that the solutions are effective and relevant to our needs. I have felt this so strongly as a member of VOICES. We are finally getting asked our opinions about the things that we are struggling with. It's about time! And I get to be in a group of people who understand me." – **VOICES Member**



Sharing power and leadership space with PWLE in decision-making on issues that affect them is essential in addressing poverty or any other issues that impacts the person who the intervention or service is for. By including marginalised persons and groups in the decision-making processes, we have a better chance of including their voice and making good use of their unique experiences to provide more equitable and effective solutions for the households and communities they belong to. Individuals and groups that have been excluded in the decision-making processes are in fact expert knowledge holders who have the potential to make meaningful change. For PWLE to assume more positions of leadership, organisations need to develop more inclusive cultures, commit appropriate resources and establish structures and processes that enable shared decision-making. Through centring the knowledge and experiences of those with a lived experience, we can ensure a culture shift that leads to a more just and equitable society for all.



KEY POINTS OF THE FRAMEWORK

The Importance of Sharing Power

We feel strongly that sharing power with PWLE is essential for several reasons. First, it recognizes that decisions made without the input and involvement of those who are directly affected can perpetuate inequalities and exacerbate the marginalization of already disadvantaged populations (Kabeer, 2019). For instance, policies and programs implemented without considering the needs and perspectives of vulnerable communities can inadvertently reinforce existing disparities, leading to further marginalization and exclusion. Many of us have felt this way.



"Decisions made without our input often miss the mark entirely and don't address our real needs. It's frustrating to see policies and decisions that affect our lives but don't consider our experiences. For example, if the owner of the Toronto Maple Leafs wants to win, they are going to hire people who have experience of hockey but somehow when decisions are made about poverty, people who are poor are not seen as experts. People who live in poverty need to be viewed as experts on the subject. It feels very punitive and parental when decisions are made for us, without us. This is also why our VOICES group is so essential." – **VOICES Member**

Sharing power acknowledges that individuals and groups who experience poverty or another form of vulnerability have unique insights and expertise regarding their own lived experiences (Sen, 2009; Lachapelle, 2022). We feel that without lived experience people making the decisions are operating in the dark. Our perspectives and that of others like us can provide valuable information about the challenges people in poverty face, potential solutions, and the unintended consequences of certain decisions. By involving us in decision-making processes, our very specialized knowledge and expertise about the very topic being acted upon can be utilized to design more effective and contextually relevant interventions (Santos, 2018). From this perspective, PWLE at the table for issues that impact their lives is simply common sense.

"Having lived through these challenges, we have a deep understanding of what works and what doesn't. Our input can lead to more effective solutions. Most people in power don't really seem to know what is going on. They have never been in that position so they cannot know what it feels like. They are not really talking to us or sharing the power with people who know what it's like and yet they are making the decisions about us. There is a real disconnect and it really leaves you scratching your head." – **VOICES Member**

What Does it Look Like for PWLE to Take More Leadership?

A leadership role for people with lived experience in an organization involves individuals who have personal knowledge and firsthand experience of the issues and challenges faced by a particular group or community. This leadership approach recognizes the unique expertise and perspectives that individuals with lived experience bring to the table, and it aims to empower them to actively participate in decision-making processes and influence organizational directions. First and foremost, we need to be seen as valuable, because we are! Then by sharing power, organizations can benefit from the valuable insights we and other PWLE offer, foster more inclusive practices, and drive positive change forward.

In practice, a leadership role for people with lived experience entails providing opportunities for their meaningful engagement in various aspects of organizational functioning. This is the responsibility of the organization and their leadership/management teams. In our case it has meant being supported by our coordinator, the DCEC, HCIA, the Orangeville Food Bank, United Way, the county, and other community partners to develop our network, create this framework, develop our terms of engagement, and train our members to create and implement our vision. The level of detail in this work speaks to the supportive infrastructure needed from the community at large to have PWLE groups. In turn strong PWLE groups and networks can make a large positive impact. Many PWLE groups are involvement in governance structures, such as advisory boards or committees where they can contribute to decision-making processes, provide insights, and offer recommendations based on their lived experiences (Corrigan, Pickett, & Kraus, 2014). They may also be engaged in program planning and evaluation, policy development, and service delivery, ensuring that the perspectives and needs of the target population are adequately represented (Minkler & Wallerstein, 2011).

Resource Allocation

Organizations need to allocate resources and support the development of networks and platforms for individuals with lived experience to connect, share their experiences, and collectively advocate for change (Campbell, 2012). Organizations must allocate their resources into supporting PWLE as consultants and leaders. Organizations pay for what they think is essential like employees who are doing a job. We feel strongly that the knowledge of PWLE is essential to successfully creating programs and services that work, so making sure that it is budgeted as a priority is essential.



ORGANIZATIONAL REFLECTION QUESTIONS

These questions can help ensure that you are taking a Sharing Power and Creating Leadership Roles for PWLE Approach at your own organization.

- 1 How do we actively involve PWLE in leadership and decision-making processes within our organization?
- 2 What systems or structures do we have in place to ensure PWLE voices are meaningfully integrated into program design and evaluation?
- 3 How do we create safe and inclusive spaces that encourage PWLE to step into leadership roles?
- 4 Are we providing training and resources to help PWLE develop leadership skills and feel confident in contributing to organizational decisions?
- 5 How do we ensure fair compensation for PWLE contributing their expertise, and is this built into our budget planning?
- 6 How do we balance power dynamics between PWLE and other stakeholders to create a truly collaborative environment?
- 7 What strategies do we use to address potential barriers PWLE face when participating in leadership roles, such as time, resources, or emotional bandwidth?
- 8 How do we measure the impact of including PWLE in leadership roles on organizational outcomes and service delivery?
- 9 How do we communicate our commitment to sharing power with PWLE to internal and external stakeholders?
- 10 **Visualization Exercise:** Close your eyes and visualize your leadership team, including Board members and staff. How diverse are the perspectives and lived experiences represented? Do you have PWLE in any of these roles? What steps can you take to ensure PWLE are included at all levels?

WALK IN OUR SHOES: PERSONAL STORIES FROM PWLE



“Our VOICES group is a great example of genuine power-sharing. The way we operate is centred on storytelling, which allows us to share our experiences in a way that respects and uplifts each person's unique perspective. This traditional method of passing on knowledge honours lived experiences as a valuable source of wisdom. It ensures that everyone has a voice, is heard, and can actively contribute to the discussion. Our group runs on fully collective decision-making, where every member is an equal participant. There's no single authority figure; instead, our coordinator acts as a guide, not a manager. Everyone is viewed as a leader, and we place equal importance on each person's input. From the start, we emphasize active listening, taking turns to speak, and making decisions together, reinforcing the value of everyone's contribution. Our approach is decolonized, drawing from First Nations' principles that emphasize equality, inclusion, and respect for each person's voice.

Externally, we've been involved in community consultations that give us the chance to speak on issues that directly affect our lives. Making sure that people with lived experience are involved in the decisions and processes that are in place to help them, we think, is the most important way to share power. We need to be supported to rise and thrive, not have decisions made for us, without us. VOICES embodies this principle, and it is the heart of what makes this group work. There is a deep sense of equality which gives everyone safety. An example is that everyone, including the coordinator, is paid a living wage, and we all receive the same amount. This removes any financial hierarchy and truly puts the idea of shared leadership into practice. It feels empowering to know that there's no top-down structure and that we're all on the same level. Being part of this group has been an empowering experience for us all and changed how we have thought about how groups and businesses and nonprofits should be run. First and foremost, we need to include our lived experiences when we make decisions about people who live in poverty because we are the ones that are truly the experts when it comes to addressing the challenges we face.” – **VOICES Member**

WALK WITH US...

This is one chapter from a framework of 12.
Find more resources at DCEC.CA.

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