Consulting People with Lived Experience

Following their formation in 2014 as a result of the Annual Conference on Ending Homelessness, the Lived Experience Advisory Council coined the phrase: “Nothing about us without us.” Salvation Army Emergency Shelters are depended upon to include the voices of people with lived experience of homelessness (PWLE) in their endeavors to plan, evaluate, and improve programs and practices.

Situations where it is important and appropriate to solicit the input of clients (both current and former) as key stakeholders:

* Building Design & Use of Program Space
* Program Development and Evaluation
* Outcomes Tracking
* Community Needs
* Other Client-Based Research Projects (whether conducted internally or by external researchers)

When consulting those with lived experience of homelessness in order to receive input or better understand their perspective, consideration should be given to the following principles and ethical issues:

### **Checking Assumptions**

While completing a particular task or utilizing certain terminology may be straightforward for some individuals, for others **it may be a source of conflict and emotionally triggering or stigmatizing**. When working with PWLE, one must remove assumptions and consider **sources of discrimination and** **barriers to meaningful engagement**. These may include: language and communication, the availability of social supports, the location and time of the activity, and the lack of information about the activity or PWLE’s responsibilities. One of the best ways to identify and address these barriers and assumptions is to **seek the advice and** **collaboration of PWLE** (e.g. through advisory committees, focus groups led by peers), who can help determine what these barriers are as well as provide solutions that account for their perspective and experiences.

### **Equity**

Not only are PWLE the recipients of services, but also they carry **unique expert knowledge** that is necessary when **developing and designing** **buildings, programs, and policies that best meet the needs** of individuals experiencing homelessness. PWLE should be represented at all levels of the organization and in various capacities, from co-researchers and evaluators to members of committees and boards. Equitable practices should be adopted, including compensation (e.g. honorariums) for PWLE’s time and insight and suitable supports to facilitate their engagement (e.g. transit fares and meals; proper training). Recognizing PWLE as collaborators and applying their insights in a meaningful way will help **address power imbalances** and ensure programs are **person-centered** and **holistic.**

### **Autonomy**

Even if their valuable insight is acknowledged, PWLE are often relegated to small, insignificant roles due to the misguided notion that they do not have the **ability** to engage in a more meaningful capacity. There is a tendency to include PWLE as a means to meet a standard or guideline without affording them any decision-making power, a practice which is referred to as **tokenism**. One way to combat this issue is to hire PWLE. Peer support workers provide a source of support and trustthat is not always attainable through traditional support workers. **Hiring PWLE** **recognizes and promotes their capacity and autonomy**, empowering them and offering them a **sense of ownership** in the creation of solutions to end homelessness.

### **Boundaries**

Involving PWLE as equitable partners and peers requires establishing relationships that are **professional but also genuine and reciprocal**. Collaborators with lived experience should be included and encouraged to **partake in organizational meetings and/or social activities** (e.g. Christmas luncheon), ensuring they are regarded as members of the team. They should be treated with dignity and respect and consulted when appropriate, but **not be required to do things beyond the scope of their role or that are personal in nature.** **Training sessions** should be provided for various stakeholders, including PWLE, on how to work together in a professional context. It may also be helpful to set up a meeting prior to the commencement of any collaboration, where PWLE and other stakeholders can establish the parameters of their relationship and **guidelines for engagement** that are collectively constructed and agreed upon.

### **Meaningful Consent and Confidentiality**

In addition to establishing boundaries and equitable practices, it is necessary to account for the challenges, fears, and anxieties that may arise when individuals, particularly those in vulnerable situations, decide to share their stories and engage in activities as participants or collaborators. The practices of informed consent and maintaining confidentiality are critical in **promoting trust, addressing underlying power dynamics**, and **adopting a choice-focused and rights-based approach** to participant engagement. **Informed or meaningful consent** refers to a voluntary agreement to participate that is based on an individual’s understanding of the activity’s purpose and the participant’s role and rights. Informed consent may be obtained orally or in written form (e.g. consent form). **Confidentiality** is ensured by providing anonymity, for example, through the exclusion of names in discussions or written documents, the use of pseudonyms, and the secure storage of data containing personal information. Participants and/or collaborators must be assured that their opinions and thoughts will remain confidential, meaning they will not be shared with others (unless consent is provided), and that these will not have an impact on their housing and/or their relationship with TSA. Trauma-informed practices should also be adopted as part of this.

### **Avoiding Labels and Stereotypes**

Language has the capacity to **re-victimize and oppress individuals**, reinforcing existing inequalities and stereotypes. PWLE continue to be subjected to discrimination and prejudices based on their housing status, class, race, and other sociocultural factors. For this reason, it is important to employ **inclusive language** that avoids the perpetuation of labels and generalizations, and that is not emotionally triggering and oppressive. PWLE should be **involved in the formulation of terminology utilized within the organization**, including their own title as collaborators or employees, helping determine how they want and should be represented. The provision of **anti-oppressive training and adoption of anti-oppressive terminology** by all members of the organization will also help combat the issues of labelling and stereotyping.

Please see also the “Nothing About Us Without Us” resources on The Homeless Hub:

<http://homelesshub.ca/NothingAboutUsWithoutUs>