

CAPSA Code of Conduct for

Engaging with People with Lived and Living Experience (PWLLE)

We are a full partner with expertise that is independent of, and informed by, our lived and living experience.

We are stigma educators, policy analysts, researchers, and health professionals first. We know how to identify and correct instances of stigmatizing policies and practices that directly impact people who use substances. We have contributions to make at the design, delivery, branding, evaluation, and dissemination stages of any initiative. PWLLE have often been defined primarily by their substance use “stories,” rather than their full expertise. This incomplete narrative has created an unbalanced power dynamic that has caused harm.

Genuine engagement means reaching far and wide before making generalizations.

It is harmful to design any initiative based on a few stories representing those who feel most comfortable speaking up in a crowd. There are diverse privileges, oppressions, and intersecting stigmas within the substance use health community too.

Speakers share what they feel comfortable sharing.

Sometimes our stories are rough. Sometimes they are awesome. Most of the time, they are not heroic nor are they meant to evoke pity, shock, or surprise (though this may happen). To create a safe space for everyone (PWLLE or not), resist asking speakers to share additional personal details.

Don't be surprised if we don't look the “part;” there is no “part.”

We are all part of the substance use health community. 78% of people in Canada over the age of 15 use some form of psychoactive substance and 21% will experience a disorder in their lifetime. We are managers in the workplace, the person you pass on the street, colleagues in the lunchroom, researchers in the lab, and athletes at the gym. We are the “us” and the “them.”

We use person-first language for everyone:

People who use substances, *people* experiencing housing insecurity, and *people* with disabilities. Using dignified terminology is not just “nice to have” or an exercise in political correctness. The research exhaustively links the severity of stigma to declining health outcomes. While we respect the labels an individual uses on themselves, we avoid historically stigmatizing terms such as “alcoholic,” “addict,” “user” or “abuser” because it affects the way that PWLLE are treated by professionals, and perpetuates these perceptions at various levels (self, social, and systems). Studies show that using (or hearing) stigmatizing language is subconsciously or explicitly linked to behaviours that are more likely to blame or punish, rather than support or empathize.

We start with strengths.

As PWLLE, we understand the harm that has been done by support agencies and media who primarily label us by our needs and problems. These labels lead to increased self-stigma, a funneling of resources to organizations whose jobs depend on maintaining these labels, and a reliance on these organizations to “solve our problems.” These labels also overlook the considerable strengths PWLLE have used to survive and thrive, often in adverse circumstances, and often in the absence of institutional support. Programs work best when they start with a recognition of our mutual strengths.

Allyship is a practice.

We believe that most people – ourselves included – do the best they can with the knowledge, experience, and resources they have at the time. If you are reading this code of conduct, you are already showing your desire to perhaps do some things differently or to share the things you are doing “right” already. Shifting power will be awkward and uncomfortable at times, and we will all make well-intentioned mistakes. We approach all collaborations with hope, compassion, and professionalism because this is what we strive to create in our social, economic, and political structures and systems, and these were at the root of change in our lives.