

At the Table with People who Use Drugs: Transforming Power Inequities

by

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B. Sc. (Kinanthropology), University of Ottawa, 1990

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University of Victoria

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### **Abstract**

Background: People who use illegal drugs are disproportionately affected by HIV and hepatitis C, stigmatization and social exclusion. Health inequities are worsened by drug policy of criminalization, which thwarts health promotion efforts and hinders access to services. To address these inequities, people who use drugs are increasingly included in decisions that affect them by sitting on policy, service delivery and research committees. This study addressed a gap in understanding how power inequities are transformed in committees where people who use drugs are at the table. Methods: In partnership with the Drug Users Advocacy League and the Society of Living Illicit Drugs Users, this participatory critical emancipatory inquiry explored power relations in four committees in Ontario and BC. Data were collected in 2013 through meeting observations, interviews, demographics surveys and document reviews. Data analysis was guided by theoretical frameworks grounded in critical theory and transformative learning theory. Results: Findings confirmed striking socioeconomic inequities between people who use drugs and others at the table. Inconsistent measures were taken by committees to alleviate barriers to inclusion. Despite openness to inclusion, committee members tended to underestimate people who use drugs. The presence of local organizations of people who use drugs ensured a more democratic selection of their representatives to sit on committees. Once at the table, creating a safe space entailed building trust, authentic relationships, relational and reflective dialogue, and skilled facilitation. Democratic practices of negotiated relationships and consensus-based decision-making enhanced meaningful inclusion. A structural environment in which drug policy criminalizes people who use illegal drugs hindered capacity to transform power inequities by feeding stigma, which worsens health and social inequities. Committees were committed to inclusion of people who use drugs though capacity to do so varied due to budgetary and human resources constraints. Study limitations, practice implications and future research directions are offered.

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## Dedication

To my parents, Yvon and Irène Belle-Isle, who grounded me in unconditional love, surrounded me with a spirit of community, have been there for me every step of the way, and taught me to see the light of the soul in everyone. Je vous aime beaucoup.

*A soul of hospitality and a heart of humanity is a house of love, peace, freedom, liberty and justice. –Auliq Ice*

## Chapter 1 – Introduction

### Statement of the Problem

People who use illegal drugs, specifically cocaine, opioids and many pharmaceuticals for non-medical purposes, and especially by injection, are more vulnerable to adverse health outcomes such as HIV and hepatitis B and C, neuropsychiatric conditions, endocarditis, motor vehicle accidents, overdoses and suicide than the general population (Patra, Taylor, Rehm, Baliunas & Popova, 2007; Popova, Patra, Mohapatra, Fischer & Rehm, 2009; Popova, Rehm & Patra, 2006; Popova, Rehm, Patra, Baliunas & Taylor, 2007; Rehm, Taylor & Room, 2006). In addition, illegal drug use is often found within a complex set of interconnections between co-occurring diseases and health conditions at both biological and social levels which increase individuals' vulnerability to adverse health outcomes (Mizuno et al, 2015; Singer, 2008). Such interconnections, or 'syndemics', occur between drug use, mental health issues, violence and abuse and HIV/AIDS, for example (Mizuno et al, 2015; Singer, 1996, 2008; Singer & Clair, 2003).

In addition to behaviours which can lead to adverse health outcomes, the syndemics approach considers the social conditions of people who use illegal drugs, particularly conditions of social inequality and injustice which lead to health inequities (Koh, et al., 2010; Rhodes, Singer, Bourgois, Friedman, & Strathdee, 2005; Room, 2005; Singer, 2008). Health inequities, defined as “systematic differences in health status between different socioeconomic groups” (Whitehead and Dahlgren, 2006, p.2), are socially produced by unjust social processes, which result in the unfair distribution of the underlying social determinants of health across social groups (Kawachi, Subramanian, & Almeida-Filho, 2002). With this definition of health inequities and these key features in mind, it is useful to explicitly state how they relate to social

determinants of health. According to Whitehead and Dahlgren (2006), “inequities in health are directly or indirectly generated by social, economic and environmental factors and structurally influenced lifestyles. These determinants of social inequities are all amenable to change” (p. 4).

Determinants of inequities consider social processes that lead to the unequal distribution of material living conditions, understanding of the social processes that influence social position, and social processes that lead to different access to resources and opportunities that determine the quality of participation in social and cultural activities (Belle-Isle, 2011). For people who use illegal drugs, vulnerability to adverse health outcomes is disproportionately increased due to social conditions such as socioeconomic position, criminalizing policies and laws, stigma, discrimination, and social exclusion (Koh, et al., 2010; Rhodes, et al., 2005; Room, 2005).

Indeed, it is well established that poor health outcomes disproportionately affect members of society in a low socioeconomic position (Koh et al., 2010). These health inequities result from differences in access to resources and opportunities for health between socioeconomic groups at an intersection of structural disadvantages such as poverty, ethnicity, gender, lack of adequate housing, limited education and employment opportunities, involvement with the criminal justice system, and lack of social support due to unjust stigma and discrimination (Cole, Logan, & Walker, 2011; Room, 2005; Whitehead & Dahlgren, 2006). Not surprisingly, people who use drugs who are among lower socioeconomic groups have disproportionately higher drug-related morbidity and mortality than those in higher socioeconomic groups (Galea & Vlahov, 2002).

Drug use is a highly moralized behaviour in society, which often leads to stigma and marginalization (Room, 2005). For people who use illegal drugs, stigma is fed by punitive and repressive drug laws and policy aimed at eliminating certain drug use, which worsen health inequities (Cole, et al., 2011; Room & Reuter, 2012; Strathdee et al., 2010; Treloar, valentine, &

Fraser, 2011). The health and well-being of people who use illegal drugs is thus hindered by their criminalization and incarceration.

To counter stigma, people who use drugs have mobilized to gain a sense of collective identity, which evokes a sense of culture, a shared identity and ideology, by referring to themselves as “people who use drugs” (Jürgens, 2005). Expressing a collective identity can lead to social transformation when individuals driven by a collective identity join forces and mobilize. Synergy then arises to challenge dominant groups and cultural practices. Collective identity thus is the “expressions of difference and criticisms of dominant systems [that] serve as the foundation [on] which the identity of a political community is built” (Wieloch, 2002, p. 46). This collective identity represents a form of social movement or a collective form of action through ‘oppositional consciousness’ (Kwon, 2008).

Inspired by Bourdieu’s idea that capital is “accumulated labor . . . which . . . enables [actors] to appropriate social energy in the form of reified or living labor” (Bourdieu, 1986, p.46), “oppositional capital” denotes how actors in social movements re-appropriate societal symbols to express their collective identity and draw from meaning systems to redefine “stigmatization” as “status” (Wieloch, 2002). Marks of stigmatization, drawn from a larger cultural symbolic system to indicate difference, can become badges of privilege and effective tools to demonstrate discontent and represent an alternative, countercultural status system (Wieloch, 2002). Examples of oppositional capital exist among HIV/AIDS activists, for example, when they reclaim the word “positive” to indicate “positive living” as opposed to being “HIV-positive.” The expression “people who use drugs” places emphasis on people first, as opposed to the expression “drug users,” which emphasises drug use. It is a simpler expression than “people who use illegal (or illicit) drugs. The term “people who use drugs” eliminates the

words “illegal” or “illicit” and has been claimed to describe and re-inscribe the stigma associated with illegal drug use by groups of people who use drugs in Canada. For these reasons, the expression “people who use drugs” will mostly be used throughout this document, except in instances where the emphasis on illegal drug use is particularly useful.

Stigma related to illegal drug use also leads to thwarted drug-related harm reduction and health promotion efforts and discriminatory barriers to access to health and social services (Gupta, Parkhurst, Ogden & Mahal, 2008; MacNeil & Pauly, 2010; Rhodes, et al., 2005; Room & Reuter, 2012; Strathdee et al., 2010). Stigmatization of people who use drugs is amplified when they are also experiencing poverty, homelessness and/or living with a mental illness, HIV/AIDS or hepatitis C (Lloyd, 2010; Room, 2005; Strike, Myers & Millson, 2004). The stigma associated with illegal drug use can lead to social exclusion of people who use drugs from basic requirements such as employment, housing and health services and from social groups (Lloyd, 2010; Room, 2005; Strike et al., 2004).

Of specific interest for this dissertation, stigma can also result in the exclusion of people who use drugs from decisions that affect them by restricting their ability to engage with health professionals, researchers and policy makers (Ti, Tzemis & Buxton, 2012). Health inequities can thus be exacerbated by the exclusion of people who use drugs from social networks, social institutions, and broader political and economic structures (McKinlay, 1994; Neale, 2008; Raphael & Bryant, 2006). As such, social exclusion can be seen as an important determinant of inequities that hinders actions to address health inequities (Galabuzi, 2002; Labonte, 2004).

Eliminating health inequities has emerged as a worldwide public health and social justice priority (Koh et al., 2010; Rhodes, Malow, & Jolly, 2010; Commission on Social Determinants of Health (CSDH), 2008). Structural interventions that seek to address physical, social, political,

cultural, organizational, community, economic, legal or policy factors that contribute to health vulnerability are gaining ground (Gupta et al., 2008). Political empowerment through social inclusion of marginalized and excluded groups has arisen as a key structural intervention. Promising social inclusion practices have emerged whereby people who use drugs are meaningfully engaged and included “at the table” by participating in political spaces where decisions are made that affect their lives (Bristow, Entwistle, Hines, & Martin, 2009; Hanefeld, 2008; Minkler & Wallerstein, 2008; Neale, 2008). There is both political and practical momentum toward encouraging the greater, meaningful involvement and inclusion of people who use drugs (Kerr et al., 2006; Leading Together Championing Committee, 2013). In research, funding and governance bodies are increasingly requiring community-academic partnerships, while communities are increasingly demanding to be involved (Flicker et al., 2009; Jansson, Benoit, Casey, Phillips & Burns, 2010). People who use drugs have also been advocating for their inclusion in these political spaces, citing a “nothing about us without us” principle and set of inclusionary practices (Canadian Association of People who Use Drugs, 2014; Jürgens, 2005).

The premise of inclusion of people who use illicit drugs into social decision-making processes is that it challenges how social power is situated within these social structures by reducing power inequities with a promise of shared decision-making power and relating in non-discriminatory, non-stigmatizing ways (Hanefeld, 2008; Minkler & Wallerstein, 2008; Neale, 2008; Sheehy, 2004). Ultimately, it is hoped that such transformation of power relations will lead to the emancipation of marginalized groups such as people who use drugs toward greater power in decision-making power and, ultimately, greater equity in health (Hall, 2006, 2009; Hall & Clover, 2005; Henderson, 1995; Leonardo, 2004; Taylor, 2008, 2009).

Some knowledge has been produced regarding innovations in social inclusion whereby members of socially excluded groups have been included in decision-making that affects their lives: barriers and facilitators to participation and social inclusion of people living with HIV/AIDS (Flicker et al., 2009; Greene et al., 2009; Roy & Cain, 2001; Travers et al., 2008), disabled communities (Radermacher, Sonn, Keys & Duckett, 2010), and people with experience of homelessness (Norman & Pauly, 2013; Norman, Pauly, Marks, & Palazzo, 2015) have been identified to some extent in the literature. Similarly, a few literature reviews have focused on the literature related to the involvement of people who use drugs in policy and program development and identified its barriers and facilitators (Marshall, Dechman, Minichiello, Alcock, & Harris, 2015; Ti, et al., 2012). Marshall and colleagues (2015) situate the level of participation of people who use drugs and elaborate on their influence over decision-making.

While it is useful to examine such barriers and facilitators to participation, simply bringing representatives of marginalized groups to the table does not in and of itself imply transformation of inequitable power relations, nor does it get to the core of that transformative process. The process of interest in this dissertation engages with theoretical conceptions of transformative learning adults are said to experience in collaborative settings such as service delivery policy and research decision-making tables at which people who use drugs are included. In theory, the inclusion of people who use drugs at such tables leads to the transcendence of oppressive conditions for people who use drugs.

Transformative learning takes place when people develop the critical consciousness to deconstruct prevailing ideologies, recognize the social, political, economic and personal constraints on freedom, and realize that they have the power and agency to play a role in changing social conditions through actions aimed at challenging and restructuring power

(Flicker, Savan, McGrath, Kolenda & Mildenberger, 2007; Guishard, 2009; Henderson, 1995; Taylor, 2009). Fostering such transformative learning in the setting of committees where people who use drugs are included at the table may be a valuable and ideal approach to achieving the core emancipatory goals sought by social inclusion.

Few studies shed light on exclusionary processes in power relations (Radermacher et al., 2009 with disability communities), transformative learning (English and Peters, 2012 with women in non-profit organization), the role of power, process and relationships in participatory research, and the changing nature of participation within the same project (Chung & Lounsbury, 2006) with people living with HIV/AIDS). Though these studies provided useful insights, they did not pertain to the population of interest in this dissertation, people who use drugs, nor did they include in-depth critical analyses of the transformation of power relations within social inclusion initiatives and contextualize them within the greater social, political, and economic context. Furthermore, there are few practical guidelines on how to implement knowledge gained from such research to improve the practice of social inclusion.

In light of the trend toward greater inclusion of people who use drugs into policy, research and service delivery, and given the gap in the literature regarding the transformation of power relations in these contexts, it seems particularly timely to gain a deeper understanding of the transformation of power relations between people who use drugs and more powerful actors (researchers, service providers, policy makers) at decision-making tables. A better understanding of how the transformation of power relations is fostered at these tables, whether intentionally or not, will provide useful insights for organizational social inclusion practice and ultimately for social change to address health inequities.

## **Statement of Purpose**

This research contributes to a better understanding of how power relations are transformed through social inclusion practice when people who use drugs are included at the table where decisions are made that affect their lives. These decision-making tables include policy tables related to service delivery as well as research tables. It is hoped that the knowledge gained from this study will contribute useful insights to uncovering discourses and practices that facilitate or hinder the transformation of inequitable power relations in decision-making, and ultimately contribute to addressing health inequities for people who use drugs.

## **Research Objectives and Questions**

The research objectives are to:

- Describe the nature and transformation of power relations between people who use drugs and the researchers, policy makers and service providers at policy and research decision-making tables.
- Explore the underlying transformation that may or may not take place at these tables and reveal factors that nurture the transformation of decision-making power relations toward more equitable ones.
- Suggest practice strategies to transform decision-making power relations toward more equitable ones for people who use drugs and ultimately contribute to addressing health inequities.

The following central question is explored:

- Are power relations transformed toward more equitable decision-making power for people who use drugs within social inclusion practice where they are included at the table? If so, how?

This central question is approached by addressing the following sub-questions:

- How are power relations experienced and expressed between all participants within social inclusion practice where people who use drugs included at the table?
- What contextual factors positively and negatively affect power relations at the table? Contextual factors included broader political, social, and organizational factors as well as personal characteristics of everyone at the table.
- In what ways do power relations between participants at the table contribute to or hinder shared decision making power?
- What are the implications for organizational social inclusion practice based on insights gained from these findings?

### **Background of the Study**

Below, I reflect upon how this study came to be and what personal and professional experiences I bring to this qualitative research. This information sheds light on my relationships both with the topic and with the research participants and what influenced my analyses and interpretations of the findings. I then describe what I consider to be the practical and theoretical significance of this research.

#### **A pause for reflexivity.**

*Idealism increases in direct proportion to one's distance from the problem.* --John Galsworthy

I was first introduced to the importance of the HIV pandemic and the impact of social and structural factors on health through my studies for my Master's degree in Epidemiology. Later, the realization of the need for this study came about through my work as a National Programs Manager at the Canadian AIDS Society, a national coalition of more than 100 community-based

AIDS service organizations, where I have been employed since 2004. One of my portfolios, if you will, involves work in harm reduction related to drug use. Participatory processes are adhered to, to the best of our availability, in all the projects we take on. The first step of any project usually involves establishing a National Advisory Committee or National Steering Committee to guide the work, comprised of service providers and people with lived experience and other key stakeholders as needed. I gained practical experience in including people who use drugs in my harm reduction related projects through trial and error. Though my interpersonal skills allowed me to interact with people from all walks of life, I awkwardly navigated through participatory approaches without much guidance or knowledge. When I discovered community-based participatory research, I was compelled to deepen my knowledge of participatory processes and chose to pursue PhD studies in this field. My hope was to gain theoretical knowledge about participatory processes and their role in addressing health and social inequities for people who use drugs, acquire a deeper understanding of how to more meaningfully include people who use drugs in decisions that affect them, and ultimately bring back this knowledge and apply it to my organization's and my own social inclusion practice.

When I began my PhD work, I had already been immersed in community-based HIV work for 7 years. Over those years, I had found myself not only at my own decision-making tables related to my projects, but sat at numerous multi-stakeholder policy and research tables representing the Canadian AIDS Society, many of which also included people with lived experience of the topic at hand. I have an extensive network of colleagues across Canada who work in harm reduction, drug policy and community-based research. In this sense, I feel like I have been immersed in this culture as an ally with people who use drugs.

That said, and if I take a moment to be self-reflective in the context of this research, I recognize that I am in a position of power as a researcher with regard to people who use drugs, and of privilege since I am a white, middle-class, employed, educated, healthy, and housed woman. I have always felt free to pursue any life path I chose without any hindrance or fear of discrimination, even as a woman. I have, however, experienced glimpses of prejudice and marginalization as a queer woman, and slightly as a French-speaking Canadian. Finally, I have strong spiritual beliefs, highly influenced by Buddhism, earth-based spirituality, mindfulness and yoga practice, where I perceive every human being as being connected as one. Each of us, I believe, is an individual emanating from the same source of light or life source. These beliefs align well with the spirit of social inclusion, social change, and transformative learning theory from a critical theory perspective, where there is a common thread of metamorphosis from competitive, individualist ethics to collective, interdependent and cooperative ethics.

With this in mind, I espouse to Maria Lugones' concept of "world traveling" and strive for this in my interactions with any human being. Lugones, a feminist scholar, introduced her notion of world traveling as one that rejects static concepts of cultural difference and recognizes that human differences influence their negotiation of social "worlds" or contexts (Anderson, 2014, Lugones, 1987). World traveling thus involves the ability and flexibility to shift who we are, how we behave, how we communicate in different social contexts. The world traveling concept also elaborates on a person's sense of comfort in different contexts or worlds: with a sense of comfort comes agency (Anderson, 2014; Lugones, 1987).

I apply this notion of world traveling by doing my best to be open to and curious about another person's differences, which hopefully contributes to their sense of comfort, and ultimately to their agency (Anderson, 2014; Lugones, 1987; Madison, 2012). This helps me to

identify with others, perceive them from a place of love and approach social inclusion from a place of hospitality to strangers. I have approached this subject of being at the table with people who use drugs very much from a perspective of being a gracious hostess to people from different worlds.

Through the partnerships for this research with people who use drugs, I have come to believe that the people who use drugs with whom I worked trusted that I had their best interest at heart, as well as a keen interest in not only challenging processes of unfairness, including my own, but also of enhancing social inclusion practice toward greater freedom and equity. They communicate their confidence in me on a regular basis as I continue to work with them. They also invite me to some social and organizational events.

I also realize that my privileged position and dearth of lived experience in terms of illegal drug use affords me the luxury of bringing idealistic ideas to my interpretation of the findings and the practice recommendations that stem from the findings. I did strive for a healthy balance between this idealism and the realism I am reminded of in my interactions with people who use drugs, whilst believing that idealism can lead to breakthroughs.

### **Significance of the study.**

Although social structures in health research and in policy development related to service delivery have been increasingly including people who use drugs, there is a gap in understanding the context, factors and processes that contribute to or hinder the transformation of decision-making power inequities. As I will discuss later in this dissertation, this research uses a theoretical framework that combines characteristics of critical theory with transformative learning theory to dissect the power relations that take place in participatory policy and research settings to better understanding how they can be transformed into more equitable ones.

The findings yield important insights to contribute to improving social inclusion practice within organizations that make decisions that affect the lives of people who use drugs. These insights reveal areas of success in achieving emancipatory goals and expose areas for improvement and potential advocacy for social change toward social justice. A better understanding of the transformation of power relations between the various participants in policy and research contexts will hopefully encourage a process of organizational self-reflection as to how power inequities may be reproduced in their social inclusion practices and shed light on practices and processes which may be facilitating and encouraging more equitable power relation. Institutional practices can then be adapted to better enable and foster social inclusion and equity. Future research regarding the social inclusion of people who use drugs will also be proposed.

### **Overview of this Dissertation**

Chapter 1, the Introduction, provided an overview of the research problem, purpose and questions, as well as reflexive reflections and thoughts on what this research will contribute to the academic conversation on this topic.

Chapter 2, A Review of Related Literature, will provide an overview of the theoretical and empirical perspectives drawn on to address the research problem and questions: health inequities for people who use drugs, stigma, discrimination and social exclusion of people who use drugs. It will also offer an overview of the literature on social inclusion as a strategy to address health inequities for people who use drugs and of power relations in the context of social inclusion practice. It includes a literature review of research that examines the inclusion of people who use drugs at decision-making table and reveals the gap that the research presented in this dissertation will contribute to.

Chapter 3, Methods and Procedures, will describe the design of this critical emancipatory inquiry, how a community-based participatory research framework was used and how this research drew on critical ethnography procedures, then provides details of how the study was implemented.

Chapters 4 to 6 present the findings of the study. Chapter 4, Table Seating: Outsiders on the Inside for a Well-Appointed Table, provides a description of the research sites and participants. It describes the four committees included in the study, the socioeconomic inequities between representatives of people who use drugs and others at the table, and representation of lived experience and how these aspects influenced power relations at the table.

Chapter 5, Table Manners: From Power Over to Power With People who Use Drugs, elaborates on findings related to stigma against people who use drugs and how this affects power relations, as well as findings related to creating a safe space at the table through building trust, authentic relationships and dialogue then presents the practice of democracy through negotiated relationships and consensus-based decision-making.

Chapter 6, Table Setting: The Influence of Context of Opportunities for Inclusion, situates the committees within the greater political context, presents findings related to the mobilization of people who use drugs and elaborates on how these contextual factors influenced power relations at the table.

Finally, Chapter 7, Discussion, discusses the findings in terms of the theoretical concepts that guided this research, the literature review, the practice implications based on the findings, and the limitations of this study. Chapter 8, Conclusions and Practice Implications, summarizes the main conclusions and practice implications for ease of reference.

## **Chapter 2 – A Review of Related Literature**

### **Introduction**

This chapter elaborates on current research related to the focus of my research and the theoretical and empirical perspectives that I drew on in this research. First, it presents the current state of knowledge regarding health inequities for people who use drugs and links these inequities to social injustice. Secondly, it discusses the impact of stigma and discrimination on the health of people who use drugs and links stigma to current policy strategies undertaken by governments to address drug use in society. Within that discussion, it incorporates the concept of social exclusion. Thirdly, it provides an overview of social inclusion as a strategy to address health inequities for people who use drugs and discusses the transformation of power relations as part of social inclusion practice. Finally, it presents a review of research conducted to date that examines the inclusion of people who use drugs at decision-making table and reveals the gap that the research conducted for this dissertation will contribute to.

### **Review of Current Research**

#### **Health inequities for people who use illegal drugs.**

People who use illegal drugs, specifically cocaine, opioids and many pharmaceuticals for non-medical purposes, and especially by injection, are more vulnerable to adverse health outcomes such as HIV and hepatitis B and C, neuropsychiatric conditions, endocarditis, motor vehicle accidents, overdoses and suicide than the general population (Patra, et al., 2007; Popova, et al., 2009; Popova, Rehm & Patra, 2006; Popova, et al., 2007; Rehm, et al., 2006). To put this into perspective, whereas the prevalence of HIV is estimated to be 0.2% in Canada's general population, it ranges from 3% to 21% amongst people who inject drugs in various parts of Canada (Public Health Agency of Canada, 2010). Similarly, while an estimated 0.8% of the

general population lives with hepatitis C, the lifetime prevalence of hepatitis C amongst people who inject drugs ranges from 51% to 77% (Public Health Agency of Canada, 2010).

While such differences in health outcomes can, on one level, be attributed to individual behaviours (e.g. high-risk injection practices such as sharing injection equipment), the syndemics of illegal drug use situates it within a complex set of interconnections between co-occurring diseases and health conditions at both biological and social levels, which increase individuals' vulnerability to adverse health outcomes (Mizuno et al, 2015; Singer, 2008). For example, syndemics occur between drug use, mental health issues, violence and abuse and HIV/AIDS (Mizuno et al, 2015; Singer, 1996, 2008; Singer & Clair, 2003). Syndemics thus consider the social conditions of people who use drugs, particularly conditions of social inequality and injustice, or 'determinants of inequities', which lead to health inequities (Koh, et al., 2010; Rhodes, 2005; Room, 2005; Singer, 2008).

As such, health inequities directly engage with concerns of social justice such as fairness, equity and human rights and are considered unjust because they reflect an unfair distribution of the social determinants of health across social groups such as class and race, among others (Belle-Isle, 2011; Kawachi et al., 2002). Equity in health has been described as the "absence of systematic and potentially remediable differences in one or more aspects of health between groups of people characterized socially, geographically, or demographically" (Starfield, 2007, p. 1355). In this sense, health equity strives to provide everyone with the opportunity to attain their full health potential. Such considerations can guide policies to address discrimination that result in barriers to access to resources and opportunities that have an impact on health (Whitehead & Dahlgren, 2006).

To conceptualize this disproportionate vulnerability to health inequities for people who use drugs, Rhodes proposed a risk environment framework to explore intersections of economic, physical, social and policy factors that influence vulnerability (Rhodes, 2002, p.88-89; Rhodes, et al., 2005). The complex interplay between these factors can exacerbate the risk environment and increase drug-related harm. In a general sense, economic, physical, social and policy factors interact with individual behaviours of and interpersonal relations among people who use drugs, social norms, group interactions and institutional or organisational responses, as well as laws, policies, economic conditions, social inequities and cultural beliefs (Rhodes, et al., 2005). Of particular relevance for this dissertation is the disproportionate increase in vulnerability to adverse health outcomes for people who use drugs due to determinants of inequities such as socioeconomic position, as well as criminalizing policies and laws, stigma, discrimination, and social exclusion, which are described below (Koh, et al., 2010; Rhodes, et al., 2005; Room, 2005). All of these factors come into play when examining power inequities in participatory processes of social inclusion.

Indeed, it is well established that poor health outcomes disproportionately affect members of society in a low socioeconomic position (Koh et al., 2010). These health inequities result from systematic differences in health between socioeconomic groups at an intersection of structural disadvantages such as poverty, ethnicity, gender, lack of adequate housing, limited education and employment opportunities, involvement with the criminal justice system, and lack of social support (Cole et al., 2011; Room, 2005; Whitehead & Dahlgren, 2006). Not surprisingly, people who use drugs are among lower socioeconomic groups who have disproportionately higher drug-related morbidity and mortality than those in higher socioeconomic groups (Galea & Vlahov, 2002). In Canada, for example, homelessness is a predictor of overdose among people who use

illegal opioids (Fischer, et al., 2004). Homelessness and unstable housing is also linked to more frequent injection drug use (Aidala, Cross, Stall, Harre, & Sumartojo, 2005; Lloyd-Smith, Wood, Li, Montaner & Kerr, 2008; Shannon, Ishida, Lai, & Tyndall, 2006; Susser, Betne, Valencia, Goldfinger, & Lehman, 1997; needle sharing (Corneil, et al., 2006), exchanging sex (Aidala, Lee, Garbers, & Chiasson, 2006; Andia, et al., 2001; Corneil, et al., 2006; Royse, et al., 2000), number of sexual partners, and condomless sex (Aidala, Lee, Garbers, & Chiasson, 2006; Kidder, Wolitski, Pals, & Campsmith, 2008; Surratt & Inciardi, 2004) which lead to health outcomes such as HIV and viral hepatitis.

This relationship between socioeconomic position and drug use has also been explored over individuals' life course to examine how patterns of use are shaped by the historical context individuals find themselves in, social structures they navigate, critical events that take place in their lives and transitions across their life span (Hser, Longshore, & Anglin, 2007). The life course perspective considers the intersectionality of individual lives, social change and social structure (Hser et al, 2007). Lopez, Krueger and Walters (2010) observed that age was positively associated with high-risk drug injection behaviours. However, high-risk injection behaviours were negatively associated with age at first drug use. Williams Boeri, Sterk and Elifson (2008) examined the life history narratives of people who started using heroin early in life compared to those who started in their 30s or older. They found that individuals with late onset heroin use had more difficulty learning to control their use, less experience navigating in the drug using world, therefore taking more risks, and more difficulty managing their life in mainstream society. They also had less knowledge about blood-borne disease transmission. The authors explain that those who had started using heroin earlier in life had learned to manage their use and were in a better socioeconomic position than those who started using heroin later in life.

Inequities in health status between different socioeconomic groups, in this case people who use drugs, are in large part due to socially produced determinants of inequities. Determinants of inequities include social processes that influence social position, and social processes that lead to different access to resources and opportunities that determine the quality of participation in social and cultural activities (Belle-Isle, 2011). For people who use drugs, vulnerability to adverse health outcomes is disproportionately increased due to determinants of inequities such as socioeconomic position, as described above, as well as criminalizing policies and laws, stigma, discrimination, and social exclusion (Koh, et al., 2010; Rhodes, et al., 2005; Room, 2005).

### **Stigma, discrimination and social exclusion of people who use drugs.**

The complexity of the syndemics that surround illegal drug use and its impact on the health of people who use drugs is further accentuated by stigma. The concept of stigma entails many interrelated components: "...stigma exists when elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them" (Link & Phelan, 2001, p. 377). This succinct and powerful definition of a complex concept captures the various aspects of stigma as experienced by people who use drugs.

First, the process of labeling attributes as socially undesirable carries much weight. It oversimplifies human differences and divides them into categories, which are judged as desirable or undesirable and leads to stereotypes (Link & Phelan, 2001). Such labeling and stereotyping separates people into 'us' and 'them' and is fertile ground for devaluing, rejecting and excluding those linked to these undesirable characteristics. Ultimately, at its extreme, stigma results in discrimination – the unjust treatment of people on the grounds of differences in race, age, gender, and in this case drug use - status loss and power inequities (Link & Phelan, 2001). Indeed,

stigmatized groups are disadvantaged in terms of life chances related to employment, income, education, psychological well-being, social relationships, housing, health care, and health (Hatzenbuehler, Phelan, & Link, 2013; Link & Phelan, 2001, p. 371). Finally, social, economic and political power is essential to socially produce and reproduce stigma and has a tendency to take attributes of differences for granted rather than considering power differences between the categorized groups (Link & Phelan, 2001). “Stigma power”, as it is described by Link and Phelan (2014), allows those in power to exploit, control or exclude those in disadvantaged group. Stigma therefore influences multiple disease outcomes and risk factors as well as access to resources and can be considered a fundamental cause of health inequities (Hatzenbuehler, et al., 2013).

Studies illustrate the ubiquitous stigma toward people who use drugs and the impact on the health of people who use drugs. Room (2004, 2005), for instance, showed that drug addiction was rated highest by informants in 14 different countries in terms of degree of social disapproval and stigma. Addiction was viewed more negatively than being dirty and unkempt, having a criminal record for burglary or not caring properly for one’s children. Barry, McGinty, Pescosolido and Goldman (2014) revealed that public attitudes toward people who use drugs were more negative than toward people living with mental illness, that respondents did not want persons with drug addiction to marry into their family nor did they want to work closely with them. Public attitudes were accepting of discriminatory practices toward people who use drugs, reluctant to accept that treatment for addiction could be effective, and opposed to policies aimed at helping people who use drugs. Benoit, McCarthy and Jansson (2015a, 2015b) add that people who use drugs that are less socially acceptable, regardless of occupational status, experience higher levels of discrimination and depression. As a result, studies indicate that ostracization and

exclusion of people who use drugs from family, communities, employment, education, social settings and even health care services is common (Jürgens, 2010).

The criminalization of people who use drugs through current drug policies and laws aimed at eliminating the use of some drugs also feeds stigma and discrimination and exacerbates health inequities for people who use drugs (Ahern, Stuber, & Galea, 2007; Room & Reuter, 2012; Cole et al, 2011; Treloar et al., 2011). For example, the degree of social acceptability of specific substances varies based on its legal status (Benoit, et al., 2015a; Lloyd, 2010). Though presumably originally conceived to deter drug use, drug laws that criminalize people who use illegal drugs have led to negative attitudes towards people who use drugs and largely contributed to their stigmatization and the discrimination they experience (Ahern, et al., 2007).

Realizing that criminalization plays a role in aggravating stigma and discrimination has led some jurisdictions to experiment with innovative drug policy alternatives. In fact, the main impetus behind Portugal's drug decriminalization initiative was to explicitly remove and prevent stigma attached to drug use, ultimately eliminate guilt from drug use, emphasize health and address barriers to health services (Greenwald, 2009; van het Loo, van Beusekom, & Kahan, 2002).

In Canada, the health and well-being of people who use drugs continues to be hindered by policies that criminalize and incarcerate them. Despite the fact that the overall crime rate decreased 25.9% since 1998, from 8,915 per 100,000 to 6,604 in 2011, and the property crime rate decreased 38.2%, from 5,696 per 100,000 to 3,520 in 2011, the crime rate for drug offences increased 39.5% since 1998, from 235 per 100,000 population to 328 (Public Safety Canada, 2012). Other than the fact that placing people who use drugs in prison may not be the best way to provide them with health care and help they may require, and to continue with the example of

HIV and hepatitis C to illustrate health inequities experienced by people who use drugs, prisons in Canada are risk environments that significantly increase vulnerability to HIV and hepatitis C. Rates of HIV reported by Correctional Services Canada are more than 10 times higher in federal prisons than in the general population, and rates of hepatitis C are 30 times higher (Canadian HIV/AIDS Legal Network, 2008). There is also an over-representation of people charged with drug offences in Canadian prisons and drug testing programs encourage the use of injection (Canadian HIV/AIDS Legal Network, 2008). Harm reduction measures to reduce drug-related harms for people who use drugs and prevent the transmission of HIV and hepatitis C, such as needle exchange programs, are not available in Canadian prisons (Canadian HIV/AIDS Legal Network, 2008).

Stigma has fueled a near-universal resistance to harm reduction services meant to serve people who use drugs such as needle and injection supplies distribution services, safer crack inhalation kits and supervised consumption sites, rendering it the most striking example of thwarted health care services for people who use drugs (Broadhead, Van Hulst, & Heckathorn, 1999; MacNeil & Pauly, 2010; Tempalski, 2007; Tempalski, Friedman, Keem, Cooper, & Friedman, 2007). This hindrance persists despite evidence that harm reduction services are essential to prevent many of the harms related to drug use for people who use drugs, that harm reduction services improve access to other health care and supportive services, and recommendations that harm reduction services be enhanced (Bungay, Jonson, Varcoe, & Boyd, 2010; Des Jarlais et al., 2005; Fischer, Powis, Firestone-Cruz, Rudzinski, & Rehm, 2008; Fischer, Savan, McGrath, Kolenda, & Mildemberger, 2010; Masson et al., 2007; Milloy, Kerr, Tyndall, Montaner, & Wood, 2008; Strathdee & Vlahov, 2001; Strathdee et al., 2006; Tyndall et

al., 2006; Wodak & Cooney, 2005; Wood, Tyndall, Montaner, & Kerr, 2006; World Health Organization, 2006).

To add to this already complex vulnerability to health inequities for people who use drugs, stigma is intensified for people who use drugs who may also be living with other stigmatizing statuses such as poverty, homelessness, minority races, sexual orientation other than heterosexual, living with an illness that is associated with negative attributes or earning an income from an occupation that is deemed socially unacceptable (Ahern, et al., 2007; Benoit, et al., 2015a; Benoit, Shumka, & Barlee, 2010; Galabuzi, 2002; Norman & Pauly, 2013; Wailoo, 2006). Indeed, not all people who use drugs are equally stigmatized, as evidenced by the racialized, gendered and socioeconomic inequities in enforcement consequences for people who use drugs (Ahern, et al., 2007; Boyd & Faith, 1999). This web of stigmatization (Wailoo, 2006) is an important consideration in terms of stigma associated with people who use drugs given that lower socioeconomic status is associated with worse adverse outcomes from substance use (Room, 2005). It is also hypothesized that the use of less socially acceptable drugs is more frequent among the most structurally disadvantaged (Benoit et al., 2015a).

In Canada, the disproportionate impact of HIV/AIDS and hepatitis C, for example, among Aboriginal individuals who report injection drug use clearly illustrates that worse health outcomes “are not only quintessentially about behaviour or poverty or social exclusion, they are also clearly about race, about historical, institutional inequity, and about illicit drug use” (Allman, 2005, p. 118). The harms of illegal drug use are not evenly distributed among people who use drugs. Those most stigmatized are most affected drug-related harms, in part due to social exclusion.

Social exclusion takes place when structures and dynamic processes diminish and sometimes deprive individuals of opportunities for social participation and integration in economic, social, and civic life (Cole et al., 2011; Galabuzi, 2002; Neale, 2008). Galabuzi (2009, p. 254) best describes social exclusion “an expression of unequal power relations among groups in society which then determine unequal access to economic, social, political, and cultural resources”. The stigma and discrimination experienced by people who use drugs places them in a disadvantaged position in terms of power and influence (Labonte, 2004). Link and Phelan (2001) argue that stigma is dependent on such social, economic and political power inequities. As they note, “it takes power to stigmatize” (Link & Phelan, 2001, p. 375).

In the neo-liberal economic context that currently dominates world economies and which emphasizes “liberalization, privatization, de-regulation and welfare minimalism” (Labonte, 2004, p.116), it is clear that those who have access to resources have power and influence over how those resources are distributed. The neo-liberal economic ideology further contributes to social exclusion by attributing it to an individual’s failure to capitalize on their opportunities within these social structures (Galabuzi, 2002).

At the macro level, the institutional mechanisms of these social structures can also systematically exclude individuals or groups and lead to inequities by, for example, excluding them from participation in the democratic process (Galabuzi, 2002; McKinlay, 1994; Neale, 2008; Raphael & Bryant, 2006; Whitley, 2005). At the micro level, stigma may be deeply embedded with regard to specific individuals and groups, thereby contributing to their exclusion from these social structures (Whitley, 2005). Such is the case for people who use drugs, as I have described in this section. The next section explores social inclusion as a social justice approach

to addressing such power inequities and, ultimately, contributing to greater health equity for people who use drugs.

**Social justice and social inclusion to address health inequities.**

Eliminating unjust health inequities has emerged as a worldwide public health priority (Koh et al., 2010; Rhodes et al., 2010; CSDH, 2008). Social justice is concerned with human well-being, and health is a distinct dimension of well-being, as are “personal security, the development and exercise of cognitive capacities for reasoning, living under conditions of social respect, developing and sustaining deep personal attachments, and being able to lead self-determining lives” (Faden & Powers, 2008, p. 151). A commitment to social justice to address health inequities prioritizes changing the conditions of those whose life prospects are hindered across the various dimensions of well-being (Faden & Powers, 2008). To do so requires strategies to change the physical, social, cultural, organisational, community, economic, legal, or policy structural factors (Gupta et al., 2008), as well as the social processes that shape the context of vulnerability to poorer health for marginalized, socially excluded groups (Gupta et al., 2008; Pauly, 2008; Ruof, 2002). Of particular interest for this dissertation are concepts of social justice, which consider that people have a right to be included in decisions that affect them.

Debates on the best way to foster equity have highlighted distributive approaches which focus on the fair sharing of material resources, as well as procedural approaches which focus on equity in terms of power and participation in decision- and policy-making. Of particular interest for this dissertation is a concept of social justice that extends beyond the equitable distribution of material resources and encompasses what individuals are capable of doing with these resources. This concept of social justice, as espoused by Young (2001), evaluates and addresses inequities within institutional relations and processes, such as power in decision-making. She explains:

“...the objective of equalizing action is to intervene in the institutional processes and individual actions and interactions that constrain substantive opportunities of individuals who are similarly positioned from developing their capacities or enacting their morally legitimate aims” (p. 18).

Equity in power therefore means that individuals from structurally disadvantaged groups can contribute to transforming the conditions of their lives to change risk environments that lead to health inequities into safer environments that lead to greater health equity (Bess, Prilleltensky, Perkins, & Collins, 2009; Minkler, 2010; Ng, Walker & Muller, 1990; Pauly, 2008; Rhodes, 2002; Rhodes, et al., 2005; Young, 2001). To transform inequities in decision-making power, the focus needs to shift away from the individuals or groups who are excluded toward challenging the socioeconomic mechanisms and political powers that (re)produce the social exclusion of these individuals and groups (Galabuzi, 2002).

Interventions and practices that enable social inclusion into political spaces where decisions are made that affect those experiencing health inequities to enhance their participation into such decisions (Allman, 2005; Galabuzi, 2002). Social inclusion is both a process and an outcome. It is a process that strives to challenge how social power, including decision-making power, is situated by sharing the power and relating in non-discriminatory, non-stigmatizing ways. It is also an outcome since it leads to a reduction in power inequities, which advances the well-being of the historically excluded groups (Sheehy, 2004). Creating political spaces for public debate, participation and empowerment, with the inclusion and equitable representation of and partnership with the systematically excluded (Hanefeld, 2008; Minkler & Wallerstein, 2008; Neale, 2008) is therefore believed to help “remedy economic, social and political injustices and exclusion” (Bristow, et al., 2009, p. 905).

If we create such inclusive political spaces, how can we ensure, however, that social inclusion practices are not simply reproducing mechanisms and practices of inequity and domination (Barros, 2010)? For example, organizations that provide services to people who use drugs likely have dominant values of helping, caring and serving, and breaking free from their entrenched role of service professionals may be challenging, especially when the relationship between service provider and client is also reinforced by expectations from those receiving services (Bess et al., 2009). The participation and inclusion of historically excluded individuals and groups might be rendered passive in that power relations might involve consulting them and providing them with an opportunity to voice their opinions, but might not give them any decision-making power, resulting in tokenism (Bess et al., 2009; Arnstein, 1969). Power relations in these political spaces must therefore be transformed to transcend oppressive conditions. I will now further explore the concept of transformation of inequities in power through social inclusion.

### **Transforming power inequities through social inclusion.**

Social inclusion resides in the realm of human relations (Labonte, 2004). Transcending oppressive and exclusionary conditions therefore can be achieved through transforming power relations. For the purposes of this dissertation, I draw from Foucault's perspective of power which is based on the way power operates in relations between individuals or groups (Foucault, 1982). Foucault sees power relations as a "web of discourses and practices found in institutions, communities, and families, and exercised through actions in multiple relationships" (Wallerstein & Duran, 2008, p. 34). I approach power relations as a phenomenon that is exercised through social relations whereby one individual or group's actions have an effect on others' actions, and where there are power imbalances, this exercise of power can control, oppress or constrain others

(Cooper, 1994; Kannabiran & Peterson, 2010). Transforming oppressive conditions which leads to power inequities requires, in my view, a multi-faceted approach which involves resituating decision-making power in political spaces, fostering critical consciousness and transformative learning in everyone at decision-making tables, as well as influencing the social, political and organizational contexts within which power inequities are reproduced.

***Resituating decision-making power.***

The transcendence of oppressive conditions related to decision-making in political spaces where people who use drugs are included first requires resituating decision-making power at the table. Social inclusion and participation can be conceptualized as a continuum whereby different levels of participation involve different levels of the process and outcomes (Chung & Lounsbury, 2006). Ideally, to meet goals of emancipation and greater equity for historically excluded individuals and groups, power relations must be shifted into partnerships where they hold the majority of decision-making seats as opposed to the traditional power elite (Arnstein, 1969). Full social inclusion and participation thus consists of equality of voice and absence of coercion (Barros, 2010). This redistribution and sharing of power with historically excluded individuals and groups can thus lead to changes in decision-making power structures (Chung & Lounsbury, 2006; Horowitz, Robinson & Seifer, 2009; Minkler, 2010). Understanding these power relations as well as the continuum of participation is essential if, as a society, we seek to improve our social inclusion approaches and practices and ultimately contribute to addressing inequities (Chung & Lounsbury, 2006).

A key element to meaningful participation therefore lies in the location of power in decision-making political spaces (Barreteau, Bots & Daniell, 2010). It is important to challenge the assumption that participation is always a social good and a positive experience for those

being included (Hayward, Simpson & Wood, 2004). It is also crucial to be explicit from the onset about how participation will be implemented in practice, where the power in decision-making will reside within the structure, and what will be expected of those who are being included (Barreteau et al., 2010). Chung & Lounsbury (2006) suggest three important factors to consider in social inclusion practice: “(1) developing a negotiated understanding of what...participation means in the context of shared work; (2) a joint commitment to the emancipatory aspects of this work, and (3) the ability to unmask power and authority among those involved” (p. 2139). Thus, people at the table need to reflect on issues of power.

*Frameworks of levels of participation.*

Conceptual frameworks have been offered to assist with that reflection and dissect the level of participation, and ultimately the level of power, historically excluded individuals and groups have within settings where they are now included. Perhaps the most often cited and adapted one is Arnstein’s (1969) ladder of participation which describes different levels of participation that contribute to or hinder the genuine redistribution of power, and ultimately social change (Chung & Lounsbury, 2006; Hayward et al., 2004; Roy & Cain, 2001). There are eight rungs on Arnstein’s ladder of participation. The first two, manipulation and therapy, relate to non-participation. The next three, informing, consultation and placation, involve tokenism. The final three are attributed to citizen power whereby they are involved in partnership, delegated power, or citizen control. Table 1 offers a brief description of Arnstein’s Ladder of Participation.

Arnstein’s (1969) model has been adapted by Biggs (1989) and Probst and colleagues (2003), who offer four modes of participation: a contractual one where one actor has the decision-making power and other actors participate in activities as defined in an agreement or

‘contract’ to provide services and support; a consultative one where most decision-making power resides with one actor, but other actors provide information, identify constraints and opportunities, help set priorities and evaluation; a collaborative one where actors exchange knowledge, offer different contributions and share decision making power; and a collegiate one where actors are partners, responsibility is equally shared, and decisions are made through consensus among all actors.

Table 1.

*A Brief Description of Arnstein's (1969) Ladder of Participation*

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Non-Participation

1. manipulation: where people are placed on advisory committees for the purpose of educating them or to manipulate them into supporting an initiative.
2. therapy: where people are subjected to clinical group therapy under the pretext of citizen participation.

Tokenism

3. informing: where information is provided in a one-way flow with no opportunity for feedback or power to negotiate.
4. consultation: where people's opinions are invited, though with no guarantee that they will be taken into account.
5. placation: where people begin to have some degree of power though they may not be accountable to a constituency in the community and may also be outvoted by the power elite who hold the majority of the seats.

Citizen Power

6. partnership: where power is redistributed through negotiation between the people being included and the historical powerholders, and there is agreement to share planning and decision making.
  7. delegated power: where people have the dominant decision making authority.
  8. citizen control: where the power resides with the people to govern.
-

Similarly, Pretty (1995) identified a participation typology to categorize the participation of previously excluded groups, with seven levels of participation ranging from low engagement such as passive participation and participation in information giving, to moderate engagement of consultation and functional participation), to high engagement such as interactive participation and self-mobilization. Both Arnstein (1969) and Pretty's frameworks are useful to situate decision-making power at tables where previously excluded groups such as people who use drugs are included. Once decision-making power has been situated within a political space, participants have the option to take action to change decision-making structures toward more equitable ones. However, these frameworks have limitations and only provide one aspect of the power relations that take place at such tables.

Although such conceptual frameworks are useful to analyze the location of power between participants at a given table, Arnstein (1969) mentions her ladder of participation artificially divides the powerless from the powerful, though these groups are not homogeneous. Indeed, all participants at a table may have varying degrees of life experience, with other intersecting factors such as poverty, race, gender, class, and in the case of this study, illegal drug use experience, whether they are at the table representing that lived experience or not. Arnstein adds that her model does not necessarily capture other elements that affect the redistribution of power, such as stigma, resistance to power redistribution, contextual factors such as political socioeconomic infrastructure, knowledge-base, and barriers to organizing representative and accountable citizens' groups.

An analysis of power in the context of social inclusion must also consider who is not participating and why. For instance, individuals and groups may be exercising their power by deliberately not participating, as an act of resistance (Hayward et al., 2004). Furthermore, social

inclusion practices may be “reinforc[ing] and reproduc[ing] existing sociopolitical structures if they only promote the voices and values of those who are most articulate and easily accessible in a community...furthering the interests of an already dominant group in the community” (Hayward et al., 2004, p. 104). In addition to structural understandings of where power resides in political spaces that include people who use drugs, understanding the transformation of power inequities through social inclusion requires determining whether there were signs of critical consciousness and transformative learning taking place at the tables included in this study.

***Fostering transformative learning.***

It is thought that the transcendence of oppressive conditions in collaborative political spaces and settings leads to the emancipation of oppressed groups through a transformative learning process (Hall, 2006, 2009; Hall & Clover, 2005; Henderson, 1995; Leonardo, 2004; Taylor, 2008, 2009). Transformative learning is said to take place when people develop the critical consciousness to deconstruct prevailing ideologies, recognize the social, political, economic and personal constraints on freedom, and realize that they have the power and agency to play a role in changing social conditions through actions aimed at challenging and restructuring social structures of power (Flicker, et al., 2007; Guishard, 2009; Henderson, 1995; Taylor, 2009). To transform power relations and redistribute power in decision making at such tables, power imbalances must openly be acknowledged, discussed and challenged (Israel et al., 2008).

The contested power dynamics and differences in perceptions in these collaborative... relationships require...partners to commit to a process of self-reflection and cultural humility (Baum, MacDougall & Smith, 2006; Chávez, Duran, Baker, Avila, & Wallerstein, 2008; Wallerstein & Duran, 2006) “to recognize [their] own cultural beliefs and assumptions to break through commonly held assumptions and stereotypes getting in the way of truly being able to be “competent” or “sensitive” in another’s culture” (Chavez et al., 2008, p. 100). This challenging process enables the transformation of

social relations and building of alliances across differences by redressing power imbalances and creating an environment of mutual respect, equity and trust (Chavez et al., 2008; Chung & Lounsbury, 2006; Schensul, 2010; Stoecker, 2008). They must also work within each other's different agendas and politics (Baum et al., 2006; Rhodes et al., 2010). [P]artners must embrace the discomfort that comes with the acknowledgement of the economic, social, cultural and gender inequities that are at the root of oppression (Chavez et al., 2008; Wallerstein & Duran, 2006) in order to understand the power relations, empower the less advantaged, and work together to shift the power relations (Baum et al., 2006; Chung & Lounsbury, 2006; Hall, 2009; Israel et al., 2008). (Belle-Isle, 2011, pp. 25-26)

Participants must therefore learn to interact and relate in such a way that can foster this transformation. Transformative learning theory provides a valuable approach to examine the transformation of individuals' worldviews, which is required if we are to change and transform how we relate to others from different socioeconomic positions (Elias, 1997).

*A brief overview of transformative learning theory.*

Transformative learning theory was greatly influenced by Habermas' theory of communicative learning (Brookfield, 2009; Mezirow, Taylor & Associates, 2009), which involves "understanding what others mean when they communicate with us" (Mezirow, et al., 2009, p. 20). This understanding happens through discourse. In 1981, Jack Mezirow "...took Habermas' concern with the emancipatory dimensions of communicative action, reinterpreted emancipatory action as adult perspective transformation, and linked this to contemporary adult educational ideas of self-directed learning and androgogy" (Brookfield, 2009, p. 222). Paulo Freire, in his work on education for critical consciousness, shared Habermas' belief that a fundamentally democratic process can be achieved through dialogical, communicative learning (Brookfield, 2009). Freire believed that this dialogue between human beings generated critical thinking and led to transformative consciousness raising, which he called "conscientization" (Crotty, 1998; Mezirow, et al., 2009).

Mezirow's approach to transformative learning posited that for people to change their beliefs, attitudes and emotional reactions, they needed to engage in critical reflection on their experiences, which led to transforming their perspective (Mezirow, 1991). This approach was criticized for overly emphasizing rationality (Mezirow, et al., 2009). While rationality is important in the context of transformative learning, emotional and spiritual transformation also takes place when unraveling oppressive attitudes. This process of challenging and shifting how one copes with and makes sense of the world can be quite disorienting, and requires one to be vulnerable, as Mezirow himself points out. Edmund O'Sullivan has been credited by Mezirow as offering the "most comprehensive approach to transformative learning" (Mezirow, et al., 2008), which captures environmental and spiritual aspects of transformative learning. O'Sullivan (2003) defines transformative learning as follows:

Transformative learning involves experiencing a deep, structural shift in the basic premises of thought, feelings, and actions. It is a shift of consciousness that dramatically and irreversibly alters our way of being in the world. Such a shift involves our understanding of ourselves and our self-locations; our relationships with other humans and with the natural world; our understanding of relations of power in interlocking structures of class, race and gender; our body awareness, our visions of alternative approaches to living; and our sense of possibilities for social justice and peace and personal joy. (O'Sullivan, 2003, p. 327)

This brief overview offered glimpses into approaches to transformative learning theory. There are others, though have been the most influential. One particularly useful theoretical framework for the purposes of the research presented in this dissertation is one proposed by Brookfield (2009), as described below.

*A useful theoretical framework.*

Fostering transformative learning in the setting of committees where people who use drugs are included at the table may be a valuable approach to achieving the emancipatory goals

sought by social inclusion. This study explored whether transformative learning was taking place at selected decision-making tables, using a particularly useful theoretical framework.

Brookfield (2009) combined critical theory with transformative learning theory and offers a useful framework which contains seven learning tasks, as summarized in Table 2 and described in more detail below. To develop this framework, Brookfield focused on dimensions of adult learning which are central to the main concerns of critical theory. He explains that critical theory sees a critical adult as one who is able to discern how neo-liberalism and social structures lead people into ways of living that reproduce oppression and inequity and can then take actions to participate in creating more democratic, collectivist economic and social structures. Brookfield cites Lindeman as stating that democracy is achieved when ultimate power resides in the people, in the collectivity, thereby shifting a relationship of “power over” people to one of “power over” people.

Brookfield (2009) describes critical theory as having five distinctive characteristics. First, the dominant commodity exchange economy, which largely controls social relations, must be transformed in such a way that people can realize their humanity and freedom. Secondly, critical theory strives to unmask the knowledge and understandings that can free people from oppression. Thirdly, human beings have an innate yearning for a better, more authentic life. Fourthly, critical theory reflects on current society and aims for a just, fair and compassionate one where opportunities are not limited to the privileged few. Finally, critical theory cannot be verified unless this social vision is realized.

Table 2.

*A Brief Summary of Brookfield's (2009) Seven Learning Tasks*

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1. Challenging ideologies: where people challenge values, beliefs, myths, explanations, and justifications embedded in language, social habits, and cultural forms.
  2. Contesting hegemony: where people challenge the conditions that serve those in power.
  3. Unmasking power: where people recognize how power is exercised in social interactions and relations.
  4. Overcoming alienation: where people develop a sense of agency and are able to be themselves in an authentic way.
  5. Learning liberation: where people learn to escape ideological domination.
  6. Reclaiming reason: where people apply reason to examine how their lives are shaped by the lifeworld.
  7. Practicing democracy: where people use rational discourse, pay attention to ideal speech conditions, and pay attention to power structures related to diversity.
- 

With critical theory and transformative learning theory in mind, Brookfield (2009) devised Seven Learning Tasks, which I used to guide my analysis. The first, *Challenging Ideology*, involves challenging dominant ideas and beliefs which help to reproduce and legitimate the interests of a dominant group. Fraught with connotations of oppression and domination, these values, beliefs, myths, explanations and justifications tend to be broadly accepted. Challenging this ideology brings adults to question this taken-for-granted reality and reveals the inequity and oppression that it perpetuates.

*Contesting Hegemony* follows when people recognize this hegemony they live by, how it is reproduced in the existing social structures, and then strive to replace it with more equitable beliefs and practices. Through *Unmaking Power*, they come to recognize the power that flows in their lives and communities. Social movements develop through this learning task when people

develop agency, learn to subvert power structures and experiment with forms of collective organization and democratic process.

When people realize they are alienated, living in ways that estrange them from who they really are, and take responsibility for their own actions, they learn to develop agency and a sense that they can contribute to shaping the world to their desires as a way of *Overcoming Alienation*. *Learning Liberation* is an inner revolution that takes place when an individual develops liberation from dominant ideology. This state can be disturbing and disorienting and can lead to an outer revolution that advocates for new social, economic and political structures.

The transformative learning that takes place through these learning tasks leads to *Reclaiming Reason* when people develop the ability to act in ways that do not necessarily support dominant ideology. They now have the ability to assess evidence, judge arguments, recognize causality and decide on their actions. They have reclaimed domains of their lives that they had ceded to experts and to those who control and possess specialized knowledge. Finally, *Practicing Democracy* becomes the praxis through which groups operate, where power resides in the people, in the collectivity, where there is measure taken to address economic inequities and where democratic disciplines are practiced. In this space, people interact with openness to new perspectives and a willingness to temporarily suspend their own convictions.

Brookfield's Seven Learning Tasks were useful to interpret the findings for this study. Fostering this transformative learning does not, however, take place in a vacuum. Brookfield's Seven Learning Tasks do not capture the contextual factors that influence the interactions that take place at decision-making tables. The context, in terms of social conditions and structures, has an important influence on health equity. To capture contextual factors, Restall and Kaufert (2011) offer another useful framework, described below.

### ***Influencing the context.***

Contextual factors include broader political, social, organizational factors as well as personal characteristics of everyone at the table. Each of these factors has an impact on the processes that take place at decision-making tables as well as on the outcomes that emerge from them. Restall and Kaufert (2011) provide a useful framework for looking at how context influences the involvement of people with lived experience in policy making. Though they do not specifically focus on power relations, the themes they identified to frame context proved useful to analyse the contextual data for this dissertation.

To look at the political environment, as suggested by Restall and Kaufert (2011), I assessed the various opportunities available for people who use drugs to get involved at decision-making tables in the current Canadian political context, as well as the impact of policies on the mobilization of people who use drugs and the allocation of resources for their inclusion.

Regarding the social environment, Restall and Kaufert (2011) refer to examining socially constructed views of people with lived experience and their impact on inclusion at decision-making tables. They also consider issues related to intersectionality, stigma and discrimination. I integrated these concepts into the analysis of the findings in Chapter 6. These concepts also come into play when I discuss the impact of socially constructed views of people who use drugs on policies that affect their opportunities for inclusion, in Chapter 4, as well as the political will of decision makers to address the needs of and solutions proposed by people who use drugs.

Restall and Kaufert's (2011) concepts of institutional characteristics were useful to look at organizations' capacity for and commitment to the inclusion of people who use drugs in Chapter 6. Finally, I also considered participants' personal characteristics in terms of knowledge of inclusion policy issues, political systems and power structures, skills to express ideas,

experiences and positions as well as to listen to and understand others' ideas, attitudes related to persistence, resiliency, openness to learning, will for inclusion, optimism about making a difference, and positive representation of people who use drugs. I also considered participants' lived experiences, history and demographics. Much of these concepts were useful to present the findings in Chapter 4.

In this section, I have provided a review of the theoretical and empirical perspectives that informed my research, as well as the theoretical frameworks with assisted with the interpretation of the findings. As mentioned, transforming power relations at decision-making tables where people who use drugs are included is multi-faceted and involved resituating decision-making power in political spaces, fostering critical consciousness and transformative learning in everyone at decision-making tables, as well as influencing the social, political and organizational contexts within which power inequities are reproduced. Curious to assess the state of knowledge around social inclusion as a way of transforming power inequities at decision-making tables, I turned to the literature, as I describe in the next section.

### **Review of the Literature on Social Inclusion and the Transformation of Power Inequities**

With goals of emancipation in mind, either implicitly or explicitly, innovations in social inclusion whereby members of socially excluded groups have been partly or fully included in social structures that affect their lives have been implemented. For instance, deemed a quintessential disease of social exclusion (Allman, 2005), HIV/AIDS tends to cluster around poverty, gender inequity, social insecurity and other marginalizing conditions, thereby disproportionately affecting the most marginalized (Allman, 2005; Hanefeld, 2008; Loewenson, 2007; Rhodes et al., 2010; Sanders, Labonte, Baum, & Chopra, 2004). With roots in the gay and lesbian liberation movement, the Canadian HIV/AIDS movement has been particularly attentive

to issues of power and social inclusion (Roy & Cain, 2001), and has paved the way for social inclusion practice. The Greater Involvement of People Living with HIV/AIDS (GIPA) principle (UNAIDS, 1999) strives to involve persons living with HIV/AIDS in all decisions that affect their lives and in the organizations that serve their needs. The GIPA principle is now institutionalized into the structures of HIV/AIDS organizations in Canada (Roy & Cain, 2001).

The HIV/AIDS epidemic among people who use injection drugs since the 1980s has also precipitated public health responses such as harm reduction services to curb its transmission (Ball, 2007), and has led to the expansion of social inclusion practice to foster the participation of people who use drugs. Canada is a signatory country to the UN General Assembly's Declaration of Commitment on HIV/AIDS, which calls for not just the involvement of people living with HIV/AIDS in decision making social structures that affect their lives, but also of people from structurally disadvantaged communities such as people who use illegal drugs (Jürgens, 2005). To this end, the principle of "Nothing About Us Without Us" states that the greater, meaningful involvement of people who use illegal drugs into decision making social structures that affect their lives is a public health, ethical and human right imperative (Jürgens, 2005).

Innovative inclusionary approaches such as the GIPA (UNAIDS, 1999) and Nothing About Us Without Us (Jürgens, 2005) principles have been implemented to varying degrees into organizations across Canada as strategies and practices for the participation of members of socially excluded groups. In this review of literature, I pay special attention to social inclusion in the context of decision-making related to policy development for program and service delivery as well as health research. The paucity of literature provides only glimpses of power relations and inclusionary and exclusionary processes and practices in this context.

Roy and Cain (2001) conducted a survey and focus groups with the Canadian AIDS Society's member community-based service organizations to describe the level and nature of GIPA in the community-based HIV/AIDS movement, to identify successful GIPA promotion strategies and barriers experienced by persons living with HIV, and to develop strategies to address them. Roy and Cain (2001) identified some benefits, mainly at the organizational level, of involving persons living with HIV/AIDS in community organizations: GIPA keeps priorities and issues in focus, identifies new and changing needs for people living with HIV/AIDS, adds credibility to organizations, alleviates stigma and improves rapport with service users, to name a few. The direct participation of people living with HIV/AIDS resulted in challenges to the distribution of limited financial resources to services (less than 2% of the total budget). Government and corporate funders are increasingly recognizing the importance of including service users in leadership positions in community organizations.

According to Roy and Cain (2001), barriers to involvement remain, however, including fear of disclosing one's HIV status publicly due to stigma. Stigma and stereotyping occurred both outside and inside of the community organizations. For example, organizational workers viewed service users as "lack[ing] required talent, skills, education and experience" (p. 426) to make a meaningful contribution to the organization. HIV/AIDS disproportionately affects people at the intersection of various social disadvantages, and the authors point to increasing social divisions between mainly middle class, well-educated service providers and service users, which likely contribute to service providers' exclusionary perception of service users' limited capacity to contribute to the organization. Procedural injustices were reported in organizations' hiring practices due to this perception, disclosing a contradiction between the GIPA policy and actual practices. Empowerment of people living with HIV/AIDS was also thwarted by negative

attitudes toward their capacity to contribute. The findings of their research helped form the basis for policy change regarding GIPA in HIV/AIDS service organizations in Canada, however the proportion of participating persons living with HIV/AIDS who also have illegal drug use experience is not specified. Specific issues related to the inclusion of people who use drugs cannot therefore be teased out from this study.

Much of the literature on social inclusion in social structures relates to participation in research. Community-based participatory research (CBPR) ultimately strives to improve health outcomes and reduce health inequities toward equity and social justice through a democratic, inclusionary process, which involves those previously excluded from the research and knowledge creation process (Wallerstein et al., 2008; Ruffin, 2010). CBPR is now commonplace in HIV/AIDS research (Flicker et al., 2009), pointing to structural changes toward social inclusion. Funding and governance bodies require more community-academic partnerships, and more rigorous evaluation and accountability from community-based services, while increasingly empowered communities demand participation in research (Jansson et al., 2010; Flicker et al., 2009). Engagement in CBPR requires creating a conducive, safe environment for such partnerships to thrive and achieve their social justice goals.

In a study at the organizational level, Flicker and her colleagues (2009) studied the barriers and facilitators for Ontario HIV/AIDS community-based organizations (CBOs) to engage in CBPR. They identified that there were poor incentives and capacity for both community members and academic researchers to be partners in CBPR, and that funding mechanisms were not structured to encourage CBPR. The lack of partnership models to guide collaboration between researchers, organizations, and community members resulted in a barrier preventing individuals living with HIV/AIDS from having leadership roles in research.

Facilitators to CBPR included trust between partners and the promotion of change within existing systems. Similarly, Savan, Flicker, Kolenda, and Mildenberger (2009) found that Canadian CBPR was hindered by a lack of resources and the existing systemic institutional culture and facilitated by funding, reward structures and partnership support.

Still at the organizational level, Travers and his colleagues (2008) investigated how CBPR efforts in Ontario have adhered to the GIPA principle. Barriers to the inclusion and participation of people living with HIV/AIDS included HIV-related stigma and fear of disclosure, uncertainty over the value of community member participation, assumptions about their lack of skills and ability to participate, and the lack of available organizational leadership and resources to conduct research and to implement GIPA. Organizations recognized that the benefits of participation included higher quality prevention and care programming, enhanced policy development, and enhanced credibility of HIV/AIDS community-based organizations as policy actors. They also saw how the inclusion of people living reduced stigma and isolation for people living with HIV/AIDS and increased feelings of empowerment and self-worth. The authors note that engaging community members requires consideration to both structural and social factors affecting them. Health-related challenges of living with HIV/AIDS and dealing with other life priorities such as food, shelter and income also hindered their participation.

One study by Greene and her colleagues (2009) conducted focus groups with people living with HIV/AIDS, investigated their involvement as peer research assistants and highlighted important methodological practices and considerations in doing so. Peer research assistants felt empowered by participating in the research process and gained research capacity. They felt useful and reported health benefits, though worried about the sustainability of their peer research skills, employment and identity.

Chung and Lounsbury (2006) offer another relevant study, which explored the role of power, process and relationships in participatory research for HIV/AIDS programming in the United States. Their case study illustrated that participation in a CBPR project is dynamic and requires ongoing negotiations in a complex web of roles and relationships. The authors caution that inattention to power differentials can contribute to disempowering outcomes. They offer yet another conceptual framework for a participation continuum and found that the nature of participation changes over the course of a single project.

Guta, Flicker and Roche (2013) conducted an insightful qualitative examination of employing people with lived experience of homelessness, HIV, being an immigrant or refugee, identifying as transgender, or living with mental illness as peer research in the context of CBPR. Their paper focused on understanding how CBPR principles are being operationalized in terms of the authenticity and impact of community participation and the power inequities at play. The theoretically informed paper questioned whether CBPR was actually empowering and offered that emancipatory goals were often lost to the reproduction of forms of governance that supported a neoliberal agenda. This paper offers useful insights to critically examine power relations that take place at research tables. Specifically, the authors speak of a paradox of hiring peer researchers who truly represent the lived experience of interest while having to function in a working environment that may be unfamiliar to them, thereby identifying a tension between empowerment and efficiency. The authors also point to an example of communication and cultural clashes between researchers and peer researchers, where different rules play out and may result in the dismissal of peer researchers. Such a dismissal is problematic given that CBPR is meant to lead to the emancipation of marginalized groups toward greater equity.

Hiring peer researchers is, however, only one model of practice to include people with lived experience in CBPR. In an earlier report, Roche, Guta and Flicker (2010) described three models of practice in CBPR: 1) the advisory model whereby people with lived experience provide advice for the research; 2) an employment model, as described above, whereby people with lived experience are part of the research staff; and 3) the partner model whereby people with lived experience partner and participate in all aspects of the research and decision-making is shared. The authors emphasize the importance of clearly defining the roles, responsibilities and expectations when including people with lived experience in research, including discussions about the limitations of their inclusion in research. According to the authors, the partnership model “shows great promise toward reconciling some of the challenges of ensuring meaningful inclusion of community members in research” (p. 3). The partnership model, according to Arnstein’s (1969) ladder of participation, lends itself better to shifting power relations towards more equitable ones for people with lived experience. Roche, Guta and Flicker’s (2010) report will be revisited in the discussion.

Regarding the Nothing About Us Without Us principle, one Australian study highlighted the importance of embedding participatory structures and processes in organizational settings that serve disabled communities (Radermacher et al., 2010). They took a critical look at an organization’s efforts to enable participation of disabled people and interviewed both disabled and able-bodied individuals involved in the organization. These authors found statements regarding the limited capacity of disabled people to fully participate due to perceived and real lack of ability, skills, experience and education. Divergence between individual and organizational agendas as well as lack of structure caused some tensions and conflict regarding decision-making processes. Lack of resources such as time, funding and support also hindered

participation. The authors deliberately chose to focus on barriers to rather than facilitators to participation, thus they could not draw conclusions as to the perceived strengths of disabled people. They point out that organizational exclusion still occurs even when an organization is attuned to the needs of disabled persons. The study provides some glimpses of exclusionary practices that could be addressed to enhance participation and social inclusion.

Of particular interest to this dissertation is the “Nothing About Us, Without Us” (Jürgens, 2005) project led by the Canadian HIV/AIDS Legal Network, in partnership with the Vancouver Area Network of Drug Users (VANDU), CACTUS Montréal, the British Columbia Centre for Excellence in HIV/AIDS, HIV/AIDS service organizations and federal, provincial and territorial governments. A consultative process was conducted to determine what the greater, meaningful involvement of people who use illegal drugs means and what it requires to be successful. In total, 100 people who use drugs from across Canada provided input, as did 76 individuals from HIV/AIDS or related organizations and services. The authors produced useful information about what needs to be done to increase inclusion of people with illegal drug use experience and to address the systemic barriers to their greater involvement (Jürgens, 2005). The document includes a list of ‘dos and don’ts’ when consulting with people who use drugs, as well as a manifesto. These recommendations provide useful insights as to some actions that could be taken to create a safer environment that fosters greater inclusion and ultimately contributes to greater equity in power relations for people with illegal drug use experience. For example, in terms of empowerment, ‘user groups’ ask that they be the ones to select their own representatives. They also ask that other stakeholders critically self-reflect and acknowledge that they need to be open to learning and need to listen to the user representatives.

There is also a body of literature on the mobilization of people who use illegal drugs to address health crises, inadequacies in services and government inaction. One case study captured the Vancouver Area Network of Drug Users' (VANDU) genesis, structure, and activities, which stemmed largely from a philosophy of user involvement and empowerment (Kerr et al., 2006). The authors confirm that several founders of VANDU were influenced by principles of social justice and emancipation. VANDU proposes user-based actions. It abides by guiding principles of inclusion, user-driven decision making, and peer mentorship. They “bring the “voice of users” into mainstream political discourse” (p. 63) and have been at several tables where decisions are being made that affect their lives. Signs of emancipation and improved health were apparent, with some interviewed participants noting that they viewed themselves more positively than the societal stigma imposed on them, and some speaking of adopting healthier behaviours. VANDU struggles with lapses in funding. The authors encourage greater efforts to assist with the formation and inclusion of drug user organizations.

A meeting to form a national grassroots group for people who use drugs, the Canadian Association of People Who Use Drugs, took place in June 2010 (CAPUD, 2010a). The minutes from the meeting reveal some insights with regard to social inclusion from the perspective of people who use drugs. The meeting participants report that they have applied three times for funding for a national project for and by people who use illegal drugs, without success. Forming a national group would build their capacity to coordinate and support regional groups. The participants expressed that forming a national group would empower them to democratically select and send their own representatives to local and national policy meetings, and to speak with a unified voice, thereby influencing policy. The representatives would also be strong role models and potentially have a positive impact on how other people who use illegal drugs view

themselves and their potential. This would also help alleviate social stigma. The meeting participants created CAPUD and issued its Statement of Unity (CAPUD, 2010b).

Following this inaugural 2010 meeting, however, CAPUD had no resources to build capacity and develop into the strong, united voice it envisioned. It took a few years for momentum to build. SOLID, an organization of people who use drugs in Victoria, British Columbia, had been building its organizational capacity and had mobilized into offering peer leadership training. SOLID approached researchers at the University of Victoria's Centre for Addictions Research of BC to assist them in obtaining funding to organize another national meeting to build on the first meeting that took place in 2010. In October 2013, representatives from 14 organizations of people who use drugs gathered to continue building a collective voice and influence decisions that affect people who use drugs (CAPUD, 2014). In their report, they identify principles of participation and self-representation, obstacles to their meaningful participation, and ways to enhance their participation.

Beyond the grey literature related to the inclusion of people who use drugs, a few literature reviews have focused on the literature related to the involvement of people who use drugs in policy and program development and identified its barriers and facilitators (Marshall, et al., 2015; Ti, et al., 2012). Ti and her colleagues (2012) carried out a narrative literature review of the involvement of people who use drugs in policy and program development and identified its barriers and facilitators. More recently, Marshall and his colleagues (2015) conducted a useful systematic review of the various roles of people who use drugs in harm reduction initiatives. In their article, they provide a detailed description of the systematic, organizational and individual barriers and facilitators that influence the involvement of people who use drugs in service delivery, research, policy and evaluation. The authors situate the level of participation according

to Pretty's framework (1995) and elaborate on its impact on people who use drugs' influence over decision-making. However, while it is useful to examine such barriers and facilitators to participation, simply bringing representatives of marginalized groups to the table does not by itself imply transformation of inequitable power relations, nor does it get to the core of that transformative process.

As described above, Radermacher and colleagues (2009) took a critical look at an organisation's efforts to enable participation of disabled persons and provided glimpses of exclusionary processes and power relations. English and Peters (2012) touched on power relations in their study of transformative learning for women who work or volunteer in feminist non-profit organisations. Chung and Lounsbury (2006) conducted a case study into the role of power, process and relationships in participatory research, providing useful information with regard to the changing nature of participation within the same project. Though these studies provided useful insights, these authors did not conduct in-depth critical analyses of the transformation of power relations within social inclusion initiatives, nor did they contextualize them within the greater social, political, and economic context. In addition, most of these studies did not pertain to the population of interest in this dissertation, people who use drugs.

Although barriers and facilitators to participation for some marginalized groups have been identified to some extent in the Canadian context, especially with regard to the GIPA principle in the context of CBPR, this literature review reveals that studies have mostly been at the organizational level. The perspective of people with drug use experience has been mainly found in the grey literature, with a few exceptions, which only provides glimpses into their experiences with social inclusion efforts in matters that affect them. Chung and Lounsbury's (2006) case study into the role of power, process and relationships in participatory research

provides useful information with regard to the changing nature of participation within the same project. However, no in-depth critical analysis of social inclusion initiatives with people who use drugs, with a specific focus on an in-depth understanding of transforming power relations between participants, and contextualized within the greater social, political, and economic context was found.

A few studies point to the contrast between the GIPA and Nothing About Us, Without Us policy rhetoric and the actual practices (Roy & Cain, 2001; Radermacher et al., 2010, respectively). One study alludes to the issue of tokenism, indicating that practices may be missing the mark (Roy & Cain, 2001). Another study confirms that exclusion can still occur in an organization with social justice intentions (Radermacher et al., 2010). Practices can remain “non-inclusive of the intersectional disadvantages experienced by” people who use illegal drugs and despite their best intentions, insensitive to cultural differences (Wearing, 2011, p. 538). It would be useful to critically explore the power relations between participants in social inclusion efforts with people who use drugs to gain insights as to whether such efforts are on track with their transformational social justice intentions and to identify implications for social inclusion practice. In addition, structural approaches do not work the same for all populations, settings and contexts (Gupta et al., 2008). The literature on social inclusion has focused largely on the participation of people living with HIV/AIDS, and not much on the inclusion of a diversity of socially excluded groups such as people who use drugs. The next chapter presents the research methodology, design and implementation of the study presented in this dissertation.

## **Chapter 3 – Methods and Procedures**

### **Introduction**

This chapter describes the ontological and epistemological underpinnings of the critical emancipatory methodology used for this study. It elaborates on the research design, which used a participatory research approach and drew on critical ethnography procedures. It then provides details regarding the implementation of the study in terms of gaining access and entering the field of interest, obtaining and maintaining ethics approval, collecting and analyzing qualitative and quantitative data and taking measures to enhance the quality and integrity of this inquiry.

### **Critical Emancipatory Inquiry**

This research was informed by a specific paradigm or way of looking at the world in a specific context, of interpreting what was seen and heard, and of deciding what seemed real, valid and important to document (LeCompte & Schensul, 2010). This research drew extensively on the critical and emancipatory paradigm which assumes that “truth resides in and is created through relationships of power” and “[w]hat is accepted as known thus becomes what those in power in a field state or events disclose or declare” (LeCompte & Schensul, 2010, p. 63). The critical and emancipatory paradigm assumes that knowledge is socially constructed, historically situated, and based on values, and places this context at the centre of the research process (Henderson, 1995; LeCompte & Schensul, 2010). Knowledge is also influenced by individuals’ backgrounds and context in terms of their position and understanding of their place in society related to the intersections of gender, race, class, sexual orientation, culture, and many other factors (Henderson, 1995; Johnson-Bailey, 2012; LeCompte & Schensul, 2010; Leonardo, 2004). Thus, people make sense of their experiences through the dominant ideology, and from their

contextual position in the structures of dominance (Cranton & Taylor, 2012; LeCompte & Schensul, 2010).

A critical and emancipatory inquiry challenges societal beliefs, assumptions and perspectives, brings attention to and scrutinizes the relationship between social systems and individuals, uncovers sources and dimensions of inequities and focuses on the empowerment of human beings to overcome and transform structural disadvantages (Creswell, 2007; Henderson, 1995; LeCompte & Schensul, 2010; Leonardo, 2004; Madison, 2012; Merriam & Kim, 2012). Research conducted under the critical and emancipatory paradigm views knowledge production as an emancipatory, liberatory act (Henderson, 1995; Leonardo, 1994). It places critique at the very centre of knowledge production, and “functions to cultivate... [the] ability to question, deconstruct, and then reconstruct knowledge in the interest of emancipation” (Leonardo, 2004, p. 12). The critical and emancipatory paradigm stems from the premise that critique is aimed at systemic and institutional structures, their creation, and how they may be changed to minimize or eliminate their oppressive effects on certain groups (Leonardo, 2004). Critical and emancipatory inquiry seeks emancipation, both within the research process and within society, rather than merely prediction or understanding (Henderson, 1995). The critical and emancipatory paradigm does not, therefore, simply embrace critique but includes the transcendence of oppressive conditions and the emancipation of oppressed groups (Leonardo, 2004). This goal is realized through a transformative knowledge production process (Henderson, 1995).

The praxis that leads to this transformative learning is the space where “reflection and action upon the world in order to transform it” (Freire, 1972, p. 28) take place indissolubly (Crotty, 1998). Here human beings are co-intentionally “engaged in intervention in the world as transformers of that world” (Freire, 1972, p. 47). The praxis that leads to this critical

consciousness, or ‘conscientization’, requires true dialogue between human beings, which generates critical thinking, and true dialogue cannot occur without critical thinking. People who have been oppressed and socially excluded have been dehumanised, and conscientization moves towards humanisation through praxis (Crotty, 1998). “[W]hen people become critically aware and take action to humanise their situation, their social and political organisation and the creation of necessary institutions assume central importance” (Crotty, 1998, p. 156). In this way, transformative learning is *both* about individual transformation *and* about social change (Cranton & Taylor, 2012).

### **Community-based Participatory Research Framework**

With these ontological and epistemological underpinnings in mind, this study used a community-based participatory research (CBPR) framework where I partnered with members of two community-based organizations of people who use drugs, SOLID and DUAL (Harris, 2006). CBPR is a collaborative approach to research that involves sharing and partnership in every step, values experiential and popular knowledge, acknowledges power inequities, raises critical consciousness, and strives for equity and democracy in the production of knowledge in order to contribute to social action and change (Henderson, 1995; Wallace, Pauly, Perkin, & Ranfft, 2015). Through examining and better understanding power relations at decision making tables that include people who use drugs, I hope to contribute to social action to address power inequities, and ultimately health inequities, by providing insights into transforming power inequities.

With regard to power relations for this research, this project ultimately involved my dissertation in the pursuit of my PhD, so the power for decision-making resided more with me as a researcher. To share some of the decision-making power, I established a partnership approach

with people who use drugs, similar to Arnstein's (1969) partnership rung on her ladder of participation whereby I shared decision-making power through negotiation with them. This process was explicitly agreed on with my research partners at the onset, as I later discuss in the implementation of the study. This participatory approach fits well within a critical and emancipatory paradigm, which is described below.

Ideally, a participatory research project should be initiated by the community of interest. In this case, the work for this dissertation stemmed from previous work I conducted, conversations I have had over the years with people who use drugs, and from a review of the published and grey literature, which led to the identification of the research questions. For instance, peer involvement, or the inclusion of people who use drugs, was the third most important topic of discussion to emerge from focus groups a colleague and I conducted in nine Canadian cities (Belle-Isle & Cavalieri, 2008).

In that project, people with lived experience expressed a desire to get involved in the conceptualization, development, implementation and delivery of services offered to them. During the focus groups, participants expressed a genuine commitment to helping others, which brought meaning to their lives. They said that involvement also brought them self-esteem, a sense of purpose, a feeling of being heard, and feeling useful. Since it was not the focus of that particular project, I did not analyse factors that may have contributed to these outcomes nor the conditions that might have fostered the transformation of power inequities when they participated in decisions that affect them. The dearth of literature on this topic and my own experience of the importance of transforming power inequities at decision-making tables did, however, pique my curiosity. Details of how I integrated participatory considerations throughout

this research are included in the section on the implementation of the study below. First is a description of how this study drew from critical ethnography procedures.

### **Critical Ethnography Procedures**

The interest of this study in addressing injustice in power inequities and improving inclusion practice toward greater equity lends itself well to drawing on critical ethnography procedures (Madison, 2012). Embedded within conventional ethnography, critical ethnography shares many fundamental characteristics with conventional ethnography, though has a specific style of analysis and discourse (Thomas, 1993). Conventional ethnography attempts to systematically describe cultures and interpret meanings and social expressions between people and groups in communities, institutions, and other settings (what is) (Berg, 2009; LeCompte & Schensul, 2010; Thomas, 1993). Critical ethnography stems from conventional ethnography though has a clear and explicit political purpose, one that seeks positive social change and emancipation for participants (what could be) (Berg, 2009; Thomas, 1993).

Critical ethnography is particularly well suited when wishing to study issues of power relations which may lead to the marginalization of specific groups, and wanting to advocate for their emancipation (Berg, 2009; Cohen, Manion & Morrison, 2000; Creswell, 2007; Madison, 2012). Critical ethnography “takes us beneath the surface appearances, disrupts the status quo, and unsettles both neutrality and taken-for-granted assumptions by bringing to light underlying and obscure operations of power and control” (Madison, 2012, p.5). It does this in a specific context and by revealing the political, social and material influences that affect individuals’ or groups’ power (Allen, Chapman, Francis, & O’Connor, 2008). The focus and process of critical ethnography are on issues of power, domination, voice and empowerment (Cohen et al., 2000). In drawing on a critical ethnographic approach, I am being explicit in my intention to modify

consciousness or invoke a call to action by using the knowledge gained from this research to influence social inclusion practice and hopefully inspire transformation and social change (Thomas, 1993).

The field of ethnography has a rich and complex history influenced by a range of theoretical foundations and disciplines. It does not have a clear and standard definition and varies greatly in its approaches and forms of practice (Hammersley & Atkinson, 2007). Perhaps the clearest link between the research presented in this dissertation and critical ethnography lies in how the data were collected and analysed. First, social inclusion practice was studied *in situ* by actually attending meetings where people who use drugs were included at the decision-making table and interacting with all participants to gain insights and observe power relations (Hammersley & Atkinson, 2007).

Traditionally, ethnography involves daily or frequent and long-term interactions in the field site of interest (Falzon, 2009). Time spent in a specific field is also usually the factor that enables ethnographers to achieve depth (Falzon, 2009). In this study, the field was the actual decision-making tables at which sat policy makers, service providers, researchers and people who use drugs. Since I have already been involved in work with people who use drugs for over a decade, including them at the table as part of steering committees for projects aimed at producing information to improve harm reduction services in Canada, I felt that I had already set foot in the field of interest for this study. I have been at many tables where people who use drugs have been included, in policy consultations, program and service delivery planning settings and in research settings, including those I have chaired myself. In this sense I felt I had some personal insights into the perspectives of those at such tables striving to be inclusive.

In addition, the study included four committees in two provinces. For practical and financial reasons as well as time constraints, the fieldwork of this study was condensed to observing one meeting for each committee, and relied more heavily on data collected through semi-structured interviews with various members of the selected committees. In addition to participant observation *in situ* and individual semi-structured interviews, the study involved document reviews. For these reasons, the methodology for this qualitative critical emancipatory research is described as drawing on critical ethnography procedures rather than being a pure critical ethnographic inquiry.

This condensed approach to fieldwork, sometimes referred to as a focused or mini ethnography, has been deemed appropriate when the investigator has partial knowledge of the culture of interest at the onset of the study (Roper & Shapira, 2000). Although less time was spent in the field than traditional forms of ethnography suggest, risking some accuracy in interpretation, this risk was mitigated both by my prior knowledge of the field as well as by the participatory approach of this research. Indeed, consultations with people who use drugs at every step enhanced the interpretation of the findings. Data collection and data analysis are described in greater detail later in the chapter.

Ethnography typically seeks “to describe how a cultural group works and to explore the beliefs, language, behaviors, and issues such as power, resistance and dominance” (Creswell, 2007, p. 70). Thus, it is important to define the culture-sharing group of interest for this study, people who use drugs. People who use drugs cannot be clustered together into a single community given the ethno-cultural and geographic diversity among the Canadian population (Allman et al., 2005). Some people who use drugs in Canada have become empowered, have mobilized and have self-identified, in their words, as ‘people who use drugs’ (CAPUD, 2010b,

2014; Friedman, Schneider, & Latkin, 2012; Kerr et al., 2006). For this study, people who use drugs were involved at decision-making tables at the time of the study to contribute their perspectives and input and provided a glimpse into this culture and related experiences with power relations in that context. With the described ontological and epistemological underpinnings of a critical emancipatory inquiry, a participatory research framework, and procedures that draw from critical ethnography, the study was implemented as described below.

### **Implementation of the Study**

#### **Gaining access to the field.**

For over a decade, I have developed and maintained relationships with various organizations of people who use drugs, as well as with organizations that develop policy, provide services or conduct research that affect the lives of people who use drugs. To gain access to this field for my research, I first reached out to SOLID and DUAL and expressed my desire in partnering with them on this research. Important elements of relationship building include trust and regard, as well as agreement on roles, responsibilities and objectives of the research to be conducted (Harris, 2006). I feel that I already had the trust of both SOLID and DUAL members, having worked with them in the past. I met with their respective boards of directors and presented my research ideas to them in October 2012 (see Appendix A – Consultation for Partnership). I clearly outlined the proposed research and was explicit about the roles, responsibilities and research objectives from the onset. We agreed on the purpose of the research, timelines, responsibilities and roles of the various parties, the processes for decision making, compensation for their time whenever possible, and a dissemination plan of the findings. Both organizations agreed to a partnership and assigned three representatives each to work with me (see Appendix B – Partnership Agreements).

In keeping with a participatory research framework and critical and emancipatory approach, I worked with SOLID and DUAL representatives to adapt the research to their needs as much as possible while keeping in mind the requirements for my PhD dissertation and the theoretical concepts I drew on from the literature. Most importantly, the research questions and interview questions stemmed in part from discussions I had with people who use drugs over the years about their inclusion at decision-making tables. I met with both SOLID and DUAL representatives in March 2013 to review the proposed research and interview questions and finalize them, agree on which committees to include as research sites, finalize the semi-structured interview questions, and agree on how best to relay the results of the research back to them. As a useful tool to deliver to SOLID and DUAL at the end of this research, we decided on a 2-page summary of practice suggestions to improve on current practices regarding the inclusion of people who use drugs at decision-making tables.

Throughout the research, I acted as facilitator to oversee and guide the process. We agreed at the onset to have a few meetings at various stages of the research, as described in our partnership document. I also provided both organizations with my contact information and invited them to communicate with me at any time should they have any questions or concerns about this project. Since I also have communications with both organizations through my employment, we also had chances to check in with each other along the way. I was able to provide them with updates of where I was at in the process on a regular basis.

To engage the four committees of interest for this research, I approached the chairs of each committee. I scheduled meetings with each of them to discuss the research project and request permission to attend an upcoming meeting to introduce the research project to the committee members. Each chair agreed and I met with each committee, either in person or by

teleconference, and expressed my desire to both observe a future meeting once ethics approval is obtained and conduct individual interviews, along with a brief demographics questionnaire, with willing committee members. The stage was set, pending ethics approval.

### **Ethics approval.**

Ethics approval was obtained from the University of Victoria/Vancouver Island Health Authority Joint Research Ethics Sub-Committee (Ethics Protocol Number J2012-86) and from the Ottawa Public Health Research Ethics Board (Research Project #184-13) (see Appendix C – Ethics Letters of Approval).

### **Entering the field.**

Once I obtained ethics approval, I was ready to enter the field. The chairs of each committee provided contact lists of all of the committee members. I sent all committee members an email with the recruitment script explaining the project and inviting their participation (see Appendix D – Recruitment Scripts), along with the consent forms for both participation observation and individual interviews (see Appendix E – Consent Forms). Committee members were contacted individually to ensure confidentiality in our communications so that no other committee member was aware of who accepted to be interviewed, including the chairs. No committee member expressed any concerns about my presence to observe their meeting, though two participants declined to be observed.

At each observed meeting, the chairs granted me some time at the beginning to briefly describe the research and its purpose and to walk the committee members through the Participant Observation consent form (see Appendix E). Signed consent forms were collected from committee members before observations began. The Participant Observation and Individual Interview process are described in greater detail below in the section on Data Collection.

At the onset, I had concerns that the committee chairs might be resistant to participate in this study. I thought that perhaps they would feel threatened by being observed in this setting for research purposes, especially that they knew me or of me, and might have felt that I was there to somehow evaluate them. My experience and reputation in this field, however, seemed to facilitate rather than pose challenges with regard to entering the field, in the sense that I already had working relationships with some of the chairs and/or members of the committees. Through word of mouth, with both SOLID and DUAL acting as my references, and with the chairs' interest in the findings this research would generate, the committees agreed to participate in this research. I tapped into the good will I have witnessed at such tables over the years, presented this study as a win-win situation for all concerned and emphasized the importance for all of us to be self-reflective and open to change if we are to collectively transform power relations and redistribute decision-making power in social structures that affect the lives of people who use drugs. The committees involved shared my interest in examining these research topics.

As for people who use drugs, I believe that my reputation with them was also beneficial to this research. I had gained the trust of many of them through my previous work. Far from silencing them with my presence in their field, I experienced their eagerness to speak to me about their experiences, issues and concerns. At such times, some have expressed their surprise at my interest in even listening to them, perhaps hinting at some internalized oppression of not feeling worthy of being listened to. Once in the field, I began collecting data as I explain in the next section.

### **Data collection.**

Using ethnographic data collections methods, sufficient data were collected to obtain meanings that shaped the analysis (Thomas, 1993) through participant observations, individual

interviews, and a brief demographics survey. Confirmatory redundancy, or triangulation, was built into the data by gathering data from multiple sources (LeCompte & Schensul, 2010). For example, data were also collected through reviewing relevant documents such as terms of reference and strategic plans when they were accessible, documents describing the committees and their work, websites, and any other document the committee members felt were relevant. These documents shed light onto decision-making structures and helped to confirm or negate what was actually observed during the course of committee meetings at which people who use drugs were included. The next sections present the details of the data collection methods used to address the research questions.

***Participant observations.***

To gain understanding of what takes place at the table when people who use drugs are included, I attended and observed one meeting for each of the four committees selected, for a total of 16 hours of observations, between April and December 2013. Once in the field, I strove to become a ‘fly on the wall’ so that my presence was as inconspicuous as possible while I observed the meetings. This approach worked fairly well for the most part, in that committees seemed to resume business without engaging me in the discussions, with a few exceptions. In one committee meeting, members commented to me that the meeting had not followed its usual format. They did not attribute this to my presence at the meeting as much as to the fact that the committee chair was not as prepared as usual for the meeting and had not set an agenda, so the meeting was less structured than usual.

During this fieldwork, at each observed meeting, detailed field notes (see Appendix F – Observation Tool) were hand written in a research notebook then transcribed into electronic format. Field notes focused on what occurred from my perspective through verbal exchanges,

practices, actions and interactions (Berg, 2009). Field notes recorded situations as they occurred (physical setting, acts, activities, interactions, meanings, beliefs, emotions, objects) and the meanings of these events at the time for all participants at the table (LeCompte & Schensul, 2010). In the field notes, I described what I observed while attempting to minimize interpreting what I saw. In instances where I wanted to clarify or confirm something I observed in the meetings, I did my best to speak to the participants in question directly after or soon after the meeting.

I took copious notes during the meetings and found myself struggling somewhat with getting caught up in the content of the meeting, given that these meetings related to harm reduction work which I am also involved in, rather than observing power relations at play. When I became aware of this occurring, I simply shifted my observations toward interactions between the individuals at the table. That said, some of the content of the meetings and how it was approached or discussed was at times also relevant to the power dynamics being displayed, in which case I made a point of noting that.

### ***Individual interviews.***

Forty individual, qualitative semi-structured interviews (10 from each committee) were conducted to gain more depth into the perspectives of all participants at the table with regard to power relations. Forty brief demographics surveys, which accompanied the individual interviews, were also collected. This data collection took place between April and December 2013 at mutually convenient times for the interviewer and interviewee. Some interviews were conducted before observation of their respective committee, others after, depending on when I could be in either British Columbia or Ontario. Since the interviews were about the committees' processes and power relations in general and did not pertain to the specific meeting observed, the

timing of the interview did not matter. In instances where the interview was held before the observation of the meeting, the interviewees provided insights on what I should look for. Conversely, when the interview occurred after the observed meeting, I was able to verify and discuss assumptions about what I had observed, though this also took place with some participants I had conversations with after each meeting.

Purposive criterion sampling was used whereby study participants were selected based on criteria that capture their typicality in meeting the specific needs of the research questions (Berg, 2009; Cohen et al., 2000; Creswell, 2008). In this study, the purpose was to identify individuals who met the following criteria: they had relevant illegal drug use experience (other than cannabis) and were included at the table as representatives of people who use drugs, or they were currently participating at a table where people who use drugs also sat. Focusing on people who use illegal drugs other than cannabis coincides with the focus of harm reduction services, which cater to providing information and supplies related to injection drug use and inhalation of crack cocaine, mainly, in order to prevent the transmission of HIV and hepatitis C. I also strove to ensure that I had good representation from not only people who use drugs but also policy makers, service providers and researchers.

The response to the request for individual interviews was very positive and some willing participants were turned down to keep the number of interviews manageable. Interviews were first accepted on a 'first come, first serve' basis, based on the response received from the initial email invitation. Once the first round of participants was selected, selection was more strategic, at times following up with participants who would contribute to achieving a good representation of the various groups enumerated above. To recruit people who use drugs, some snowball sampling was used whereby the research partners referred me to people who use drugs they had

sat at a table with in the past, in order to obtain enough interviews from people who use drugs (Berg, 2009).

Qualitative semi-structured interviews were conducted to gather the perspectives of participants at the table regarding their experiences with current or prior social inclusion practice. Draft interview questions were prepared based on the initial meeting with both partner organizations, DUAL and SOLID. The draft questionnaire was then presented to and discussed with my doctoral studies co-supervisors, who provided comments. The questionnaire was once again revised and then discussed with representatives from both SOLID and DUAL. They provided input into the questions and suggested changes and additions to the questions. In a pretest fashion, they also considered and shared how they might answer these questions themselves. This process assisted with finalizing the questionnaire for the individual interviews.

The interview questions (see Appendix G – Semi-structured Interview Questions) probed for historical, social and political context information, for discourses and practices that shed light on factors that help or hinder power relations, and for both public transcripts (official language) and hidden transcripts (what participants think) (Madison, 2012) with regard to the social inclusion of people who use drugs, to contribute in answering the research questions.

Most interviews were conducted face-to-face though a few were conducted over the telephone, at a mutually convenient and comfortable time and location. Although face-to-face interviews allowed for more rapport between interviewer and interviewee, the few telephone interviews seemed as rich in content as the ones conducted in person. The fact that I had met the telephone interview participants in person at their respective committee meetings before the telephone interview was conducted minimized the challenges of establishing a rapport over the phone.

Each interview was digitally recorded on a cellular phone then transferred immediately to a password protected file on a laptop, which is also password protected. Once the transfer was completed successfully, the audio file was deleted from the phone. Each interview was then transcribed verbatim into password protected Microsoft Word files.

A brief demographic questionnaire (see Appendix H – Demographics Survey) captured participants' self-reported role(s) at the table, their gender, age, marital status, ethnic or cultural heritage, geographic location, current or former illegal drug use experience (other than cannabis), education level, food security, housing status, and income.

I purposely chose not to collect HIV and hepatitis C status information. While this omission may seem odd given that I use examples of HIV and hepatitis C throughout this dissertation to illustrate health inequities, I considered both the human impact and the methodological limitations in my decision. First, the people whom I interviewed are my colleagues. For the most part, they are people I work with on an ongoing basis or am likely to in the future and with whom I may have ongoing working relationships. I already know some of them are living with HIV and HCV. I respect their boundaries and their right to disclose or not to disclose their disease status and did not wish to place them in a situation where they might feel coerced to disclose.

Secondly, it is already known that people who use drugs are disproportionately affected by HIV and hepatitis C. This study was not trying to assess prevalence among study participants of either disease to show that. Collecting information on HIV and hepatitis C status would have simply confirmed that some people are living with HIV and hepatitis C, and the limited sample size of 40 interviewees would not have allowed to estimate prevalence and determine whether it significantly differs between people who use drugs and others at the table. Again, I felt it was

enough to capture some of the interviewees' lived experiences with HIV and hepatitis C as an indicator that these realities are present in this sample. Data collected on income, education and food security provided a means whereby to measure health inequities since it is also well documented that these variables are associated with greater vulnerability to HIV and hepatitis C.

The demographics information was collected anonymously at the time of the interview and provided information regarding intersecting social position factors. The data collected from the demographics survey were entered into a Microsoft Excel password-protected spreadsheet. Each survey was numerically coded to be linked to the corresponding interviewee.

Through the consent process, study participants were informed that they could choose not to answer any of the interview or demographics questions, that they could terminate the interview at any time, and that their input was confidential. The informed consent form (see Appendix E – Consent Forms) was read and discussed with each participant, and signed once the participant's questions and concerns had been addressed. A copy of the consent form was offered to each participant for their records.

Each interview lasted between 45 minutes to one hour and a half, for which the participants were given a gift of \$25. Some participants participated in the interview during work hours for which they are already remunerated, in which case they declined the honorarium. No other reimbursement was required to cover participants' costs to participate in the interview.

#### ***Documentation review.***

To gain a holistic view of the context in which people who use drugs were included at the table in social structures, relevant information was sought from written documents such as policies and procedures of the organizations that were including them, terms of reference of committees which included them, and any historical documentation that could assist in the

analysis (for example, strategic plans). The documents obtained were all publicly available. Heads of the tables observed were assured that their organization would not be directly identified with any specific observation or finding. To situate the experiences of participants at the table with power relations in social inclusion practice within the social, historical, political and economic context at the time of data collection, additional information was sought online to describe the climate and context.

Triangulation of data obtained from participant observation, interviews and supplementary sources of information contributed to enhancing the quality and integrity of the methods and findings (Polit & Tatano Beck, 2008; Roper & Shapira, 2000). More details regarding the strategies used to enhance the quality and integrity of this qualitative inquiry are discussed later in the section on ‘Enhancing the Quality and Integrity of this Inquiry.’ First, the data analysis process is described.

### **Data analysis.**

Given the various data collection methods used, the approach to data analysis was multifaceted. It consisted of borrowing from ethnographic data analysis technique to analyze field notes and interview transcripts using theoretical frameworks (Brookfield, 2009; Restall & Kaufert, 2011) and a critical and emancipatory lens to interpret the findings, as described previously, to guide the analysis. The demographics survey analysis utilized quantitative methods.

### ***Ethnographic data analysis.***

Ethnographic data analysis is a recursive and iterative process that begins during the data collection phase, and involves a continuous process of raising questions and developing and generating ideas about theory generation in the field (Cohen et al., 2000; LeCompte & Schensul,

2010; Thorne, 2000). Field notes and interview transcripts were analyzed using an analytic induction strategy whereby the theoretical frameworks were used to guide what to look for as the data were coded and analyzed (Thorne, 2000).

Data analysis was as participatory as possible. Historically, perhaps due to the nature and complexity of data analysis or a lack of interest or time, community members have tended not to be involved in data analysis in participatory research (Minkler & Baden, 2008). I involved SOLID and DUAL in the interpretation of preliminary research findings for their crucial feedback. More details about a participatory approach to data analysis are included in the following steps.

Cohen and colleagues (2000) offer seven steps to ethnographic data analysis. Using Atlas.ti qualitative data analysis software, units of analysis were established by ascribing descriptive codes to the data (as described by Miles & Huberman, 1984 or ‘unitizing’ as described by Lincoln and Guba, 1985). These codes were derived from the data through an inductive process of iteration and reiteration, going through the data more than once, modifying and refining codes as necessary until consistency and exhaustiveness are reached. The data analysis and interpretation of the findings was sensitized and guided by theoretical concepts described in the section on ‘Transforming power inequities’ using useful frameworks from Brookfield (2009) to uncover the transformative Seven Learning Tasks, and Restall and Kaufert (2011) to uncover the contextual factors at play, as well as by a critical and emancipatory lens as described above. In accordance with Carspecken (1996), in critical ethnography, reconstructive analysis also needs to take place to identify value systems, norms and key concepts that may be influencing situations. To do this, the data were examined for “patterns of interaction, power

relations, roles, sequences of events, and meanings accorded to situations” (Cohen et al., 2000, p. 154) which were identified with high level codes.

Following the high level coding, a domain analysis was done whereby codes were grouped into symbolic categories or ‘domain codes’ (‘categorization’ as described by Lincoln and Guba, 1985) (Cohen et al., 2000). Some codes were clustered in more than one domain. Relationships and linkages were then established between the domains by identifying confirming cases and looking for underlying associations and connections between subsets of data. These descriptive steps then moved to inference by beginning to posit some interpretations as to what was taking place in the field in terms of power relations.

This preliminary analysis was presented to SOLID and DUAL for debriefing and input. The presentations to these community partners served to validate the approach to presenting the findings and clarify some of the language used to present the findings, rather than to dissect the approach to coding. Both groups confirmed that the preliminary findings resonated with their experiences with power relations on such committees. They expressed satisfaction with the confirmation of the wide disparity in socioeconomic demographics data between people who use drugs and others at the table and wished for this information to be made more readily available. One group stated their concern with the use of the term ‘economic levelling’ to describe measures taken to attempt to alleviate the financial strain people who use drugs experienced to participate on such committee. They felt these measures hardly contributed to levelling of any sort given the fact that, in most cases, they were not remunerated for their time while others at the table participated as part of their employment. The preliminary findings were also presented to each of the four committees for additional feedback. Once again, these discussions focused

more on their interest in and questions about the findings rather than on the way the data were coded.

There were in-depth discussions about the approach to the analysis and coding, however, with my co-supervisors as well as with my colleagues at the Centre for Addictions Research of BC. Presentation of detailed preliminary findings as part of an in-house seminar resulted in insightful input into common threads across the findings as well as suggestions for further analyses. This presentation was followed by a meeting with my co-supervisors to refine the interpretation of the findings. The analysis was further developed in subsequent drafts of the dissertation. The final results were presented to both SOLID and DUAL for final perusal and input, and before being released.

#### *Demographics survey data analysis.*

Analysis of the data collected through the demographics survey was conducted with IBM SPSS Statistics Version 22. Frequency counts, percentages and cumulative percentages were calculated for the nominal and ordinal variables and were used to generate bar charts. Means and standard deviations were obtained for the numerical variables. An ANOVA test was performed to compare mean age between people who use drugs and other participants (policy makers, researchers and service providers). Variables for marital status and ethnic and cultural heritage were converted into binomial variables and chi-square tests for 2x2 tables were used to compare proportions between people who use drugs and others for various illegal drug use experiences (current, former, currently on methadone/other substitution program, never), gender, marital status, ethnic and cultural heritage, province of residence, and living in an urban or suburban area. Cross-tabulations were performed and nonparametric tests of significance for ordinal data were used to compare socioeconomic variables status between people who use drugs and other

participants for education, food security and income. Statistical significance for all tests was determined at  $p < 0.05$ . The next section elaborates on the strategies employed to enhance the quality and integrity of this research.

### **Enhancing the quality and integrity of this inquiry.**

In qualitative research, there has been much debate about how best to define what constitutes high quality research. Various terms and frameworks of quality criteria have been offered and extensively debated. Summarizing this debate is beyond the scope of this dissertation, and I refer you to Polit and Tatano Beck (2008) for a useful overview. Suffice it to say that researchers all agree that the quality and integrity of research, often referred to as validity, rigor and trustworthiness, are important. I therefore chose to elaborate on the strategies I used to enhance this inquiry's quality and integrity.

In ethnographic research, the quality and integrity of the research are inherently enhanced by the fact that the researcher has the opportunity to observe several events and interview several participants, sometimes more than once, during the data collection period (LeCompte & Schensul, 2010; Roper & Shapira, 2000). I strove to listen intensively during the interviews and observations in the field, probe for more in-depth and comprehensive information where I saw fit, audio recorded the interviews, and endeavoured to spend sufficient time in the field to achieve an in-depth understanding of power relations at the table (Polit & Tatano Beck, 2008). Though perhaps not as intensive as a traditional ethnography, the time I spent in the field before and during this study contributed to building trust and rapport with participants, which hopefully led to more accurate information. I strove to collect rich field notes that described what took place in the field, as mentioned in the section on Participant Observations. I also took notes of the participants' demeanour and behaviours during the interviews, as much as possible. Finally, I

kept a journal and copies of relevant email correspondence to record any decisions, reflections and observations that may be valuable to enhance quality and integrity.

Triangulation, using multiple sources of information and multiple methods to draw conclusions, enhanced quality and integrity by helping to obtain a more complete and contextualized portrait of power relations at the table (Polit & Tatano Beck, 2008; Roper & Shapira, 2000). This triangulation was further improved by the fact that data on power relations were collected in multiple sites, and from different people who sit at the table and offer multiple perspectives (Polit & Tatano Beck, 2008).

The participatory approach used in this research enhanced the social and cultural quality and integrity of the research findings (Benoit, Jansson, Millar & Phillips, 2005; Cargo & Mercer, 2008; Flicker et al., 2007; Israel et al., 1998; Minkler & Wallerstein, 2008; Polit & Tatano Beck, 2008). After each interview and observation in the field, I checked in with participants to ensure that I had properly understood their meanings, as necessary. I also consulted with SOLID and DUAL to obtain their feedback on the preliminary data analysis and the final data analysis, as described above, which validating that the findings captured their own experiences with power relations at these committee tables. To minimize the possibility of any participant's reluctance to express any disagreement with my interpretations, I strove to communicate in such a way as to ensure that they understood that I was open to challenges and I welcomed their insights since they are the experts of their meanings.

In addition, the brief demographics questionnaire enabled me to collect some quantitative data that provided valuable information to clearly illustrate the significant socioeconomic differences between people who use drugs and others at the table. These data were useful to enhance the qualitative findings. The next three chapters present the findings of this inquiry.

First, Chapter 4 provides findings on socioeconomic inequities between people who use drugs and others at the table, socially constructed views people at the table have of people who use drugs, and issues of representation of lived experience and how these aspects influenced power relations at the table. Chapter 5 then elaborates on findings related to creating a safe space at the table through building trust, authentic relationships and dialogue then presents the practice of democracy through negotiated relationships and consensus-based decision-making. Finally, chapter 6 situates the committees within the greater political and organizational contexts and presents findings on how these contexts influenced power relations at the table. It then situates decision-making power within the various committee structures included in the study and reveals findings on the impact this had on power relations at the table.

## **Chapter 4 – Table Seating: Outsiders on the Inside for a Well-appointed Table**

### **Introduction**

To practice social inclusion at decision-making tables involves inviting people who use drugs to the table and arranging the table seating accordingly. This chapter begins by describing the four decision-making tables included in this study in terms of where decision-making power was situated and its impact on power relations.

Findings then provide an overview of the participants at these tables and reveal significant socioeconomic inequities between people who use drugs and others at committee tables. The effect these differences had on power relations are described, as well as the measures that were taken by committees to attempt to minimize the impact of these inequities on the capacity of people who use drugs to meaningfully participate.

The chapter ends with findings related to issues of representation of people who use drugs in terms of how representatives of people who use drugs were selected and what voice they represented. This representation had an impact on power relations at the table. Data also revealed that the line between people who use drugs and ‘others’ at the table was blurred, which also brought considerations for how power relations played out at the table.

### **“Realistic Expectations”: Situating Decision-Making Power in the Organizational Context**

Decision-making bodies do not exist as stand-alone structures. They are part of a broader system with varying independent decision-making power. To contextualize decision-making power relations within the committees examined in this research, it is helpful to situate the committee within those systems and organizational structures to first determine how much decision-making power each committee had and then discuss the decision-making power within

that structure. Contextually, it is also helpful to consider how each committee’s commitment to and capacity for the inclusion of people who use drugs.

Four committees were included in this study, summarized in Table 3 for ease of reference. Based on data collected on each, findings reveal that there were three different committee structures in terms of inclusion of people who use drugs: a policy committee where people who use drugs were not members and were consulted once a year, two service provider committees which included two representatives of people who use drugs, and one research committee primarily comprised of people who use drugs.

Table 3.

*Summary of the four committees’ purpose and structure.*

	Policy Committee	Service Providers 1	Service Providers 2	Research Committee
Purpose	Develop and coordinate a jurisdictional strategy on policy and best practices for harm reduction; Support harm reduction services; Oversee fiscal resources for harm reduction supplies	Provide input on local issues related to policy, programs and services to the local public health authority	Promote the health and dignity of individuals and communities impacted by drug use	Participate and help steer a community-based participatory research project aimed at understanding the risk of HIV/AIDS and hepatitis C and improving access to health care for people who use drugs in the city
Membership	People who use drugs are not members of the committee. They are invited once a year to a face to face meeting.	Two representatives from an organization of people who use drugs	Two representatives from organizations of people who use drugs	Majority of seats for people who use drugs

**Where people who use drugs were not members.**

*Committee purpose and setting.*

The policy committee included in this study established goals and policy for harm reduction service delivery in the jurisdiction and reported to public health authorities. While the committee developed policy related to harm reduction, in accordance with the jurisdiction's position on harm reduction, each area within that jurisdiction operationalized that policy by providing direct service delivery and exerted autonomy as to what they chose to implement. The policy committee had two co-chairs.

Membership included representatives from the various areas within the jurisdiction and from the public health authorities. There were no seats specifically designated for people who use drugs, however people who use drugs were invited to a yearly face-to-face meeting for consultation and input on the jurisdiction's harm reduction distribution program. The purpose of the committee was to develop and coordinate a strategy on policy and best practices for harm reduction for the jurisdiction, support harm reduction services, and oversee fiscal resources for harm reduction supplies. The committee had power to set jurisdictional policy for harm reduction and, to a certain extent, to support its delivery in the areas of the jurisdiction, though did regulate the areas' implementation of harm reduction services.

This understanding of where the committee is situated within the broader health system and decision-making structure, and of the committee's power for change within it, was not clear to all committee members.

*I think that's something that we're missing is that... maybe at the beginning of the... committee meetings, we could do a better explanation of, and maybe something visual of where are the [health areas], how does the [committee] fit in here... who gives us our money, ...what kind of power DO we have... what do we have the power to change and what do we not have the power to change. (service provider)*

In addition to where the committee's power is situated within the greater health system in the jurisdiction, decisions made within the committee were influenced by external factors such as budgetary constraints for the harm reduction supplies distribution program, public perception of and political buy-in into harm reduction efforts.

*Ultimately the power does rest with the committee and particularly with the institutions behind the committee... A few years ago we'd started adding PVC tubing as a sort of stem cover to protect people's lips. Mixed reviews as to how effective that is. We thought it was a step towards engaging people who smoke crack rather than just [people who inject drugs] but the question about whether we should fund glass pipes is a challenging one. There [are] challenges both in respect to the budget. It would be expensive to add something new like that. And with respect to public perception, whether there would be political buy-in from various kinds of stakeholders. [People who use drugs] who come spoke very clearly about the need for it and the value of it and so ultimately the power doesn't rest with them to make that decision and everybody knows it. (policy maker)*

This example clearly illustrates the breath of contextual factors that influence decisions made within this committee and the tension between the needs of people who use drugs, the goal of service providers to engage people who use drugs in health and social services, and the policy makers' need to balance these needs with the public's perceptions. A committee's decision-making power within the greater context is therefore complex, as is the decision-making power of people who use drugs who are invited to these tables.

### ***Structure and power.***

Indeed, in terms of the inclusion of people who use drugs, social inclusion spans across a continuum of levels of participation with varying levels of power. When looking at the structure of this policy committee, the participation of people who use drugs was one of 'consultation' based on Arnstein's ladder of participation. While people who use drugs were invited to participate in a face-to-face meeting once a year to provide input to the committee, there were no guarantees that their input would be taken into account. This limited power was not lost on

members of the committee. It resulted in some people who use drugs feeling tokenized and not kept informed of the committee's activities and decisions throughout the year, in-between meetings. When asked about the committee's decision-making process, one interviewee stated:

*I think the realization that the power does rest with the committee members and everybody knows it. There was at one point [a person who uses drugs] brought up [their] frustration at feeling tokenized and feeling like yeah, you bring us here but then we go back and wait for another year. Like nothing happens and you know I think [they] had the sense that [they] wanted to see much more funding and much more utilization of [their] capacity and I can understand why [they were] saying that. (policy maker)*

Not being a member of the committee and being invited once a year to a face-to-face meeting did leave one person who uses drugs wondering about their role at the table:

*I'm not really quite sure what our role is, to be honest...It feels like we're there because they wanted to have [people who use drugs] there and it doesn't really feel like that much of what we say is really taken into effect... I just don't really feel like that we really serve a purpose there other than to say that they've included [people who use drugs] at the table. (person who uses drugs)*

The fact that people who use drugs only participate in the committee once a year limited opportunities for them to get a sense of where the committee's decision-making power is situated within the greater system. This lack of context limited dialogue between people who use drugs and others at the table. Because people who use drugs were consulted once a year, they were also not at the committee meetings when most decisions took place.

*The [public health authority] just doesn't get involved in any kind of direct operationalization of anything including patient involvement, that kind of stuff. It's really an expectation of the [health areas] to do that, to manage their sort of key... stakeholders and identify how money gets spent in that way so [people who use drugs] brought up I think a very valid point but didn't necessarily have the understanding of the whole health system and power structures within the health system to allow for a response that would be meaningful back to [them]... I found that personally frustrating 'cause I didn't say anything. I just didn't want to open up a huge can of worms about how the health system works and why and then putting [the health areas] on the spot for having to follow up with [them]... Also some of the key decisions AREN'T going to be made at the time that [people who use drugs] are there. (policy maker)*

Furthermore, continuity between yearly face-to-face meetings was dependent on how follow-up was handled by the harm reduction worker in each health area. Without this communication, people who use drugs who participated in the face-to-face meeting did not get a sense of how or whether their input had any influence or resulted in any program or policy changes:

*[Our public health authority rep] is really good about meeting with us and telling us what's going on... It's just that one time a year you get like caught up before the meeting and then that's like you go to the meeting and that's like there's not really much follow up unless I guess your... [health area] representative like talks to you about it. (person who uses drugs)*

The policy makers were aware of the limitations of inviting people who use drugs once a year and had been working with the committee to introduce processes to strive for better communication between people who use drugs and the committee before the face-to-face meeting:

*We're always learning so I think we had a lot more processes in place [this year] and also like allocating I think the [health area] reps to connect closer with [people who use drugs] and having more one on one time... if you're inviting a [person who uses drugs] like you need to make sure that they're prepared for the meeting, go over the agenda, go over what we do and... just be a bigger support... And this also I think encouraged the reps to also think more...about how to connect with [people who use drugs in their area]. (policy maker)*

However this model where a harm reduction worker in each health area acted as an intermediary between the committee and people who use drugs was challenging in that it required much planning and support:

*I think that [the inclusion of people who use drugs] is something... that has been on the radar for people as important... But it's something that requires like, you know, a lot of planning and support and so it hasn't been an easy thing to do. (service provider)*

In addition, during the meeting I observed, people who use drugs expressed the need to get together and organize as a collective in advance of the meeting, with more notice as to when the meeting would take place. One person who uses drugs suggested that there should perhaps be

fora for people to have the opportunity to come together on a regular basis. One co-chair expressed their openness for that to be arranged, perhaps in advance of the next face to face meeting. There was a suggestion that round tables for people who use drugs could take place every 6 months, either in person or by teleconference.

During this exchange between committee members and people who use drugs, committee members assumed that the mobilization of people who use drugs should be led by each health area. One policy maker described the health areas as “clumsy, huge, obstructionist organizations” that were not community organizations. They emphasized the importance of finding ways to include people who use drugs in all structures, with a framework for input and cooperation, and not just in this committee once a year or just in organizations of people who use drugs. There was agreement that different mechanisms and options were needed and that bureaucracies needed to be held accountable for the inclusion of people who use drugs. One of the co-chairs stated that this was an important conversation to have and proposed that one way to move forward with better inclusion was to integrate it into the work plan. There was agreement among committee members that there was a lot of capacity within the committee to move forward with better inclusion of people who use drugs. During the meeting, it was apparent to me that there was a lot of excitement about this topic and the whole room seemed engaged in the conversation. When the co-chair asked for volunteers to take this on, however, there was less clarity as to who was willing to step forward, perhaps because of lack of clarity about whose responsibility it was to commit to improving inclusion, or perhaps because of concerns about capacity and resources. The next section explores commitment to inclusion and capacity for inclusion.

***Commitment to and capacity for inclusion of people who use drugs.***

While some consideration was given as to whether people who use drugs should become permanent members of the committee, or even attend both face-to-face meetings every year, committee members wondered whether people who use drugs would be interested in being involved more often than once a year in committee meetings given the nature of the work that the committee does.

*I mean I think it would be great as long as we're talking about stuff that's relevant where people actually do want to participate in all the discussions that we're having. (service provider)*

Some of the committee's work involved some high-level policy work. At the meeting, for example, there were presentations on a conceptual model for programs for Indigenous communities. I observed a dissipation of interest in the room during this presentation, though this was the case for everyone and not just for people who use drugs. People in the meeting were looking around more than in the rest of the meeting. Some were listening, while others were glancing at each other and having side conversations. I wondered whether it was appropriate for the committee to discuss committee-specific items that were not relevant to their invited guests. This presentation was followed by another high-level presentation on the province's new public health plan which covered many harm reduction interventions. There was a bit more interest in this, followed by a question from a committee member during the question period.

To verify whether assumptions that people who use drugs were not interested in ongoing participation in the committee, I asked some of the people who use drugs who attended the face-to-face meeting whether they would like to be included in the committee on an ongoing basis. One person pointed out that they had expressed this interest to the committee in the past:

*...we said we'd be willing, without getting paid or anything like that, to be involved in the teleconferences, whatever, to like you know just be there for their meetings throughout the year. (person who uses drugs)*

Another person mentioned that there could be a place for people who use drugs on the committee but placed more importance of being kept informed throughout the year, in-between meetings:

*I DO think there's a place for that. I would be interested in doing it every year and like having it continue, flow, and so I've been there for this and this and see the progression. And, you know, maybe effect some change in how they include us in decision making... I don't think it would be important to be at EVERY meeting. I think like the major one every year is, you know, but it would be nice to get some feedback from maybe from the other meetings?... Just have an idea of what's happening throughout the year. (person who uses drugs)*

When asked about whether they found the content of the presentations at the meeting interesting and relevant, one person who uses drugs answered:

*I: For the most part. I like information of any kind. I like to know, you know, what's going on, so yeah, I find it interesting like how many needles were distributed and the change over the years and so yeah, I found it all relevant.*

*L: OK, good. I wondered about that as I was sitting there watching, thinking does everybody need to know this? But...*

*I: Well, maybe not everybody needs to know that but I find it helpful. I mean just my own personal observations. (person who uses drugs)*

Even if the committee meetings' content was not always the most interesting, one person who uses drugs would still like to have an opportunity for input:

*I'm sure [the meetings] wouldn't be like super exciting but it would be good to have input, right? Especially because like it's our peers that are using the supplies and, you know, the strategies that they are talking about. (person who uses drugs)*

In addition to people who use drugs' interest in being included on committees, each committee included in this study was committed to including people who use drugs in decision-making, though levels of commitment, and capacity to do so, varied. For the policy committee, despite the fact that there were no seats on the committee for people who use drugs, the committee consulted with people who use drugs on a yearly basis. The co-chairs of the

committee were committed to the “Nothing about us, without us” and saw this partial inclusion as an initial experiment and a first step to what they hope will be greater inclusion in the future:

*We had an agreement that we wanted to better involve people with lived experience in the committee in some way and so the first step was to let's invite them to one of our face to face meetings. I don't think it was thought about as sort of an ongoing thing at that point. It was just like more of a one off. Let's try it out and see what happens. And then so we did that. (policy maker)*

They also realized that consulting people who use drugs only once a year in a face-to-face meeting, and not including them as official members of the committee, could be perceived as being tokenistic:

*I can imagine from a very critical perspective, it would be easy to paint this as a tokenistic exercise. We're trying to not have it be that. We're trying to provide opportunities for meaningful input that we can actually use for making decisions and making the RIGHT decisions but there's obviously lots of constraints. (policy maker)*

In addition, although the committee met face-to-face twice in the year, budgetary constraints as well as support and capacity considerations limited the committee from inviting people who use drugs to both face-to-face meetings at the time of this study:

*And then again it was I think partly budget 'cause we fund all of the [people who use drugs] and the support and building capacity within the [health areas] to... identify [them], support them in traveling and stuff. We decided that once a year would be, for a start, would be the way that we do this kind of involvement and although there was discussion also about is that sufficient? Like why not both face to face meetings? You know, if we are really wanting to include in an equal way and so I think it's more of a trial basis right now and going with both the budgetary issues and the sort of experimental nature of it, we're going with the once a year. (policy maker)*

Other constraints to better inclusion included the fact that this committee was a jurisdictional one which needed to involve the commitment and capacity of all health areas to make it successful. Findings during interviews and observations revealed that different health areas were at different places in terms of their commitment to and capacity for inclusion. Each health area had assigned a harm reduction position in part to act as a liaison between the policy

committee and people who use drugs in each area. Some of these positions were new, as were the people in that role, while others were more established. Even when the person in that position had taken on this liaison role, communications with people who use drugs still only mainly took place right before the face-to-face meeting:

*[Our liaison person] is really good about meeting with us and telling us what's going on... It's just that one time a year you get like caught up before the meeting and then that's like you go to the meeting and that's like there's not really much follow up unless I guess your... [liaison person] talks to you about it. (person who uses drugs)*

Committee members also realized that organizing such a jurisdictional face-to-face meeting between committee members and people who use drugs from every area of the jurisdiction required much coordination and logistical planning:

*I think that [the inclusion of people who use drugs] is something, at least since I've been involved, I think that it's something that has been on the radar for people as important... But it's something that requires like, you know, a lot of planning and support and so it hasn't been an easy thing to do. (service provider)*

Indeed, to address these challenges, after the first year where people who use drugs attended the face-to-face meeting, the committee hired personnel to assist the co-chairs with facilitating the involvement of people who use drugs by coordinating their travel and logistics and providing secretariat support to the committee. The meeting I observed was the third face-to-face meeting at which people who use drugs had been invited, and having that extra help with planning and support improved capacity for inclusion. This progress was noticed by committee members:

*I think back to what the committee was like when we just started...there wasn't a lot of support in terms of like staff... supporting the work of the committee... That's kind of my read on how things have changed... that that's what makes it an effective committee is it has...the support now that it didn't before. It has support and buy-in from all the [health areas]. (service provider)*

Clearly, people who use drugs were interested in being involved in the committee on an ongoing basis throughout the year, and people in charge of the committee were committed to including people who use drugs in the committee's work, though the model of how best to include their participation on an ongoing basis, with adequate resources to make that happen, was not clear. Nevertheless, Arnstein (1969) would describe the 'consultation' role of people who use drugs in the committee structure as it existed at the time of this study as tokenistic. The committee was open to exploring how to shift power in decision-making toward more citizen power though were grappling with the complex structure of the health areas and the limited capacity and resources to do so.

The two service provider committee had included a few people who use drugs as members. The next section explores power relations where two people who use drugs are at the table.

### **Where there were two representatives of people who use drugs.**

#### ***Committee purpose and setting.***

Two of the committees were mainly harm reduction service provider committees established as fora to provide input related to harm reduction policy, programs and services to their local public health authorities. Both committees included mostly health and community service providers, as well as researchers, policy makers, and one or two persons who use drugs who sat as representatives of a local organization of people who use drugs. These committees identified emerging issues and service gaps in their respective communities and provided advice, guidance and recommendations related to the operations of harm reduction service delivery, for consideration by their local public health authority. These committees also fostered collaboration

and coordination between service providers to better respond to the needs and concerns of the community and of people who use drugs.

One of these two service provider committees had taken on a stronger advocacy role to advance harm reduction policies, practices and programs, increase knowledge of and access to harm reduction resources and tools and advocate on issues that impact the health and well-being of people who use drugs, and promote evidence-based practices in prevention, care, support and treatment for people who use drugs. This committee was also explicit in its intention to meaningfully involve people who use drugs. Both committees linked to provincial initiatives related to harm reduction.

Glimpses of service provider committee members' understanding of their respective committee's purpose surfaced during the interviews. Members' description of their committee's purpose included networking and information sharing about services and trends in the city, coordinating efforts for needle exchange in the city, meeting with other frontline service providers to debrief, notice trends among service users, share them with each other and adapt services accordingly, brainstorm about local issues and troubleshoot together to address them, support each other in this challenging work, and provide feedback and statistics to the local public health authority about harm reduction supplies and services. There was also mention of one committee's role in bringing the voice of people who use drugs to other decision-making tables:

*It's also had a very strong role in advocacy and...I think trying to bring...the voice of people who use substances into, you know, to other tables and to have them heard.*  
(service provider)

While service provider committee members seemed aware of their committee's purpose, not every committee I interviewed was familiar with their committee's terms of reference:

*I vaguely remember now. (service provider)*

*I should probably take a look at that if I'm on that [committee]. (service provider)*

As one service provider notes, the terms of reference had been briefly introduced to the committee and passed quickly, done deliberately to keep the atmosphere less formal and more open and relaxed.

*We've got terms of reference which we kind of tried to pass as quickly and painlessly as possible. We really try not to have a lot of formal structure associated with it... We want to have a conversation about harm reduction... There will be an agenda and things like that but there's hopefully a real casualness to it that makes it accessible to people. (service provider)*

One committee had developed a logic model to guide their work, as one committee member explains:

*We also have the systems logic model which was really our thinking at the time of... in an ideal system, what sorts of things need to be in place. This has kind of been a guidance document around advocacy and efforts to put different services in place as opportunity arises. These are the types of things that need to be in place if you want to do harm reduction, good care for people who use drugs. There's also a research mandate within here around supporting... researchers... around, you know, promoting best evidence based practice around knowledge exchange, so that's part of our terms of reference as well. (service provider)*

In the interviews, one member appreciated this committee's strategic planning purpose and saw the committee's impact on influencing change, while another was frustrated with what they perceived to be the committee's lack of action and advocacy while still recognizing its impact on change:

*We do a lot of planning and moving forward, so, you know, bringing back issues that have been brought forward to us, so issues with the tools. If they don't like them, improvements can happen and we bring that back to the committee. (service provider)*

I: *It wasn't really directed towards much action, I guess, I felt like. It was just kind of getting together and talking about stuff and so I didn't see it as too much of like an action oriented organization...*

L: *...What kind of actions were you thinking?*

I: *More work to get like a safe injection site or a safe inhalation site... or really focusing on expanding services. Yeah, and like what would be required to do that... we're not really working together at all, aside from those meetings. There's no tasks I guess we are working on. (service provider)*

In these two service provider structures, their power in decision-making was limited to providing input to their local public health authority on harm reduction policy and services from their experiences on the ground. For public health authorities in each respective city, input from these committees had to be weighed against other health policy priorities and against perceived community views on harm reduction, reinforcing the committees' limited power in decision-making:

*The number one substance use in the city is alcohol so that's where all this energy went to [for their report]... And so where was harm reduction in that? You know, so it was really squeezed out of this report, you know? And so a lot of our [committee members] were really pissed off. (policy maker)*

*I don't have very much faith in the impact that that committee has on any decision making. (service provider)*

While the committee members saw benefit from meeting with one another, and one committee in particular was making efforts to advocate and affect change, there was frustration at the limited actions taken by the committee. These service provider committees therefore had limited power to context existing hegemony locally, though brought together key local harm reduction stakeholders in their communities in a political space where this flow of power could be unmasked and where experimenting with forms of collective organization which included people who use drugs could begin.

***Structure and power.***

Both service provider committees acted more as networking and coordinating bodies in their respective city and as advisory committees to their regional public health authority. Ultimately, these committees did not make program and services decisions directly but were able to provide input and feedback to the public health authorities for their consideration.

*As a group, are we making decisions? Probably not. Are we making some recommendations, yeah... So there's stuff that OK, I'll bring this back to my supervisor. (policy maker)*

*[The committee] doesn't make decisions about [specific organizations] or the things that we do, I mean we don't have that authority to do that but we may try to influence, so it's more influence than decision making. So maybe that's a more helpful way to think about it. (service provider)*

If we consider Arnstein's (1969) ladder of participation, these committees could be seen as falling somewhere between 'informing', where the focus is on information exchange between committee members, and 'consultation' in the greater health and social services system where committee members had equal say in providing input to the public health authority although they were not guaranteed that this input would be taken into account. Within that structure, people who use drugs who were at the table theoretically had the same standing as other committee members. One committee member described the committee as playing an advisory role to local public health authorities:

*It's like it's a consulting group for...the different programs that are there so it has a bit of an advisory capacity to it so [the public health authority] uses that to "Hey we're thinking about doing this, what do you guys think?"... I think this is a kind of a group of professionals and people with lived experience who they... like to run things passed to validate. (service provider)*

These committees had an influence on public health in their area by documenting their concerns and bringing them to the public health authority representative, who can then take it to their superiors:

*I really encouraged our partners, say, “Document it. Send me something on paper. That way I can go back to management here and say: “What do you want me to do? It’s not going away.” (policy maker)*

These committees exemplified a setting where the public health authority had ‘power over’ rather than ‘power with’ committee members. In both committees, therefore, the public health authority representatives, who chaired or co-chaired the committees, were seen as having more power than other committee members and acted as a liaison between the public health authorities and the committee members:

*I think they kind of look at you as making some of the decisions though... As being... the one with the power, and it’s like, really, I have no power... I’ll just bring it back to my supervisor and they... can make the decision, you know, about where we’re going with that. (policy maker)*

The fact that the local public health authority also provided funding to many of the organizations represented at the table further reproduced the ‘power over’ governance structure of the committee:

*I think all of us realize that yeah, there is this big body over us. We’re all kind of working against it... there seems to be like a common... frustration. (service provider)*

*Like obviously our funder is at the table... I mean obviously there’s certain things that I wouldn’t say. Like... if we’re having a down time for something. I’m not going to report on like office drama or something like that. But... I’m not afraid to say anything else. Yeah. So that would be the only thing. It’s like you still have to be a little bit... you have to be professional. (service provider)*

This situation influenced power relations at the table in terms of what committee members were comfortable sharing or not.

Committee members understood the limited power of their respective committee. In some cases they felt frustrated and powerless to influence change in any meaningful way. This feeling of powerlessness stopped some from speaking up.

*We all have a voice, but whether it is... heard, but whether that makes a difference is a different story, right?... In the end... it's the [public health authority], right? That has the final stamp on that but, you know, I feel like if we didn't have a voice and we weren't going to be heard, then why the hell would we be in the committee? So obviously, you know, our voice is, as a group, and individual, must make SOME difference. Otherwise you wouldn't have us there, right? (service provider)*

*I would say a challenge again would be that there is no mechanism for making any significant changes through that committee... there's so many things that come up that are really, really impacting the lives of people that we work with and the things that are absolutely barriers to harm reduction services in town. And we can't do any advocacy around that. So it's like why couldn't there be an advocacy component in that committee?... Or some way to... formalize our complaints? (service provider)*

For one person who uses drugs, their input seemed futile and they felt that the public health authority already had made their decisions about what programs and services they would implement:

*We were asked our different opinions on different things but [the public health authority] didn't implement any of our input because it didn't agree with theirs. So a lot of times if we're asked for input, they'll only utilize our input if they're already in agreement with that but if our input is not what they want to hear, then they won't implement it. (person who uses drugs)*

These excerpts outline not only each committee's limited power within greater institutional structures but also show the limited power committee members have within that committee.

Meanwhile, the public health authority representatives on these committees acted as a liaison between committee members and the public health authority. They assisted committee members with determining which actions or suggestions might be welcomed by the public health authority and which will be met with resistance and likely not acted on. That said, some

committee members felt that the public health authority representatives had power to decide what issues were brought to the public health authorities.

*[The public health authority representative]’s really upfront like “Yeah, I really like your idea but [the public health authority] is not going to go for that.” So [they] kind of help us figure out, like, how are we going to sell stuff to [the public health authority], right? Like how do we get them on board... how do we find that middle ground, really, ‘cause we all know what we want and what we would like things to be like, right?... And [the Chair] knows exactly how far it’s actually going to go. (service provider)*

*[The public health authority rep] is basically the person that makes the final yay or nay, right?...So... someone will bring up an idea, we’ll discuss... the idea, people will give their opinions, and then I guess [the public health authority rep] has... the final no, ok, well I’ll take this further or no well that’s not going to work. (service provider)*

Some members felt that the public health authorities would likely not be swayed by their input:

*[The public health authority rep]’s going to take like our input back to [the public health authority] and say something ‘cause [the public health authority] already made up their mind anyways, right? (person who uses drugs)*

While the public health authority representative served as a bridge between the committees and the public health authorities, they also had some power over which issues were brought back to the public health authorities.

During observations of one meeting, an example of these power relations played out. The public health authority representative mentioned an upcoming meeting at the public health authority where goals for programs would be discussed and invited committee members to state their priorities. When a service provider offered supervised consumption facilities as a priority, the public health authority representative stated that the public health authority was not going to do that. The public health authority representative also expressed concerns about organizations planning to offer unsanctioned supervised consumption facilities and that should organizations proceed with such actions, the public health authority would not back them up. The service provider who had offered the suggested priority replied by stating that if the public health

authority representative was genuinely asking what service providers see as a priority, that supervised consumption facilities was one of them. This type of resistance to harm reduction efforts by the public health authority brought tension to the committee's table and between the Chair of the committee and other committee members.

These findings provide examples of committee members correlating the functioning of social institutions with the democratic processes available to them through these committees. Committee members had to learn to live with the partial functioning of the democratic ideal whilst attempting to find ways to challenge the status quo for people who use drugs in their respective city. The committees' lack of power for social change fed the committee members' frustrations. In addition, in as much as committee members had limited power, the voice of people who use drugs was taken into account at the same level as the voice of other members.

That said, at the time of this study, there were only two representatives representing the voice of lived experience on both committees, and only one of them attended meetings on a regular basis. Upon observation of one committee's meeting, the only person with lived experience in attendance left the meeting early, leaving no voice of lived experience at the table for nearly half of the duration of the meeting. Issues of representation were discussed in Chapter 4. Suffice it so say that in terms of this committee's structure, the need for more representatives with lived experience was recognized since one individual can really only represent their own experience and cannot speak for the entire community of people who use drugs.

*We've had one representative, the same person of the same agency so I think there's room for improvement there if we really want to focus on... people with lived experience... Sometimes it's good to give a voice to others with different types of lived experience. (service provider)*

Representation of people who use drugs on these service provider committees was dependent on each committee's commitment to and capacity for inclusion of people who use drugs, explored in the next section.

***Commitment to and capacity for inclusion of people who use drugs.***

Both service provider committees were committed to the inclusion of people who use drugs in their terms of reference to provide various perspectives related to harm reduction service in their respective cities. The committees included the participation of people who use drugs in their membership. In both cases, the local public health authorities and community organizations had assisted people who use drugs to take leadership and establish an organization of people who use drugs, from which representatives were sought for the service providers committees.

Organizations of people who use drugs did their best to ensure that at least one representative was present at committee meetings, though they had limited capacity to do so. People who use drugs were often busy providing the actual services their organizations offered and were not always available at the time of the meeting. During interviews, one committee member remarked that including people who use drugs in decisions that affect them has become common practice. Another committee member was glad to have the voice of lived experience at the table and saw this inclusion as an improvement. However, some members would like to see even more inclusion, in a more meaningful way. This unmasking of power in committees and desire to experiment with new forms of collective organizing was prevalent in these two committees.

*I think this group is very comfortable with... First of all I don't think that they would think that including people with lived experience was anything particularly special. I think it's just part of how you do business. (service provider)*

*I personally see a lot of benefit in having people with lived experience either currently or in their past because you get a lot of information otherwise that stays behind closed doors, like you know, certainly drug trends and the way the people are using the substances... it really gives us a perspective of what's happening on the ground. And I think it's really important that, you know, if we are making decisions for people who use drugs that they need to be included in it as well. They have tons of resources as information and so much power in sharing that in the community, more so than we get in the office. So I hope to see, you know, more and more folks getting involved and more programming starting to bring [people who use drugs] into work. So it's happening, it's happening. (service provider)*

The second excerpt captures the essence of the importance of including people who use drugs on such committees and the valuable perspective they contribute to the committee's decisions.

Where there were a few people who use drugs on service provider committees, they were included as equal members on the committees and shared the limited decision-making power the committees actually had to effect change. People who use drugs, however, were outnumbered and faced some challenges and limited capacity to be able to attend all meetings. Representation often rested on the shoulders of one individual who managed to attend meetings. Though committees were committed to inclusion of people who use drugs and had supported local organizations of people who use drugs, more work and reflection needed to take place to better support their inclusion at these committees. The next section examines a committee where people who use drugs held the majority of seats.

### **Where people who use drugs held the majority of seats.**

#### ***Committee purpose and setting.***

Finally, the research committee included in this study was established to respond to a requirement for evidence to build a case for implementing a supervised injection site in the city, as mentioned in Chapter 6 in the section on "It's Policy That's the Problem", in response to the *Respect for Communities Act*. The research committee was struck specifically to participate in

and steer a community-based participatory research project, including identifying research questions and areas of interest, participating in the research tools and protocols, in the data collection, recruitment of participants, data analysis and preparation of presentations and publications, as well as organizing fora, events and peer training and awareness. The committee was comprised primarily and intentionally of people who use drugs, with a few frontline support workers from the community, and a few academic researchers as ex-officio members. The majority of seats were thus held by people who use drugs. There were also medical students who worked with the committee to gain experience in community-based participatory research, foster co-learning between them and people who use drugs and expose them to issues related to inner-city health, though they were not part of the committee.

True to community-based participatory research, an important aspect of the research project consisted of building the capacity of the people on the research team, mainly comprised of people who use drugs. Members of the research committee were trained on community-based participatory research, HIV and harm reduction, interviewing and administering surveys, verbal and non-verbal communication, and research ethics. Interviewers were also trained to administer HIV point-of-care testing to their peers as part of the interviews. This research committee was independent of government structures and had control over the research project.

***Structure and power.***

At the onset, researchers sought out representatives from the local organization of people who use drugs, helped them obtain office space so that they could grow as an organization, and partnered with them to recruit committee members for the research project through a “greet, eat and meet” meeting:

*[We] put together what we were going to call a 'greet, eat and meet' meeting, like everybody in the community who wanted to be a part, specifically people with lived experience, about forming a committee to try to improve services for [people who use drugs] in this... community, specifically, you know, probably a [supervised injection site]. So we had probably 40 people. We rented a church. It took a lot of planning, cooked a big meal, and had about 40 people show up and then we just hashed out what [people who use drugs] need and what things work in the community, what things that don't, and then hashed out how to go about it. (person who uses drugs)*

Interested participants at that meeting were invited to complete an application to join the research committee. Application forms and a brief description of the project idea were also posted in local community centres and needle exchange facilities. Applicants were interviewed by a person who uses drugs and a researcher who then selected committee members.

This research committee's structure was a key element in contributing to shared decision-making power. Its composition was specifically thought through to focus on the participation of people who use drugs and, according to the terms of reference and my own observation, was comprised of at least 70% of people who currently or formerly used drugs. During the meeting I observed, there were nine people who use drugs in attendance and five researchers and research coordinators. Two medical students were also present though not part of the committee. The majority (65%) of committee members with decision-making power were people who use drugs.

In addition, a person who uses drugs was co-principal investigator on the study. The research committee also had an executive committee composed of the principal investigator, the co-principal investigator, researchers and research coordinators. The Executive Committee made final decisions, and ultimate decision-making power rested with the principal investigator, and this was well understood by the committee members, which speaks to the clarity with which the committee's governance structure was established. In fact, in the terms of reference, it was stated that the committee as a whole decided on its governance structure at its first meeting.

When considering Arnstein's ladder of participation, this committee's structure could then be described as one of 'partnership', where decision-making power is redistributed through negotiation between people who use drugs and researchers and there is agreement to share planning and decision-making. Even if the co-principal investigator on the executive committee was a person who uses drugs, and committee members agreed the executive committee had the final decision-making power, there were still decisions being made at that level without the co-principal investigator. This governance structure was nevertheless the most inclusive and participatory of the four committees included in this study. Researchers described how they viewed the governance structure and its limitations:

*So research decisions, the ultimate, ultimate authority is [the principal investigator]. [They] very rarely use it unless [they] feel very strongly but we always do defer when [they] make a final decision about something. But generally, in terms of the research process, and like the research pieces, it's more within, like, [the executive committee]... who are here every day, dealing with the details every day, writing the grant applications, so there is decision making power just by the nature of we're here doing the work and we don't get to speak to the committee every single minute of every single day. And so there definitely is more power there and I think it is felt and known and noticed. (researcher)*

*I think we spend most of our time at these [executive] meetings talking about managing that committee, what we need to do. So I think there's not decisions so much about the project... All that stuff all happens at the committee meeting... this [executive committee meeting] is really kind of nuts and bolts, you know. Who needs contracts, who are we paying, who's having problems, how we deal and who's meeting with whom... I guess it could be viewed that there's some underlying decision-making. (researcher)*

Indeed, the distinctions expressed by the researchers as to the type of decisions made by the executive committee did not seem to be clear to committee members. One ally expressed some frustrations about final decisions being made by the executive committee. They noted that there was also a tendency for committee members to defer decisions to the researchers. For the most part, though, even if people who use drugs realized that the final decision power rested

mostly with the executive committee, they felt that they had significant influence over those decisions and that their input was integrated into the decisions. Some saw a practical element of having a decision-making body to make final decisions which may otherwise take a long time to make.

*We're not there at the table when they're actually making the final decision... But I mean, you know, they're using all of our opinions to make those decisions... and it's a fine way to do it because... there would be probably a lot more arguing and bickering... so I think it's a good way to do it. (person who uses drugs)*

*Final decisions were made by the Executive, I think, on the questions but we have lots and lots of influence... I feel I have influence, yes, power, yes. Not complete, you know, but no less than anyone else on the committee. Well, besides [the principal investigator] and [the co-principal investigator]... (person who uses drugs)*

The difference between this committee and the other three featured in previous sections of this chapter seems to lie in a feeling of meaningful representation amongst people who use drugs on this research committee. Their input mattered and had an impact on the decisions and actions taken by the committee. Of course the research context is quite different from the public health context. In public health structures, the other committee had less influence over decisions made by the public health authorities despite good power relations between individuals at the table. In research, such a committee has more freedom to provide a context in which people who use drugs can influence decisions compared to public health authorities.

Despite the limitations of the governance structure expressed by some of the committee members, there was a feeling of shared decision-making power among committee members:

*I can't say I feel like a hundred percent an equal but it's as close as I come, definitely, in this community with anything that I've done. (person who uses drugs)*

*We're all kind of equal except for [the principal investigator], obviously, being the head researcher and everything, it's [their] baby... We're the people that know the realities on the street though and we know the realities of addiction and... I think that [the principal investigator] relied quite heavily on that... to change the way studies are done. I think it's a ground breaking thing, from what we've been told and I'm glad I'm a part of it.*  
(person who uses drugs)

These excerpts from the interviews alluded to a change in power relations between community members and researchers. This community-based participatory research project was intentionally designed with what could be referred to as a reverse power structure where community members took the lead and researchers facilitated the process and provided research expertise.

*I think part of what's allowed it to do that is that decision making... power structure is kind of reversed in this sort of thing... It's very much every idea that is brought to the table has the same value 'cause it comes from someone who is at the table and that's all that matters.* (service provider)

In that sense, there was a true attempt at equalizing decision-making power, which, according to some committee members, appeared to be working.

This reverse power structure also contributed to equalizing the power relations between service providers and people who could potentially be their clients:

*We're all committee members. And generally I'm in like a client-service provider relationship... and so on the committee I think that's been a great opportunity to get rid of that hierarchy and really try to see you know we're all equal voice on this committee, we all have equal say.* (service provider)

Researchers were also aware of dropping their role as leaders of the research and strove to share power and ownership of the project:

*It was really their committee and I didn't take a real leadership, you know, at the meetings... They knew that I was interested in doing research but I really wanted to make the point this was kind of their project... and I think they bought into that.* (researcher)

These excerpts provide good examples of this committee's attempt to challenge power structures and experiment with new ways of collectively organizing to challenge power inequities. These

examples also speak to the researchers' strong commitment to the meaningful inclusion of people who use drugs.

One important point made by a person who uses drugs was that despite how inclusive the research committee had been, there were still important socioeconomic differences between researchers and people who use drugs that maintained inequity between committee members:

*I'd say, of the committees I've been on, it's the MOST inclusive. Although things at the upper level... because [the co-principal investigator] is a lived experience person... and [is] working with [the principal investigator] directly as co-investigator so that is a pretty, you know, lofty position. BUT it's not paid well. So THIS is what really tells.*  
(person who uses drugs)

This excerpt pointed to the fact that even though the co-principal investigator was a person who uses drugs, the remuneration for this position was presumably much lower than the remuneration researchers were receiving for this work, raising questions regarding socioeconomic inequities. Addressing decision-making power inequities through governance structure changes only partially contributes to remediating inequities at the greater socioeconomic level. Equalizing power inequities is also restrained by the committee's commitment to and capacity for inclusion of people who use drugs, as I explore in this next section.

***Commitment to and capacity for inclusion of people who use drugs.***

The research committee included in this study was built on a strong community-based participatory research framework. It was innovative in its engagement of people who use drugs in a large-scale prospective cohort study. The strong commitment to inclusion of people who use drugs was demonstrated at the onset of this study when the researchers partnered with the local organization of people who use drugs. The co-principal investigator was a person who uses drugs and the research committee was made up of mostly people who use drugs and oversaw all

aspects of the research project. The researchers expressed their strong commitment to inclusion of people who use drugs and ownership of the project by people who use drugs:

*It was my idea to do more research in this area and just to really try to focus more on the community and not be tokenistic about it... you know, let's just do this right. This is what community-based research [is], let's see how it goes. And I think it's worked out better than I would have anticipated. (researcher)*

*[People who use drugs] have been involved from the beginning so from day one our focus and our point was to really do community-based research differently... Everyone talks about doing community-based research but that can look very different and no one really talks about how they do it... We decided we really wanted to have complete inclusion and ownership of the project by, you know, like really have everyone involved in every aspect of it. (researcher)*

The researchers were committed to inclusion and had the capacity to properly support the people who use drugs who joined the research committee to ensure their ongoing involvement. They found people who use drugs who were also committed to the project and its purpose and ensured that they were compensated for their time. Although providing stipends may have provided incentive for people who use drugs to participate in the project, the commitment of the people involved extended beyond their financial gain and was demonstrated by the longevity of the continued participation:

*I guess... the heart of it was engaging with [people who use drugs] and... having like a conscious effort to get people involved who use drugs at the beginning of it. I think that's probably helpful... Trying to find people who felt that they wanted to be involved and trying to support them I guess too in their own issues and trying to make them continuously stay involved. Yeah. So that's useful. And also paying them. They're getting paid for every time they go to a meeting, so that helps. (service provider)*

*I really believe that most of the people stuck with it not because of the stipends. I mean they all collected their money at the end but the commitment that we saw, you know, through 20 months now has been quite extraordinary actually so... We've lost two members both for, you know, reasons that had quite a bit to do with their own life circumstances. (researcher)*

In terms of capacity of people who use drugs to participate in the committee, the organization of people who use drugs that was approached to partner on this study was just forming. Partnering with the researchers assisted the organization in its development:

*So I presented this idea [to the local organization of people who use drugs]. We had these discussions. I'd like to, you know, do some research here. I think that your organization could be instrumental in sort of helping with that... So [they were] quite open to the idea... So we really started from there. I got some money to set [them] up... with an office so that helped. (researcher)*

The design of this community-based participatory study, with its careful attention to including people who use drugs in every decision and every aspect of the project, required much support of people who use drugs from the research team. It helped that the researchers involved in the project had previous experience with community-based participatory research with people who use drugs and an understanding of health equity. Some of the researchers on the project were also social workers who were familiar with and committed to addressing oppressive structures. In addition, the principal investigator was readily available as needed and made a point of participating in committee meetings:

*[The principal investigator]'s very much involved in everything though. [They've] been to every committee meeting and we have weekly research meetings. [They] come to all of those so [they're] pretty hands on with the project. (researcher)*

*Over time I've met with everybody, you know, at least two or three times in the last year, like scheduled things that just how are you doing, so one on one with me and then if there's issues that come up, I'm quick to offer to meet with that person and try to get people back on track... [the researchers] spend a lot of their time doing that. (researcher)*

The capacity to properly include and support people who use drugs required an important investment of time and energy from the researchers. According to one researcher, this level of commitment to support people who use drugs was required when including people who were truly part of the community of interest and still experiencing challenging life circumstances associated with this syndemic:

*You know the biggest lesson that, you know, people should really need to know that community-based research is very difficult in this population and that you spend a LOT of time supporting people because you want people that are on the edge enough that they really ARE part of the community and I think a lot of community-based projects pick people that are quite distant from that life. (researcher)*

Achieving the right balance between supporting people who use drugs on the research committee and ensuring that the research team has a healthy work/life balance was an ongoing part of the learning process for everyone involved. It was also limited by the available resources. When asked about the challenges they encountered to participate in the research committee, one researcher remarked:

*Exhaustion. We're a really small team. I think for the first seven months I worked seven days a week and like we're still working crazy hours all the time to make it happen and we do that because we care and believe in the project... The biggest challenge is just exhaustion and to stay focused and committed when there is so much to do all the time. And the project keeps growing. There's always a demand for it to keep growing but our resources haven't grown so it's hard to meet all those demands. (researcher)*

Part of the learning process of truly being inclusive also requires changing preconceived notions of how much time activities such as research will require in this inclusive configuration:

*We have to be very cognisant of how much we can push people and so that's been I think a committee challenge to try and hold us together and try to get to know people personally and back off when they're having a bad week and engage them when they're not. And having realistic expectations for people. 'Cause... everybody's enthusiastic at the beginning but really their lives are really challenging and... so we have to be very flexible... What I've learned most is the more responsibility you give to people who are actually in the situation... and are living the experience, that just the more flexible you have to be and things will take longer. And that's the trade-off of getting very authentic... being ready at being slower. Like we're just not getting it done as fast as we could have. And the other great thing is the capacity. Having seen the committee members actually grow themselves so that the structure that they're part of and the buy-in that they have, it just shows. They never miss meetings and...rarely, you know, except for their bad weeks, they show up for their shifts and they've been very consistent and so I think they'd all tell you, hopefully, that they've benefited personally from being involved in the whole project. (researcher)*

This researcher's perspective revealed a tendency to compare community-based participatory research to previous experiences of conducting research. While this research project challenged the way research and knowledge creation was usually conducted, unmasked decision-making power and experimented with a new democratic process, it was still being compared to prevailing research systems. This view is supported by the way university settings function and research is funded, which value deliverables such as publications with little recognition of the processes involved in CBPR and the time required to do it properly and meaningfully.

Contesting hegemony in the research context would be best served by striving to replace this view with one that considers community-based participatory research as its own research method, one which factors in sufficient time and resources to allow its process to unfold and ensure that people who use drugs and researchers are well supported for a healthy work/life balance. A key mantra of harm reduction is 'meeting people where they are at' and that certainly applies in the context of including people who use drugs on a research team in every step. Meeting people where they are at also entails consideration to the socioeconomic inequities present at decision-making tables, as discussed in the next section.

### ***“Kraft Dinner or Vegetables and Fruit”?* Socioeconomic Inequity at the Table**

*Democracy will remain a grisly joke, but an ironic joke, unless we learn how to make it operate in an era of economics.* (Lindeman, [1935] 1987, p. 144)

To strive for shared power requires shared, democratic processes in decision making. Making organizational practices increasingly democratic includes ensuring that power increasingly resides with the people. An organization needs to therefore replace “power over” people with “power with” people. That said, democracy is severely compromised if the privileged can use wealth or status for undue political influence or if the socioeconomically

disadvantaged are so deprived that they are incapable of exercising their basic civil or political rights and meaningfully participate in decision-making (Lindeman, 1987). Findings revealed that although the committees included people who use drugs at the table, the participation of people who use drugs was still compromised by the challenging life conditions and disparate socioeconomic situations they faced. This section examines the socio-demographic inequities among the interviewees then presents ways in which committees have attempted to address some of these inequities. It then explores the impact of economic inequities on power relations at the table.

### **Socio-demographic description of interviewees.**

Table 4 presents the primary roles of study participants at the decision-making tables included in this study. This primary role was determined by information collected from the committee chairs as well as by discussions with the participants and a review of the committees' terms of reference. Each person, however, was asked to self-identify the role(s) they represent at the table, usually resulting in the identification of more than one role. It is worth noting that while 12 people sat at these tables representing people who use drugs, an additional four reported that they sat at the table as people who use drugs, whether or not this was disclosed to the rest of the committee members. For the data presented in Table 4 and Figure 1, study participants were classified using their primary role at the table in terms of who they represented.

Table 4.

*Primary and Self-identified Roles of Study Participants at Decision-Making Tables*

Variable	n	%
<b>Primary Role at the Table (n = 40)</b>		
People who use drugs	12	30
Service provider	21	52.5
Researcher	3	7.5
Policy maker	4	10
<b>Self-identified Roles (n = 40)</b>		
People who use drugs	16	40
Service provider	24	60
Researcher	11	27.5
Policy maker	6	15

Table 5 below provides a sociodemographic description of the study participants. Not surprisingly, study participants differed significantly in terms of their current illegal drug use experience, currently being on methadone or other substitution therapy, and having never used illegal drugs. There was no statistical difference between the proportions of people who use drugs or others at the table who had formerly used illegal drugs, however the sample size was small. Eleven interviewees not currently at the table as people who use drugs declared that they had used illegal drugs in the past, at some point in their life. The number of people who disclosed either current or former illegal drug use (n = 28) on the demographics survey coincided with the number of interviewees who discussed having illegal drug use experience during the interviews.

There were significantly more women than men in the sample and no one from other genders. The mean age between people who use drugs and others did not significantly differ. There were statistically significant differences in marital status and ethnic and cultural heritage between people who use drugs and others in the study, with more people who use drugs being single, separated or divorced and identifying as having an ethnic and cultural heritage other than

Caucasian. Participants were from Ontario and British Columbia, with similar proportions, and lived in suburban and urban areas. All study participants were housed.

Figure 1 displays results from education, food security and income comparisons between those identified as people who use drugs and other participants. Even at first glance, it is clear that people who were included in these committees as representatives of people who use drugs were at a socioeconomic disadvantage compared to those who were at the table as researchers, service providers or policy makers. None of the people with lived experience had university education whereas 78.6% of the ‘others’ did. While 82.1% of researchers, service providers and policy makers never worried about having enough food, almost half (45.4%) of people who use drugs always worried about food security. Almost all (90.9%) people who use drugs interviewed had a yearly income under \$20,000 while more than half of the researchers, service providers and policy makers had a yearly income of \$40,000 or more. Non-parametric tests confirm the statistical differences between people who use drugs and others (policy makers, researchers and service providers) at the table in terms of education, food security and income.

Although all interviewees indicated that they were currently housed, experiences of past homelessness emerged:

*I come from a background of many years being on the streets.* (service provider)

*I was homeless for the longest time.* (person who uses drugs)

Similarly, although no specific data were collected on interviewees’ HIV and hepatitis C statuses, personal stories related to HIV and hepatitis C surfaced during the interviews, indicating the presence of such lived experience. Even having the confirmation of one person living with HIV in a sample of 40 interviewees (or 2500 per 100,000) dramatically exceeds the

current estimated prevalence rate of HIV in the Canadian population of 208 per 100,000 by more than 10 times (Public Health Agency of Canada, 2012).

*I was an intravenous drug user for many years... and... of course, I got hep C and HIV.*  
(person who uses drugs)

*My hep C was really bad and then I was going through treatment.* (person who uses drugs)

These data clearly indicate that people who use drugs were in a disadvantaged socioeconomic position compared to the policy makers, researchers and service providers they share decision-making tables with.

### **Income inequity and power relations.**

The quantitative data presented in Table 5 and Figure 1 provide a glimpse into the socioeconomic contextual factors that come into play at decision-making tables where people who use drugs are included. The realities of economic inequity influenced how people who use drugs experience power relations and had an impact on their participation at such tables. People sometimes had to make tough decisions between participating in a meeting or working to earn income.

One person with lived experience, who was not compensated for their participation in committee meetings, did not even seem to see this choice as an important challenge and took responsibility for foregoing income despite the impact on their food security. When asked about whether they encountered any challenges in participating in committee meetings, they stated:

*No, not really any challenges. Not really, no. Maybe a little bit financially because I've had to sometimes, like there's... shifts... that I work at, like missed shifts and that to go to that meeting. It's a pick, like you know... am I going to eat Kraft Dinner all weekend or am I actually going to have a little bit of vegetables and fruit, you know what I mean?*  
(person who uses drugs)

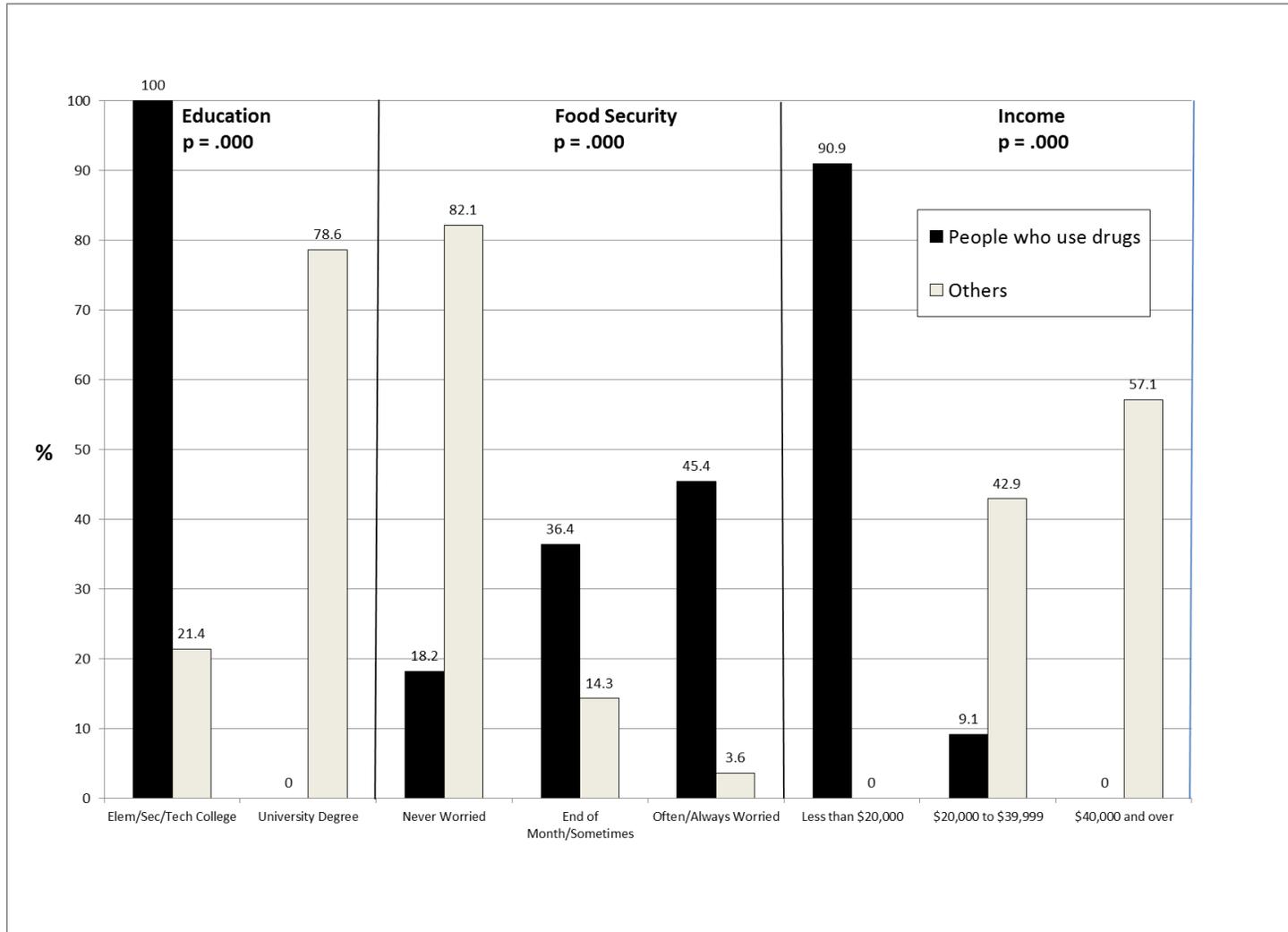
**Table 5. Sociodemographic Description of Interview Participants**

Variable	n	%	p
Illegal Drug Use Experience (Except Cannabis) (n = 39)			
Currently using illegal drugs	13	33.3	.002*
People who use drugs	8	20.5	
Others <sup>1</sup>	5	12.8	
Former user of illegal drugs	15	38.5	.582
People who use drugs	4	10.3	
Others	11	28.2	
Currently on methadone/other substitution program	8	20.5	.000*
People who use drugs	8	20.5	
Others	0	0	
Never used illegal drugs	11	28.2	0.13*
People who use drugs	0	0	
Others	11	28.2	
Lived Experience Disclosed in Interview (n = 40)	28	70	-
Gender (n = 40)			.047*
Women	29	72.5	
People who use drugs	6	15	
Others	23	57.5	
Men	11	27.5	
People who use drugs	6	15	
Others	5	12.5	
Other gender	0	0	
Mean Age (years ± standard deviation) (n = 40)			.127
People who use drugs	42.75 (± 11.75)		
Others	37.11 (± 9.92)		
Marital Status (n = 40)			.008*
Single/Separated/Divorced	24	60	
People who use drugs	11	27.5	
Others	13	32.5	
Married/Common law	16	40	
People who use drugs	1	2.5	
Others	15	37.5	
Ethnic or Cultural Heritage (n = 40)			.001*
Caucasian	33	85	
People who use drugs	6	15	
Others	27	67.5	
Other ethnicity or cultural heritage	7	15	
People who use drugs	6	15	
Others	1	2.5	
Province of Residence (n = 40)			.529
Ontario	22	55	
People who use drugs	7	17.5	
Others	15	37.5	
British Columbia	18	45	
People who use drugs	5	12.5	
Others	13	32.5	
Currently Live in (n = 40)			.243
Rural or remote area	0	0	
Suburban area	6	15	
People who use drugs	3	7.5	
Others	3	7.5	
Urban area	34	85	
People who use drugs	9	22.5	
Others	25	62.5	
Have Spent Most Nights in Past Month (n = 39)			-
In own house, apartment or room	39	100	
People who use drugs	11	28.2	
Others	28	71.8	

\* statistically significant at p &lt; 0.05

<sup>1</sup> Others are policy makers, service providers and researchers

Figure 1. Comparison of Education, Food Security and Income between People who Use Drugs and Other Study Participants.



However, not all people who use drugs were willing to participate in committees when they did not receive compensation, as pointed out by one policy maker, and confirmed by another person who uses drugs:

*And [the other person who uses drugs] is there maybe a third of the time, you know?... It frustrates [them] too 'cause [they] feel a lot more strongly about being remunerated for stuff [they do]... And yeah so, that would deter [their] attendance a bit. (person who uses drugs)*

In contrast, and perhaps indicative of privilege and lack of awareness of or thought to the realities of people who use drugs, committee chairs were not always aware of whether people who use drugs at their table were remunerated for their time to be there or whether they had the resources to attend meetings.

*L<sup>1</sup>: Are [people who use drugs] compensated for attending those meetings in any way?  
I: No... not by us. It may be considered part of their jobs where they are or part of their role with some of the other compensation they have but [this committee] does not compensate them for their time. (service provider)*

These findings reveal much about the power relations that are experienced and expressed between people who use drugs and people in positions of power at the table. First, if we consider Brookfield's (2009) framework, there were differences in the level of consciousness and agency between people who use drugs. There were those who had not yet learned liberation and accepted the dominant ideology and oppression by choosing to participate at the decision-making table without financial compensation or remuneration. This behaviour and choice was reproduced by those in power, in this case a service provider who co-chaired the committee, who did not think to verify whether the person's participation caused them financial hardship.

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<sup>1</sup> L = Lynne (interviewer); I = Interviewee

On the other hand, other people who use drugs seemed to have reclaimed power in that they challenged this dominant ideology and refused to participate unless properly financially remunerated. They acted in a way that does not automatically support the logic of the dominant ideology. These findings speak to the importance of *explicitly* enquiring about the financial needs of people who use drugs who are invited to the table and adequately compensating them financially as part of social inclusion practice. Taking measures to alleviate the financial burden for people who use drugs would also convey to them that their work and input are *valuable*.

**Taking measures to address economic inequities.**

***Remuneration for participation on committees.***

There were examples of people being aware of the importance of taking measures to address and somewhat alleviate the realities that economic disparities introduced in the lives of the people who use drugs who were invited to the table, though this awareness was not always clear or acted upon by the chairs of the committees I observed. Assumptions were also made about whose responsibility it was to provide measures to compensate for economic disparities, for example providing food or financial support. As one service provider states:

*I think one thing I've learned is that it's really important when you are working with folks who are living in poverty to take those conditions into consideration. And so, you know, for example food is a big thing... because you obviously can't concentrate if your belly is grumbling, and so at the [committee] meeting sometimes there's snacks and sometimes there's not... I don't know that that's been identified or brought up... I just noticed, for example, at the last meeting, I don't think there was any snacks... I think it's left up to each organization to financially support the people who are coming to those meetings, right? So, you know, [chair] called the meetings, made the [committee] meetings happen, but doesn't provide any funding. So [organizations of people who use drugs], for example, are both smaller organizations that are peer-run and they both struggle with capacity and resources, just like the rest of us but even more so, and I don't think they get extra funding to send representatives to the table... So there's those kinds of things that I'm aware of and I don't know that they are being addressed and... I don't know that [the chair]... has thought that through. (service provider)*

Moreover, although there was acknowledgement of the need to address the fact that organizations of people who use drugs face barriers to obtain funding due to stigma, organizations that include people who use drugs grappled with how to compensate them for their time on committees. They were inconsistent about whether they provided compensation or not, and if so, what form that compensation should take – cash or gift cards. Some interviewees acknowledged that giving people who use drugs gift cards instead of cash was rather insulting. Consideration must also be given in terms of the amount people who use drugs receive as honoraria since it may have an impact on their disability benefits or social assistance, depending on their circumstances.

*I: Honorarium is such a messy subject. And then the people on [disability pensions] or [social assistance], it can affect [their benefits]... We do the honorarium piece so... sometimes I find it's tokenistic though... It can equate to \$10 an hour. It can also equate to \$20 an hour depending on what they're doing... It depends.*

*L: And do you guys give them cash?*

*I: Yeah we do. We've advocated for that 'cause I find giving a card really insulting. (service provider)*

Some organizations worried about compensating people who use drugs too well, stating this may hold them back from better employment. Conversely, others were concerned about not compensating people with lived experience well enough, resulting in stretching them too thin.

*...the reality is that that's not really a job, and yet, you know, if you pay people so well, then often, you know, it's really hard for them to move on to other things. (service provider)*

*Peers aren't compensated the same way that other people at the table are, so are we stretching them? Stretching them. Stretching them. Using them. Tokenism. (service provider)*

These findings point to evidence of committee chairs being detached and not fully aware of the realities and financial hardships of the people who use drugs they invite to the table. Service providers were a bit more critically aware of such realities and the challenges these

realities bring to the participation of people who use drugs at these tables. Food insecurity is a significant issue for people who use drugs, yet the committees were inconsistent in providing food at meetings. Of the four committee meetings I observed, only two of them provided food and beverages. There were individual differences in level of awareness around financial constraints, which impede people who use drugs' participation in committees. There were also individual differences in attitudes regarding people who use drugs' participation, with some expressing concerns about people who use drugs becoming dependent on remuneration through committee work, which would hold them back from better employment, while others seeing this remuneration as not adequate and stretching people who use drugs too thin. These assumptions as to how people who use drugs may experience remuneration did not consider the agency of people who use drugs in deciding how they wish to spend their time. Thinking that remuneration would hold them back from better opportunities also hints at attitudes toward harm reduction work in general, which is devalued and stigmatized.

Contextually, organizations did not have clear policies around alleviating financial hardships for people who use drugs to participate in meetings, nor did they consistently have a budget allocated to this end. At the macro level, stigma associated with people who use drugs affected organizations of people who use drugs' ability to obtain funding for their activities as well as posed challenges as to the form of financial compensation people who use drugs were offered for their time spent on committees (CAPUD, 2014). There were signs, however, of organizations contesting hegemony by challenging these views and making it a policy to compensate people who use drugs in cash. Finally, the greater system for disability benefits and social assistance also influenced the ability of people who use drugs to receive compensation for their time on these committees. This section considered remuneration issues that emerged

regarding people who use drugs' participation in committee meeting. There were also considerations that emerged regarding hiring people who use drugs as employees, as described below.

***Hiring people who use drugs.***

Some organizations had hired people who use drugs and grappled with how to remunerate them in terms of lived experience equivalence to education and in terms of professional accreditation. They expressed concerns about hiring people who use drugs because of client confidentiality, since as employees they might overhear conversations about clients and these clients might be their peers. There were also concerns about further marginalizing people who use drugs by having conversations about situations which may be out of grasp for them, such as vacations abroad. Such interactions between the privileged and the disadvantaged, which likely happen in many other settings, brought about awkward social interactions. There were specific boundary issues associated with people who use drugs transitioning from clients to employees, in terms of being privy to confidential information about their peers:

*Another whole issue to consider with peer workers... is... salary. How do you decide?... We have that one [person] who's taken advanced courses and works as a co-facilitator... so to me [they're] doing a job that's more complex and requires more preparation than our greeters. So but then there are other people in the organization that feel that they should make the same as other staff members here even though there's less education and less formal education in the case of the other [person] so and you want to set some standards for the organization... so it's really complex. (service provider)*

*There is still always a little bit of 'other' that's involved in the work that we're doing and I don't know how easy it is to cross it. So for example, you know, we wanted to have somebody with lived experience employed here full-time, you know. Do they come to case conferences? Do they come to the lunch room, you know? As we have conversations in the lunch room, how does that change us and how does that change the behaviour?... What if at the [committee] meeting, you know, I'm talking about, you know, my latest vacation that I took down south or over to Europe or something like that and, you know, is THAT marginalizing people in terms of, you know, if that's not a possibility for them? (service provider)*

The importance of having someone with lived experience on a hiring committee was illustrated in this example where, were it not for the input of a person who uses drugs, some candidates may have been overlooked and not hired to be part of the project team. Because the person with lived experience knew the individuals being interviewed, they were able to dig beneath how they expressed themselves in a job interview and look beyond the struggles they face as a person who uses drugs.

*But there's been some really positive examples like that too, like... hiring certain people on the committee, like that they didn't necessarily want to hire right away because, you know, it's a twenty minute interview and someone's dope sick that day or just not feeling it and, you know, the interviewer I was with was just really insistent on certain things and I fought [them] tooth and nail on it and we have that awesome committee because of it, you know, and that's one of the best things I've ever done. (person who uses drugs)*

Other considerations in hiring people with lived experience entailed tailoring their responsibilities to their life circumstances since they may be facing challenges related to their health and living conditions. It also meant having to draw a line at how much support and accommodation can realistically be offered within the confines of an organization's resources.

*I don't think I could handle much more responsibility at this point, you know?... At this point in my life, I'm reducing off the methadone and... I have a bad [situation at home]... I would... take more responsibility... if the situation was a little different. (person who uses drugs)*

*Unfortunately the hard thing with that is a lot of [people who use drugs] are trying to survive as well so if asking for time in volunteering and not really having much to support that. (person who uses drugs)*

*Unfortunately... [people who use drugs] have to be able to read and write, you know what I mean? Like I hate excluding people based on literacy and that but... we can train, but only so much. (person who uses drugs)*

Findings related to hiring people who use drugs in organizations reveal that many questions remain with regard to establishing remuneration policies: how can lived experience be valued? Professional ethical concerns also have to be addressed when a person who uses drugs is

now privy to confidential information about their peers. Some people were also sensitive to topics of conversation which may be uncomfortable in front of people who use drugs who may not enjoy the same privilege, hinting at the need to develop openness to others' perspectives, as is required to practice democracy. Accommodations would also have to be made for people who use drugs' daily realities and life priorities that may affect their capacity to take on employment responsibilities, and this within an organization's capacity. Organizations need to carefully consider the resources necessary to adequately support and accommodate people who use drugs and allocate resources accordingly, within their means. Realizing this need also brings about a responsibility to advocate for more resources for organizations to be able to properly practice inclusion of people who use drugs. These insights show signs of some organizations contesting hegemony in their attempt to replace existing ways of operating with practices which include people who use drugs. Much work remains to be done, however, to find ways to overcome the alienation of people who use drugs in hiring and employment practices.

***Personal investment, personal cost.***

In addition to economic considerations, there were immeasurable personal investments and personal cost considerations at play when including people who use drugs. First and foremost, decisions made at committees such as the ones included in this study had a direct impact on the lives of people who use drugs. Bringing them into that environment can be very emotional, exposing them to challenging life conditions and circumstances drama and trauma on a regular basis. Inclusion can also motivate and inspire people who use drugs to act to change and improve their life conditions and those of their peers. The emotional investment also came into play for allies working with people who use drugs. For everyone involved, their investment spilled beyond work hours and carried over into their personal life, as did the benefits and

transformation. The individual investment by everyone involved was significant. Working within such restrained resources stretched everyone beyond the call of duty.

*We ARE... the people... these are people we KNOW dying, right?... We have an invested emotional interest in it... And harm reduction saved my life. (person who uses drugs)*

*The biggest challenge is just exhaustion and to stay focused and committed when there is so much to do all the time. And the project keeps growing. There's always a demand for it to keep growing but our resources haven't grown so it's hard to meet all those demands. (researcher)*

Considerations of personal time and emotional investment are important when examining the inclusion of people who use drugs in work and decisions that affect them. People involved in harm reduction work, including people who use drugs, have learned to unmask power in their lives and communities, appreciate that power permeates their everyday thoughts and actions and work at redirecting this power to serve the interests of the collective, glimpses of the learning that takes place as Brookfield (2009) described. These are characteristics of the social movement aspect that emerges from such social inclusion of people who use drugs.

While harm reduction work is demanding and not properly resourced, it brings valuable benefits and rewards to those who engage in it. The current social, political and economic context that stigmatizes people who use drugs and devalues harm reduction work as a way of helping is evident in the statements above. People involved in this work are stretched thin with few resources to do harm reduction work, though find the work rewarding. There is also a clash between the dominant ideology that equates one's worth to one's salary versus the incalculable worth of doing meaningful work, signs of the learning task of reclaiming reason, since people involved in harm reduction work are not automatically supporting the logic of dominant ideology. This section highlighted some of the key socioeconomic factors that come into play

when including people who use drugs at the table. The next section examines socially constructed views of people who use drugs and measures to challenge those views.

### **“The Voice” of Lived Experience: Issues of Representation**

As allies and people in positions of power, including people who use drugs at decision-making tables raises the following questions: Who comes to the table to represent the lived experiences of people who use drugs? Where are such representatives to be found? How many representatives should be invited? What perspectives do they bring to the table? Perhaps some people at the table also bring some lived experiences related to drug use but have not disclosed. How can a safe environment be created to encourage disclosure? Many considerations come into play when inviting people who use drugs to the table. This section addresses such considerations based on the study’s findings and discusses their effects on power relations at the table.

#### **Representatives from organizations of people who use drugs.**

The committees’ first step in finding people who use drugs to invite to the table usually began by contacting or crossing paths with a local organization of people who use drugs when one existed in the area. Even when representatives came from an organization of people who use drugs, questions arose regarding the perspective they brought to the table: Did they represent their own lived experience or the collective experience of their members? Were they at the table as service providers or as people with lived experience? How is the perspective of people with lived experience represented when the organization sends a staff person in their stead? Who comes to the table when there is no organization of people who use drugs in the area? This section explores these questions in terms of their effect on power relations.

***Did they represent their own lived experience or the collective experience of their members?***

Representatives from organizations of people who use drugs could of course speak from their own experience when they were at the table. It was more challenging, however, for them to represent the perspectives of a community that is not homogeneous. In addition, not all people who use drugs in a community were necessarily involved in a local organization of people who use drugs, as expressed by these service providers:

*What people who smoke crack experience may be very different from people who inject and, you know, if you're younger, the scene is very different than if you're older, and so you know, I think you can't have one person who speaks for the whole community. The drug using community is not homogeneous enough that it has a voice and it doesn't really have a democratic process to elect people to be the voice. (service provider)*

*There's a lot of people who use drugs who aren't members of [the organization of people who use drugs] and aren't connected with [it]... I think [the organization of people who use drugs] is representative of... not the entire population of people who use drugs and not the entire population of [people who use drugs] who access services through all of our organizations. (service provider)*

The above statements, however, did not mention that the organizations of people who use drugs who were involved in this study *were* a collective. They were established by and for people who use drugs and had a board of directors. In this sense, the selection of representatives to be the voice of people who use drugs was more organized than if such organizations did not exist, ensuring more of a democratic process for selection. People who use drugs from these organizations worked together to address issues of common concern, to the best of their ability. As well, these organizations were connected to a larger network of organizations of people who use drugs across Canada through CAPUD. In that sense, then, the people involved in such organizations had a better sense of issues that affect people who use drugs from a variety of lived experiences than people who use drugs who were not connected to such organizations:

*Like our drop in. You know, there's no other place where people can come in, a safe space, and talk about the things that they do in regards to us... We do our best to represent, you know, a whole lot of different people. (person who uses drugs)*

Organizations of people who use drugs created a safe space for people who use drugs to share their experiences and challenges. While true that not all people who use drugs in one area were members of such organizations, representatives from these organizations did their best to represent more than just their own personal perspective.

One policy committee I observed brought in representatives from various areas in its jurisdiction. The question was raised about how two representatives from one area could truly represent the voice of people with lived experience in their area:

*We've had this conversation this year and last year about the actual representation of two [persons who use drugs] coming from each [area... to one meeting... per year as not being particularly inclusive or representative... And so that it would maybe be better if... [service providers] worked with the organizations to pull a bunch of people together in a meeting or something so that more [people who use drugs] could come because it's really unlikely that two [people] can speak to all the different drug use practices and needs of individuals in their [area]. (service provider)*

During the meeting, I observed, there was a suggestion about a possible mechanism to improve representation of local issues whereby public health authorities in each area could work with local people who use drugs to bring groups of people who use drugs together to identify local issues and priorities to bring forth at the jurisdiction's face-to-face meeting. There was a lot of excitement about this possibility and the co-chairs seemed committed to follow through with this idea. According to one service provider, this discussion had taken place amongst committee members before. I have since had discussions with the co-chairs of this committee which indicate that they are moving forward with this idea. Again, this example points to efforts of unmasking power and experimenting with forms of collective organization and democratic processes in the interest of greater equity in inclusion of people who use drugs.

Finally, representatives from organizations of people who use drugs may have past or current lived experience of drug use but still strongly identify with that community and its realities, such as in the example above and this statement below:

*I still identify with that community. I always will. I always will. I don't care whether I stick a needle in my arm or I don't. I still identify with that community. I still have the toils and, you know, all the toils that I went through, they're going through.* (person who uses drugs)

The above statement was supported by the demographics data collected about participants' lived experiences with illegal drug use, where only eight out of the twelve representatives of people who use drugs indicated that they currently used drugs. The other four identified as *formerly* using drugs. Eight of the twelve representatives of people who use drugs interviewed were currently on methadone or some other substitution therapy, indicating some overlap between the categories. Categorizing people with lived experience is not that clear cut. The importance lies in how people self-identified, such as the person above who related to the toils of that lived experience, and was still in touch with that community and able to represent their concerns. It is important to note that representatives of people who use drugs had chosen to refer to themselves as 'people who use drugs'. As pointed out by Brookfield (2009), a person's lifeworld permeates and shapes their identities. People reclaim reason when they learn to become aware of the presence of this lifeworld in various situations, including at decision-making tables.

In terms of practice implications, these findings point to the importance of supporting organizations of people who use drugs in order to enhance their capacity to practice and participate in democracy. During interviews, the question arose as to whether such representatives came to the table more as service providers, however, than as people with lived experience of drug use, as addressed in the next section.

***Were they at the table as service providers or as people with lived experience?***

In one of the committees studied, people who use drugs were seen by the service providers and policy makers to be at the table more because they were service providers than people with lived experience. Their peer-run organization of people who use drugs provided harm reduction outreach services in an urban centre. People who use drugs were paid for their outreach hours, through funding obtained from the local public health authorities, although the pay they received was below minimum wage. Nevertheless, the fact that they provided services did have an effect on what perspective they were perceived to represent on the committee.

Committee members saw the voice of lived experience as diluted or simply not present:

*The [people who use drugs] are service providers too though so they are straddling that line... I see [their] role more as like a service provider... I think more typically they are talking about the services that they provide and less about the lived experiences... If [people who use drugs] are invited more as service providers and are related to as service providers, perhaps the perspective [of lived experience] gets diluted. (service provider)*

*I don't think anybody really is there being the voice of [lived experience]... There's no one really there speaking on the behalf of a [person] who's using. (service provider)*

Service providers on the committee wondered about the difference between people who use drugs who were at the table representing the voice of lived experience and those who were at the table as service providers. The main concern was whether people who use drugs could truly be open about their lived experience while also being in a service provider position which, in their view, would influence the authenticity with which they represented their lived experience:

*[People who use drugs] can openly talk about [their] experiences but it's very clear, like [they] can't be high when [they] come to work and so there are still very clear boundaries about when and how and where [they] can use, right? And so [they're] probably going to be very careful about how [they] talk about that experience, in a certain sense. (service provider)*

According to these service providers, a person who uses drugs who is also providing services has to behave and speak within certain boundaries that are socially acceptable, thereby limiting their capacity to be open about their lived experiences. In this sense, then, they related to these people with lived experience as they do to other service providers, and as if a person has to be either a person who uses drugs or a service provider, but not both.

This value held by these service providers that a person cannot be both a person who uses drugs and a service provider speaks to the prevalent view about what is appropriate drug use and what is not, and assumes a person cannot function as a service provider if one has consumed drugs. This discourse can be challenged and disrupted by asking questions such as: How many people at the table were questioned about whether they had a glass of wine at lunch before attending a meeting? Would the reaction be as negative and as limiting to a person's freedom to express their lived experience? This attitude also indicated imposing a dominant service delivery model on people who use drugs, implying that there was a right and wrong way of providing services to people who use drugs, feeding the stigma and power inequities. It did not allow for people who use drugs to determine for themselves how best to serve their peers. It also does not account for the different role a peer can hold as a peer service provider, one who shares lived experience with the peers they serve. Finally, not all members of an organization of people who use drugs provide services. Many are simply members of the organization.

These findings identify struggles in power relations based on what representatives are perceived as representing, specifically when they come from organizations of people who use drugs. The next section addresses representatives of people who use drugs who are not affiliated with an organization of people who use drugs.

***Who comes to the table when there is no organization of people who use drugs in the area?***

In areas where there were no organizations of people who use drugs, the committees relied on local service providers to find people with lived experiences to sit on the committee. There was an important difference between representatives from organizations of people who use drugs and individuals who were recruited from among the patrons of harm reduction services. People who use drugs who were recruited from organizations of people who use drugs tended to be exposed to other perspectives and lived experiences and had a better sense of the pulse of their community. Individuals recruited from harm reduction services were at committee tables representing their own perspective, as indicated in this example where the person acknowledges not having sought the views of their peers:

*I never really... gave [the committee] too much information... except about myself personally... I never really sat down and talked to anybody on the street about it too, hey? (person who uses drugs)*

Once again, this finding speaks to the important role organizations of people who use drugs play in practicing democracy and shifting power to the collectivity. While individual voices of lived experiences are valuable at decision-making tables, there is more power in representatives democratically selected to represent themselves and their peers as well as a variety of lived experiences. There is also value in having more than one representative of lived experience at a decision-making table. Two of the four committees I observed had two representatives of people who use drugs on record as being part of the committee, although usually only one or none attended the committee meetings. The next section explores a situation where there was no representative of people who use drugs at the table.

### ***What happens when there is no person with lived experience at the table?***

In one meeting I observed, there was one representative of people who use drugs among a group of 17 people at the table. There were two representatives identified on the committee's list, but the other representative, I was told, only occasionally attended meetings. A bit more than half way through the meeting, this representative left the meeting for another engagement, leaving no voice of lived experience at the table, at least overtly. Although it did not seem to affect the meeting in any particular way, since the committee carried on with its agenda. However, it did leave me wondering about instances when there is no voice of lived experience at the table. Some examples surfaced during the interviews. Although some reported the indirect presence of the voice of lived experience at the table when service providers shared what they heard from the people who use their services, there was still a sense of not being able to properly answer some questions when that voice was not directly present.

*When there's no sort of [person who uses drugs] at the table, sometimes I feel like we are sitting around talking about things that we don't know about... If we just had people [who use drugs] at the meeting then we wouldn't have been talking about that for twenty minutes trying to figure out what that's about. (service provider)*

*I've heard [the service provider] from [that agency], for example, when [they] talk about an issue, [they] talk about "Well when I talk to people who use my services, this is what they say" so... we are representing in a way, even if they are not AT the table... There's this ongoing sense of... ongoing data gathering from them... We're regularly sampling, you know?... there are mechanisms that people are constantly providing feedback and we recognize that we really only know a small bit of this as service providers and of the greater kind of reality of people's lives out there we don't know anything about. (service provider)*

Clearly, for inclusion of people who use drugs in decisions that affect them to take place, having representatives of people who use drugs is an essential component. Without their presence at the table, there was no inclusion, nor could there be transformation in power inequities at these tables. These findings indicate that committees need to include enough

representatives as members so that there can usually be representation at meetings, as a first step. The need for voices from a variety of lived experiences was also expressed, as described in the next section.

***The expressed need for a number of representatives and ranges of perspectives.***

Finally, despite the presence of some representatives of people who use drugs at the committee tables in this study, many expressed the need for more seats for representatives for people who use drugs and for more diversity in perspectives and lived experiences they bring to the table. Some of the perspectives mentioned included youth, various areas of the city or province, and voices other than white male voices.

*I want youth representative... We need their feedback because... I don't know what fuckin' ecstasy is, I don't know what bath salts are... I can pull stuff, you know, on the internet and find out for ya, but that's not a true lived experience. I know nothing about it. (person who uses drugs)*

*It's also the same voices all the time so we get a lot of white male voices. White male drug using voices... There are some communities where... the Asian community, there's no voice for drug use... We don't have any women who use who come to the [committee]... We don't have a lot of young people. (service provider)*

Indeed, an important part of practicing democracy, according to Brookfield (2009), is learning to honour diversity. Ideally, for that to happen, there needs to be diversity at the table, not just in terms of the roles people play such as policy makers, researchers, service providers and people who use drugs but in terms of lived experiences of people who use drugs if decisions are being made that affect them. Committees need to reflect on how many people who use drugs they can include at their table and strive for diversity in that representation.

**Finding the 'we' in 'us and them'.**

Throughout this dissertation, for simplicity, study participants have been categorized according to their primary role at the table, namely the researchers, policy makers and service

providers. Digging a little deeper, however, through analyzing the demographics data, the distinction between ‘us’ and ‘them’ was not that clear, as described in the section on ‘Socio-demographic description of interviewees’. There were in total 12 committee members out of the 40 individuals interviewed who were at the table as representatives of people who use drugs. On the demographics survey, where they could tick as many roles as applied, an additional four interviewees ticked that they were representing people who use drugs, even if that was not their primary role at the table. Another 12 individuals disclosed their past experience of drug use during the interviews though were not at the table as representatives of people who use drugs. Thus, in total, 28 out of the 40 interviewees, or 70%, had some lived experience with illegal drug use other than cannabis. These data suggest that the line between ‘us’ and ‘them’ is not clear.

While some people in roles other than representatives of people who use drugs were comfortable disclosing their past lived experience of drug use, others were not. There was also acknowledgement that the lived experience committees were seeking to include was not strictly just about drug use but rather an intersection of drug use and other factors that contribute to marginalization such as poverty, homelessness, and disease status such as HIV and hepatitis C.

*I am in a really unique position here at [my organization] where I can be open about my drug use... And if we want to combat drug stigma, the best way to do it is own it... We want to talk about real inclusion of people with more than just drug experience but the things that go along with that, so experience with poverty and homelessness and health concerns, HIV, that I think is probably lacking. (service provider)*

*Here’s another sort of personal thing... not being able to out myself as a drug user. You know, I feel like I have a role to uphold there and... feeling like the kinds of marginalization that I experience with the certain kinds of drug use that I’m involved in, there’s no point in sort of bringing them up there because mostly it’s about poverty and, you know, other sort of systemic issues although I think there are commonalities, you know. The stigmatization around being someone who uses an illegal drug is universal. I feel like I have to uphold a certain presentation in that context that doesn’t allow for the kind of disclosure that I think would actually break down some of the barriers between us. (policy maker)*

Contextually, organizational policies and environments influence a person's comfort and risk in disclosing illegal drug use experience. Ideally, if everyone felt comfortable and safe to disclose their lived experience of drug use, it would likely contribute to bringing down some of the walls between 'us' and 'them' and reveal more of a 'we' than we realize. However, the sociodemographic differences between representatives of people who use drugs and others at these tables revealed the divide that still needs to be overcome, as presented in the next section.

### **Summary**

This chapter offered findings on considerations related to table seating when inviting people who use drugs to decision-making tables where they have historically not been at. Power relations at the table between policy makers, researchers, service providers and people who use drugs were influenced by the organizational setting in which the table was situated as well as by what each person brought to the table in terms of the socioeconomic position they occupied in society and the voice they represented.

At the organizational level, situating the committees' level of decision-making power within the greater political context as well as understanding the committees' power structures helped shed light on power relations that unfolded at the table. When committees were part of the greater health care system and institutions (e.g. the policy committee and the service providers committees), they had less power and influence over change and improvement of harm reduction services. Participation of people who use drugs was therefore limited to a role of consultation, where there were no guarantees that their input would be taken into account, or one of informing, where the focus was on information exchange between committee members.

In the research context, however, the committee had more leeway to experiment with forms of collective organization. In the research committee included in this study, people who

use drugs were thus able to be included in a true partnership, where decision-making power is redistributed through negotiation between people who use drugs and researchers. In this context, there was agreement to share planning and decision-making. As a result, people who use drugs felt that they had significant influence over decisions and that their input was truly integrated into those decisions. Their inclusion was therefore more meaningful and decisions were collective and more equitable.

Sociodemographics data starkly confirmed the vast difference in socioeconomic positions between people who use drugs and others at the table, which influenced power relations. People who use drugs were more likely to be male, single, and of ethnic or cultural heritage other than Caucasian than others at the table. None of the people who use drugs had a university degree. They also experienced significantly greater food insecurity and lower income. These socioeconomic differences influenced power relations at the table.

People who use drugs faced financial challenges to be able to participate in committee meetings. Committees varied in terms of their awareness of such barriers and the measures they took to alleviate them in terms of providing food at meetings and compensating people who use drugs for their time and expenses. People who use drugs also varied in terms of their choice to participate despite limited financial compensation. These findings speak to the importance of *explicitly* enquiring about the financial needs of people who use drugs who are invited to the table and adequately compensating them financially as part of social inclusion practice. Taking measures to alleviate the financial burden for people who use drugs would also convey to them that their work and input on committees is *valuable*.

To obtain the voice of people who use drugs, representatives of people who use drugs had to be found and invited. This process was facilitated by the presence of a local organization of

people who use drugs. Such organizations were comprised of a collective of people who self-identified as people who use drugs. These organizations could select their own representatives to represent them, thus providing a more democratic process of selection than simply inviting individuals who use harm reduction services. Being part of an organization of people who use drugs, these representatives were more likely to represent a broader perspective than their individual experiences. They had a better sense of issues that affect people who use drugs from a variety of lived experiences than those who were not connected to such organizations.

Organizations of people who use drugs, however, faced barriers to develop and mobilize, ranging from limited capacity and challenging access to funding to stigma and marginalization. Some of the committees included in this study had supported organizations of people who use drugs while others were exploring ways to bring people who use drugs together to facilitate their mobilization and provide an environment conducive to the development of an organization, such as hosting local or regional meetings.

The presence of representatives of people who use drugs at committee tables challenged the dominant views of what it means to be a service provider. Some of these representatives were also providing services to their peers through their organization of people who use drugs. As a result, others at the table tended to relate to them as service providers based on their perspective that a service provider cannot also be a person who uses drugs. This perspective did not account for the unique role of a peer service provider who shares lived experience with the peers they serve.

Findings also revealed that most participants interviewed expressed a need for more representatives of people who use drugs on their committees to bring a wider range of perspectives and lived experiences to the table. In some cases, the number of seats for people

who use drugs was low, resulting in the absence of the voice of lived experience from some meetings. Striving for more diversity in representation of people who use drugs is an important part of practicing democracy (Brookfield (2009)).

That said, some committee members who were at the table also reported lived experience in terms of drug use and other related lived experiences such as poverty and homelessness, though they were not at the table primarily to represent the voice of people who use drugs. While some were in a position where they could disclose their related drug use experience, others were impeded from doing so for fear of professional and personal repercussions due to stigma and marginalization of people who use drugs. Some participants felt that if the context was safe to be able to disclose this lived experience, it might contribute to bringing down some of the walls between ‘us’ and ‘them’ at the table, thereby fostering better power relations.

Chapter 4 considered issues related to Table Seating. Chapter 5 on Table Manners will reveal findings related to the impact of stigma against people who drugs on power relations. Findings on creating a safe space once people are at the table, one where people can feel free to express themselves, as well as democratic processes that nurture the equalization of power relations in decision-making, will follow.

## Chapter 5 - Table Manners: From Power Over to Power with People who Use Drugs

*We need to give each other the space to grow, to be ourselves, to exercise our diversity. We need to give each other space so that we may both give and receive such beautiful things as ideas, openness, dignity, joy, healing, and inclusion. — Max de Pree*

### Introduction

Once people who use drugs have been invited to the decision-making table, conditions conducive to their emancipation can be fostered. First, this chapter looks at the presence of stigma that lingered at the observed tables when participants brought socially constructed views of people who use drugs to the table. Such views tended to underestimate people who use drugs' knowledge, capacity and skills. There were, however, signs of challenging these views. Intentionally challenging these socially constructed views, realizing that representatives with lived experience of stigmatization and marginalization often live under different economic realities than the other participants at the table, and accommodating for those realities were essential components to strive for more equitable inclusion.

The chapter offers factors that either enhanced or hindered the creation of a safe space where people who use drugs could overcome alienation. It then explores the factors that contributed to or hindered democratic processes. Ultimately, the chapter offers how the committees studied used this forum as a place to transform power relations from having decision-making power *over* people who use drugs to having decision-making power *with* people who use drugs.

### **“Selling Us Short”: Bringing Stigma against People who Use Drugs to the Table**

*We're not stupid people. We have knowledge... We stopped believing in ourselves so... sometimes we just need people to believe in us until we start believing in ourselves again, and that's harm reduction. But treating us like we are stupid is not going to get us anywhere. (person who uses drugs)*

Perhaps the most important hindrance to sharing decision-making power with people who use drugs stems from socially constructed views of and stigma against people who use drugs. As much as the people involved in the committees I included in this study were open-minded and working toward the inclusion of people who use drugs in decisions that affect them, there were still some displays of stigma and negative assumptions about people who use drugs, which resulted in underestimating people who use drugs in terms of their capacities and knowledge. Intentionally challenging these socially constructed views can help transform these power relations toward more equitable ones.

### **Underestimating people who use drugs.**

One theme that emerged from the committees I observed and the interviews I conducted was a tendency to have low expectations of people who use drugs. There were examples of underestimating people who use drugs in terms of the skills and expertise they brought to the table, signs that much work remains to be done to challenge broadly accepted ideas and beliefs about people who use drugs. One interviewee referred to this view as ‘the deficit story’ which focuses on what is ‘wrong’ with individuals rather than the strengths and skills they contribute. One policy maker referred to instances of ‘once a client, always a client’. One person who uses drugs acknowledged that there is room for ‘experts’ to manage the project they were involved in though wished that more trust and responsibility would be given to them and their voice.

Excerpts from the interviews illustrate these points:

*Drug users are not necessarily at the [committee] meeting for their strategic planning abilities, right? They are there because they are a lived experience that needs voice and that’s what they bring to the table. They don’t necessarily bring policy development or program management or anything like that. Those aren’t their skills. (policy maker)*

*I understand why there has to be like that managing by people who have the experience in the field and everything but at the same time I think it's also kind of selling us short and maybe if you like trust us a little more or gave us a little more room to have like responsibility and grow then, you know?... I think we're all capable of being rational and having a say... But like we're just not given enough chance to, if you know what I mean."* (person who uses drugs)

Once again, the situations above reveal signs of struggles to overcome the underestimation of people who use drugs. People who use drugs were often only valued for their drug use experience and not taken seriously for their input on other matters and others at the table noticed this dynamic.

*They all listen to us and think we are experiential when it comes to... experience of having been users. But when it comes anything else, it's like we're stupid.* (person who uses drugs)

*Pretty well [people who use drugs] just mostly get asked about stuff that is related to the supplies and what people are doing and in terms of drug use, which is something that's kind of problematic ... they get valued for their knowledge that is about drug use and not other things.* (service provider).

Conversely, people who use drugs seemed to overcompensate to meet or even exceed the dominant standards. They put a lot of pressure on themselves to excel and perform to a higher standard. While some people who use drugs were driven to get involved by wanting to provide hope to their peers, others wanted to challenge the stereotypes and show that people who use drugs can be held to the same standard and be responsible. They felt that their performance affected how ALL people who use drugs were perceived. These examples unveiled signs of people who use drugs striving to overcome alienation. In his framework, Brookfield (2009) describes alienation as living "in ways that estrange us from who we really are" (p. 50), which in his view is the opposite of freedom. This alienation is shaped by the dominant views of people who use drugs. People who use drugs were fighting these alienating, stigmatizing forces

intentionally and using their own individual liberation as a way toward collective liberation for all people who use drugs:

*When I got clean and sober and I started this job... I give one hundred and fifty percent. I don't do anything half ass. And I want people to know that there is hope because I sure as hell didn't have any... So it's important for me to let people know that, you know, you CAN do it. You CAN do it. There IS hope out there. (service provider)*

*We shouldn't always provide people with excuses because they're late or they blow off shifts and stuff like that, you know. And say "Oh well, they use drugs" and excusing it because of that is just as condescending as not letting them to the table. I feel really strongly about that. If we want full equality, we'll be treated equally on the good things and on the bad things and that's getting called on your shit... That stigma is not going to really end until we are treated equal on all levels and that's expectations as well as empathy, you know? (person who uses drugs)*

Despite these signs of striving to overcome alienation, there was some mention of the awareness of internalized oppression or self-hate by people who use drugs brought on by dominant views of people who use drugs. One service provider made it a point to challenge people who use drugs' views about themselves:

*Yeah well, you know, forty years of drug war propaganda... and I mean we know that people with lived experience have internalized this as well, right? I mean they're the ones I'm correcting most of the time when they say outrageous stuff about themselves and about how they failed their treatment. I say no, the treatment failed you. (service provider)*

This service provider's quote reflects the internalization of stigma experienced by people who use drugs. In this example, the service provider was challenging this stigma by raising awareness among people who use drugs about how society has created these situations, a concrete example of transformative learning and conscientization.

It was also noticed that people who use drugs still had a tendency to yield to 'the experts' and accept their suggestions more readily than those of people with lived experience. This dynamic played out in the research committee I observed. The committee, which was comprised mainly of people who use drugs, had not quite reclaimed reason and were ceding to experts who

possess specialized knowledge. This service provider, sharing the table, had noticed these power relations:

*We've spent, you know, a couple of meetings trying to figure some stuff out and then we say, you know, this is what we think and then have one of the research members come in and say "So this is what I think" and then everybody goes "Oh, OK". You know? And I've been finding that happening over and over again throughout so that's been a little bit frustrating to me. (service provider)*

These findings provide examples of the impact of stigma on power relations between people who use drugs and others at the table. Despite good will to be inclusive, there were still ideas and beliefs about people who use drugs that legitimated the interests of those in power and distorted what people who use drugs were capable of. These instances belied the fact that there was still some dormant critical consciousness with regard to attitudes toward people who use drugs among the very people involved in attempting to address power inequities.

Underestimating people who use drugs hindered their participation by alienating them, dismissing their important contributions, limiting the amount of responsibility they were assigned and restricting their input only to issues directly related to drug use. These attitudes exerted pressure on people who use drugs to perform above dominant standards in order to change these perceptions and overcome this alienation. One person strongly believed that people who use drugs should be held to the same work ethics and standards as others for true equity to take place. Service providers also reported how people who use drugs have internalized these low expectations of them and reproduced these attitudes by believing them.

Unmasking power in the context of these committees was also challenging yet necessary for people who use drugs to reclaim domains of their lives they have ceded to experts. This process undoubtedly takes time, even in the context of committees intentionally attempting to

unmask these power dynamics and liberate its members from the dominant ideology that ‘researchers know best’, as described above.

An interesting and important feature of transformative learning is the discomfort and disorientation that takes place when challenging dominant ideologies about people who use drugs. The examples above displayed how some people in positions of power (e.g. service provider) contested these belief systems with the hope to change these views over time and showed expected signs of struggles in doing so. In social inclusion practice, allies such as service providers, researchers and policy makers play an important role in challenging stigma and socially constructed views of people who use drugs.

One way to overcome these stigmatizing views about people who use drugs and transform the power relations that reproduce power ‘over’ people who use drugs is to challenge those socially constructed views. The next section examines this learning task within the context of the four committees included in this study.

### **Challenging socially constructed views.**

To challenge deeply held assumptions and socially constructed views about people who use drugs and to recognize the power inequities requires questioning and critical reflection. There were glimpses of critical reflection in the meetings I observed and the interviews I conducted. I found, however, that people were struggling with how to do this well. It was noted that until socially constructed views are challenged and changed, it is challenging to move forward and have dialogues with each other. One policy maker raised the issue that all people around the table make assumptions about each other and that there is a lack of skilled facilitators to help groups challenge socially constructed views.

*I: I mean it's like we're raised with those kinds of beliefs and until you move through that, it's difficult to have dialogue and, you know, [one person who uses drugs] would say to me "Well, what the hell do you know about it? You don't know anything about it." It's like really? You don't think I know anything about it? Like how do YOU know?...How do YOU know what my experience with drugs is?*

*L: Making assumptions.*

*I: Yeah, right? We both do it, like both sides of a table, you know, do that kind of thing and we don't have skilled practitioners to work through that, right? (policy maker)*

There was some acknowledgement of intentional deconstruction of oppression and the challenge that that entails in one committee. The committee had taken measures, however, to critically reflect on their processes and had built in an evaluation component to their processes. The committee member below was explicitly aware of their attempts to deconstruct oppressive power relations and pointed out the importance of trial and error in unmasking power and experimenting with ways of collective organizing and democratic processes. They mentioned how they learned from their ongoing evaluation and adapted accordingly:

*There's also tensions in terms of how the community is typically treated... in terms of experiences of oppression and then looking for it... It's so intrinsic in society. It's always there. It's what we're trying to deconstruct and not always perfectly successful in.*  
(researcher)

One person who uses drugs was aware of how innovative the inclusion of people who use drugs in every step of the process was and their ownership of the project as a result of that was evident in this statement:

*What really impressed me from the beginning was that it was soooo... innovative... this whole [project] was really created like from the bottom up by people from the community... When I am going through the consent form with people, it's something I like to point out, like when I am kind of explaining what a cohort committee is, I like to explain that it's, you know, it wasn't a bunch of doctors sitting around deciding what we should ask you, you know, it was people from YOUR community who did this FOR you.*  
(person who uses drugs)

By being included in every step, this person felt that this project was truly stemming from people who use drugs. During the consent process for study participants, they expressed this sense of

ownership by pointing out that this project was *by* people who use drugs, *for* people who use drugs.

There were also challenges in practicing democracy in the sense that some committee members were hesitant to challenge people who use drugs regarding their views. This hesitation was viewed as disrespectful, condescending and patronizing. They felt there was room for honesty and a way to create a space for that to be expressed respectfully:

*I think sometimes we do run the risk of over-subscribing to what the... voice [of people who use drugs] is in these things. It's kind of like a reverse discrimination kind of thing of... not calling them as well on kind of their perspective on things so I don't think that's being respectful if we don't do that. I think we have to have a place where we can challenge each other around this without feeling like we're being oppressive 'cause we're certainly not and it's not either our intention. (service provider)*

*I don't have much of an issue of saying to anybody, regardless of who they are or what they're bringing to the table, that I disagree with them... but lots of people DO have difficulty challenging [people who use drugs], right?... If we're going to engage in [inclusion], you have to be honest... There's room and there's cushions for people to fall and there's like you make things safe. But safety is not just nodding your head in agreement when you don't agree. That's not creating a safe space. It's patronizing and condescending. (policy maker)*

Indeed, as Brookfield (2009) explains, Habermas' communicative action approach considers "ideal speech conditions" as an important part of practicing democracy. All parties need to be open to new perspectives and willing to temporarily suspect their own convictions. Such ideal speech conditions should include the capacity to challenge each other's views in a respectful and constructive way. Not doing so reproduces the alienation of people who use drugs by treating them differently than others at the table. Creating a safe space where everyone can feel free to express their views and thoughts is an essential component of practicing democracy at decision-making tables. It contributes to shifting the power to the collective. Meanwhile, one person with uses drugs offered a reminder that the line between 'us' and 'them' is blurry at decision-making tables and that anyone could find themselves in similar situations:

*Yeah, there is an imbalance of power. It's like we're not stupid people who used or use drugs, right?... We've had jobs, we've had education, some of us maybe yes, some of us no. It's life... Life drove us. I mean it could be any one of them sitting at the table who could be the next one on the street. I mean I never thought I'd end up homeless when I was [employed]... and I did. I never thought I would put a needle in my arm and I did, right? So you never know, right? You never know what curve... life will throw you, right?... Some of them like they act so like...if we have a good idea, it's like "Oh wow!" it's like "The dummy has an idea!" (person who uses drugs)*

This person was aware of the imbalance of power between people who use drugs and others at the table caused by the socially constructed views of people who use drugs and challenged this ideology.

This section examined the impact of socially constructed views of people who use drugs at decision-making tables and how these views hindered the true participation of people who use drugs. It revealed examples of the impact that both social stigma and criminalizing policies have on power relations at these tables and signs of struggles committees face to foster transformative learning to transform these power relations.

### ***"An Even Playing Field": Creating a Safe Space***

*The more you get to know each other, the more you respect each other and then everyone's just kind of on an even playing field. (person who uses drugs)*

Creating a safe space entails adopting approaches and creating conditions that foster a sense of freedom among people at the table so that they can overcome alienation (Brookfield, 2009). This section explores factors that contribute to getting comfortable with one another and building trust, the importance of authentic relationships and conditions conducive to relational and trustful communication and dialogue.

### **Getting comfortable with each other and building trust.**

When people came together from different walks of life, it took time for everyone to acclimatize to each other and get comfortable in a new space. This was especially true when

people came from different social locations in terms of power and life opportunities. Some people who use drugs had no experience sitting around a table at a committee meeting so they had to become familiar with that culture. People at these tables also needed some time to establish their role at the table and to settle into it. Facilitation skills enhanced the ease with which people settled in.

*The first couple of meetings, you could tell there's people that hadn't sat at even a table full of other people in eons, if ever, you know? And then there were the people who were very accustomed to it because they probably just graduated from university or they're used to meetings and things. And I noticed at the very beginning people not knowing how to give and take in conversations with people. They'd either sit or wait to be told what to do. "Well what do you want us to do?" And the response was always... what do YOU want to do? What do YOU think's important? So the people that were heading it did a fantastic job at being inclusive. (person who uses drugs)*

The most important element of these interactions was how the people in power were consciously challenging the notion that they had all the decision-making power and were turning it back to the people who use drugs for them to contribute to deciding how the committee proceeded. The situation explained by the interviewee above displayed how this committee worked at unmasking the flow of power in the committee and worked at shifting it to the people with lived experience to have a say in the committee's work.

I witnessed this type of shift in my observations at a committee meeting. During my observations, I watched people at the table debrief their selection process for new committee members. It was acknowledged that the process could be improved yet also recognized that the committee was a great group in which people stayed for the long run. People at the table discussed how everyone could be involved in the integration and training of new members. The group reminded each other of how it took the committee a year to get to where they were at the moment. A brainstorm session ensued about how to best welcome and support new committee

members. The discussion was animated and everyone was engaged. It was agreed that new members should receive an official welcome during the meeting, that there should be some social gatherings for all committee members to get to know each other, and that a buddy system should be established for support. The effort the committee adopted to make committee members feel welcome and comfortable was appreciated by committee members. This type of effort contributed to the committee's positive culture of inclusion. The process the committee used to decide how to welcome new members demonstrated how they had learned to share power in decision-making.

Another important element of creating a safe space for everyone involved how people who use drugs were recruited and invited to be at committee tables. The way this was done played an important role in the support they received and in their level of comfort and trust at the table. In one committee, people who use drugs were first recruited by public health professionals who, according to some committee members, did not have regular contact with people who use drugs nor the skills to support them. They did not have an ongoing established relationship with them. In part to address this, the public health professionals created positions for harm reduction workers who worked directly with people who use drugs, which helped in terms of selecting people who use drugs to invite to the committee meeting and to support them in that process.

*It's an evolving situation but yeah, prior to [the creation of the harm reduction worker positions], the... public health representatives... were usually like a public health nurse and a sort of management role within HIV prevention or bloodborne pathogen prevention. And some of those individuals historically didn't necessarily have the skill I would say at navigating or facilitating and supporting [people who use drugs] in that kind of way in terms of travel and making sure everybody's safe and looked after... Or finding the right person to attend... I think having the dedicated harm reduction coordinator positions has really helped with that and I think we saw it. This most recent meeting was I think a success or building on the success of the first one. More successful I think than the first one. (policy maker)*

Familiarity and trust helped ease some of power tensions at the table. The role of each person at the table seemed less important than their individual characteristics. For example, in one case, the Chair of one committee was a representative from the public health authority. Many of the organizations at the table received funding from public health. What helped power relations was the fact that the Chair had previous experience working in community organizations, was able to relate to people at the table, and also facilitated off the record discussions where committee members could express themselves without fear of negative repercussions. The Chair had gained the committee members' trust. They also trusted the Chair's opinion on what decisions the committee could or could not move forward. Ultimately, though, the power still resided with public health, and committee members were well aware of that, but relations at the table were more conducive to collaboration.

*I think [the Chair]'s helpful from a strategic perspective and I think [they're] also open to us having conversations at those meetings that are off the record or that [they don't] take back to [the public health authority], and that's more of a personal dynamic that I appreciate about [them] and maybe if it was somebody else from [the public health authority], it would be different. I think that's just a strength of [the Chair]'s... [They] allow us to take that space up with those conversations... But I think that only works because we all have a certain level of trust in [them]. (service provider)*

*I think the... group there appreciate the position I'm in. I think that they do appreciate me as an ally more than a funder and... I have loads of experience and many of them I've worked with for many years in different capacities, right? So I think that there is a certain amount of trust of, you know, [I] can only do this much, right?...Or we can't do that here. (policy maker)*

One important finding in this example is that when both the decision-making power is clearly situated for all committee members to understand, and when the committee members have trust in the person in power, there is more room for practicing democracy. According to Brookfield (2009), Lindeman identified "learning to live with the partial functioning of the democratic ideal" as an important democratic discipline within a group. Committee members, in

this example, understood that they did not have much power but the Chair's approach and the trust they had in them helped with the group's functioning.

It also took some time for people who use drugs to come to trust allies. When I asked one person who uses drugs what made the difference between who they considered an ally and who they didn't, the answer was simple: allies walked their talk. Allies also spoke *to* people who use drugs, not *at* them:

*What makes the difference? Uh, actions. Actions speak louder than words. And "Trust me, trust me, trust me because I'm an ally" means I'm NOT going to trust you. (laughter) You know?... it doesn't matter who you are, like, or if it's on the street or wherever... if a person says "trust me, trust me, trust me", that's the last thing you are going to do... [One researcher]'s a fucking ally, wow! Yes and it's...that sense of you talk TO us, not AT us. So there is that difference. (person who uses drugs)*

Trust developed between people who use drugs and others at the table was precarious, however, and could easily be eroded with careless, stigmatizing remarks:

*I: Just like sometimes dealing with like stigmatizing people like, you know, you sort of have your guard down and then all of a sudden like there's some person, it's almost like a wolf in sheep's clothing, right?*

*L: It surfaces.*

*I: Yeah, and then you're just like taken aback, right, because you felt so comfortable and all of a sudden you are like "oh, oh shit, like I'm not safe here", like you know what I mean? (person who uses drugs)*

Trust also must go both ways, in that allies need to trust people who use drugs with responsibilities. This point gets back to the dominant tendency to underestimate people who use drugs, as discussed in Chapter 4.

*I think we're all capable of being rational and having a say in... decision-making about what happens to people on our committee and stuff. So like I think we're capable of that. I think we all are. But like we're just not given enough chance to, if you know what I mean. (person who uses drugs)*

*I think it feels good for the people themselves to be invited, to like be trusted to stay in a hotel and to like, you know, to sit at the table and, you know, to sort of feel like you're a part of something and to sort of talk with a lot of the people that maybe at one point would be making decisions about you. (person who uses drugs)*

These measures taken by committees created a safe space where people who use drugs and others at the table could feel comfortable. There were intentional attempts to include people who use drugs in the committee's decisions and to build trust building. This atmosphere contributed to fostering a sense of freedom in participants, which ultimately helped to overcome alienation according to Brookfield's Seven Learning Tasks.

Another important element contributing to creating an even playing field, one that was common to all committees included in this study, was a sense of common purpose and solidarity to work together to improve life conditions and services for people who use drugs. Amidst a social environment where people who use drugs are criminalized, marginalized and stigmatized, unmasking power and working to improve conditions in which people who use drugs can live healthier lives can be seen as a social movement:

*What I value about it as well is just I think sometimes that work related to illicit drug use and harm reduction in particular is really isolating and so to have an opportunity to just share information and share a sense of camaraderie and solidarity is really, really important and so I've really appreciated it just for that. (service provider)*

This social movement climate in the committees fit well into transforming power relations as it shifted the focus toward serving the interests of the many instead of the few. It contributed to enhancing a collective, collaborative purpose to the committee's work. It provided mutual support for both people who use drugs and people who work with them who often experience stigma for working in harm reduction. This common purpose seemed to also encourage everyone to share the responsibility for change:

*The people really want to see the change, you know? Like that they're willing to act on it and that everyone around the table is willing to take on a little piece of the responsibility. It doesn't always fall back on the chair or on the people who run the [committee].*  
(service provider)

In a sense, the alienation experienced by service providers working in harm reduction and serving people who use drugs helped them relate to people who use drugs and the stigma they experience. Together, they could work toward fighting those alienating forces, thereby contributing to shifting from power over to power with people who use drugs. Furthermore, this sense of solidarity contributed to learning liberation from dominant ideology, in the sense that individual liberation was seen as being dependant on collective liberation. This inner revolution can lead to an outer revolution that calls for new ways of social, economic and political organization.

Overcoming alienation was also fostered through supporting each other. One committee had succeeded at creating a supportive culture amongst its members, as described below. People who use drugs had been well supported in the committee process and had learned to do that for others on the committee as well. The quote below provides a good example of learning a culture of mutual support and inclusion in the context of such committees.

*I: There's so many eyes watching and we're all looking out for each other that someone is going to come to you. I mean it's happened to me many times where someone has come up to me and has been like "You started to say something and stopped at the meeting. Was there something you wanted to say?"*

*L: Oh, lovely, yeah.*

*I: You know? "If you think of it, if you don't remember now and you think of it, let me know, call me. Was it this?" You know sometimes even if it's nothing at all.*

*L: Yeah, but they check.*

*I: Absolutely. So there's a lot of eyes watching, and not just from [the researchers] either. At the beginning it definitely was, and it still is 'cause that's their jobs and they're really good at it. But now we do it for each other as well, you know what I mean?*

*L: Yeah yeah. You've learned that process, I guess.*

*I: Totally. Totally. And especially some of us that would have never, never done that before, you know what I mean? (person who uses drugs)*

Support for people who use drugs to ensure they were prepared to participate in committee meetings also contributed to leveling the playing field. For people who use drugs to feel comfortable and included at the table, and for them to be properly equipped to participate in a meaningful way, it was recognized that there should be time invested in bringing them up to speed on the committee's work:

*That's something again... [we] need to be doing as good a job as possible to identify the right people to come to the table, to prepare them in a way that's going to allow them to have their voices heard and feel like they could speak up... I know some of the people who were supporting did do a really good job of preparing [people who use drugs] and others much less so and I think it was obvious or apparent in the interactions of the contributions by those specific [people who use drugs]... it was the support they were getting in preparation that led to their involvement in a certain optimal way. (policy maker)*

Properly informing and preparing people who use drugs to attend committee meetings also provided a form of informed consent, which was not always the case, so that the people invited to speak from lived experience knew what to expect and what was being asked of them and they could then decide whether they wanted to participate:

*I also explained how [the committee] works, like sort of reassuring that what kind of people [they are], what kind of room they were walking into... And also put upfront that they would be getting paid... It was like before you say yes, you should know these things and you can say yes or no depending on whatever. And you can change your mind at any time. (service provider)*

Similar to measures taken to attempt to alleviate the financial hardships that may hinder people who use drugs' capacity to participate in committee meetings, measures have to take place, as much as possible, to attempt to level knowledge of the committee's mandate, processes, meeting etiquette, and decision-making structure and the context within which the committee operates. Properly preparing people who use drugs who are invited to committee meetings is another way to shift from power over people who use drugs to power with them.

One other important development to point out is the learning that took place from one year to the next regarding the inclusion of people who use drugs at the table and the improvements that were made or planned for the future.

*So that process is improving every year. There's a lot of organizational materials and meetings that we do with the [committee] reps prior to inviting [people who use drugs]. For example, just a guideline regarding what the day is going to look like, how to organize[their] travel and who's taking on that responsibility to help oversee the taking care of the [people who use drugs] coming... So things that we talk about before is like stipends, transportation... And so and the reps are supposed to meet with the [people who use drugs they invited]... before and brief on what the committee is and what the committee does. Just so like we don't do everything and just so they are sort of aware as to what our mandate is. Also then thinking with [people who use drugs] as to what they want to bring to the table and share at the table. (policy maker)*

*Yeah, basically it's to let them know the format and what we're seeking, what knowledge, and letting them know that they DO have knowledge and they ARE a partner but it is a place where you are going to be in an environment that's totally different than what you are used to. Making sure they know where supports are available, when they're available there and that they can have breaks and what I do when I prepare is recognizing the difference and the awkwardness 'cause it's a HUGE awkwardness and difference when you go into a facility or government type environments. They're very unfamiliar and uncomfortable for the most part. (service provider)*

In these examples, there was recognition that a democratic process that enables people who use drugs to come together and to select who they want to represent them at committee tables was an important component of inclusion. There was also recognition of the importance of honouring the diversity of backgrounds and experiences people may or may not bring to the table and taking measures to make inclusion practice more comfortable for everyone. These elements are part of practicing democracy, as described by Brookfield (2009).

Once measures were taken to establish a safe place where people at the table could feel comfortable and come to trust one another, the setting was ripe for authentic relationships to blossom. The next section touches on authentic relationships and their role in transformative learning for social change.

### **Authentic relationships.**

More authentic relationships develop between humans who have developed an awareness of who they are and how they relate to others (Dirkx, 2006). Referred to by Carl Jung as ‘individuation’, this process involves coming to a deeper understanding of who we are as individuals, separately from the influences of social and cultural contexts in which we find ourselves. As we learn to become more fully and authentically who we are as individuals, we enter more fully and authentically into relationships with others (Dirkx, 2006).

In this study, establishing more authentic relationships allowed people at the table to promote critical reflection and have questioning discussions, share information openly, and achieve greater mutual understanding. For committee tables to be spaces where power inequities can be transformed, building trusting and authentic relationships is essential (Taylor, 2009).

For the most part, people at the tables included in this study felt support from coming together, as well as a sense of common purpose and solidarity. The atmosphere was generally welcoming and accepting of differences, despite signs of lingering stigma regarding people who use drugs mentioned in Chapter 4. These next few quotes offer glimpses of the importance of authentic relationships:

*I found it pretty warm and inviting, you know. There was no, I don't know, I guess what would you call it? Degrading a person because they are where they are, right? I found it, you know, like they were pretty accepting people and their problems or whatever's involved, right? So it was, you know, it was kind of good. You know, there was no hypocrites there. Well, there was a little bit of that there but, you know, not as much as I thought there would be... I felt accepted there, put it that way... I just didn't feel out of place, put it like that. (person who uses drugs)*

*[The Chair] just sort of respects people and builds their capacity as opposed to like squashing them... [They're] very protective and I'd say [they're] very real. (service provider)*

A warm, inviting and respectful atmosphere where people felt they could be themselves helped overcome alienation. The idea of ‘being real’ emerged, as did the importance of dropping one’s role and relating to each other as human beings:

*I think that that’s such an interesting thing that happens though, hey? Like when people just meet as human beings as a group. Like that’s what I love and I feel like even with the committee... I don’t actually really see people showing up in their roles. (service provider)*

When people, especially people who use drugs, did not feel like others were being real, they had a tendency to seek support with their peers. It also shut down communication between them and the people they did not feel were relating to them authentically:

*I might like talk to [a peer] about some stuff that bothers me but... there’s like a certain type of social worker... but I can never tell if I’m talking to a real person, you know? It’s like you’re a perfect little social worker clone and you’re fantastic but I can’t connect with you on a human level. Like there’s just this perfect veneer all the time... there’s a lot of things that I just don’t see what the point of talking about it would be because I would just get the typical answers like “oh well, you know, like that’s how it is” and just like the typical things that I already know but it’s not fixing anything. Do you know what I mean?... And it’s like just where’s the real person? So... like it took me like a year of working with like my boss at [another organization] before I got to the point where I was like I need to talk to the real [you] right now! And [they were] like OK. (person who uses drugs)*

People who use drugs felt welcomed when others were relating to them the same way they related to everyone else:

*I: They made us feel very welcomed. I was very comfortable there.*

*L: What made it that you felt welcomed?*

*I: I think just they interacted with us like they did with everybody else. There was no “Oh, you’re a [person who uses drugs]”. You know, some people look down a little but there was none of that. They were very welcoming and ready to talk and non-judgmental. (person who uses drugs)*

As this last interviewee points out, authentic relationships enhanced a welcoming atmosphere, as did people’s openness to dialogue and open-mindedness. Relating authentically

contributed to overcoming alienation. It also brought about ideal speech conditions which Habermas identified as essential in communicative action (Brookfield, 2009).

Curious as to whether it would be beneficial in some way for committees to dedicate some time to getting to know each other by sharing each other's stories, I asked interviewees whether the committees they participated in ever provided the opportunity to do this. I wanted to know if there was ever any intentional effort for people to hear about and open up to each other's differences. None of the committees I included had done that, and committee members I interviewed did not seem to think this needed to be done. In fact some even mentioned that *not* sharing personal stories contributed to everyone being treated equally. The space created in the committees seemed conducive to people having the option to share their story if they chose to.

*It's open to share if you want to but we've never gone around and been like "Tell me your background or tell me where you're from"... We just kind of respect like... you're in the business [of harm reduction] which means you're in for a reason... Like it's just we're all equal and we've never been questioned... It's actually kind of nice to be at a table where that stuff isn't directly talked about. Like I don't have to be like "Well I have a social work degree, and I work in addictions because blah blah blah blah blah, right? Like it's just nice that everyone kind of accepts that like you might have education, you might not have education, you might have practical experience, you might use drugs... right? Like I don't know anyone's background so I just treat everyone's information as completely valid 'cause I have no reason to discount it or to give it any more or less weight than anyone else. (service provider)*

*But that's something that's nice too like if you DO want to share, like people are open. You can share as well so... it's pretty balanced. (service provider)*

My curiosity about the impact of storytelling stemmed from thinking that perhaps this would contribute to fostering authentic relationships. The other important aspect, in my view, was that people with lived experience came to these tables to share their personal experiences. This placed them in a vulnerable position of opening up and exposing their life experiences and conditions. It felt quite one-sided to me. Trust was generally important for people to feel safe to tell their stories. Personal stories did, however, establish the credibility of the person with lived

experience in the context of these committees. Authentic relationships entail *shared* vulnerability, especially if our goal is to transform power relations toward more equitable ones. I also think that doing so would create a bridge between ‘us’ and ‘them’ once people realized that some of them share common experiences. A few interviewees shared my views:

*I think like we’re really, in our work, really cautious about asking people about their lives. It’s like people offer so much already that I rarely ask anybody about like where they’re from... you know, that type of thing. But I suppose... if that would be something that would benefit, you know, the community who are working with us, like the [people who use drugs], if they would feel safer in these environments for us sharing more about us, ourselves, I would be open to that idea... ‘Cause staff, like, we know usually why if there is a person there, why they are there, why they are representing or who they are representing and so, yeah, it would be interesting. It’s very one sided, though. Like I know a lot about a lot of people and... in my work who don’t know anything about me. (service provider)*

*Yeah, I don’t know. Yeah, that’s interesting. ‘Cause like I think if you start like... all of a sudden you just have like that kinship ‘cause we both like went through those experiences, right? And if you could break down like some of those barriers like maybe everybody could feel more comfortable. (person who uses drugs)*

However, sharing personal stories might also serve to reinforce some of the power inequities.

The findings regarding whether sharing each other’s stories would contribute to more authentic relationships was therefore inconclusive and warrants more probing.

One measure that was generally agreed on in terms of building authentic relationships and getting to know each other was through social activities and co-learning activities.

Socializing with each other helped people relate to each other:

*Having the food there and having an opportunity to sort of mix and mingle and chat a bit more informally. (policy maker)*

There was still a tendency, in some cases, for people to socialize with their peers:

*I have some lived experience. I also have some research experience... and because we are, say, organized along different social markers, different groups in the committee socialize with each other and I'm in between, right?... it's kind of me in between sometimes I'm hanging out with the people doing the administration, sometimes I'm hanging out with the [people who use drugs], sometimes I'm, you know, doing nothing listening to music, right, just hanging around, so... it's been a tightrope, almost for me. (service provider)*

Nevertheless, some expressed the need for more social time between committee members:

*The only thing I don't like is we don't have enough social time. We'd like more social time with each other. Yeah, you know, just have fun. A little bit more, anyways. We're all busy people, you know, 'cause it's basically volunteer work... none of us are in it for the money 'cause it doesn't pay much anyways so we're in it for the love! We want stuff to happen so a little bit more fun would be good. (person who uses drugs)*

At one gathering I observed, before the actual committee meeting, everyone participated in a training session on overdose prevention. This co-learning session was a great way for everyone to share an experience together and get to know each other:

*We had the naloxone training the previous day... In some ways we were all learners during the training part so there was some equalizing. (policy maker)*

It had the added value of each of us walking away knowing what to do in case of an opioid overdose. People who use opiates also walked away with overdose prevention kits. In the session, everyone was learning together. If anything, people who use drugs had the upper hand in the sense that they could share their expertise as some of us attempted to inject an orange. The session provided humour on a serious topic, broke the ice and contributed to preparing everyone to share a meeting table the next day and it evened the playing field:

*Everybody was like I think really keen on getting naloxone training and also it's like kind of an activity that we all do together. I think that... it really helped like break the ice, right? It's like when you're in a classroom about something you don't even know, like all of a sudden you're just closer 'cause you're working together and learning things together. (policy maker)*

*We were all really excited, we get to stab an orange. You know, it was kind of light hearted about a serious matter but it was good. I think it helped us all to kind of just get into something and be all in the same playing field, all at the same level. (person who uses drugs)*

Through this training on overdose prevention and administering naloxone, all participants got to share a learning experience. For those who had never used an injection before, including myself, it exposed us to a world that was not their own. Through this experience, we learned liberation from our everyday life, to a certain extent, in a situation which temporarily estranged us from our everyday world, by providing a glimpse into the world of people who use drugs. This type of estrangement, according to Brookfield (2009), is disturbing in a revolutionary way.

Finally, in terms of creating a safe place, committees took specific considerations into account to cater to everyone's needs to enable them to feel safe and have a positive experience. In the same way as most meeting hosts poll their participants in terms of dietary restrictions and mobility challenges before a meeting, measures specific to the realities of people who use drugs were taken. Key considerations included travel considerations such as identification requirements, providing harm reduction supplies, information on where to obtain methadone close to the meeting, support for people who choose abstinence and/or who may experience triggers, and access to nearby health and support services.

*So if there's methadone, people get carries... so methadone mostly people do get carries with them. If not, we can just arrange for them to pick up their methadone at a pharmacy up here... and regarding harm reduction supplies, actually there's two [people who use drugs] that were at the meeting and we hire them also to be [city] guides and the [people who use drugs] knew that if they needed something, you know, to stay safe... talk to the two [people] from [the local organization of people who use drugs]... and I let the [people who use drugs] know that I actually have packages with harm reduction supplies in little paper bags that they could take with them. For THIS year I think for most [people who use drugs], they didn't pick up the safer supplies, mostly because they... could travel by car... So I think most peers sort of if they needed anything, had brought their own...*

*The peer who traveled by plane didn't have any ID. Like no photo ID whatsoever but they traveled with [a committee rep] and got on the plane there and back together. (policy maker)*

The efforts made to cater to these needs were not always clearly communicated to people who use drugs, as there were some discrepancies between what people who use drugs were aware of and what meeting organizers felt they provided. There were also inconsistencies from one meeting to the next:

*Last year they had people from [the local organization of people who use drugs] come meet us. They brought us like peer packs, like all the [people who use drugs] like got like rigs and whatever they could have possibly needed... So... it was... more well thought through last year than this year... yeah, it was just, I guess an oversight or something and like there was no sharps containers or anything like that. (person who uses drugs)*

Some of the participants' needs, however, were not met in terms of being supported through triggers brought on by the content of the meeting:

*Yeah, they definitely didn't think of [people who choose abstinence]. I ended up using... from watching that video that we watched... everybody is talking about doing dope and I was just like oh my god! It's like I'm magnetized down to [a certain part of the city], right? (person who uses drugs)*

Hosting meetings where people who use drugs were invited required addressing some of their particular needs to make them feel comfortable and to create a safe space. When people felt this was achieved, and when they could relate to each other more authentically, they were more apt to be open to dialogue.

### **Dialogue.**

Dialogue provides a medium through which transformative learning is promoted and developed (Taylor, 2009). As part of creating a safe space, findings showed that conditions conducive to relational, trustful and reflective dialogue included encouraging openness to alternative points of view, ensuring equal opportunity to participate in the dialogue without

coercion, and ideal speech conditions. Trust developed through dialogue. The setting also needed to help participants live with some discomfort and conflict that arose during dialogue. Creating this setting for dialogue was greatly influenced by skilled facilitation.

In terms of equal opportunities to participate in the dialogue at the table, findings revealed that the people who use drugs interviewed and observed were quite outspoken in general:

*I want things for [people who use drugs]. And I'll speak up 'cause you know I'm outspoken. I'll speak up for them.* (person who uses drugs)

*If I want to say something, I say something. Ha ha. I don't really care... I just can't help but say something when I hear something, I'm like "no, no, no, hold on."* (person who uses drugs)

This finding speaks to personal characteristics of the type of person who was drawn to participating in committees. It also reflected the open and safe atmosphere at the tables observed:

*I: Everybody was very open and, you know, interested in what anybody had to say. You know it's not like anybody was being ignored by any means.*

*L: Yeah. So you felt that they gave you lots of space to provide input if you wanted?*

*I: Yeah, exactly, yeah.* (person who uses drugs)

One person did share with me their views on some of the challenges some people who use drugs may face in expressing themselves at the table. Challenges included difficulty in expressing themselves clearly and of being asked for their opinion in a committee setting that may not be familiar to them:

*Maybe a little shy at the beginning at certain points. And also just not being used to wording things, you know what I mean, when I have a real struggle with words and how to put them in order... (person who uses drugs)*

*I think is kind of scary sometimes, you know, especially when you are being asked your opinion...when it comes down to it where a piece of paper is put in front of you, and it's like "Well OK, you've had some really great points, why don't you pop those down and then you can say that at the next meeting or at a forum" and that's pretty scary.* (person who uses drugs)

All of the examples above point to the importance of the approaches and conditions that foster a sense of freedom in people who use drugs at committee tables. While some people who use drugs display agency and did not hesitate to speak, others have had to learn to develop agency, which is part of Brookfield's learning task of unmasking power. There were also times when some people who use drugs dominated the discussion and took the opportunity to rant about an issue that concerned them.

*It's sometimes quite difficult to reign in an angry [person who uses drugs] who has a rant, who's going to... "I don't care what this committee's about, this is what we're talking about". So even just to get through that stuff requires longevity and patience and structure. And honesty, you know? (policy maker)*

How such situations were handled had an impact on people who use drugs' participation in committee meetings. Facilitation skills that helped address this imbalance included patience, structured meetings, honesty, specifically asking people who use drugs for their input and a hand raising policy:

*We have some very strong personalities that CAN dominate a bit during decision-making processes and other people can be quite silenced by that as much as we do try to have a hand raising policy and ask people who have been quiet. We are cognisant of that but it is certainly at play so I think there have been instances where people have NOT felt like their voices have been heard in decision making. (researcher)*

In one reported case, in an attempt to subdue one person who uses drugs, the situation was handled in a patronizing way which deterred the person who uses drugs from participating in committee meetings:

*Yeah, [one person who uses drugs] very sporadically comes though, yeah. And I don't blame [them] either... They're really condescending to [them], you know, like kind of just appeasing [them] and stroking [them] all the time and it's really quite offensive. It's not cool at all, like "There, there,... relax. You'll have your turn." Talking to [them] like a kindergarten teacher sort of thing and I could see how [they] wouldn't like that. (person who uses drugs)*

In my observations, I also witnessed people being allowed to express themselves, even in an angry, agitated manner, without others escalating into rage. In fact, in one meeting, the facilitators were skilled at dissipating the anger and agitation by remaining calm, and validating the person's concerns. According to my field notes, I was struck by how many committee members focused on a person's expressed concerns, rather than the way the message was being delivered. By acknowledging and valuing the person's concerns and truly listening to what they were expressing, the energy was easily dissipated and the meeting carried on. This way of allowing people various ways of communicating while remaining constructive was valued by committee members. It contributed to creating ideal speech conditions which in turn enhanced democratic processes, as described in Brookfield's (2009) framework:

*I think it's probably one of the most inclusive tables I've been at just because [the Chair] really sets an example of allowing for those variances in how people communicate and doing the best they can to change the committee, like getting the feedback and then respond to the feedback that they receive and changing it to make it more accessible. (service provider)*

Even though I witnessed people being allowed to voice their concerns, even in an angry and agitated manner, and it being facilitated well to the point of remaining constructive, one policy maker expressed concerns about the lack of structures and skills to be able to truly talk to each other and hear each other:

*We don't have structures in place to learn how to talk to each other... I don't think we're taught to hear value in... what somebody is saying. They might not be articulate, right? They might not speak a language that bureaucrats or policy makers understand but they are bringing a piece of information that's... important...And you need to be able to hear it, which generally means you have to lose a lot of your baggage and stereotype and discriminatory ideas that we're all raised with. (policy maker)*

Being able to hear what someone was saying, regardless of how it was delivered, required one to be able to challenge one's own dominant beliefs and stereotypes about others, an important transformative learning task.

During observation of one meeting, it was also pointed out that people need to be mindful of the language and terms used at these tables, especially when it comes to referring to people who use drugs. The example of using the word 'peer' came up in one interview with a researcher where they felt that it could be stigmatizing:

*We have to be able to show the world that the knowledge that comes from lived experience is SO valuable and so INCREDIBLY important and more important than academic knowledge in this case in terms of harm reduction, in terms of community capacity, to affect change in their own community. That is the most important knowledge and we privilege that knowledge more. So we need to celebrate that and be like look, we have peer researchers and they're doing amazing work. Look, we have peer HIV testers and it's working and it's more accessible to the community. So we have to be able to like shout that out to people so they pay attention, but at the same token, that's labelling the people in our committee who we work with as colleagues... And so we talked a lot about the fact that within [this study], we are all researchers... There was a lot of talk about getting the barriers between those two groups knocked down. And so like bottom line, everybody's a researcher... We're trying to figure out the best way to kind of push forward the agenda of peer inclusion without over labelling or over stigmatizing that role. And that's challenging. (researcher)*

Indeed, being mindful of language and using ideal speech conditions contribute to practicing democracy, as does being open to alternative points of view.

Keeping the dialogue constructive fostered an environment where people could share differing views:

*If it's an idea that you start with, it can be built around the table, and even, you know, there's always some opposition, but it's always constructive. You know, no one ever kind of throws their hands up and says it's ridiculous. It's always well received and it's a discussion that everybody has around the table. (service provider)*

Others' views were generally well received and if someone's view was opposed, they were provided with the proper explanation. Handling opposing views with respect was valued amongst the committees.

*I think the fact that we're like comfortable and respectful with each other. Like yeah, there's never like a big argument or anything but like, you know, we can like have a back and forth of ideas and stuff but then, yeah. It's respectful. (person who uses drugs)*

There was also evidence of committee members displaying empathy and concern about important issues raised by their colleagues.

*Hearing other people's perspectives on different things... gives me pause for like considering where people are coming from. (service provider)*

The example above reveals a display of Habermas' ideal speech conditions whereby people at the table were open to new perspectives and willing to temporarily put aside their own perspective to consider the perspective of others (Brookfield, 2009). This important aspect of dialogue is essential for practicing democracy.

Furthermore, the fact that people bring many perspectives to the table was valued and, as one interviewee put it, "the truth is kind of in the middle of everything that everybody's discussing". All these perspectives and views contributed various angles of a bigger picture and were complimentary.

*I think that we balance that, you know, recognizing like anybody else around the table, [people who use drugs] are coming from a perspective on things and that the truth is kind of the middle of everything that everybody's discussing and that it's not anybody's particular point of view as the right thing but as we hear about it from as many angles as possible, we get a better sense of what the picture is. (service provider)*

This openness to each other's perspectives and views contributed to creating a space where people could still express their strong views, oppose each other and argue, and maintain the

respect and constructive purpose of the meeting. This atmosphere was conducive to practicing democracy and, based on the above example, led to collective ownership of ideas.

This section on “An Even Playing Field” summarized findings that emerged in interviews and observations related to creating a safe space to practice democracy. Important components of creating that space include taking measure to host people who use drugs and make them feel comfortable and safe, shifting the dialogue toward including people in taking responsibility for decisions made, fostering trust, providing support, relating to each other authentically, providing social and co-learning opportunities and facilitating meetings in such a way that allows for various ways of expression and mindful language that does not reproduce stigma. Once a safe space had been created around the table and people felt free to express themselves, it provided an environment conducive to practice democracy.

### ***“No Burrs under the Saddle”*: Practicing Democracy**

To move from having decision-making power over people who use drugs to having power with them, findings revealed two important aspects of practicing democracy in the inclusion of people who use drugs: the importance of negotiated relationships and consensus-based decision-making. First, for context, this section briefly makes the distinction between the various models of giving power to people who use drugs.

If we look back on Arnstein’s (1969) ladder of participation, described in Chapter 2, she identified three different echelons of citizen power, namely partnership, delegated power and citizen control. It is important to note that the committees included in this study did not completely cede decision-making power over to people who use drugs, as is suggested in Arnstein’s ‘citizen control’ rung where the power to govern resides with the people. Rather, they were strategic alliances whereby people who use drugs came to the table and the ultimate power

resided with an organization or institution and where people who use drugs contributed to decision-making to a greater or lesser extent, as described later in Chapter 6, when power is situated within each committee. What is important to point out, however, in the democratic process, is the extent to and clarity with which relationships with people who use drugs were negotiated prior to their engagement in the respective committees' work.

### **Negotiated relationships.**

Negotiating relationships prior to people who use drugs coming to the table is an important part of meaningful inclusion and democratic practices, similar to the role informed consent plays in the recruitment of study participants in research. The information in this section was extracted in large part from document reviews, and complemented with data from interviews and observation. For each of the committees included in this study, relationships between people who use drugs and the policy makers, service providers and research who invited them to the table had been negotiated to varying degrees. Clarity as to one's role and level of power at the table influenced power relations and the practice of democracy.

In the policy committee, people who use drugs were *not* committee members and were invited to a yearly face-to-face meeting for consultation. Some people who use drugs knew what to expect and what was expected of them prior to attending the meeting, while others didn't. Some understood what they were walking into and their role at that table. More importantly, some were better prepared and told the extent to which they could possibly influence the committee's decisions.

In the case of the two service providers committees where one or two representatives of people who use drugs participated, decision-making by the committee was minimal and people participated more for exchange of information and support than to contribute to decisions that

affect them. One person who uses drugs saw their role on this committee as one of consultation. Other people who use drugs mentioned they were at the table more as service providers than as people with lived experience, as explained in Chapter 4. There was therefore some lack of clarity regarding their role at those tables and what was expected of them as representatives of people who use drugs.

In the case of the research committee, however, while the ultimate decisions resided with the principal investigator even though the majority of seats on the committee were held by people who use drugs. Regardless of the level of influence people who use drugs have at a table, it is essential that relationships between people who use drugs and researchers, policy makers and service providers be properly negotiated at the onset. One researcher shared their views about negotiated relationships:

*I think there are a lot of times when I have been involved in projects that say that they are inclusive of community and that means that they have a very specific kind of role that they allow people to enter and I think what I love about THIS project is because it's so grassroots and it's so evolving, we're able to kind of negotiate these relationships in a much more meaningful way. We're not bound to these bureaucracies and these kinds of role definitions that were pre-existing. We got to invent them on our own. (researcher)*

The research committee had clearly defined the role of people who use drugs at the table and, furthermore, as part of Brookfield's learning task of unmasking power, was deliberately innovative at experimenting with how to organize collectively to maximize their democratic process. The role of people who use drugs in this research committee was clear and co-created, put into practice and discussed along the way. The dynamics of the importance of negotiated relationships played out in the decision-making processes practiced by each committee, as explored in the next section.

### **Consensus-based decision-making.**

Ultimately, when decision-making power was shared between various parties at the table, consensus-based decision-making seemed to be optimal for meaningful inclusion. One small example of this emerged during observation of the policy committee meeting. The agenda had the meeting going until 12:30 pm before pausing for lunch. One person who uses drugs was fading and expressed a preference to pause for lunch at noon before moving on to the next agenda item. After a brief discussion, the proposal was accepted. The person who uses drugs felt comfortable enough to express that need and the committee adopted the suggestion, after a brief discussion, and by consensus.

In a more ongoing decision-making situation, like in the case of the research committee, all committee members contributed ideas. Committee members felt that their voices had repercussions.

*Here, [what I say is] really taken seriously and considered and, you know, quite often put into place, you know what I mean? Because I think they do value my voice and, you know, know my love and passion for my people and this program and harm reduction in general. (person who uses drugs)*

In terms of decisions, ideas were built on, changed, discussed, negotiated, debated until such a time as consensus was achieved. Proposed ideas were discussed to the point that whoever proposed the original idea was often lost and became collective ideas.

*It's such a negotiation all the time. Pretty much anything I've thrown out to the committee has been debated excessively and changed by the time it gets to the acceptance phase. (researcher)*

Even though, as mentioned earlier, the principal investigator had final decision authority for the project, decisions were usually made by the committee and rarely did the principal investigator exercise this ultimate power over the committee's decisions.

Finally, the research committee truly avoided the temptation to bypass the democratic process to reach a fast decision, an important democratic discipline (Brookfield, 2009). In fact, as one committee member put it, they really strove to avoid ‘burrs under the saddle’ in their decision-making process, which could continue to be sources of aggravation. They valued consensus above anything else. Though time consuming, this process contributed to the committee’s culture of valuing everyone’s voice:

*I: We would much rather have consensus than anything else. Yeah. If we can. I mean if there’s one person who’s adamantly against something, well there’s a reason there and we’re going to go down that road until we find that reason and, you know, it could be something personal to them or it could be that they see a fault in a lot of us, you never know. It could be one person can see something the others can’t. It’s usually not that way but, you know. Usually it’s not the one person. Usually it’s the one person that has the odd opinion, not all the rest.*

*L: So OK so you guys discuss it until that person is either what, convinced?*

*I: Or at least half convinced or can go along with it. You know like we don’t want someone adamantly against something. It’s going to be like a burr under our saddle. It’s not going to sit well with us. We’re going to want to talk about it... It’s not always bringing THEM around, the one person, sometimes it’s bringing everyone else around to THEIR position. It could work either way. (person who uses drugs)*

This practice of consensus-based decision-making had an impact of turning individual ideas into collective ones and encouraged practicing openness to others’ perspectives.

Consensus-based decision-making helped shift decision-making power from power over to power with people who use drugs.

## **Summary**

This chapter explored Table Manners by reporting findings observed *in situ* and heard through interviews with committee participants on the interactions that took place around committee tables. Findings were revealed with regard to stigma against people who use drugs and its impact on power relations, as well as creating a safe space at the table for people who use drugs to feel free to express themselves and overcome alienation, get comfortable with each

other, build trust, relate to each other more authentically and engage in meaningful dialogue. It also explored elements conducive to the practice of democracy, namely negotiated relationships and consensus-based decision-making.

People at committee tables brought with them their socially constructed views about and stigma against people who use drugs. Despite best intentions of social inclusion and willingness to challenge power inequities, there was still a lingering tendency to underestimate people who use drugs' capacity, skills and expertise other than their lived experiences related to drug use. These views hinder the true participation of people who use drugs. People who use drugs also held these views and expressed some internalized oppression and self-hate. As a result, they often overcompensated to meet or exceed the dominant standards. They strove to excel and perform to a high standard in order to challenge the stereotypes attributed to people who use drugs. To help challenge the stigma and stereotypes associated with people who use drugs, there were example of some allies challenging these views. There were signs of critical reflection among the committees to deconstruct these socially constructed views.

Creating a safe space encompassed creating an environment where everyone at the table could get comfortable with each other and build trust. Achieving these goals required time for everyone to establish their role at the table and settle into it. Properly preparing people who use drugs before their attendance at meetings contributed to their level of comfort at the table. Trust between people who use drugs and others at the table took time to grow and could be quickly eroded with careless and stigmatizing remarks. Everyone at committee tables shared a common purpose and solidarity around improving harm reduction services for people who use drugs, which helped foster an environment of collaboration and mutual support to combat and face stigma attributed to people who use drugs and harm reduction services to serve them. Skilled

facilitation that involved consciously distributing power in decision-making and turning it back to people who use drugs for them to contribute to decisions helped the shift from power over people who use drugs to power with them. Setting the example of mutual support and inclusion resulted in fostering an inclusive and supportive culture at the table.

Fostering authentic relationships between people at the table, where they could develop a deeper understanding of who they are as individuals separately from social and cultural contextual influences, helped foster mutual understanding and transform power relations. A warm, inviting and respectful atmosphere where people felt they could drop their roles and be themselves helped create a safe space. Social activities outside of meetings as well as co-learning activities helped foster authentic relationships.

To create a safe place, some committees also took specific measures to cater to the needs of people who use drugs to enable them to feel safe and have a positive experience. In the same way as most meeting hosts poll their participants in terms of dietary restrictions and mobility challenges before a meeting, key considerations included travel considerations such as identification requirements, providing harm reduction supplies, information on where to obtain methadone close to the meeting, support for people who choose abstinence and/or who may experience triggers, and access to nearby health and support services. A safe space was conducive to relational, trustful and reflective dialogue, which promoted transformative learning. Skilled facilitation that allowed for various ways of expression and the mindful use of language that does not reproduce stigma also contributed to creating a safe space.

In terms of democratic practices, two important aspects contributed to shifting from power over to power with people who use drugs: negotiated relationships and consensus-based decision-making. Regardless of how much decision-making power people who use drugs had at

committee tables, the extent to and clarity with which relationships with people who use drugs were negotiated prior to their engagement in the respective committees' work was important for the democratic process. Clarity as to one's role and level of power at the table influenced power relations and the practice of democracy. Sharing decision-making power between various parties at the table through consensus-based decision-making seemed to be optimal for meaningful inclusion. In this process, ideas were built on, changed, discussed, negotiated, debated until such a time as consensus was achieved, to the point that whoever proposed the original idea was often lost and ideas became collective ones.

In Chapter 5 on Table Manners, findings related to fostering a shift from power over to power with people who use drugs. Next, Chapter 6 focuses on political contextual factors and how these affected power relations at committee tables.

## **Chapter 6: Table Setting: The Influence of Political Context on Opportunities for Inclusion**

### **Introduction**

For power relations to take place between people who use drugs and people in positions of power who make decisions that affect their lives, opportunities and spaces must exist for everyone involved and affected to come together at decision-making tables. Political contextual factors as well as personal characteristics influence opportunities for setting up such tables. Once those opportunities exist, the power relations that take place at the table are also influenced by such contextual factors.

Based more heavily on document reviews and some relevant literature than previous chapters 4 and 5, this chapter contextualizes opportunities for people who use drugs to be at decision-making tables. It presents findings on the trend in mobilization of people who use drugs and how this movement is challenging power relations at decision-making tables. Finally, it offers findings on the influence of policy on power relations at the table. These findings are complemented with relevant findings from interviews and observations and touch on core elements of transforming power inequities in these contexts.

### ***“It’s Policy that the Problem”*: The Political Context**

*Harm reduction really is about dealing with the consequences of bad drug policy. It’s nothing to do with drug use. It’s policy that’s the problem.*  
(service provider)

In the global context, the political landscape related to drug laws has been in a state of flux as world leaders reach a critical mass to reconsider the status quo. An international momentum to challenge existing drug conventions and the criminalization of people who use drugs has been brewing as the world prepares to sit down and review these conventions at the United Nations General Assembly Special Session on Drugs in 2016. Perhaps most notably, the

Global Commission on Drug Policy, comprised of 22 world leaders and intellectuals, has been calling for significant drug policy reform, including the end of criminalization of people for drug use and possession, alternatives to incarceration, greater emphasis on public health approaches to drug use, and experimentation with alternatives to legal regulation (Global Commission on Drug Policy, 2014). As such, there have been growing opportunities for people who use drugs to be included in political spaces.

### **Growing opportunities at the international level.**

A global civil society movement mobilized and called for a Civil Society Task Force to ensure the engagement of civil society with the United Nations system that sets international drug conventions (International Drug Policy Consortium, 2014). The Civil Society Task Force was launched in December 2014 by the Vienna NGO Committee on Drugs and the New York NGO Committee on Drugs to bring the voices of civil society to UNGASS 2016 (Vienna NGO Committee on Drugs, 2015a, 2015b). The structure of the Civil Society Task Force includes 26 members, 18 regional representatives, and eight representatives from affected populations (Vienna NGO Committee on Drugs and New York NGO Committee on Drugs, n.d.). The International Network of People who Use Drugs currently represents the voice of people who use drugs on the Civil Society Task Force's members. Organizations of people who use drugs are gaining momentum internationally in being included in key decisions that affect their lives. In Canada, however, recent years have been challenging for the mobilization of people who use drugs.

### **Reduced opportunities at the national level.**

At the national level, Canada's Drug Strategy was launched in 1987, and renewed in 1992, 1998 and 2003 (Collin, 2006). The long-term goal of Canada's Drug Strategy was "to

reduce the harm associated with alcohol and other drugs to individuals, families and communities” (Zilkowsky, 2001, p. 3). Among its key principles were multi-sectoral partnerships and the involvement of target groups such as people who use drugs (Zilkowsky, 2001). Canada’s Drug Strategy focused on four pillars of prevention, treatment, harm reduction and enforcement (Collin, 2006).

in 2005, after extensive nationwide consultations through ten roundtables followed by thematic workshops on recurring priority issues related to problematic substance use, the then Liberal Government of Canada, in collaboration with the Canadian Centre on Substance Abuse released the *National Framework for Action to Reduce the Harms Associated with Alcohol and Other Drugs and Substances in Canada* (Government of Canada and Canadian Centre on Substance Abuse, 2005). The National Framework was guided by principles of approaching substance use as a health issue shaped by social and other contextual factors, evidence and evaluation, human rights, strong partnerships, responsibility, ownership, accountability, harm reduction, and most relevant to this study, meaningful involvement of those most affected.

At the consultations that led to the National Framework, sitting among addiction and mental health specialists, epidemiologists, social scientists, physicians and other health practitioner, lawyers and other legal experts, frontline workers, researchers, policy makers, non-governmental organization representatives, Aboriginal service providers, police and enforcement representatives, youth and governmental officials were the few yet vocal and most importantly *present* representatives of organizations of people who use drugs.

From my perspective, as I sat at those tables as a representative of the Canadian AIDS Society, I was personally moved by the perspectives that people with lived experiences brought to those difficult discussions. They contributed pragmatic, no-nonsense observations and shared

their challenging realities, which in my opinion brought the conversations to the core of the matters being discussed. In 2007, however, no such process was followed in the creation of the National Anti-Drug Strategy, therefore no opportunity existed for people who use drugs to come to the table at the national level, nor has any existed since to this date.

In 2007, the Conservative government of Canada, elected a year earlier, took steps to reinforce its ‘tough on crime’ stance by first releasing the National Anti-Drug Strategy. The National Anti-Drug Strategy omitted harm reduction from the previous four pillars framework while retaining action plans on enforcement, prevention and treatment (Government of Canada, 2014). This significant policy change sent a message across the nation that the current government was favouring a drug control approach over a public health response to drug policy (Ball, 2007). It is also important to note that the National Anti-Drug Strategy was a federal government strategy developed by 12 federal department and agencies and was not developed in collaboration with Canada’s ten provinces and three territories. There was no mention of key principles of multi-sectoral partnerships or inclusion of target groups guiding the National Anti-Drug Strategy, nor was there a consultative process with key stakeholders who are affected by such policy to develop it.

These oppressive policy developments since 2006 have led to strong opposition and social action. On October 19<sup>th</sup>, 2015, however, the Conservative government was defeated by the election of a Liberal majority government that has been clear about its intentions to legalize cannabis and its support for harm reduction and supervised consumption facilities. It remains to be seen whether policy development at the national level will include people who use drugs in the process.

### **A case of making the best of restrictive policies.**

In addition to leaving out harm reduction from its National Anti-Drug Strategy, the Canadian Conservative government has been openly and aggressively resistant to harm reduction initiatives. For example, the government of Canada fought against the evidence-based and rigorously evaluated effective services of Insite, the only legal supervised injection facility in North America, all the way to the Supreme Court of Canada (*Canada (Attorney General) v. PHS Community Services Society*, 2011).

After Insite's unanimous win in the Supreme Court of Canada, the Conservative government introduced Bill C-2, an Act to amend the *Controlled Drugs and Substances Act* entitled the *Respect for Communities Act*. This Bill, which received Royal Assent on June 18<sup>th</sup>, 2015, imposed an excessive application process on public health authorities and community agencies planning to offer supervised consumption services for people who use drugs. Section 56.1(3) of the Bill outlines the requirements which need to be submitted before an application can be considered (Parliament of Canada, 2013). Briefly, these requirements include an extensive list of letters and reports on the municipality in which the site would be located. Much of this information can only be obtained through research. Given the extensive research that already exists related to supervised injection services and the Supreme Court of Canada's decision related to Insite, many professional and community-based organizations met the Bill with resistance, including the Canadian Medical Association, the Canadian Nurses Association, the Canadian Association of Nurses in HIV/AIDS Care, the Public Health Physicians of Canada, the Canadian Public Health Association, the Registered Nurses Association of Ontario, and the

Urban Public Health Network, the Canadian Drug Policy Coalition and the Canadian HIV/AIDS Legal Network.

Ironically, these extensive requirements for local research in municipalities interested in offering supervised consumption services have led to the establishment of the community-based, participatory research committee included in this study. This reality is not lost on one person with lived experience I interviewed:

*I might say it wasn't even our choice whether or not we got to do the research in the first place. There's all this stuff's already known in this city. [Another researcher] did [a] study four years ago, five now. It's a hoop that they are making us jump through, right? So I mean we're as democratic as we can be [in this research initiative] but there's something heartedly undemocratic about the fact that I'm still here, that this study has to be done in the first place. (person who uses drugs)*

The struggle with supporting harm reduction efforts is also reflected in the inconsistent support across provinces and territories in Canada. While provinces and territories are responsible for the provision of health care services, commitment to harm reduction varies from one province/territory to another (Carter & MacPherson, 2013). The two provinces of interest for this study, Ontario and British Columbia, however, are committed to harm reduction and to the inclusion of people who use drugs in decisions that affect them, although their approaches to inclusion are different. Such initiatives have been influenced by policies of inclusion in other areas of health care.

### **Organizational policies of inclusion create opportunities.**

Both the provinces of Ontario and British Columbia have adopted policies of inclusion of people with lived experience. In Ontario, Health Quality Ontario (2014), an independent government agency, is developing a Public and Patient Engagement Strategy which will strive to engage the voice of patients and families in shaping the health care system. Ontario's Ministry of

Health and Long-Term Care recently released the *Patients First: Action Plan for Health Care* (2015) which commits to making decisions informed by patients so that they can be included in affecting system change. People who use drugs, however, are less likely to access the health care system, so it remains to be seen whether they will be included. This philosophy of inclusion of patients in decisions that affect them has trickled over to other areas of health services.

Previously, however, the Ontario Needle Exchange Coordinating Committee, which represented the Ontario Needle Exchange Network, released best practice recommendations for Ontario needle exchange programs (Strike, Leonard, Millson, Ansrice, Berkeley and Medd, 2006). Nested within the best practices is the importance of adhering to the Nothing About Us, Without Us principle and including people who use injection drugs in all aspects of policy and program development and implementation. In fact, the very idea for establishing best practices for needle exchange programs in Ontario is credited to a person who uses drugs who at the time managed harm reduction programs. The Ontario Ministry of Health and Long-Term Care also established a Harm Reduction Advisory Committee comprised of service providers, service users, researchers and policy makers (N. Zurba, personal communication, February 26, 2015).

In British Columbia, the BC Ministry of Health launched the Patients as Partners (n. d.) initiative in 2007 to formalize the relationship between patients and health care providers and include the patient voice in improving health care. Although Patients as Partners have yet to include people who use drugs, this patient inclusion philosophy has spilled over and influenced various areas of health services, and some work is taking place to include people who use drugs in decisions about harm reduction services. There has been synergy between the growing inclusion of people who use drugs and the mobilization of people who use drugs, as covered in the next section.

### **“Nothing About Us, Without Us”: The Mobilization of People who Use Drugs**

The increasing mobilization of people who use drugs influenced the transformation of power inequities at the table. Contextually, at the international level, we have seen people who use drugs increasingly displaying empowerment, exercising agency and mobilizing into organizations of people who use drugs (Kerr et al., 2006; Friedman et al., 2007; Friedman, et al., 2012; CAPUD, 2010a, 2010b). Representatives from organizations of people who use drugs have been participating in various policy decision-making processes at the municipal, provincial, national and international levels (Kerr et al., 2006; Friedman, et al., 2012), and there is growing interest in encouraging their greater, meaningful involvement and inclusion in policy settings (Kerr et al., 2006; Leading Together, 2013).

The influence of the growing international movement of people who use drugs led to policy makers and service providers realizing the importance of their inclusion in decision-making and, in some cases, organizations assisting with the development of a local organization of people who use drugs. According to one service provider I interviewed, one policy maker attended the 17th International Conference on the Reduction of Drug Related Harm, Harm Reduction International, in Vancouver in 2006, at which they came to realize the importance of supporting the creation of a local organization of people who use drugs. This realization led to providing local support for the development of an organization of people who use drugs:

*So [they'd] come back from that and just, you know, it became really really clear to [them] afterwards that what was seriously lacking in [this city] was something like a drug user committee or advocacy group as well... but also just recognizing that internationally that's where a lot of movement began to really really happen is when people with lived experience around using drugs started getting more active. So we again*

*we tried several times to try to get something going. [The public health authority] had a bit of a pocket of money that they were willing to put into a little bit of coordination but primarily around developing that support for the people with lived experience to get involved with it. (service provider)*

In Canada, the aforementioned “Nothing about us, without us” principle (Jürgens, 2005)

developed by people who use drugs and advocating for their inclusion in decision-making spaces has not fallen on deaf ears and has influenced policy makers to include people who use drugs in the committee they chair:

*I think first of all philosophically recognizing that, you know, for example, [we] are very supportive of the idea of the concept of Nothing About Us, Without Us... We were talking about how could we be consistent with the philosophy that we espouse, you know? How do we make our actions match our words? And one of them was well let's start inviting [people who use drugs] to the table. (policy maker)*

When people who use drugs mobilize, they challenge the moral basis of existing systems and disturb the status quo in a revolutionary way. They also challenge socially constructed views and stereotypes about people who use drugs and reclaim domains of their lives that had been ceded to those in control, as noted in Brookfield's Seven Learning Tasks (2009).

In all four committees in this study, the existence of organizations of people who use drugs was instrumental in leading to their inclusion. Synergistically, existing organizations of people who use drugs have either been approached or have approached committees to get involved in them.

*So [a person who uses drugs] asked about [the committee] and I'm like well why don't you just come to [the meeting] then, you know? So [they] started to come... and I think it was really important to see that... it's a good platform for the work that [they were] doing at the time 'cause [the organization of people who use drugs] was very new... so I think it's great that people who have lived experience have a voice, I think it's really important. (policy maker)*

Having existing organizations of people who use drugs assisted policy makers, researchers and service providers to find representatives with lived experience to invite to

decision-making tables. Being part of an organization of people who use drugs enabled people who use drugs to be linked into the local network of services and to hear about opportunities where their participation might allow them to share in decisions that affect them. As an organization, they can mobilize and commit to getting involved in decision-making structures. They can also work with allies and assist in establishing committees:

*[The researcher] wanted my help to put together... specifically people with lived experience... a committee to try to improve services for drug users in this community. (person who uses drugs)*

In this study, one organization of people who use drugs challenged hegemony by creating an organizational structure whereby people who use drugs formed a board of directors and hired a staff person. The presence of representatives from the board as well as the staff person at meetings disturbed power relations in a revolutionary way, as explained below:

*One of the problems we had even with [the Chair] at the beginning is... I think it's because probably so many agencies, the staff are in charge, right?... [The Chair] was directing all [their] questions at the beginning [to our staff person]... Me and [the staff person] sat down and wrote a letter to [the Chair]... about how the decision making is done [in our organization]... and [the staff person] has to really stand [their] ground [when the Chair is] wanting last minute decisions made. And putting [the staff person] in that position and pressuring [the staff person] to make decisions... and [the staff person] stood [their] ground, saying "Look it, I got to bring it to the Board". "Well we need an answer now." So the way [the Chair]'s treating it, they ask [our staff person] to make decisions for us.*

*L: And has it changed since you pointed it out?*

*I: ...It's changed quite a bit but only because [the staff person] has held [their] ground... Basically, we're the bosses and [they're] the staff, you know? (person who uses drugs)*

The chair of the committee had to adapt to the fact that the staff person did not make decisions on behalf of people who use drugs. The people who use drugs were their employer and the staff person had to consult with the board of directors regarding decisions. People who use drugs were clearly in the position of power in this organization. These power relations also had to be learned

by the staff person. These people who used drugs had clearly managed to reclaim their reason and challenge what it means to organize society fairly, as described by Brookfield (2009).

The example above offers a glimpse into people who use drugs truly challenging the power relations within a committee. However, people who use drugs face challenges when attempting to mobilize. Socially constructed views of people who use drugs were discussed in greater detail in Chapter 4. Suffice it to say that because of stigma, people who use drugs struggle for support to mobilize in their communities. In one meeting I observed, one person who uses drugs shared that they wanted to establish a peer outreach program in their community but could not find an avenue for support to put it into practice. They also had difficulty keeping their meeting space for their peer group, stating that the people in charge of the space did not trust people who use drugs. It was also a challenge for organizations of people who use drugs to obtain funding.

*Drug user organizations have a lot of difficult time getting funding because of the stigma so I think we need to do a better job dealing with that reality. (service provider)*

In one meeting, one person who uses drugs shared how they started up an organization of people who use drugs in their basement in 2006 and had just obtained funding, so they were now in the process of looking for office space. Small successes are encouraging though much work remains to be done if people who use drugs are truly to be included in a meaningful way in decisions that affect them. Mobilization is largely dependent on resources, and resource allocation is highly influenced by current drug policy. Organizations of people who use drugs face barriers to develop in the current political context. The next section discusses how current drug policy affects resource allocation towards initiatives for people who use drugs, and ultimately power relations.

### **“The Elephant in the Room”: Impact of Policies on Power Relations**

The current realities of the Canadian political funding climate regarding harm reduction surfaced during my observations and interviews and affected power relations between committee members. Despite the existence of provincial harm reduction policies and best practices, the extent of the work is limited within the constraints of a tight budget:

*Canada actually has a limited range of supplies that we can choose from and also within our very tight fiscal budget. So we as a committee we decide on what supplies to include on our distribution list and it keeps growing every year but the money has to keep growing every time we add something too. (policy maker)*

The limited allocation of resources toward harm reduction efforts can have a detrimental effect on power relations at the table. When asked about challenges related to including people who use drugs in the policy committee, one policy maker stated:

*I think the sense of probably sometimes having [people who use drugs] walk away feeling let down, feeling like maybe they're not having as much influence as they would like to have. Not being able to provide the most robust harm reduction services that I think all of us in a utopian world would like to have available, you know?... we're not even able to get into the big elephant in the room around drug policy, the macro environment of the international drug control system. But really about, you know, the resource limitations and so yeah, feeling like we know we are never doing enough and to raise expectations perhaps on the part of those who get invited to the table, you know, feeling like in some ways we're all being set up for failure. They're coming with expectations, we know we are not going to be able to deliver everything that they want and we can't even deliver what WE want. (policy maker)*

In the example above, the policy maker felt that people who use drugs perhaps had raised expectations about the power they may have by being at the decision-making table, whereas the reality was that policy makers themselves feel they have limited power over influencing funding allocation for harm reduction services.

The drug policy ‘elephant in the room’ was clearly present at the tables included in this study as contributing to those limited resources. Another impact on power relations from limited resources allocated to harm reduction services came from the fact that it sent a message that issues faced by people who use drugs are not of value. There was also compassion expressed for people who use drugs, realizing that talking about not having enough resources to help people who use drugs must be especially difficult for them to hear:

*And it’s just hard to talk about money... right?... It’s like “oh, we can’t do this because we don’t have enough money”. Like that’s what, you know, anybody who it’s affecting them, like it’s hard to talk about ‘cause we don’t want to put it down to dollars too, right? (policy maker)*

This restricted funding environment also makes it challenging for committees to properly support representatives of people who use drugs they invite to the table in terms of remunerating them for their work on these committees.

Inviting people who use drugs provided them with a better understanding of how ‘the system’ works, as acknowledged by people who use drugs during interviews and noticed by others at the table.

*I feel that it gives me a better insight as to KNOW what’s going on and KNOWING what policies and KNOWING where the problem is by being at these meetings... but at the same time sometimes I get frustrated and angry because I’m tired of all the bureaucracy and I’d like just to help people. (person who uses drugs)*

*I think for them to understand the realities of funding and bureaucracy and reporting is ugly. It’s somewhat depressing. (service provider)*

This awareness of the greater context within which policy makers and service providers operate in allowed everyone to share the frustration when faced with resource limitations.

*You have to accept that there’s power structures that you can have influence over if you are willing to compromise and bite your tongue sometimes and swallow decisions that sometimes you think are unacceptable or even frankly wrong... I guess that’s part of the learning process. (policy maker)*

It is clear, however, that the impact of this sense of limited power was personal since it affected people who use drugs and their peers directly. They expressed frustration and anger from not being able to better help people. The sense of injustice, however, was shared by all.

Finally, in some cases, people who use drugs were frustrated by the inaction of bureaucracy and of people in positions of power, contributing to a loss of respect for them.

Frustration for people who use drugs also came from the fear people had to stand up for injustice.

*I understand bureaucracy a lot more actually. Yeah, oh yeah. I've gained a lot of knowledge... It pisses me off because it's frustrating. There's so much talk and not enough action. I believe in saying what you think, not beating around the bush. It's opened my eyes a lot to think less and less of [policy makers]... Yeah, and seeing how much even people [in the public health authority], how many people disagree but are afraid to stand up and say what they think. Because when someone does, they see that person being punished and so they're afraid to speak up. (person who uses drugs)*

Clearly, drug policy and its impact on resource allocation thwarted efforts to help people who use drugs. This reality created tensions between people who use drugs and others at the table. Although participating in committees helped people who use drugs understand the system better and see the limitations others at the table face to improve life conditions for them. The down side was that it resulted in others at the table feeling like they are letting people who use drugs down, and people who use drugs losing respect for others' lack of action in the face of fear. However, there were some encouraging stories of resources being allocated to the committees included in this study which led to some positive developments. Basically, allocating resources to the committees led to them being more efficient and being able to dedicate more time and support toward the inclusion of people who use drugs.

Power relations were clearly affected by the current political climate in Canada. In line with its tough on crime approach, the Canadian Conservative government enacted the *Safe Streets and Communities Act* in 2012 which introduced Mandatory Minimum Sentences for some

drug offenses (Government of Canada, 2012), further entrenching the criminalization of people who use drugs. This legislation was met with much opposition, including from the Canadian Bar Association (2011) and Canada's Auditor General (Office of the Auditor General, 2014) among others, yet passed in the House of Commons. Meanwhile, other jurisdictions, most notably the United States, have been realizing the negative impacts of Mandatory Minimum Sentences and moving away from this approach (National Research Council, 2014). It remains to be seen whether the new Canadian Liberal government, elected in 2015, will amend these Mandatory Minimum Sentences.

Meanwhile, with these policies that propagate a drug control approach by criminalizing people who possess, produce or sell some drugs in Canada, resources for public health approaches such as harm reduction continue to be thwarted. The Canadian government's investment in harm reduction within its drug strategies has historically been low. Within Canada's Drug Strategy, renewed in 2003, 73% of its funding was allocated to law enforcement, while 3% went to prevention, 14% to treatment, and only 3% to harm reduction for 2004/2005 (DeBeck, Wood, Montaner, & Kerr, 2009). Within the new National Anti-Drug Strategy announced in 2007, while 70% of funding was allocated to law enforcement, 4% to prevention and 17% to treatment, only 2% of funding was allocated to harm reduction (DeBeck et al., 2009).

The lack of harm reduction as a policy and funding priority extends well beyond Canada and has been deemed a crisis by Harm Reduction International, an international non-governmental organization. Their latest report points out how international and national funding for essential harm reduction services is disastrously short of need (Harm Reduction International, 2014).

In addition to the impact of policy on power relations at the table, committees have varying degrees of power to influence decisions within the greater social structures. These decision-making structures also influence how much power each person at the table has. The next section elaborates on where decision-making power is situated in the four committees included in this study.

## **Summary**

This chapter has explored findings on how political contextual factors influence power relations at the decision-making tables included in this study, to complement findings from Chapters 4 and 5 on organizational context, sociodemographic characteristics of people at decision-making tables, representation considerations, stigma against people who use drugs, and the creation of safe spaces where democracy can be practiced.

Findings revealed the important impact of current drug policy, which criminalizes people who use drugs, on power relations at the table. At the international level, resistance to a punitive approach to drug laws has spurred a civil society movement that calls for the reform of drugs laws based on a public health and human rights approach. This civil society movement includes the mobilization of organizations of people who use drugs to call for their inclusion in decisions that affect them. In Canada, since 2006, the political climate has adopted a tough on crime approach. The Conservative government increased legal consequences for people who use drugs through mandatory minimum sentences and significant reduced or eliminated policies that support harm reduction services.

In this unfavourable national climate, provincial policies continued to support harm reduction as well as the inclusion of people who use drugs in decisions that affect them. Meanwhile, people who use drugs continue to mobilize and develop organizations of people who

use drugs across Canada. Findings showed that this “Nothing about us, without us” movement has influenced committees to include people who use drugs at their tables. This mobilization of people who use drugs, and the strategic alliances they have formed with policy maker, researcher and service provider allies, has been challenging power relations within existing social structures such as the committees included in this study. Inclusion of people who use drugs at these decision-making tables has been facilitated by the presence of organizations of people who use drugs.

Organizations of people who use drugs enable people who use drugs to be linked into networks of services and to become aware of opportunities for inclusion at decision-making tables. These organizations have also been challenging existing power structures by experimenting with forms of collective organization and democratic processes that might be different from dominant structures and more suited to their purposes. Their presence, therefore, at committee tables has been disturbing power relations in a revolutionary way by exposing these committees to alternative power structures whereby people who use drugs are in power. Organizations of people who use drugs have been facing barriers to develop in the current political context though have been working with allies to progress with their mobilization.

At the table, the current challenging climate for harm reduction had an impact on power relations by raising the expectations of people who use drugs about the power they may have to influence change related to harm reduction services. The restraints on harm reduction funding might sent a message to people who use drugs that they are not worth improving harm reduction services for. People who use drugs also came to better understand how the political system worked, which helped them understand the struggles their allies faced in working with them to improve harm reduction services and share in their frustration. The weight of this challenging

climate stirred up anger, frustration and a sense of injustice in people who use drugs who would “*like to just help people*”. People who use drugs were also frustrated by the inaction of bureaucracy and of people in positions of power, which contributed to a loss of respect for them. This reality created some tension at committee tables, though this was somewhat dissipated by the fact that others at the table usually shared their frustration and anger.

The next chapter discusses all of the findings from Chapters 4, 5 and 6, offers my reflections on lessons learned and the practice implications of these findings, and suggestions for future research.

## Chapter 7 – Discussion

This inquiry aimed to explore and describe power relations between people who use drugs and researchers, policy makers and service providers at decision-making tables. Specifically, in this study, I examined how power inequities were transformed toward more equitable decision-making power for people who use drugs within social inclusion practice by revealing factors which contribute to this transformation and looking for underlying signs of transformation of decision-making power relations toward more equitable ones. Through this exploratory critical emancipatory inquiry, and drawing on critical ethnography procedures, I observed four committee meetings at which people who use drugs were included. I also interviewed members of each committee, collected sociodemographic information and amassed relevant documents. Combining these data and using theoretical frameworks allowed me to situate decision-making power within each committee setting, describe evidence of transformative learning tasks at play in these settings, and explore the influences of the social, political, and organizational context on power relations. These data allowed me to address specific research questions:

- How were power relations experienced and expressed between all participants within social inclusion practice where people who use drugs included at the table?
- In what ways did power relations between participants at the table contribute to or hinder shared decision making power?
- What contextual factors positively and negatively affected power relations at the table?
- What are the implications for organizational social inclusion practice based on insights gained from these findings?

## **Organizational Context**

Committees were part of a broader system with varying degrees of decision-making power. Findings showed how decision-making power was situated within three different committee structures and explored how each committee's commitment to and capacity for inclusion of people who use drugs affected power relations at the table.

Where people who use drugs were not members of the committee and were consulted yearly, their input was not guaranteed to be taken into account in committee decisions. Some people who use drugs felt tokenized. They were also not kept informed of the committee's activities and decisions throughout the year in between meetings. They were left wondering about their role at this table. Policy makers were aware that this structure was not ideal for including people who use drugs and were exploring processes to address these limitations. For example, they were considering hosting ongoing tables of people who use drugs throughout the year. They were conscious of the tokenistic nature of the participation of people who use drugs in this structure and were exploring ways to shift the participation of people who use drugs from one of consultation, as per Arnstein's (1969) ladder of participation, toward more citizen power.

The model of inclusion described above could be compared to Roche, Guta and Flicker's (2010) advisory model of inclusion whereby people with lived experience held an advisory role. While people with lived experience had the opportunity to provide their insights and advice to the committee's work, they were, however, distanced from the ongoing work of the committee in between yearly consultations. These findings supported those of Roche, Guta and Flicker. In addition, while the policy committee had Terms of Reference, these did not include a clear description of the role of annual consultations with people who use drugs and the nature and

extent of these consultations. As a result, some of the people who use drugs who participated felt tokenized, confirming once again Roche, Guta and Flicker's findings.

Where there were one or two representatives of people who use drugs at the table, these committees provided input related to harm reduction policy, programs and services to their public health authorities and acted as a forum for various stakeholders involved in harm reduction to network and coordinate with each other and strategize together to improve local service delivery. They included people who use drugs at their tables as they did all other members of their committee, and had not specifically taken measures to accommodate special considerations such as financial compensation for their time or support to ensure that people who use drugs were up to speed with the committees work and decisions. The voice of lived experience was lost when there was no representative of people who use drugs at particular meetings. While these committees had limited decision-making power within their local health system structure, they did provide a venue for people who work in harm reduction to exchange information and find support. Representatives from public health authorities were perceived as having more power in these committees, even if they were only reporting back to their superiors within their public health authorities. They did, however, act as a liaison between the committee and the public health authorities. In terms of inclusion of people who use drugs, these structures fell somewhere between Arnstein's (1969) informing rung where the focus is on information exchange between committee members, and consultation rung where committee members had equal say in providing input to public health authorities though the committee was not guaranteed this input would be taken into account.

When compared with Roche, Guta and Flicker's (2010) models of inclusion, these service provider committees perhaps add a fourth model to the advisory, employment and

partner models suggested by the authors: the membership model. Different than an advisory model, I offer that a membership model is one where people who use drugs have seats on the committee as do other members of the committee. While having the voice of lived experience at the table is an advantage to this membership model, challenges arise when representatives of people who use drugs are greatly outnumbered by, in these committees, service providers, thereby thwarting their voice.

Where people who use drugs held the majority of seats, the committee was intentionally structured to give people who use drugs more control in a community-based participatory research project. The committee had mindfully included capacity building for people who use drugs to ensure they could meaningfully participate in all aspect of the research project. Relationships with people who use drugs and researchers were negotiated at the onset and the research project was co-created with people who use drugs. This structure and process were key components in contributing to shared power in decision-making. The committee also build in an ongoing evaluation process and adapted its processes based on the results. They consciously experimented with this way or collectively organizing and were pro-active in challenging dominant power relations to ensure they were more equitable. According to Arnstein's (1969) ladder of participation, this committee reflected the partnership rung where decision-making power was redistributed through negotiation between people who use drugs and researchers and agreement on sharing planning and decision-making. While ultimate decision-making power still resided with the principal investigator, this committee was the most inclusive and participatory of the four committees studied. Nevertheless, there were still important socioeconomic differences between researchers and people who use drugs which maintained inequity. These findings showed that addressing decision-making power inequities through more equitable

governance structures only partially contributed to remediating inequities at the greater socioeconomic level in the short term.

Comparing to Roche, Guta and Flicker's (2010) models of inclusion again, this CBPR project adopted both the employment model whereby people who use drugs were hired as peer researchers on the project, and the partner model whereby people who use drugs were partners in all aspects of the research. A person who uses drugs also had the title of co-principal investigator and sat on the project's executive committee. While this innovative structure did address some of the power inequities in decision-making, there were still important socioeconomic inequities between people who use drugs and others at the table. The employment model aspect of the research committee I studied provided skills building and training though, as offered by Roche, Guta and Flicker, insufficient for them to fully conduct research and offered limited opportunities in the future. These findings reveal that the model of practice of inclusion of people who use drugs thereby influenced power relations greatly.

All committees included in this study were committed to including people who use drugs at their table, though levels of committee and capacity to do so varied. Committees had budgetary and human resource constraints to properly compensate and support people who use drugs to be at their tables. In some cases, they had not thought about the financial and support considerations and had therefore not planned for them to ensure more equitable inclusion of people who use drugs. These findings indicated a clear need for guidelines to properly and thoughtfully include people who use drugs at their tables as well as pre-invitation negotiations with people who use drugs to establish this process collaboratively.

The need for guidelines at the organizational level for social inclusion of marginalized communities has been expressed elsewhere when working to include people who experience

homelessness (Norman & Pauly, 2013) and with people living with HIV/AIDS (Flicker, et al., 2009). Findings from this study related to the limited human and financial resources organizations faced despite their commitment to inclusion of people who use drugs support Restall and Kaufert (2011) similar findings. Flicker and her colleagues (2009) also found that, in the context of research, capacity for both community members and academic researchers to partner in community-based participatory research was limited and funding mechanisms were not structured to encourage such participatory processes.

### **Socioeconomic Inequities**

The most striking way that people who use drugs and others at the table experienced power relations at the committees included in this study was through their significant socioeconomic differences, which cut across all committees. Confirmed by the demographics survey, people who use drugs were more likely to be single, separated or divorced and identifying as having an ethnic and cultural heritage other than Caucasian than the researchers, policy makers and service providers at the table. None of the people who use drugs had university education compared to the majority of other people at the table. Almost half of the people who use drugs were always worried about food security and nearly all of them had a yearly income below \$20,000.

To this effect, people who use drugs faced challenging life conditions and difficult choices to attend committee meetings, at times foregoing revenue generating activities. Committee chairs varied in their level of awareness of these disparities and in taking measures to address them to enable more equitable inclusion of people who use drugs. People who use drugs varied in challenging power inequities being reproduced when they were invited to committee

tables without remuneration. Socioeconomic inequities therefore had an important impact on people who use drugs' capacity to participate at committee tables.

The socioeconomic inequities found in this study between people who use drugs and others at the table were striking and confirmed that people who use drugs faced intersecting determinants of inequities of poverty, food insecurity, ethnic or cultural background, and limited education, rendering them more vulnerable to health inequities (Cole, et al., 2011; Galea & Vlahov, 2002; Koh, et al., 2010; Room, 2005; Whitehead & Dahlgren, 2006). Dealing with life priorities such as food and income has also been identified in the literature as hindering the participation of marginalized groups in decisions that affect them (Travers, et al., 2008). Providing financial compensation to people with lived experience facilitated their involvement (Travers et al., 2008).

To address these economic inequities, there was variation and inconsistency in measure taken to alleviate economic inequities by committees whereby people who use drugs were remunerated for their participation or food and financial support were provided for meetings. Participants in this study grappled with the best way to address economic inequities and to recognize the equivalence of lived experience monetarily, and no clear policies existed to guide them. Emerging from these findings was the need for policies that clearly identify whose responsibility it is and how to provide measures to alleviate financial barriers and better enable the inclusion of people who use drugs in these committees.

The issue of remuneration or financial compensation of people with lived experience from marginalized groups has been explored in the literature, usually in the context of engaging people with lived experience in research. Flicker and her colleagues (2007) conducted a content analysis of forms and guidelines used by institutional ethics review boards to determine whether

they reflected common experiences in the context of community-based participatory research. The authors offer that compensating people with lived experience for their time and effort in participating in research, in an effort to ensure more equitable compensation for all team members, is an ethical imperative. They found that the majority of ethics boards were concerned with financial conflicts of interest such as coercion, less than a handful of boards considered the potential power imbalances between researchers and people with lived experience. No ethics board enquired about equitable distribution of resources. In fact, Flicker and her colleagues conclude that

“...economic differences are often addressed by giving little or no incentives to either individual respondents or community representatives... This further disempowers individuals and communities by suggesting their time, energy, and resources may be of little worth, and they should participate simply because they have been invited.” (Flicker, et al., 2007, p. 485).

These findings suggest that not addressing issues of remuneration of people with lived experience for their participation reproduces power inequities. In addition, in another study, Flicker and her colleagues (2009) found that not providing any or adequate financial compensation to people with lived experience resulted in poor incentives for them to participate, further contributing to hindering sharing power in decision-making with people with lived experience.

In addition to financially compensating people who use drugs to participate in committees, organizations grappled with how to hire people who use drugs as employees and how best to determine the value of lived experience, compared to education and professional credentials. These findings reflect those of Marshall and his colleagues (2013), who studied how a community-based participatory research project attended to income and employment equity when hiring people who use drugs as ‘peer researchers’. Using Nancy Fraser’s three-dimensional

model of social justice and data from interviews conducted as part of their ongoing process evaluation, the authors explored economic redistribution of resources as a transformative response toward greater economic equity for people who use drugs. They found that the inequities in income and employment opportunities for people who use drugs sustained systemic poverty, although people who use drugs reported that their continued involvement in the study was related to their interest in the project outcomes more than to the financial compensation. Once again, as in the findings in this dissertation, people who use drugs were willing to accept economic inequity in order to participate.

The need for explicitly enquiring about the financial needs of people who use drugs who are invited to the table and for taking measures to alleviate their financial barriers to participate emerged from this study. Providing adequate financial compensation was hindered by committee chairs' lack of forethought, lack of clear policies on how to do so and by limited funding available to organizations to be able to do so. Working within such restrained financial resources stretched everyone involved beyond the call of duty, especially people who use drugs who were already at a greater socioeconomic disadvantage. People who use drugs also accepted the trade-off of participating without remuneration instead of not having a voice at the table.

In Canada, one policy was developed to provide tips on compensating people with lived experience who get involved in community-based research (Pacific AIDS Network, 2014). Though aimed at people living with HIV/AIDS, the tips sheet provides useful considerations related to compensation of people with lived experience as well as helpful resources for additional information. Collectively, people who use drugs have requested to be provided honoraria, in cash, for their participation on such committees (Jürgens, 2005) though, as confirmed by findings in this study, this request has not been implemented consistently. Indeed, people who

use drugs have provided useful guidelines for their allies to consider when inviting them to one of their meetings (CAPUD, 2015; Jürgens, 2005). Clearly, clear policies regarding economic redistribution measures are needed when including people who use drugs in committees where decisions are made that affect them.

In addition to financial considerations, in a context where harm reduction work was demanding and not properly resourced, and despite personal and emotional challenges, people who work in harm reduction, including people who use drugs, found this work valuable and rewarding. This finding indicates a clash between the dominant neo-liberal ideology that equates one's worth to one's salary versus the incalculable worth of doing meaningful work, signs that study participants had reclaimed reason by not automatically supporting the logic of capitalism and neo-liberalism. Of course, people who use drugs still have to make a living and earn an income, and their participation on committees should not be at the expense of their own survival.

That said, doing valuable and rewarding work is important when considering the transformation in power inequities. While some literature has documented increased feelings of empowerment, self-worth and feeling useful among people with lived experience (in this case, people living with HIV/AIDS) engaged in CBPR (Greene, et al., 2009; Travers, et al., 2008), this study sought to explore and find evidence of challenging existing power structures that lead to power inequities. Documenting that people who work in harm reduction, including people who use drugs, were willing to invest the time and effort required despite limited financial gain revealed the underlying social movement striving to unmask and challenge power inequities and dominant ideology, as described by Brookfield (2009). This transformative learning task of unmasking power contributed to a willingness to experiment with forms of collective organization and share power in decision making. While economic inequities markedly

contributed to power inequities at decision-making tables, socially constructed views of people who use drugs were an important hindrance to sharing decision-making power with people who use drugs.

### **Stigma against People who Use Drugs**

Despite an openness and good will to invite people who use drugs to the table, findings revealed signs that committee members tended to underestimate people who use drugs. These findings showed the extent to which ideas and beliefs about people who use drugs were deeply rooted, even among people who work in harm reduction. People who use drugs were generally only valued for their drug use experience. The tendency to underestimate people who use drugs reinforced their struggle to overcome alienation.

This tendency to have low expectations of people who use drugs supported Link and Phelan's (2001) concept of stigma which labels and stereotypes people who use drugs and devalues their contribution and participation in decision-making. It also showed the ubiquitous nature of stigma against people who use drugs, even amongst people who work in harm reduction, reinforcing Room's (2004, 2005) and Barry and colleagues' (2014) findings related to public attitudes toward people who use drugs. The sociodemographic data collected in this study illustrated the lower socioeconomic status of people who use drugs and power inequities between them and others at the table and supported Link and Phelan's (2001) concept that stigma leads to disadvantages with regard to life chances related to income and education, among others. In contrast, people who use drugs expressed a desire to have more voice, more trust and more responsibilities at these decision-making tables. To counter the stigma, they tended to overcompensate to meet or exceed dominant standards and placed pressure on themselves to excel and perform in order to change the perception of people who use drugs.

In terms of decision-making, power inequities were reproduced by people who use drugs' tendency to yield to experts in a 'researchers know best' manner, displaying the need for more learning with regard to reclaiming reason and domains of their lives that they ceded to those in power (Brookfield, 2009). Others at the table were hesitant to challenge people who use drugs, which people who use drugs experienced as disrespectful, condescending and patronizing. This tendency showed that committee members had more learning to do with regard to challenging dominant ideology and practices in order to assist people who use drugs to overcome alienation (Brookfield, 2009). Participants expressed a desire for honest communication between committee members where all parties can be open to new perspectives and willing to temporarily suspend their own convictions, which Habermas refers to as ideal speech conditions in his communicative action approach (Brookfield, 2009).

Though committee members expressed glimpses of critical reflection in terms of challenging socially constructed views of people who use drugs, they were generally struggling to do this well. Few were doing so explicitly and intentionally. Some committee members realized that there was a lack of skilled practitioners to help groups challenge socially constructed views. The research committee seemed better skilled at challenging ideology and power inequities and had taken measures to critically reflect on decision-making processes. They had built in a process evaluation into their committee practices and, through trial and error, adapted their practices accordingly to render them more equitable.

Findings from this study support earlier findings that the inclusion of marginalized groups alleviates stigma (Roy & Cain, 2001; Travers, et al., 2008), in the sense that these committees were taking time to critically reflect on socially constructed views of people who use drugs and practices that may reproduce or challenge those views. While previous studies

identified stigma as a barrier to inclusion of people with lived experience, findings from this study shed light on how stigma hindered meaningful inclusion of people who use drugs and influenced decision-making. Although awareness of the impact of stigma varied between committees, the need for explicit critical reflection on committee attitudes and processes and skilled facilitation to guide committees through such deconstruction of dominant views about people who use drugs emerged from the findings.

While findings on socially constructed views and how these affect power relations at decision-making tables were useful, it was also useful to consider issues of representation of people who use drugs at these tables.

## **Representation**

Representatives of people who use drugs were usually found by committees through local organizations of people who use drugs. These representatives could speak from their own lived experience and also represent issues that affect a variety of lived experience since they were connected to a larger network. The organizations of people who use drugs could also select their own representatives, thereby ensuring a more democratic process of self-representation. Canadian organizations of people who use drugs requested to be the ones to select their own representatives on more than one occasion (CAPUD, 2010a, 2014; Jürgens, 2005).

Challenges arose, however, in representatives from organizations of people who use drugs being perceived more as service providers than people with lived experience by the other committee members. Consequently, others at the table tended to project their dominant service delivery models onto people who use drugs in terms of expecting them to speak and behave within certain socially accepted professional boundaries, thereby limiting their capacity to be open about the lived experience of the representatives of people who use drugs. These imposed

views did not allow for people who use drugs to determine for themselves how best to serve their peers, or at least for their lived experience to be heard.

Where there was no local organization of people who use drugs, committees relied on local service providers to find representatives for committee meetings. While individual voices of lived experience were valuable at decision-making tables, there was more power in representatives from organizations since they were more likely to be democratically selected and were exposed to a variety of lived experiences through working together on common issues. Additionally, committees that included only one or two representatives of people who use drugs struggled with having the perspective of people who use drugs at the table and often operated with no representative. In such cases, while committee members recognized that they could provide an indirect presence of the voice of people who use drugs in their absence, based on their interactions with people who use drugs when providing services to them, it is clear that without the presence of people who use drugs, transforming power inequities between them and others at the table could not take place. The committees also recognized the need for more diversity in representatives of people who use drugs. These findings point to the importance of having strong organizations of people who use drugs that can facilitate diverse representation. This diversity and increasing organizing of people who use drugs was evident at the National Meeting of Peer-run Organizations of People who Use Drugs in Victoria, British Columbia, in October 2013 (CAPUD, 2014).

Representatives of people who use drugs varied in whether they had current or past lived experience. What mattered most was that people self-identified, that they could relate to the toils of that lived experience and that they were still in touch with that community to represent their concerns. Finally, and contextually, organizational policies and higher level political

environments influenced committee members' comfort and risk in disclosing their lived experience related to illegal drug use. It was felt that if everyone felt comfortable and safe to disclose their lived experience, it would likely contribute to bringing down some of the walls between people who use drugs and others at the table.

Findings from this study illustrate the complexity of the considerations to take into account regarding having representative voices of people who use drugs at the table. The transformation of power inequities required more than simply bringing people who use drugs to the table. It required careful thought as to the selection of representatives, critical self-reflection and openness to hearing the perspectives of people who use drugs, and the allocation of enough seats on a committee to capture a greater diversity of voices of people who use drugs. Arnstein (1969) referred to genuine levels of participation and offered that people in power were influenced by stigma, a paternalistic approach and a resistance to power redistribution when practicing inclusion at decision-making tables, while people from marginalized groups lacked the political socioeconomic infrastructure and knowledge-base and experienced difficulties in organizing a representative group in the face of such barriers.

In practice, and based on the considerations behind genuine representation and inclusion, the findings of this study indicate that researchers, service providers and policy makers could make important contributions to the social inclusion of people who use drugs by assisting people who use drugs with local meetings, supporting the development of organizations of people who use drugs, co-facilitating and mentoring people who use drugs as needed, and providing support to assist them to obtain funding to organize. Once representatives of people who use drugs were invited to the table, create a safe space to practice democracy and share power in decision-making could begin.

## **Creating a Safe Space**

To shift decision-making power from power over people who use drugs to power with them required creating a safe space where people felt comfortable with and learned to trust each other, could relate to each other authentically and could engage in dialogue. Getting comfortable with each other took time, especially given that people at committee tables came from different social locations in terms of power and life opportunities. For some, finding themselves at such tables was unfamiliar. Skilled facilitation enhanced the ease with which people settled into committee spaces: transforming power inequities consisted of consciously challenging the notion that one or a few people had all the decision-making power by turning decision-making back to people who use drugs. How people were approached and supported to participate in committees also added to creating a safe place. Recruitment of people who use drugs by people they were familiar with and trusted helped ease power tensions at the tables. Trust could quickly erode with careless, stigmatizing remarks.

The sense of purpose and solidarity, common to all committees included in the study, stemmed from the alienation everyone involved in harm reduction experienced. Together, all committee members fought those alienating forces against harm reduction and people who use drugs, which enhanced a collaborative, collective purpose to the committees' work. Overcoming alienation fostered a committee culture of supporting each other, a behaviour that was learned and reproduced by people who use drugs. Creating a safe space included properly supporting, preparing and equipping people who use drugs to participate in the committee's work in a meaningful way.

Authentic relationships where committee members dropped their roles and related to each other helped overcome alienation, created a warm, inviting and respectful atmosphere, promoted

critical reflection, openness and mutual understanding. Relating to each other authentically, according to Taylor (2009), is essential to transforming power inequities. This atmosphere also fostered ideal speech conditions as described by Habermas (Brookfield, 2009). In practice, findings revealed that building authentic relationship took place outside of committee settings, though social activities and co-learning activities. Catering to specific needs of people who use drugs contributed to creating a safe and positive environment for them to attend meetings: travel considerations, providing harm reduction supplies, information on where to obtain methadone near meeting sites, support for people who choose abstinence and/or who may experience triggers, and information on nearby health and support services. However, these measures were not always clearly communicated to people who use drugs.

Finally, creating a safe space conducive to relational, trustful and reflective dialogue was achieved through skilled facilitation. People who use drugs were outspoken in general. Some of them expressed challenges with speaking clearly and discomfort with being asked for their opinion. Different styles of expression did not deter from the content of what was being said. Skilled facilitation created this safe space through patience, structured meetings, honesty, providing opportunities for quieter committee members to speak, inviting comments and opinions, and encouraging a hand raising policy. Remaining calm, validating a person's concerns and focusing on a person's expressed concerns rather than the way the concern was expressed dissipated tension and anger among committee members. It allowed various ways of communicating while remaining constructive. Encouraging a constructive dialogue and handling opposing views with respect encouraged people to share differing views. The need for more skilled facilitation was expressed by some interviewees.

These findings on creating a safe space in committee settings support Brookfield's (2009) learning task of overcoming alienation. Indeed, approaches and conditions which helped committee members get comfortable with one another and in a committee setting, build trust, relate to each other authentically and engage in constructive dialogue fostered a sense of freedom in committee members, as suggested by Brookfield. Freire believed that dialogue generates critical thinking and leads to transformative consciousness raising (Crotty, 1998; Mezirow, et al., 2009). Findings from this study also align with Taylor's (2009) core elements that foster transformative learning. Taylor writes that

It is within the arena of dialogue that experience and critical reflection play out. Dialogue becomes the medium for critical reflection to be put into action, where experience is reflected on, assumptions and beliefs are questioned, and habits of mind are ultimately transformed. (p. 9)

Since transforming power inequities requires first and foremost critical reflection on power relations at play in committee settings, creating a space where dialogue can take place to encourage such critical reflection is an important aspect of committee settings where people who use drugs are included.

Similarly, establishing meaningful, genuine, authentic relationships with each other allows committee members to build trust, question each other, share openly and achieve a greater understanding of each other (Taylor, 2009). In fact, the concept of relationship is integral to power relations, since power relations are exercised through actions in relationships as Foucault explains (Wallerstein & Duran, 2008). Transformative learning involves in large part our understanding of relationships with other humans (O'Sullivan, 2003). Though Bess and colleagues (2009) stated that, for service providers, breaking free from their entrenched role of

service professionals may be challenging, findings from this study suggest that it can be achieved within committees with skilled facilitation and activities to foster authentic relationships.

Similarly, Guta, Flicker and Roche (2013) identified clashes in communication strategies between people with lived experience of street involvement and researchers, using an example of a person who was dismissed from a research project for expressing survival strategies that had served her well in other contexts. The authors found the dismissal troubling given that CBPR is meant to embrace authentic lived experience and work toward emancipation of marginalized groups. In their words,

The message that Bernadette received is that her experience of homelessness was important, as was her ability to navigate the social spaces homeless people occupied, but that she needed to manage those ostensibly desired behaviors when dealing with project stakeholder. (Guta, Flicker, & Roche, 2013, p. 446)

As revealed in Chapter 5, such clashes of cultures can be handled with sensitivity and skill by allowing people to express themselves, even in an angry, agitated manner, without others escalating into rage. Findings showed that skilled facilitation for handling such situations involved remaining calm, validating the person's concerns and focusing on what a person is expressing as opposed to the way it is being expressed. This way of allowing people various ways of communicating while remaining constructive was valued by committee members. It contributed to creating ideal speech conditions which in turn enhanced democratic processes

Transformative learning enables the transformation of power relations and creates an environment of mutual respect, equity and trust (Chavez et al., 2008; Chung & Lounsbury, 2006; Schensul, 2010; Stoecker, 2008). While findings from this study reveal the presence of these aspects of transformative learning in harm reduction committee settings where people who use drugs are included, they also offer examples of practices that foster transformative learning and

ultimately lead to transforming power inequities. In addition to creating a safe space, democratic practices contribute to sharing power in decision-making.

### **Practicing Democracy**

Key democratic practices that emerged from the findings included negotiating relationships and consensus-based decision-making. Regardless of where decision-making power resided in a committee along Arnstein's ladder of participation, the extent to which committees clearly negotiated relationships with people who use drugs at the table had an influence on power relations. Similarly to informed consent, people who use drugs who were better prepared and understood the extent to which they could influence the committees' decisions enriched the democratic process and contributed to shifting power toward sharing it with people who use drugs. People who use drugs had a clearer sense of their role at the table and what was expected of them as representatives of people who use drugs. While three of the committees varied in terms of how well they clarified the roles of people who use drugs in decision-making at their table and did not negotiate this role *per se*, the research committee made a point of intentionally negotiating relationships with and roles of people who use drugs at the table in a meaningful way. The role of people who use drugs at this table and the influence they had on decision-making was therefore co-created, put into practice, questioned, discussed and adapted along the way. Decision-making was thus consensus-based.

Such consensus-based decision-making was common in the committees studied and seemed optimal for meaningful inclusion of people who use drugs. As a result, in the case of the research committee where all committee members contributed ideas, committee members felt that their voices had repercussions. Interestingly, proposed ideas were built on, changed, discussed, debated until consensus was reached and became collective ideas, with shared

ownership. Though this consensus-based process for decision-making was time consuming, it valued everyone's voice and helped shift decision-making power from power over to power with people who use drugs.

Arnstein (1969) reported that in many instances, committees did not negotiate sharing decision-making power with community members, and this was observed in this study. In such situations, unless community members demanded that decision-making power be shared, people in power did not take the initiative to negotiate sharing decision-making power. In the case of the policy committee in this study, people who use drugs did express interest in being involved on an ongoing basis as members of the committee though, at the time, committee chairs consulted with them once a year as a first step towards inclusion and there were no immediate plans of assigning seats to people who use drugs on the committee. The research committee, however, was set up at the onset as one where decision-making power is intentionally negotiated and shared with people who use drugs. Research committees, however, have more freedom to experiment with their structure than do committees entrenched in the greater health services institutions and structures.

According to Arnstein, failing to negotiate power results in tokenism where are negotiating whereas true partnership and inclusion takes place when power is redistributed through negotiation. Other authors have expressed the importance of being explicit at the onset about how participation will be implemented in practice, where the power in decision-making will reside within the structure, and what will be expected of those who are being included (Barreteau et al., 2010; Chung & Lounsbury, 2006). Findings from this study further support and provide examples of the importance of negotiated relationships in social inclusion practice.

Regarding consensus-based decision-making, Biggs (1989) and Probst and colleagues (2003) consider this to be part of a collegiate mode of participation where all actors are partners

and the responsibility is shared. Findings from this study support these authors' points and add to them by describing the impact consensus-based decision-making had on participants involved: a sense of collective ownership of decisions made.

Power relations at committee tables where people who use drugs were included took place within a greater political and organizational context, explored in this last section of the discussion.

### **Influence of the Political Context**

Findings from the study revealed that there was international momentum toward challenging current drug policy and conventions that criminalize people who use drugs. As the world prepares to come together to discuss current approaches to drug policy at the United Nations General Assembly Special Session on Drugs in 2016, many leaders and intellectuals are calling for drug policy reform and the end of criminalization of people who use drugs. A Civil Society Task Force has been struck to ensure the inclusion of civil society voices, including the voice of people who use drugs, in these important deliberations. People who use drugs are represented by the International Network of People who Use Drugs.

While opportunities for inclusion of people who use drugs grew at the international level, the Conservative Government of Canada, in power since 2006, adopted a touch on crime stance with its National Anti-Drug Strategy, which eliminated harm reduction as one of its four pillars, and a *Safe Streets and Communities Act* which imposed mandatory minimum sentences for some drug offenses, and a *Respect for Communities Act* which requires an extensive application and prohibitive application process for jurisdictions planning to provide supervised consumption services to people who use drugs. In addition to being overtly resistant to harm reduction efforts, the Conservative government ceased all consultations regarding drug policy developments with

civil society which used to take place and included people who use drugs under the prior Liberal government. Opportunities for inclusion of people who use drugs in decisions that affect them have therefore decreased at the national level. Perhaps the new majority Liberal government, elected on October 19<sup>th</sup>, 2015, will reintroduce inclusive dialogues which include people who use drugs as it sets forth to revisit drug policy and harm reduction efforts in Canada.

Provincially, while both provinces of interest for this dissertation, Ontario and British Columbia, adopted policies of inclusion of people with lived experience in its health care systems, including people who use drugs. There was also increasing mobilization of people who use drugs and a growing number of organizations of people who use drugs. The existence of such organizations was instrumental in their inclusion in decisions that affect them, since they provided venues to approach to find representatives to invite to committee tables. The resistant political climate to harm reduction services in general and to people who use drugs specifically affected the attempts for people who use drugs to mobilize by hindering support in their communities and limiting financial opportunities available to them.

Indeed, financial constraints on all harm reduction efforts were pervasive and affected power relations at the table. While inviting people who use drugs to decision-making tables raised their expectations in terms of having power to influence change, they came to realize the limited power and systemic constraints policy makers faced to bring about more harm reduction services. People who use drugs and others at the table shared a common frustration and sense of injustice when faced with these barriers, though for people who use drugs, this sense of limited power was deeply personal. They had also repeatedly experienced difficulties in obtaining funding for CAPUD (CAPUD, 2010a). Marshall and his colleagues (2015), who conducted a systematic review of the various roles of people who use drugs in harm reduction initiatives, also

identified political climates as important systemic obstacles to funding for organizations that support or promote harm reduction. The limited resource allocation to harm reduction services sent the message that the issues faced by people who use drugs were not of value, reinforcing stigma. It also caused tension between people who use drugs and others at the table, since people who use drugs were frustrated at others' perceived lack of courage to stand up to this injustice.

It is clear from these findings that the political environment in Canada, which thwarted resource allocation to harm reduction efforts, hindered the inclusion of people who use drugs in decisions that affect them, and fed the stigma toward people who use drugs and services to help them, contributed to a risk environment for people who use drugs, as proposed by Rhodes and his colleagues (Rhodes, 2002; Rhodes, et al., 2005). Unlike Portugal, a country that realized that criminalization plays a role in aggravating stigma and discrimination, strove to explicitly remove and prevent stigma attached to drug use by decriminalizing drug use, emphasized health and addressed barriers to health services (Greenwald, 2009; van het Loo, et al., 2002), Canada continued to reinforce a risk environment for people who use drugs.

Furthermore, Canada's approach to drug policy and harm reduction hindered committees' commitment to social justice to address health inequities and efforts to change conditions that contribute to such inequities. Indeed, changing policy structural factors has been identified as important to address health inequities for people who use drugs (Faden & Powers, 2008; Gupta et al., 2008) and challenging such policies was difficult for committees involved in harm reduction in such resistant political environments. Findings show that the impact of current policies related to drug use and harm reduction in Canada hindered more equitable distributive approaches which focus on the fair sharing of material resources, such as the allocation of funds to harm reduction efforts, and negatively influenced more equitable procedural approaches which

focus on equity in terms of power and participation in decision- and policy-making (Bess, et al., 2009; Minkler, 2010; Ng, et al., 1990; Pauly, 2008; Rhodes, 2002; Rhodes, et al., 2005; Young, 2001).

Travers and his colleagues (2008) pointed out, in previous research, that organizations recognized enhanced policy development as a benefit of inclusion of representatives from marginalized communities. They also reported that the inclusion of people with lived experience helped reduced stigma and isolation, increased feelings of empowerment and self-worth, and noted that engaging community members required consideration to structural factors. Findings from this study show how structural factors such as the political context hindered possible benefits to policy development from the inclusion of people who use drugs on committees given the already stunted level of power and hesitation such committees had to influence harm reduction policy.

This study has provided useful findings to advance the academic conversation with regard to including people who use drugs in decisions that affect them in an attempt to render power relations more equitable. Interpretation of these findings must be accompanied by considerations for the study's limitations.

### **Limitations of this Research**

First and foremost, this study was exploratory in nature in an attempt to get beyond simply stating barriers and facilitators to inclusion of people who use drugs and go deeper to uncover glimpses of how transformation of decision-making power inequities takes places at tables that include people who use drugs. Data collection was cross-sectional and only captured observations from one meeting of each committee and one interview with members from each table. These data do not therefore allow exploring transformation of power inequities over time.

Additionally, given that research has shown that the nature of participation can change over time within the same project, the findings from this research only captured the location of power and the nature of power relations at a given point in time.

Since the findings only captured social inclusion practices in a few settings within a limited time, they are not generalizable to other contexts. The findings were obtained from a relatively small sample size, which were not selected randomly. Results from this study are therefore specific to the context of the four committees included in this study and not generalizable to all such committees involved in harm reduction services decisions in Canada.

That said, the findings from this exploratory inquiry are definitely transferable and provide sufficient details for readers to be able to use the insights in their own contexts, with people who use drugs or other marginalized groups. The findings increase understanding of including representatives of marginalized groups at decision-making tables, which can apply in many settings.

Though some observations were included in the analysis, findings were largely interpreted based on data from interviews, which may introduce a social desirability bias in that interviewees may have had a tendency to say what they thought the interviewer wanted to hear.

As the person who collected the primary data and conducted the qualitative analysis, my place of privilege may have influenced my interpretation toward being overly idealistic, though I did strive to be true to what I observed in meetings and heard from the interviewees. I also brought in my own experience at committee tables which included people who use drugs which helped me tease out findings I found most relevant and important as to their practical implications. It is likely that my interpretation of the findings was also influenced by

unconscious biases. Throughout this research, I also learned valuable lessons that have influenced by own inclusion practice.

### **Lessons Learned**

Working within a CBPR framework, I truly appreciated my partnership with both DUAL and SOLID. In Chapter 3, I elaborated on how the partnership was defined and established before proceeding with the research. DUAL and SOLID representatives agreed to participate in decisions along the way through negotiations, understanding that ultimately this research was for my PhD dissertation. Nevertheless, they were involved in every step and I felt that this research was as participatory as it could be under the restrictions of time and funding, and with agreed upon parameters. Most importantly, the research led to the development of practice guidelines that will hopefully be taken up by allies who want to put action behind their words. As an ally myself, I certainly have learned valuable lessons along the way.

First, with regard to the CBPR approach I used, the partnership agreement I established with DUAL and SOLID worked well for our purposes. At the onset, we discussed the extent of their involvement and it was clear that they wanted to be partners, though not necessarily to be peer researchers. It was also clear that I did not have the research resources to train them to become peer researchers. They also did not express any interest in being involved in doing data analysis. We negotiated that I would consult them at every important step (i.e. setting the research questions, developing the demographics survey and interview questions, review preliminary analyses and obtaining final results before their release). They felt strongly, as I did, that this research should yield practical results and requested that I produce a short document with practice guidelines that they could hand out to allies who request their presence at a decision-making table. The results of this research are now summarized in a CARBC Bulletin for

this purpose. Finally, with regard to our partnership, we agreed that any publication would clearly acknowledge their participation as partners in this research. Some of the DUAL and SOLID representatives expressed a desire to be co-authors as well, which I will honour.

For our meetings, I brought honoraria for SOLID and DUAL representatives as well as food if I met them in person. These efforts were greatly appreciated. I also brought drafts of documents to be discussed, which I sent them in advance of our meetings. In retrospect, some of the concerns they expressed ended up coming out in the findings. For example, in the interview questionnaire, they pointed out that it was important to ask participants, especially people who use drugs, if they understood why they were at a specific meeting and if they were aware of whom else was at the table. They also expressed concerns about being provided with space during meetings to speak and some flexibility and understanding about how they express themselves. SOLID and DUAL representatives were also wanting to know, before attending meetings, how their knowledge and input would be applied, and how their needs would be met during meetings. Being well prepared prior to a meeting, understanding why they were invited to a table, addressing socioeconomic inequities and skilled facilitation around dialogue and communication were addressed in the findings and discussion.

At the onset, I wondered how SOLID and DUAL would feel about the collection of demographics data for this research. I wondered how invasive they would find this part of the data collection and whether they would feel uncomfortable with this information being collected. We worked through the questionnaire to ensure the language was sensitive and accessible. During our meeting to go over preliminary results, it became clear how important the demographics data were, since they strikingly revealed the significant socioeconomic inequities between people who use drugs and others at the table. Upon seeing these results, my research

partners insisted that I reveal these findings. They expressed feeling somewhat validated by seeing these results, in that the results clearly indicated what they felt they already knew about these inequities.

Another important aspect of preliminary findings meetings was their input around my use of language. For example, I originally described “measures to address socioeconomic inequities” as measure of economic levelling, as is described in the literature. This language generated an animated discussion around the fact that the measure taken by committees such as providing a stipend were hardly levelling their socioeconomic position to that of their researcher, policy maker and service provider colleagues. I agreed to change the wording. For the most part, though, conversations around the preliminary findings served to validate many of their experiences with power relations at decision-making tables, which reassured me that I was capturing their voices.

The relationships I nurtured with both DUAL and SOLID extended beyond their involvement in this research. Through my work as a National Programs Manager at the Canadian AIDS Society, I had the privilege of obtaining funding through the MAC AIDS Fund to develop a resource by and for people who use drugs on how to get involved. With the insights I gained through this research, my approach to managing this project significantly changed. My usual approach in the past was to be the project lead and obtain input from an advisory committee. For this project, however, I intentionally chose to take a step back, let go of the reins, and let the project emerge from the representatives of people who use drugs I recruited. I approached the Canadian Association of People who Use Drugs (CAPUD), which had expressed a need for such a resource, and asked representatives to come forward to work on developing the resource. At first, I was cautious and reluctant to do so, but as I let go, I watched the magic unfold.

Indeed, from the onset, I made it clear to the group that this was their project and resource and that they would be the ones developing the content, and I would assist by facilitating the process. We started by first finding out what aptitudes each person brought to the team and developed our approach from there. The MAC AIDS funding made it possible for everyone to be paid for their time in the meetings, as well as for their contribution to the document. As it turned out, and to my great delight, each of the team members was interested in writing excerpts for the document. It was agreed that we would produce a manual on how people who use drugs can get involved in their community. Together, we developed the outline for the manual based on what they thought was important for their peers to know and what they wished they had known when they first began to get involved in their local community. In addition to each team member taking on writing specific parts of the document, it turned out that one of the team members was good at graphic design, while another was good at translation. We therefore did not have to source this work outside of the team. For most of them, creating this manual was a larger task than they had ever previously undertaken, which provided a valuable opportunity to build their experience and capacity. My role, as an ally, was to help out where I could, provide guidance as needed given my experience in producing such documents, and taking care of the logistics to make it happen. The team shared a sense of ownership over the document, *Peerology: A guide by and for people who use drugs on how to get involved* (CAPUD, 2015), and proudly presented it at the 2015 Alberta Harm Reduction Conference.

The success of *Peerology* helped CAPUD obtain a second grant from the MAC AIDS Fund to develop as an organization. The Canadian AIDS Society hosts the funding and I continue to work with them to assist wherever I can, having learned to take their lead and let them develop the organization as they see fit. “Actions speak louder than words”, as they say.

I am very grateful for the transformative learning I have experienced and continue to experience throughout my collaborations with people who use drugs. I have faced my own judgements and assumptions about people who use drugs and their capacity to take on such projects. My shift in consciousness has reminded me that when one expects the best from people, one gets the best from people. I have grown as an individual and as a community-based participatory researcher. I hope that this work contributes to improving equity for people who use drugs who participate in decisions that affect them.

### **Recommendations for Future Research**

It would be interesting to further explore the transformative learning that takes place at more decision-making tables where people who use drugs are included, only partly included and also at tables where they are excluded. This study explored Brookfield's (2009) Seven Learning Tasks *in situ*, with participants who I assume had no prior knowledge of these learning tasks. It might be useful to conduct intervention studies where committee members at such tables are purposely trained, through a workshop, on these learning tasks and can participate in committee meetings with greater awareness and conscientization as to how to challenge dominant ideologies and deconstruct how power inequities are reproduced in such settings.

This study was approached from the perspective of allies, who work with people who use drugs and strive to include them in decisions that affect them, with some input from people who use drugs. It would be interesting to develop a community-based participatory research project which was situated in the perspective of people who use drugs to further explore decision-making power inequities and how these may be transformed at committee tables, to see if findings differ when interpreted directly by people who use drugs.

Finally, since it is unlikely that a truly equitable distribution of decision-making power can be achieved at such tables where there is such disparity in life situations and lived experience between people at the table, more research on the best ways to avoid tokenism and reproducing inequities is warranted.

## Chapter 8 – Conclusions and Practice Implications

### Conclusions

This exploratory critical emancipatory inquiry, which adopted a participatory framework and drew on critical ethnography procedures to examine how decision-making power inequities may be transformed at tables that include people who use drugs led to the following conclusions:

#### **Organization context.**

Where people who use drugs held the majority of seats, the committee was intentionally structured to give people who use drugs more control in a community-based participatory research project. The committee had mindfully included capacity building for people who use drugs to ensure they could meaningfully participate in all aspect of the research project. Relationships with people who use drugs and researchers were negotiated at the onset and the research project was co-created with people who use drugs. This structure and process were key components in contributing to shared power in decision-making. The committee also built in an ongoing evaluation process and adapted its processes based on the results. They consciously experimented with this way or collectively organizing and were pro-active in their challenging dominant power relations to ensure they were more equitable.

All committees included in this study were committed to including people who use drugs at their table, though levels of committee and capacity to do so varied. Committees had budgetary and human resource constraints to properly compensate and support people who use drugs to be at their tables. In some cases, they had not thought about the financial and support considerations and had therefore not planned for them to ensure more equitable inclusion of people who use drugs. These findings indicated a clear need for guidelines to properly and

thoughtfully include people who use drugs at their tables as well as pre-invitation negotiations with people who use drugs to establish this process collaboratively.

### **Socioeconomic inequities.**

Striking socioeconomic differences between people who use drugs and others at the table were confirmed by the demographics survey conducted as part of this study. People who use drugs faced intersecting determinants of inequities of poverty, food insecurity, ethnic or cultural background, and limited education.

There was variation and inconsistency in measures taken by committees to address these socioeconomic inequities whereby people who use drugs were remunerated for their participation or food and financial support were provided for meetings. Committee chairs grappled with the best way to address economic inequities and to recognize the equivalence of lived experience monetarily, and no clear policies existed to guide them.

### **Socially constructed views of people who use drugs.**

Despite an openness and good will to invite people who use drugs to the table, committee members tended to underestimate people who use drugs. People who use drugs were generally only valued for their drug use experience, which devalued their contribution and participation in decision-making. People who use drugs tended to yield to experts in a ‘researchers know best’ manner. Others at the table were hesitant to challenge people who use drugs on their views, which people who use drugs experienced as disrespectful, condescending and patronizing.

To counter stigma, people who use drugs tended to overcompensate to meet or exceed dominant standards and placed pressure on themselves to excel and perform in order to change the perception of *all* people who use drugs.

### **Representation.**

Representatives of people who use drugs were usually found by committees through local organizations of people who use drugs. These representatives could speak from their own lived experience and also represent issues that affect a variety of lived experience since they were connected to a larger network. The organizations of people who use drugs could also select their own representatives, thereby ensuring a more democratic process of self-representation.

### **Creating a safe space.**

To shift decision-making power from power over people who use drugs to power with them required creating a safe space where people felt comfortable with and learned to trust each other, could relate to each other authentically and could engage in dialogue. . Social activities, co-learning activities and skilled facilitation enhanced the ease with which people settled into committee spaces and engaged in relational, trustful and reflective dialogue. Authentic relationships where committee members dropped their roles and related to each other helped overcome alienation, created a warm, inviting and respectful atmosphere, promoted critical reflection, openness and mutual understanding.

Skilled facilitation created this safe space through patience, structured meetings, honesty, providing opportunities for quieter committee members to speak, inviting comments and opinions, and encouraging a hand raising policy. Remaining calm, validating a person's concerns and focusing on a person's expressed concerns rather than the way the concern was expressed dissipated tension and anger among committee members. It allowed various ways of communicating while remaining constructive. Encouraging a constructive dialogue and handling opposing views with respect encouraged people to share differing views.

### **Practicing democracy.**

Key democratic practices included negotiating relationships and consensus-based decision-making. The extent to which committees clearly negotiated relationships with people who use drugs at the table had an influence on power relations. Similarly to informed consent, people who use drugs who were better prepared and understood the extent to which they could influence the committees' decisions enriched the democratic process and contributed to shifting power toward sharing it with people who use drugs. People who use drugs had a clearer sense of their role at the table and what was expected of them as representatives of people who use drugs.

Consensus-based decision-making was common in the committees studied and seemed optimal for meaningful inclusion of people who use drugs. As a result, committee members felt that their voices had repercussions. Interestingly, proposed ideas were built on, changed, discussed, debated until consensus was reached and became collective ideas, with shared ownership. Though this consensus-based process for decision-making was time consuming, it valued everyone's voice and helped shift decision-making power from power over to power with people who use drugs.

### **Influence of the political context.**

Current drug policies which criminalize people who use drugs and thwart harm reduction efforts hindered capacity to transform decision-making power inequities for people who use drugs at committee tables toward more equitable ones.

With the insights obtained through this research, and as agreed with my research partners, I now offer practice guidelines to contribute to better inclusion of people who use drugs at ally decision-making tables.

## **From One Ally to Another: Practice Guidelines to Include People who Use Drugs**

From one ally to another, I propose some guidelines for better inclusion of people who use drugs at decision-making tables.

### **Before you invite people who use drugs to your decision-making table.**

- Be clear about the purpose of inviting people who use drugs to the table, what you plan on doing with their input, and how you plan on including them in committee meetings.
- Consult with people who use drugs and negotiate this relationship with them. Have clear terms of reference which describe the committee structure and decision-making process.
- Plan for financial compensation and proper support of people who use drugs to ensure more equitable inclusion of people who use drugs. See tips below under ‘Catering to specific needs of people who use drugs’. Negotiate these measures clearly with people who use drugs to ensure you will be meeting their needs.
- Explicitly enquire about each person who uses drugs’ financial and support needs to meaningfully participate in your committee. Do so individually, confidentially and with respect and sensitivity.

### **Explore various models of including people who use drugs.**

- If people who use drugs are not members of your committee and you occasionally consult them for input, keep them informed between meetings and let them know how their input was used in your committee’s decisions.
- Assign specific people to liaise between the committee and people who use drugs and be consistent about how these communications take place.
- Consider hosting local or regional ongoing tables of people who use drugs to get their input on a regular basis and to report to them about committee activities and decisions.

- Explore hosting an advisory committee of people who use drugs to inform your ongoing organizational activities and decisions.
- If you bring people who use drugs as members on your committee, ensure they have several seats so that their voices can be represented at your table even if a few are absent.

**Cater to the specific needs of people who use drugs.**

- Travel considerations: If people who use drugs are traveling to attend your meeting, they may require identification documents. They may require support to obtain those prior to a meeting. Alternatively, they may require accompaniment during travel to have a person who can confirm their identity.
- Harm reduction supplies: Make harm reduction supplies available at your meeting and provide breaks to ensure people who use drugs can tend to their needs.
- Support people who use drugs who are on substitution treatment or choosing abstinence: Provide information on where to obtain methadone near meeting sites. Refer people who choose abstinence and/or who may experience triggers to nearby health and support services or provide those onsite.
- Assign specific coordinators to ensure the needs of people who use drugs are met and clearly communicate the support that is available to people who use drugs.

**When hiring people who use drugs.**

- Value lived experience as much as you would education and professional accreditation. Encourage your organization to develop human resources policies regarding hiring people who use drugs.
- Identify and discuss ethical dilemmas regarding confidentiality of clients with people who use drugs you hire, since these clients may be part of their social network.

- Include people who use drugs on your hiring committee.
- Tailoring the responsibilities assigned to people who use drugs to their life circumstances and their capacities, in negotiations with them.

**Skilled facilitation at meetings.**

To challenge stigma against people who use drugs and power inequities:

- Explicitly deconstruct and challenge stigma against people who use drugs and processes that reproduce stigma within your committee
- Build in an ongoing committee process evaluation and adapt your processes accordingly.
- Experiment, by trial and error, with different ways of organizing collectively.
- When in doubt, ask: Verify assumptions with people who use drugs. For example, if you assume they would not be interested in being on your committee, ask them if this is the case.

To create a safe space conducive to relational, trustful and reflective dialogue:

- Facilitate the meeting with patience and honesty.
- Drop your roles and relate to each other authentically as human beings.
- Organize social activities and co-learning activities around your meeting to help build rapport, trust and authentic relationships between committee members.
- Structure the meeting so that everyone is clear on how the meeting will unfold.
- Provide opportunities for quieter committee members to speak and invite comments and opinions. Manage the time allotted to the more vocal members.
- Encourage a hand raising policy.
- Allow people to express themselves and communicate in different ways. Remain calm and validate a person's concerns. Focus on a person's expressed concerns rather than the way the

concern was expressed in order to dissipate tension and anger among committee members and remain constructive.

- Practice consensus-based decision-making, realizing that this process will be time consuming.

**Support organizations of people who use drugs.**

- Offer to assist people who use drugs with organizing local/regional meetings of people who use drugs.
- Offer to provide support with funding applications, mentoring, and co-facilitation within the means of your organization's resources.

**Advocate for action on the social determinants of health.**

- Advocate for the greater and meaningful inclusion of people who use drugs.
- Advocate for people who use drugs to speak for themselves.
- Advocate for drug policy reform and an end to the criminalization of people who use drugs.
- Advocate for addressing intersecting determinants of inequities such as poverty, stigma and discrimination.

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## **Appendix A – Consultation for Partnership**

### **“At the Table” with People who Use(d) Illegal Drugs: A Critical Ethnography into Power Relations Lynne Belle-Isle, CARBC, University of Victoria**

Presentation to and Consultation with SOLID’s Board of Directors: October 1, 2012

Presentation to and Consultation with DUAL’s Board of Directors: October 17, 2012

#### **Agenda**

1. Round of introductions
2. Background – how I came to wanting to do this study
3. Summary of the proposed research
4. Tasks and timelines
5. Next steps

#### **Summary of the Proposed Research**

Of all members of society, those in a low socioeconomic position are disproportionately affected by poor health outcomes. Eliminating health inequities has emerged as a worldwide public health and social justice priority. Health inequities are worsened by current drug policy aimed at eliminating the non-medical use of cannabis, cocaine, opioids and many pharmaceuticals. The health and well-being of people with illegal drug use experience is hindered by criminalization and incarceration, thwarted harm reduction and health promotion efforts, and barriers to access to health and social services. Inequities for people who use(d) illegal drugs may be further compounded by marginalization due to differences in social position in terms of class, political, racial, gender and other differences. Inequities can also be exacerbated by how society is organized into social structures such as social networks, social institutions, and broader political and economic structures. Social exclusion from social structures where decisions are made that affect the lives of people with illegal drug use experience, for example, can result from stigma regarding the use of illegal drugs. This risk environment fosters behaviours for disease transmission as well as the marginalization, stigmatization and social exclusion of people with illegal drug use experience. Social exclusion is thus an important determinant of health inequities and can hinder actions to address health and social inequities.

In an attempt to address health and social inequities, promising social inclusion practices have emerged whereby people with illegal drug use experience are meaningfully engaged and included “at the table” in social structures such as policy making processes by participating in political spaces that affect their lives. People who use(d) drugs have also been advocating for their inclusion in these political spaces, citing a “Nothing about us without us” principle. The premise is that the inclusion of those historically excluded due to race, gender, culture, language, or other characteristics (e.g., illegal drug use experience) into social policy decision-making structures and processes challenges how social power is situated within social structures by

reducing power inequities, sharing the power and relating in non-discriminatory, non-stigmatizing ways.

Social inclusion thus resides in the realm of human relations. The transcendence of oppressive conditions in such collaborative settings is thought to lead to the emancipation of oppressed groups through a transformative learning process. Transformative learning is said to take place when people develop the critical consciousness to deconstruct prevailing ideologies, recognize the social, political, economic and personal constraints on freedom, and realize that they have the power and agency to play a role in changing social conditions through actions aimed at challenging and restructuring social structures of power. One key element of this transformation is shared power and decision making.

People with illegal drug use experience have displayed empowerment, exercised agency and mobilized into organizations of people who use drugs. Representatives from organizations of people who use drugs have been participating in various policy decision-making processes at the municipal, provincial, national and international levels, and there is growing interest in encouraging their greater, meaningful involvement and inclusion in policy settings. For example, representatives from the Society of Living Illicit Drug Users (SOLID) currently sit on an advisory committee for a research project with the University of Victoria, as well as on public health committees.

Some knowledge has been produced regarding innovations in social inclusion whereby members of socially excluded groups have been included in social structures that affect their lives. Barriers and facilitators to participation and social inclusion of some marginalized groups such as people living with HIV/AIDS and disabled communities have been identified to some extent in the literature. Most of these studies do not pertain to the population of interest in this dissertation, people with illegal drug use experience, and do not focus on analysing power relations in decision-making. Furthermore, there is both a political and practical momentum toward encouraging the greater, meaningful involvement and inclusion of people with illegal drug use in social structures where decisions are made that affect their lives. In research, funding and governance bodies are also increasingly requiring community-academic partnerships, while empowered communities are increasingly demanding to be involved.

In light of the trend toward greater inclusion of people who use(d) illegal drugs into social structures, and given the gap in the literature regarding power relations in this context, it seems particularly timely to gain greater understanding of the power relations and interactions between people who use(d) illegal drugs and others (researchers, service providers, policy makers) “at the table” and whether the interactions between all parties at the table are actually contributing to shared power and decision-making in social inclusion practice.

The purpose of this study is to produce knowledge that seeks to understand and clarify decision-making power relations between people with illegal drug use experience and others at the table. This knowledge will be contextualized to account for personal and historical relationships among everyone at the table where decisions are made as well as the broader social, historical, political and economic context in which decisions take place. My main objective is to

contribute to addressing health inequities affecting people with illegal drug use experience through a better understanding of power relations within social inclusion practice between people who use(d) drugs and others “at the table” where decisions are made that affect their lives. Specifically, these “tables” include policy, service delivery and research decision-making tables. Such knowledge will contribute to uncovering discourses and practices that may be facilitating or hindering the meaningful involvement and social inclusion of people with illegal drug use experience through the sharing of power and decision-making. Such an inquiry will thus yield important considerations and insights to improve social inclusion practice within organizations that make decisions that affect the lives of people with illegal drug use experience. It will also identify important areas for people with illegal drug use experience to further advocate for their meaningful inclusion in social structures where decisions are made that affect their lives. Understanding social inclusion practice and power relations between the various participants in policy contexts will hopefully encourage a process of organizational self-reflection as to how inequities may be reproduced in their social inclusion practices, and shed light on practices and processes which may be facilitating and encouraging shared power and decision making.

### ***Proposed Research Questions***

With this problem statement and purpose statement in mind, I propose the following central question for this dissertation:

- How are power relations experienced and expressed between all participants within social inclusion practice where people with illegal drug use experience are included “at the table”?
- In what ways do power relations between participants “at the table” contribute to or hinder shared power and decision making?
- What contextual factors positively and negatively affect power relations “at the table”? Contextual factors include personal and historical relationships among everyone at the table, as well as the broader social, historical, political and economic context in which decisions take place.
- What impact (positive and/or negative) has the social inclusion of people with illegal drug use experience had on the lives of all participants who are at the table?
- What are the implications for the organizational social inclusion practice based on insights gained from these findings?

## Tasks and Timelines

- Who:** Participants at decision making tables where people who use(d) drugs are included: health research, service delivery, policy making tables
- What:** Critical ethnography. Participant observations, one on one interviews, short demographic survey and supplementary sources of information.
- Where:** Observations will take place during actual meetings. Interviews will be arranged individually and will take place at a mutually convenient and comfortable place.
- When:**
- |                           |   |
|---------------------------|---|
| Pre-ethics consultations: | October 2012  |
| Data collection:          | Winter and Spring 2013  |
| Data Analysis:            | Spring and Summer 2013  |
| Input on Findings:        | Fall 2013   |
| Write-Up of Dissertation: | Fall 2013 and Winter 2014. I hope to finish and defend my dissertation in the spring of 2014. |

### **How:**

Before ethics approval – fall 2012: seek agreement in principle to approach research sites for data collection

Once ethics approval received – Winter 2013: Once ethics approval has been obtained, data collection can begin. I will attend meetings at which SOLID and DUAL members are included. I propose to first present my research to the committee in question in detail, with opportunities to ask questions. I will hopefully obtain their consent to observe and take notes during the meetings. I will request one-on-one interviews with as many participants from these tables as are willing to participate. Full informed consent will be sought from each participant. Data collection will take place in the winter and spring of 2013.

Data analysis: I will conduct the preliminary data analysis in collaboration with DUAL and SOLID. I will present preliminary findings to the committee for input. This will take place in the summer or fall of 2013. I will then conduct any additional analysis and come back to both groups for final input and approval.

Data dissemination: With SOLID and DUAL, we will prepare whatever products to disseminate the findings – a report, pamphlet, whatever we decide would be most useful. I will prepare a manuscript for publication, in co-authorship with participating members of SOLID and DUAL. I will present the findings at relevant conferences and meetings and disseminate them widely through vast networks. Members of SOLID and DUAL will be invited to co-present the findings with me whenever possible.

**Why:** Findings will provide insights into how power relations and redistribution within institutional environments foster and promote or hinder social justice. Implications for organizational social inclusion practice will be discussed and disseminated.

**Next Steps**

- discuss proposed idea with the committee and decide if there is interest to participate in principle
- obtain a written communication of this agreement for the ethics application in the next few weeks
- I will communicate with you again once ethics approval has been obtained.

## Appendix B – Partnership Agreements

### Partnership with SOLID – Victoria, BC

**S. O. L. I. D.**  
Society of Living Illicit Drug Users

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SOLID Board Meeting  
Minutes taken by: Jill

Minutes typed by: Ashley

Date: October 1, 2012

In attendance: Michelle, Jill, Dan, Mark, Katie, Ashley

Chairing: Mark

1. Meeting called to order at 1100
2. Approved board minutes from August 27, 2012
3. Approved agenda
4. Lynne Belle-Isle presented her research on “At the Table” a critical ethnography about how people who use drugs are included in meetings and decision-making processes. She plans to observe and do interviews with folks who attend the VNEX meeting, the HRSS meeting and others. She wants to partner on this project with DUAL (Drug Users Advocacy League) and SOLID.

What’s in it for us?

-Out of this could come guidelines for how to practice “nothing about us without us” for our participation in decision-making processes.

-Honorariums

She asked if SOLID wants to partner with her. The board unanimously agreed to be a partner. She will need a letter from us in the next couple of weeks. Will email us.

---

empathy \* compassion \* education \* peer support \* harm reduction \* acceptance

**Partnership with DUAL – Ottawa, ON**

**Re: Re: Re: talk this week?**

Sean  
LeBlanc

Saturday, October 20, 2012 07:08AM

To:Lynne Belle-Isle

I most certainly do agree to participate in this research, and am proud to do so...

**Re: Re: Re: talk this week?**

RICHARD  
SPROULE

Thursday, October 18, 2012 12:16PM

To:Lynne Belle-Isle

Hello Lynne:

Yesterday's meeting was very uplifting for me, as it always is when I talk with someone so close to my way of thinking on this and other subjects. Thank you for discussing the details of " At the Table " with us and we would love to partner with you and SOLID on this.

Sorry that Malcom couldn't make it but Sean and I have filled him in since the meeting.

Bye for now Lynne, Yours, Rick Sproule DUAL vice-chair

**From:** Lynne Belle-Isle

**To:** RICK

**Sent:** Wednesday, October 17, 2012 3:37:09 PM

**Subject:** Re: Re: Re: talk this week?

Hi Sean and Rick,

It was a pleasure to meet with you both this morning, as members of the DUAL Board of Directors. Too bad Malcolm could not join us though maybe I will get to meet him when I come for a visit in December.

Thank you both for your interest in partnering with SOLID and I on the research I described to you in the attached summary and during our teleconference. I am very much looking forward to working with DUAL on this.

As you know, the next step will be for us to meet to go over the research questions and details so that I can have your input to guide the data collection. I will be in touch with you about this once I have received ethics approval.

Could you please simply respond to this email and state we have discussed the details of this study and that you agree to partner on this research? I can then submit this email as part of my ethics application.

Have a great day, and take good care.  
Lynne

---

Lynne Belle-Isle  
National Programs Manager, Canadian AIDS Society  
Chair, Canadian Drug Policy Coalition  
PhD Candidate, CARBC, University of Victoria

-----Lynne Belle-Isle/CAS wrote: -----

To: Sean LeBlanc  
From: Lynne Belle-Isle/CAS  
Date: 10/16/2012 02:38PM  
Cc: "RICK"  
Subject: Re: Re: Re: talk this week?

For sure. It will be a nice way for me to start my day : )

By the way, I am attaching a summary document regarding my research. I will be presenting the details to you and asking DUAL to partner with me and SOLID. I will tell you how much time commitment this would be, and what's in it for you.

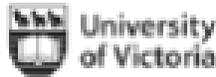
Talk to you tomorrow,

Lynne

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Lynne Belle-Isle  
National Programs Manager, Canadian AIDS Society  
Chair, Canadian Drug Policy Coalition  
PhD Candidate, CARBC, University of Victoria

## Appendix C – Ethics Letters of Approval



UVic/VIHA Joint Research Ethics Sub-Committee  
 Human Research Ethics, University of Victoria  
 PO Box 1700, Stn CSC, Victoria BC, V8W 2Y2  
 Tel 250-473-4545 Fax 250-721-8960 Web www.research.uvic.ca



Vancouver Island Health Authority, Memorial Pavilion, Kenning Wing  
 1952 Bay Street, Victoria BC, V8R 1J8  
 Tel 250-370-8261 Fax 250-370-8106 Web www.viha.ca

### Certificate of Approval

PRINCIPAL INVESTIGATOR: <b>Lynne Belle-Iste</b>	ETHICS PROTOCOL NUMBER: <b>J2012-86</b>
POSITION: <b>Ph.D. Student</b>	ORIGINAL APPROVAL DATE: <b>04-Mar-13</b>
DEPARTMENT: <b>CARBC</b>	APPROVED ON: <b>04-Mar-13</b>
SUPERVISOR: <b>Dr. C. Benoit; Dr. B. Pauly</b>	APPROVAL EXPIRY DATE: <b>03-Mar-14</b>
<p><b>PROJECT TITLE: "At the table" with People who Use(d) Illegal Drugs: A Critical Ethnographic Inquiry into Power Relations</b></p> <p>RESEARCH TEAM MEMBER UVic: Dr. Cecilia Benoit (Supervisor), Dr. Bernie Pauly (Supervisor)                  VIHA: Jill Carter (Research Partner, SOLID)</p> <p>Other Agencies: Sean Leblanc (Research Partner, Drug User Advocacy League – DUAL)</p> <p>DECLARED PROJECT FUNDING: CIHR HIV/AIDS Community-Based Research Program- Doctoral Research Award</p>	
<b>CONDITIONS OF APPROVAL</b>	
<p>This Certificate of Approval is valid for the above term provided there is no change in the protocol. Extensions or minor amendments may be granted upon receipt of a Request for Annual Renewal or Modification form.</p> <p><b>Amendments</b>                  To make any changes to the approved research procedures in your study, please submit a "Request for Modification" form. You must receive ethics approval before proceeding with your modified protocol.</p> <p><b>Extensions</b>                  Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Annual Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol before your expiry date.</p> <p><b>Project Closures</b>                  When you have completed all data collection activities and will have no further contact with participants, please notify the UVic/VIHA Joint Research Ethics Sub-Committee by submitting a "Notice of Project Completion" form.</p>	
<b>Certification</b>	
<p>This certifies that the UVic/VIHA Joint Research Ethics Sub-Committee has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants and the Vancouver Island Health Authority Research Ethics office.</p>	
 _____ Dr. Rachael Scarth Associate Vice-President, Research	 _____ Dr. Louise Costello Acting Co-Chair, Joint UVic/VIHA Sub-committee

J2012-86 Belle-Iste, Lynne

Certificate issued On: 04-Mar-13

April 9, 2013

Research Ethics Board  
Ottawa Public Health  
100 Constellation Crescent,  
7<sup>th</sup> Floor West  
Ottawa, ON K2G 6J8

**Re: Research Project #184-13**

**Renewal/Expiry Date: April 8<sup>th</sup> 2014**

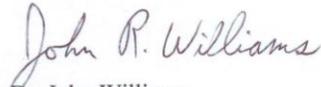
Dear Ms. Lynne Belle-Isle,

I am pleased to inform you that the Ottawa Public Health Research Ethics Board has reviewed and accepted your research proposal entitled *"At the Table" with People who Use(d) Illegal Drugs: A Critical Ethnography into Power Relations* . You may begin data collection as per the schedule you have established.

You are reminded to inform the Board if you have any major changes in your proposal by completing **Appendix F** (attached). At the end of your study, you are to submit an end of project report using **Appendix H** (attached). If you wish to extend your project by the expiration date, please fill in **Appendix G** (attached). All completed forms should be submitted to the Ottawa Public Health Research Ethics Board Secretariat at [oph.ethics@ottawa.ca](mailto:oph.ethics@ottawa.ca).

On behalf of the Board, we wish you well in your research. Please do not hesitate to contact the Secretariat to the Research Ethics Board at [oph.ethics@ottawa.ca](mailto:oph.ethics@ottawa.ca) or 613-580-2424, ext. 16543 if you require further information.

Sincerely,



Dr. John Williams  
Chair,  
Research Ethics Board  
Ottawa Public Health



## **Appendix D – Recruitment Scripts**

### **Recruitment Script – Participant Observations and Individual Interview**

Hello \_\_\_\_ (name) \_\_\_\_\_,

My name is Lynne Belle-Isle and I am a PhD student at the Centre for Addictions Research of BC (CARBC), at the University of Victoria (UVic). My co-supervisors are Drs. Bernie Pauly and Cecilia Benoit. I am conducting this research in partnership with the Society of Living Illicit Drug users (SOLID) in Victoria, BC and with the Drug Users Advocacy League (DUAL) in Ottawa, ON.

Thank you very much for giving me the opportunity to present my research during a previous committee meeting. As I mentioned at the time, including people who use(d) drugs on committees where decisions are made that affect their lives is increasing in practice as a way of contributing to addressing differences in their status, health, rights and access to goods, services and opportunities. Although this practice is increasingly being adopted, there is a lack of knowledge about whether this is being done well and whether it is leading to the desired outcomes of inclusion, shared decision making power, better health, less stigma and discrimination, better access to good and services, and ultimately better life conditions. The purpose of this research project is to contribute to a better understanding of “power relations” between committee members, which are the interactions between all committee members which have an impact on people who use(d) drugs’ power and ability to influence decisions that affect their lives.

As discussed, I have now received ethics approval to begin this research and am seeking your consent to participate. Please find attached two consent forms: one requesting your permission to observe your meeting and take notes (Participant Observation), the other to request your participation in a one on one interview (Individual Interview), either in person or by telephone/Skype, which we would schedule at our mutual convenience. I may come back to observe a second meeting if needed, in which case I would confirm your continued consent. The consent forms provide more details about the study and what your participation would involve both for the observations and the interview.

Please note that your participation in this research is completely voluntary. If you decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study, your data will not be used.

If you wish to participate in the participant observation, the individual interview, or both, please print and sign the consent form. You can return the signed form to my attention:

- by fax at 240-472-5321;
- by scanning it and emailing it to me at [lynnebel@uvic.ca](mailto:lynnebel@uvic.ca);
- or by bringing it with you in person at the meeting I plan on attending and at the interview.

I would greatly appreciate hearing back from you in advance of the meeting. If you choose to participate in an interview, I will follow up with you to arrange a time.

If you have questions, please do not hesitate to contact me at [lynnebel@uvic.ca](mailto:lynnebel@uvic.ca) or 250-853-3235. In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the Vancouver Island Health Authority at 250-370-8620 or at the University of Victoria at 250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca).

Have a great day and I thank you for your time and consideration.

Lynne Belle-Isle

PhD Candidate, Social Dimensions of Health Program

Centre for Addictions Research of BC

University of Victoria

## Appendix E – Consent Forms



University  
of Victoria

Centre for Addictions  
Research of BC



### Participant Observation Consent Form

#### “At the Table” with People who Use(d) Illegal Drugs: A Critical Ethnography into Power Relations

You are invited to participate in a study entitled “*At the Table*” with People who Use(d) Illegal Drugs: A Critical Ethnography into Power Relations that is being conducted by Lynne Belle-Isle, PhD Candidate, in partnership with the Society of Living Illicit Drug Users (SOLID, Victoria, BC) and the Drug User Advocacy League (DUAL, Ottawa, ON).

Lynne Belle-Isle is a graduate student at the Centre for Addictions Research of BC at the University of Victoria and you may contact her if you have further questions by email at [lynnebel@uvic.ca](mailto:lynnebel@uvic.ca) or by telephone at 250-853-3235. As a graduate student, Lynne is required to conduct research as part of the requirements for a PhD degree in Social Dimensions of Health. It is being conducted under the supervision of Dr. Bernie Pauly and Dr. Cecilia Benoit. You may contact Bernie at 250-472-5915 and Cecilia at 250-853-3132.

This research is being funded by the Canadian Institutes of Health Research – HIV/AIDS Community-Based Research Program – Doctoral Research Award.

#### Purpose and Objectives

Including representatives from segments of the population which have historically been excluded from decision making structures that affect their lives, such as people who use(d) drugs, is increasing in practice as a way of contributing to addressing differences in their status, health, rights and access to goods, services and opportunities. Although this new way of including people who use(d) drugs on committees is increasingly being adopted, there is a lack of knowledge about whether this is being done well and whether it is leading to the desired outcomes of inclusion, shared decision making power, better health, less stigma and discrimination, better access to good and services, and ultimately better life conditions. The purpose of this research project is to contribute to a better understanding of “power relations” between committee members, which are the interactions between all committee members which have an impact on people who use(d) drugs’ power and ability to influence decisions that affect their lives. Specifically, this study will address the following research questions:

- How are power relations experienced and expressed between all participants where people with illegal drug use experience are included “at the table”?
- In what ways do interactions between participants “at the table” contribute to or hinder power relations and decision making?
- What contextual factors positively and negatively affect power relations “at the table”? Contextual factors include personal and historical relationships among everyone at the table, as well as the broader social, historical, political and economic context in which decisions take place.
- What impact (positive and/or negative) has the inclusion of people with illegal drug use experience had on the lives of all participants who are at the table?
- What are the practice implications for organizations that include people who use(d) drugs based on insights gained from this study?

Updated Version - February 26, 2013

**Importance of this Research**

Research of this type is important because it will contribute to uncovering the language and practices committees use that may be facilitating or hindering the meaningful involvement and inclusion of people who use(d) drugs through the sharing of power and decision-making. This study will yield important considerations and insights to improve the inclusion of people who use(d) drugs within organizations that make decisions that affect their lives. It will also identify important areas for people who use(d) drugs to further advocate for their meaningful inclusion in decision making social structures. Understanding inclusion practice and power relations between the various participants in such contexts will hopefully encourage organizations to stop and think about how they are actually including people who use(d) drugs and shed light on practices and processes which may be facilitating and encouraging shared power and decision making.

**Participants Selection**

You are being asked to participate in this study because you are currently a member of a research, service delivery or policy making committee which includes people who use(d) drugs. This committee was selected by members of SOLID or DUAL as one of four committees which would be of interest for the purpose of this study. Lynne will observe one or more of your committee meetings while it goes about its usual business to gain insights into power relations while "at the table."

**What is Involved**

If you agree to voluntarily participate in this research, your participation will include being observed while you participate in your meeting in your usual manner. Lynne will be taking notes about what she observes, jotting down her thoughts and if necessary, checking in with you after the meeting to validate her observations. The observations will take place during your regularly scheduled meeting. Lynne will also approach committee members for an individual interview of about an hour and a half at a mutually convenient time and location. She will send a separate consent form for that process.

Before the results of the study are released, Lynne will come back to the committee to present the results to you for input. This presentation will allow you to make sure that you have not been identified in the results. It will also offer you an opportunity to provide input about how the results will be presented. Lynne and her research partners, SOLID and DUAL, will integrate your comments as best as they can.

**Inconvenience**

As a participating committee, this study may cause you some inconvenience as you allow Lynne to take a bit of your meeting time to remind you of her study and to ensure she knows which committee members consented to be observed and which ones did not. This inconvenience will slightly deter you from your committee business. This should only take a few minutes since you will have already received the research summary and consented or not to be observed in advance of your meeting. In addition, she may approach some participants after the meeting to validate her observations, which may pose a slight inconvenience to them. Lynne will also return at another meeting to present the results to you for your input before their release.

**Risks**

There are no known or anticipated risks to you by participating in this research.

**Benefits**

This study will emphasize the good will of all participants who come to the table and include people who use(d) drugs in decisions that affect their lives. By participating in this research, you will take part in an important exercise where together we can stop and really think about how we are including people who use(d) drugs in decisions that affect their lives. This study will shed light and provide insights as to what is working well and what needs improvement. Results from this study will contribute to informing how best to meaningfully include people who use(d) drugs, which can hopefully lead to their shared decision making power, better health, less stigma and discrimination, better access to good and services, and ultimately better life conditions.

Updated Version - February 26, 2013

**Voluntary Participation**

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study, your data will not be used.

**On-going Consent**

Although one meeting may be enough, observations may take place over more than one meeting depending on whether the researchers feels enough information has been collected to understand the power relations within this committee. In the event that more than one meeting is observed, Lynne will check in with all meeting participants before the meeting begins to make sure that you continue to consent to participate in this research. Lynne will be in communication with the committee chair(s) in between meetings to assess whether some committee members may not have been at the first observed meeting and may not have consented to being observed. In the event that a person was absent from the meeting where consent was sought, Lynne will follow up with that individual before the meeting to explain the study and seek consent.

**Anonymity**

In terms of protecting your anonymity, a total of four committees will be observed for this study. Two of these committees are in British Columbia, and two are in Ontario. All information collected during observations will be edited to delete any information that may identify individual members or the specific committee.

**Confidentiality**

Your confidentiality and the confidentiality of the data will be protected. All field notes will be saved on a password protected laptop and backed up on a password protected external drive. Copies of signed consent forms will be stored in a locked filing cabinet in a locked office at the Centre for Addictions Research of BC.

**Dissemination of Results**

It is anticipated that the final results of this study will be shared with others through Lynne's PhD dissertation, presentations at meetings and conferences, through relevant newsletters and websites, and through a peer-reviewed scientific publication. The research partners SOLID and DUAL have also requested that we develop a tool with recommendations about how best to include people who use(d) drugs in decision making structures.

**Disposal of Data**

Data from this study will be retained by the researcher as long as necessary to fulfill the original research objectives, including related purposes such as tracing, validating or auditing research results as may be required by regulators, study sponsors and/or publishers. Once these objectives are met, the data will be destroyed. Electronic data will be erased, paper consent forms and data copies will be shredded. It is estimated that data will be disposed of by the end of 2015 at the latest.

**Contacts**

Lynne Belle-Isle, graduate student, CARBC, University of Victoria, [lynnebel@uvic.ca](mailto:lynnebel@uvic.ca), 250-853-3235. In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the Vancouver Island Health Authority at 250-370-8620 or at the University of Victoria at 250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you agree to participate in this research project.

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*Name of Participant*

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*Signature*

---

*Date*

*A copy of this consent will be left with you, and a copy will be taken by the researcher.*

Updated Version - February 26, 2013



University  
of Victoria

Centre for Addictions  
Research of BC



## Individual Interview Consent Form

### “At the Table” with People who Use(d) Illegal Drugs: A Critical Ethnography into Power Relations

You are invited to participate in a study entitled “*At the Table*” with *People who Use(d) Illegal Drugs: A Critical Ethnography into Power Relations* that is being conducted by Lynne Belle-Isle, PhD Candidate, in partnership with the Society of Living Illicit Drug Users (SOLID, Victoria, BC) and the Drug User Advocacy League (DUAL, Ottawa, ON).

Lynne Belle-Isle is a graduate student at the Centre for Addictions Research of BC at the University of Victoria and you may contact her if you have further questions by email at [lynnebel@uvic.ca](mailto:lynnebel@uvic.ca) or by telephone at 250-853-3235. As a graduate student, Lynne is required to conduct research as part of the requirements for a PhD degree in Social Dimensions of Health. It is being conducted under the supervision of Dr. Bernie Pauly and Dr. Cecilia Benoit. You may contact Bernie at 250-472-5915 and Cecilia at 250-853-3132.

This research is being funded by the Canadian Institutes of Health Research – HIV/AIDS Community-Based Research Program – Doctoral Research Award.

#### Purpose and Objectives

Including representatives from segments of the population which have historically been excluded from decision making structures that affect their lives, such as people who use(d) drugs, is increasing in practice as a way of contributing to addressing differences in their status, health, rights and access to goods, services and opportunities. Although this new way of including people who use(d) drugs on committees is increasingly being adopted, there is a lack of knowledge about whether this is being done well and whether it is leading to the desired outcomes of inclusion, shared decision making power, better health, less stigma and discrimination, better access to good and services, and ultimately better life conditions. The purpose of this research project is to contribute to a better understanding of “power relations” between committee members, which are the interactions between all committee members which have an impact on people who use(d) drugs’ power and ability to influence decisions that affect their lives. Specifically, this study will address the following research questions:

- How are power relations experienced and expressed between all participants where people with illegal drug use experience are included “at the table”?
- In what ways do interactions between participants “at the table” contribute to or hinder power relations and decision making?
- What contextual factors positively and negatively affect power relations “at the table”? Contextual factors include personal and historical relationships among everyone at the table, as well as the broader social, historical, political and economic context in which decisions take place.
- What impact (positive and/or negative) has the inclusion of people with illegal drug use experience had on the lives of all participants who are at the table?
- What are the practice implications for organizations that include people who use(d) drugs based on insights gained from this study?

Updated Version - January 22, 2013

**Importance of this Research**

Research of this type is important because it will contribute to uncovering the language and practices committees use that may be facilitating or hindering the meaningful involvement and inclusion of people who use(d) drugs through the sharing of power and decision-making. This study will yield important considerations and insights to improve the inclusion of people who use(d) drugs within organizations that make decisions that affect their lives. It will also identify important areas for people who use(d) drugs to further advocate for their meaningful inclusion in decision making social structures. Understanding inclusion practice and power relations between the various participants in such contexts will hopefully encourage organizations to stop and think about how they are actually including people who use(d) drugs and shed light on practices and processes which may be facilitating and encouraging shared power and decision making.

**Participants Selection**

You are being asked to participate in this study because you are currently a member of a research, service delivery or policy making committee which includes people who use(d) drugs. This committee was selected by members of SOLID or DUAL as one of four committees which would be of interest for the purpose of this study. This committee meeting was observed while it went about its usual business to gain insights into inclusion of people who use(d) drugs and power relations while "at the table." As a member of that committee, you are being invited to participate in this interview.

**What is Involved**

If you agree to voluntarily participate in this research, your participation will involve an interview of approximately an hour and a half, plus the completion of a brief anonymous demographics survey. The information collected in the anonymous demographics questionnaire will be used to describe the characteristics of who has been interviewed to challenge stereotypes and show that committee members have diverse life conditions and experiences. For instance, there may be researchers who have illegal drug use experience, there may be policy makers who have food security issues, there may be people who use drugs who are highly educated, etc.

Lynne will be recording the interview and may take notes about what she observes, jotting down her thoughts about what she observes, and if necessary, checking in with you to validate her observations. A transcription of the audio will be made and edited to remove any information that may identify you individually or the specific committee of which you are a member. If you are not being paid by your work for your time when you participate in this interview, you will receive a \$25 honorarium in appreciation of your time.

Before the results of the study are released, Lynne will come back to the committee to present the results to you for input. This presentation will allow you to make sure that you have not been identified in the results. It will also offer you an opportunity to provide input about how the results will be presented. Lynne and her research partners, SOLID and DUAL, will integrate your comments as best as they can.

**Inconvenience**

The brief demographics questionnaire will take a few minutes. The interview will take approximately an hour and a half of your time, which may be an inconvenience for you.

**Risks**

Some of the subject matter discussed in the interview regarding your experiences with power relations at the table in the respective committee may conjure up uncomfortable memories, emotions or experiences for some participants. Please feel free to provide as much or as little information about your experiences as you feel comfortable to share. In the unlikely event that the risk of harm occurs, the principal investigator will provide you with the contact information of counseling services in your city.

Updated Version - January 22, 2013

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**Benefits**

This study will emphasize the good will of all participants who come to the table and include people who use(d) drugs in decisions that affect their lives. By participating in this research, you will take part in an important exercise where together we can stop and really think about how we are including people who use(d) drugs in decisions that affect their lives. This study will shed light and provide insights as to what is working well and what needs improvement. Results from this study will contribute to informing how best to meaningfully include people who use(d) drugs, which can hopefully lead to their shared decision making power, better health, less stigma and discrimination, better access to good and services, and ultimately better life conditions.

**Voluntary Participation**

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study, your data will not be used.

**Anonymity**

In terms of protecting your anonymity, members of a total of four committees will be interviewed for this study. Two of these committees are in British Columbia, and two are in Ontario. All information collected during observations will be edited to delete any information that may identify individual members or the specific committee.

**Confidentiality**

Your confidentiality and the confidentiality of the data will be protected. All field notes and digital audio files will be saved on a password protected laptop and backed up on a password protected external drive. Audio files will then be deleted from the recording device. Copies of signed consent forms and completed brief demographics questionnaire will be stored in a locked filing cabinet in a locked office at the Centre for Addictions Research of BC at the University of Victoria.

**Dissemination of Results**

It is anticipated that the final results of this study will be shared with others through Lynne's PhD dissertation, presentations at meetings and conferences, through relevant newsletters and websites, and through a scientific publication. The research partners SOLID and DUAL have also requested that we develop a tool with recommendations about how best to include people who use(d) drugs in decision making structures.

**Disposal of Data**

Data from this study will be retained by the researcher as long as necessary to fulfill the original research objectives, including related purposes such as tracing, validating or auditing research results as may be required by regulators, study sponsors and/or publishers. Once these objectives are met, the data will be destroyed. Electronic data will be erased, paper consent forms, paper brief demographics questionnaires and data copies will be shredded. It is estimated that data will be disposed of by the end of 2015 at the latest.

**Contacts**

Lynne Belle-Isle, graduate student, CARBC, University of Victoria, [lynnebel@uvic.ca](mailto:lynnebel@uvic.ca), 250-853-3235. In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the Vancouver Island Health Authority at 250-370-8620 or at the University of Victoria at 250-472-4545 or [ethics@uvic.ca](mailto:ethics@uvic.ca). Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you agree to participate in this research project.

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*Name of Participant*

*Signature*

*Date*

*A copy of this consent will be left with you, and a copy will be taken by the researcher.*

Updated Version - January 22, 2013

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**Appendix F – Observation Tool**

**“At the Table” with People who Use(d) Drugs:  
A Critical Ethnographic Inquiry into Power Relations**

*Note: Watch for verbal exchanges, practices, actions and interactions; record situations as they occur (physical setting, acts, activities, interactions, meanings, beliefs, emotions, objects).*

**Structured Observation**

Observer \_\_\_\_\_ Date \_\_\_\_\_

Time \_\_\_\_\_

# of People Present \_\_\_\_\_ Location \_\_\_\_\_

<b>What is happening</b>	<b>My thoughts</b>	<b>Comments from post-meeting debrief</b>

## Appendix G – Semi-structured Interview Questions

### Semi-Structured Interview Questioning Route

What was your most recent experience where you participated in a meeting where people who use(d) drugs were included at the table in:

- policy development on an advisory board, in consultation, on committee with the municipality, provincial/territorial or federal government \_\_\_\_\_
- health research on an advisory committees or as a peer researchers \_\_\_\_\_
- service delivery as a volunteer, personnel, on a committee or board \_\_\_\_\_

How did you come to be involved with this group?

How long have you been involved (were in involved) with this group?

Can you please briefly describe what this group's work was(is) about?

In general, how was(is) your experience working with this group of people in terms of it being inclusive of people who use(d) drugs in the process?

Can you recall a time when there was a discussion about how people at the table come from different walks of life and backgrounds and you were encouraged to be open to each other's differences? Can you describe what that was like for you?

How are/were decisions made regarding the group's work, priorities, policies and actions? Was the process clear to you? Did the group generally follow this process?

Do you feel you have a voice in what the group decides?

How much influence and power do/did you personally have in making decisions regarding the groups' work? (no influence, some influence, a lot of influence)

What was your experience with the group's decision-making process?

Do you have an example of a time you suggested something that was accepted by the group? How was that experience for you?

Do you have an example of a time you suggested something that was NOT accepted by the group? How was that experience for you?

Do you remember ever wanting to suggest something that the group should do but not saying anything? How was that experience for you? What do you think stopped you from making your suggestion?

In your opinion, what contributed to the fact that the group's decision-making process worked well/did not work well?

What benefits have you personally experienced from participating in this group?

What challenges have you personally experienced from participating in this group?

What impact has participating in this group had on your life?

What impact, if any, has participating in this group had on the people around you?

**Adapted in part from**

Figuroa, M. E., Kincaid, D. L., Rani, M., & Lewis, G. (2002). Communication for Social Change: An Integrated Model for Measuring the Process and Its Outcomes. Communication for Social Change Working Paper Series. No 1. New York: The Rockefeller Foundation.

Kenney, E. & Sofaer, S. (2000). Coalition Self-Assessment Survey. Ann Arbor: Allies Against Asthma

## Appendix H – Demographics Survey

### Demographics Questionnaire

1. What is your role at this table?  person who use(d) drugs  
 researcher  
 service provider  
 policy maker  
 other. Please specify: \_\_\_\_\_
2. Gender:  Male  Female  N/A  Other: Please specify \_\_\_\_\_
3. Age: \_\_\_\_\_ years
4. Marital Status  
 Single  
 Married/Common law  
 Separated  
 Divorced  
 Widowed
5. What ethnic or cultural heritage do you identify with?  
 Aboriginal (First Nations, Métis or Inuk)  
 African/Carribbean/Black  
 Arab  
 Asian/Pacific Islander  
 Black  
 Caucasian/White  
 Hispanic  
 Latino  
 Multiracial  
 Would rather not say  
 Other. Please specify: \_\_\_\_\_
6. Province/Territory of residence: \_\_\_\_\_
7. Do you currently live in a  rural or remote area  
 suburban area  
 urban area

8. Illegal drug use can be defined as the non-medical use of drugs such as cannabis (marijuana), cocaine, opioids (e.g. heroin, opium) and many pharmaceuticals. Since about half of Canadians have at some point used cannabis (marijuana), this study focuses on drugs other than cannabis.

- Are you:
- currently using illegal drugs (other than marijuana/cannabis)
  - a former user of illegal drugs (other than marijuana/cannabis)
  - currently on methadone/other drug substitution program
  - a person who has never used illegal drugs (other than marijuana/cannabis)

9. What is the highest level of education that you have completed?

- elementary school (grade school)
- secondary school (high school)
- technical and non-university education (college; CEGEP)
- university (undergraduate – bachelor’s degree)
- university (graduate school: master’s, doctorate, post-doctorate degree)

10. In the past year, were there times when you worried that you would not have enough food in your household before there was money to buy more?

- Never
- At the end of the month
- Sometimes
- Often
- Always

11. In the past month, where have you stayed or spent most of your nights?

- your own house, apartment or room
- someone else’s house, apartment or room (couch surfing)
- in a hospital, institution, detox centre
- in a shelter
- outside (on the street, in a park, etc.)
- other. Please specify: \_\_\_\_\_

12. In the last year, what was your annual income?

- |   |   |
|---|---|
| <input type="checkbox"/> Less than \$10,000   | <input type="checkbox"/> \$60,000 to \$69,999   |
| <input type="checkbox"/> \$10,000 to \$19,999 | <input type="checkbox"/> \$70,000 to \$79,999   |
| <input type="checkbox"/> \$20,000 to \$29,999 | <input type="checkbox"/> \$80,000 to \$89,999   |
| <input type="checkbox"/> \$30,000 to \$39,999 | <input type="checkbox"/> \$90,000 to \$99,999   |
| <input type="checkbox"/> \$40,000 to \$49,999 | <input type="checkbox"/> \$100,000 to \$149,999 |
| <input type="checkbox"/> \$50,000 to \$59,999 | <input type="checkbox"/> \$150,000 or more      |