From One Ally to Another

Practice Guidelines to Better Include People who Use Drugs at your Decision-making Tables

University of Victoria | Centre for Addictions Research of BC

Purpose of this Summary

Do you find yourself at committee tables where decisions are made that affect the lives of people who use drugs? Are there representatives of people who use drugs at these tables? Have you grappled with how to increase genuine participation of people who use drugs at such tables? These questions are shared by many. This document aims to answer some of those questions by summarizing the results of a research study and providing evidence-based practice guidelines for allies to better include people who use drugs at their decision-making tables.

Background of the Study

People who use illegal drugs, specifically cocaine, opioids and many pharmaceuticals for non-medical purposes, and especially by injection, are disproportionately affected by HIV and hepatitis C, poverty, stigmatization and social exclusion.[1,2,3,4,5] Current drug laws that criminalize people who use drugs make these inequities worse, hinder health promotion efforts and decrease access to services.[6,7,8,9,10,11] To address these inequities, people who use drugs are increasingly invited to sit on committees where decisions are made that affect their lives.[12,13,14] Including the perspectives of people who use drugs at these tables helps to ensure that drug-related harm reduction policies, research and services are more relevant to the realities of people who use drugs.

In theory, including people who use drugs at such committees should result in fairer and more equitable decision making.[15,16,17] In addition, through dialogue and critical reflection, it is theorized that everyone at the table will experience a shift in consciousness. This shift can change how we see ourselves and each other as well as the balance of power at the table.[18,19,20] Ultimately, these realizations will lead to greater equity and social justice for people who use drugs. However, how people are included and how these roles are enacted at such tables has rarely been studied.

Objectives of the Study

This study had three main objectives:

1. Describe the balance of power between people who use drugs and the researchers, policy makers and service providers at decision-making tables.
2. Explore the conditions and factors that either lead to or hinder the transformation of decision-making power toward a more equitable one.
3. Suggest practice strategies to shift the balance of decision-making power from one that has power over people who use drugs to one that has power with people who use drugs and ultimately contribute to addressing social and health inequities.

Methods

In partnership with the Drug Users Advocacy League (DUAL) in Ottawa, Ontario and the Society of Living Illicit Drugs Users (SOLID) in Victoria, British-Columbia, this critical emancipatory study explored power relations in four committees in Ontario and BC. Data were collected in 2013 through observing committee meetings that include people who use drugs, conducting interviews with committee members, collecting demographics surveys and reviewing relevant documents to understand the context within which these committees operated. Data analysis focused on power relations at the table, how people at the table enacted power and what conditions and factors led to the transformation of power relations.

Results

The following themes emerged from the study:

Organizational Context

On the committee where people who use drugs held the majority of decision-making seats, the committee was intentionally structured to give people who use drugs more control in a community-based participatory research project. The committee had 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 of collectively organizing and were pro-active in 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 commitment, 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 the table. 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 the table as well as pre-invitation negotiations with people who use drugs to establish this process collaboratively.

> "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

Socioeconomic Inequities

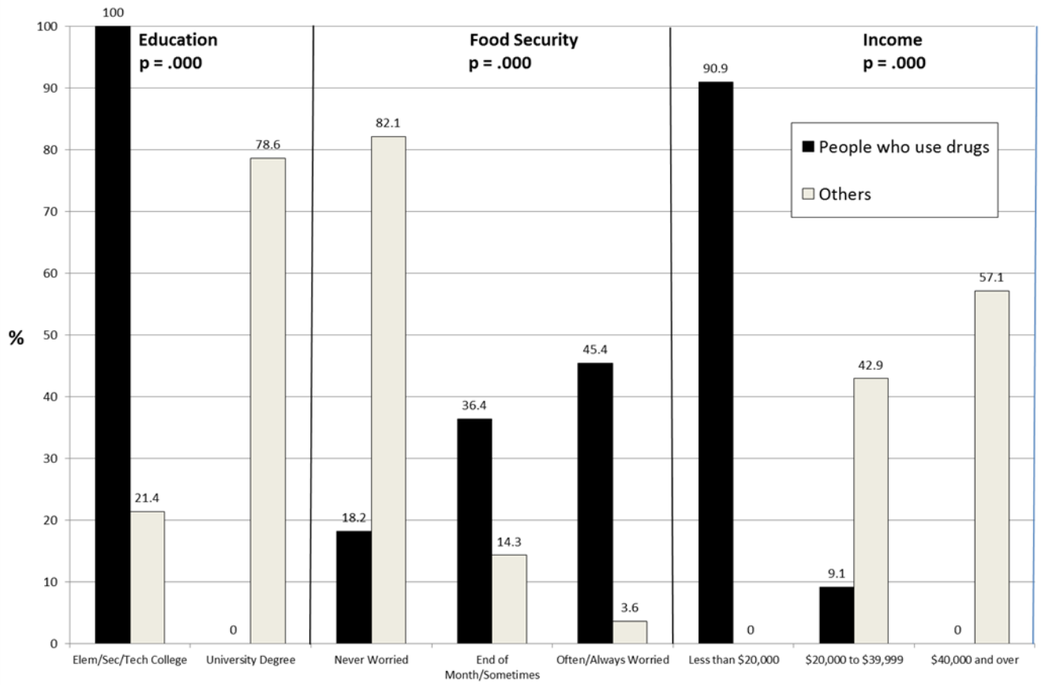
There were striking socioeconomic differences (see Figure 1) between people who use drugs and others (policy makers, researchers, service providers) at the table. People who use drugs faced challenging life conditions related to poverty, food insecurity, ethnic or cultural background, and limited education.

There was variation and inconsistencies in how committees addressed these socioeconomic inequities. For example, whether or how people who use drugs were paid for their time or compensated for any other costs associated with attending meetings or whether food was provided at meetings varied between the committees. Committee chairs grappled with this situation. While they recognized the importance of having the perspective of lived experience at decision making tables, there were no clear policies to guide them.

Influence of the Political Context

Current drug policies that criminalize people who use drugs hinder harm reduction efforts. They also limit capacity to transform decision-making power inequities at committee tables toward more equitable ones by feeding stigma against people who use drugs. Resistance to a punitive approach to drug laws, however, 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 has also led to the mobilization of organizations of people who use drugs to call for their inclusion in decisions that affect them. The "Nothing about us, without us"[21] movement had influenced committees in this study to include people who use drugs at their tables.

Figure 1. Comparison of Education, Food Security and Income between People who Use Drugs and Other Study Participants at the Four Committee Tables Included in this Study.



Stigma against 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' knowledge, capacity and skills. People who use drugs were generally mostly valued for their drug use experience, which devalued their other contributions. People who use drugs tended to take a backseat to others on the committee in an 'experts know best' manner. Conversely, others at the table were hesitant to challenge people who use drugs and call them out 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 expected standards. They placed pressure on themselves to excel and perform in order to change the perception of all people who use drugs.

There were glimpses of committees intentionally challenging and discussing stigma against people who use drugs, though they struggled with how to do this well, through trial and error. The lack of skilled facilitation to challenge stigma was identified.

> "Interviewer: What makes the difference between a person that you consider an ally and one that you don't?"
>
> "Person who uses drugs: What makes the difference? Uh, actions. Actions speak louder than words."

Creating a Safe Space

Creating a safe space enabled committees to shift decision-making power from power over people who use drugs to power with them. Social activities such as sharing a meal and co-learning activities such as participation in overdose prevention training helped people feel comfortable with each other, develop trust, relate to each other authentically and engage in dialogue. Such activities enhanced the ease with which people settled into committee spaces.

Authentic relationships where committee members dropped their roles (i.e. service provider – client dynamics) and related to each other as human beings, beyond specialized roles, helped overcome alienation. Relating authentically created a warm, inviting and respectful atmosphere and promoted critical reflection, openness and mutual understanding.

Skilled facilitation of meetings created 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

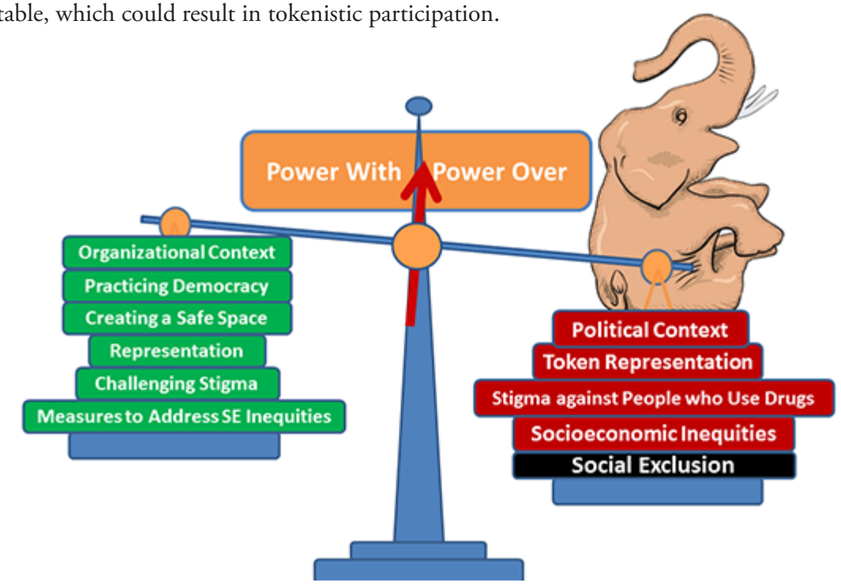
A key democratic practice included being clear about the purpose of inviting people who use drugs to the table, how their input will be used, and how they will be included in the committee's decision-making. The extent to which committee chairs clearly negotiated these relationships with people who use drugs before they came to the table had an influence on power relations. With good negotiated participation, people who use drugs had a clearer sense of their role at the table and what was expected of them.

Another important democratic practice involved consensus-based decision making. 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.

> "Talk to us, not at us."
>
> - person who uses drugs

Representation

Representatives of people who use drugs were found by committees either by inviting people who use harm reduction services or by contacting local peer-run organizations of people who use drugs. There were advantages to seeking representatives from organizations of people who use drugs: they could speak from their own lived experience and could also represent issues that affect a variety of lived experiences 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. When individuals were recruited from patrons of harm reduction services, they tended to represent their own perspective. Sometimes an individual was the only voice of lived experience at the table, which could result in tokenistic participation.



From One Ally to Another ~ Practice Guidelines to Better Include People who Use Drugs at Your Decision-Making Table

Prepare 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 opioid substitution therapy (e.g. methadone or buprenorphine) or choosing abstinence: Provide information on where to obtain their opioid substitution therapy 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. Connect people who use drugs with a local peer-run organization of people who use drugs, if available.

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.

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.
- Tailor the responsibilities assigned to people who use drugs to their life circumstances and their capacities, in negotiations with them.

Practice skilled facilitation at meetings

- Explicitly 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 decision-making structures.
- 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 trustful dialogue:

- Facilitate the meeting with patience and honesty.
- Drop your roles (i.e. service provider - client dynamic) 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.

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 poverty, stigma and discrimination.

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