

**“About Nothing Without Us”:  
A Comparative Analysis of Autonomous Organizing Among  
People Who Use Drugs and Psychiatrized Groups in Canada**

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**Abstract**

**Background:** A growing body of literature demonstrates the value of autonomous organizations of people who use drugs (PUD) in education, mutual support, and policy debates. Simultaneously, over the past 10 years, Canada has witnessed increased emphasis on what is generally termed (*service*) *user involvement* in public health, particularly among PUD and/or psychiatrized groups. Paralleling the development of autonomous organizations of PUD in relation to independent groups by and for various psychiatrized constituencies, this article traces the history of Canadian drug/service user organizing with an overt focus on structural barriers, suggesting that the psychiatric survivor and mad movements have served as critical organizing models among PUD. **Methods:** Drawing from a comparative review of psychiatric survivor/mad initiatives and organizations of PUD, in tandem with observations from the author’s cumulative ethnographic field research, this paper conducts a critique of how PUD are positioned in Canadian drug policy. **Results:** Despite popular perceptions regarding Canada’s embrace of harm reduction, recent political shifts have indicated both a clear regression to moral-criminological approaches closely aligned with the U.S. “war on drugs,” and the persistence of structural barriers among Canadian PUD. **Conclusion:** Drawing from evidenced-based research concerning peer-based forms of harm reduction, this paper argues for the fundamental centrality of autonomous organizations by and for PUD in the harm reduction movement at local and global scales, suggesting that addiction research and policy development that neglects the direct involvement of PUD bears little, if any, relevance to the people in whose interests it is ostensibly conducted.

*Keywords:* harm reduction; addiction treatment; Mad Studies; service user involvement; structural barriers; capacity building; health promotion

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Over the last century, autonomous organizing among people with lived experience of psychiatrization and/or “illicit” substance use has taken many different forms, influenced by a multiplicity of forces and factors, including organizational philosophy, membership demographics, relationship to biomedical institutions/authorities, and overall political orientation. It is, however, important to bear in mind that in both the case of “madness” and “addiction,” independent networks and organizations driven by and for people with such lived experiences have been critically examined through a social movement lens (Campbell, 1992, 2005; Crossley 2002, 2004;

Diamond, 2013; Reaume, 2002; Roe, 2005; Smith, 2012, 2016; Stoller, 1998). The notion of (*service*) *user involvement* as applied to the interrelated—and arguably increasingly conflated—fields of ‘mental health’ and ‘addiction’ encompasses a highly diverse array of principles, practices, philosophies, methods, and organizational models. The various groups and organizations that have been at the forefront of activism against psychiatry in Canada—including what Diamond (2013, pp. 65–67) has identified as the three main constituencies of (a) psychiatric survivors, (b) mad-identified individuals, and (c) anti-psychiatry activists—have been influenced by a multiplicity of intellectual movements, individual practitioners, and radical paradigm shifts in popular and professional understandings of “madness,” including centuries of cumulative writing by psychiatrized inmates, the radical orientation of individual therapists, theories from the fields of critical psychiatry (Bracken et al., 2012; Fernando, 2014; Moncrieff, 2008; Timimi, 2002 ), anti-psychiatry (Boyers & Orill, 1971; Burstow, 2015; Laing, 1959; Szasz, 1970, 1977, 1978), as well as the Mad movement/Mad Studies (Diamond, 2013; Ingram, 2007; Menzies, LeFrançois, & Reaume, 2013; Poole et al., 2012; Price, 2011; Reaume, 2002, 2008; Russo & Beresford, 2014).

Growing out of tactical alliances of affinity between people who use drugs and other “marginalized” populations—namely radical activist groups composed of people living with HIV/AIDS such as the AIDS Coalition to Unleash Power (ACT-UP), and politicized factions of the queer community—the notion of harm reduction in North America originated as an illegal, underground, direct action-based social movement that has similarly been driven by anti-authoritarian, non-hierarchical principles of affinity, autonomy, and mutual aid (Day, 2004; Graeber, 2002; Hubbard & Schulman, 2012; Roe, 2005; Smith, 2012, 2016; Stoller, 1998). Following the peak of the AIDS epidemic, however, the adoption of harm reduction as institutionalized public health policy across North America during the 1990s directly resulted in the rapid *depoliticization* of the explicitly oppositional founding philosophy of the movement, and, consequently, the displacement of people who use drugs as the central engine of harm reduction practice (Roe, 2005; Smith, 2012, 2016; Stoller, 1998). Although numerous investigations have demonstrated the value, efficacy, and ethical imperatives of user-driven forms of harm reduction, in relation to other nations of the Global North, drug/service user participation in Canada continues to face significant structural barriers (Allman et al., 2006; Canadian HIV/AIDS Legal Network, 2008; Cheng & Smith, 2009; Friedman et al., 2004, 2007; Kerr, Douglas, Peeace, Pierre, & Wood, 2001; Mason, 2006; VANDU, 2004, 2010). In other words, in spite of both the increasing emphasis on what is generally termed (*service*) *user involvement*, as well as the growing body of scholarly evidence concerning the critically important role of people who use drugs in health promotion, education, and harm reduction, Canada represents a highly uneven, fiercely contested, and conflict-laden landscape of organizing, advocacy, and activism among drug/service users (Allman et al., 2006; Cheng & Smith, 2009; Canadian Harm Reduction Network, 2008; Canadian HIV/AIDS Legal Network, 2008; Coyle, Needle, & Normand, 1998; Friedman et al., 2004, 2007; Kerr et al., 2006; Latkin, 1998; Mason, 2006; Orme & Starkey, 1999; Smith, 2012, 2016;

Toronto Harm Reduction Task Force, 2003; VANDU, 2004, 2010). Drawing from Smith (2012, p. 211), this paper eschews the normative terms *client* and/or *consumer* to describe subjects of psychiatrization and/or addiction/treatment “in recognition of the deceptive ‘medicine as business’ rationality” that such terms represent. Instead, particularly in the context of people who use illicit drugs, the paper follows Smith’s (2012) deployment of the term *user* in reference to both “harm reduction and addiction treatment subjects” proposing the term *drug/service user* as possessing an inbuilt and “potentially productive, fluid interchangeability” (p. 211).

Borrowing from elements of both Speed’s (2006) examination of “mental health service user discourses” in Ireland, and Diamond’s (2013, pp. 64–66) typology of psychiatrized constituencies in Toronto, Canada, this paper first works to compare the discourses and ideologies underlying different subgroups of people with lived experience of both psychiatrization and substance use. Specifically, drawing from an amalgam of both Speed’s (2006) and Diamond’s (2013, p. 67) analysis of the main constituencies that have formed in relation to “psychiatric oppression and sanism”—namely, (a) consumers,<sup>1</sup> (b) psychiatric survivors, and (c) the mad constituency—are compared to three variously politicized sub-groups of people with lived experience of substance use, including (a) harm reduction and/or addiction treatment clients, (b) abstinence-based recovery/support groups, and (c) politicized organizations of people who use drugs. Throughout this critical interrogation of various forms of user self-identification and discourse, each group’s implicit and explicit relationship to the prevailing pathology paradigm central to both biological psychiatry and the overwhelmingly quantitative, epidemiologically driven nature of contemporary addiction research and treatment forms a central consideration.

Asserting that the three typologies of *consumers*, *psychiatric survivors*, and the *mad constituency* closely parallel that of *drug/service user clients*, *recovery/support groups*, and *organizations of people who use drugs*, this paper argues that grassroots activism among psychiatrized groups has served as a critical source of inspiration for drug/service user organizing, particularly among the most radical factions. After establishing the parallels between various forms of organizing and self-identification among people with lived experience of psychiatrization and/or substance use, this paper proceeds to conduct a review of the growing body of literature concerning the fundamentally central role of directly engaging people who use drugs in all aspects of the policies and programs that effectively serve to inform their everyday lives, from policy development and implementation, to service delivery, to research and evaluation.

Providing a series of case studies concerning the various forms of self-identification and autonomous organizing among drug/service users, the paper then shifts to present a series of vignettes drawn from the author’s cumulative ethnographic fieldwork among people who use drugs in North America. Conducted

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<sup>1</sup> Here it is imperative to note that Diamond’s (2013, p. 67) typology focuses explicitly on three specific groups, including (a) mad movement; (b) psychiatric survivors; and (c) anti-psychiatry activists, among the diverse multiplicity of “various communities that are particularly vulnerable to psychiatrization”; but she does not include “consumers,” as they are not understood in this typology to have formed as a result of psychiatric oppression and sanism.

as part of the author's doctoral and post-doctoral research, the ethnographic observations that feature in this paper were collected with ethics approval from York University (Toronto, Canada) and the University of Pennsylvania (Philadelphia, U.S.A.), respectively. Beyond serving as a concrete site for critically interrogating the points of intersection between psychiatric survivors and autonomous drug/service user groups, both the literature review and accompanying ethnographic narratives work to identify persistent structural barriers to activism among these communities in the contemporary Canadian context. Flagging points of intersection between the micro-level observations presented in these vignettes and the broader, macro socio-political processes in which they are embedded, this work therefore draws from Burawoy's (2000) notion of "global ethnography" by unpacking these fleeting "glimpses into a fractured, fragmented, all-encompassing 'globality'" (p. 2). Corresponding to the key themes emerging from this analysis, findings from this investigation are organized according to: (a) an interrogation into the present state of drug user organizing in Canada; (b) critical case studies of the direct action tactics employed by autonomous organizations by and for people who use drugs; and (c) a comparative historical examination of drug user organizing in Canada and Australia.

Critically tracing the contemporary convergence (read: *conflation*) between the formerly distinct fields of psychiatry and 'addiction', this paper demonstrates how "illicit" substance use is increasingly understood and *treated* as a form of "self-medication" for underlying psychiatric conditions, if not as an explicit form of 'mental illness' in and of itself. Here, Smith (2012) rendered the highly complex relationship between discourse, political-economic forces, and the prevailing paradigms for 'mental health' and 'addiction' in stark terms:

Contemporaneous to the institutional adoption of the biomedical disease model, neoliberal health policy served to *de-medicalize* the subject of addiction treatment, variously rearticulating the in-built relations of authority underlying 'patient' in the terms of 'client' or 'consumer'. Here, the former patient is transformed into a '*client*' of treatment services whose counterpart is the treatment service *provider*. The displacement of doctor/patient by the client/provider dynamic is, however, further complicated by the notion of consumption, catalysing a subsequent metamorphosis into the unambiguous designation *consumer*. (p. 211)

This paper asserts that the various forms of discourse employed by psychiatric and drug war survivors represent an explicit effort to reclaim language and, in turn, re-inscribe individual and collective expressions of identity. Actively problematizing the contemporary reframing of harm reduction and addiction treatment service users as "clients" or "consumers" under present-day neoliberal public health policy, the designation *drug/service user* therefore implicitly underscores the agency of the using subject, directly serving to disrupt the passivity implied in the health service "consumer-provider" dynamic (Reith, 2004; Sedgwick, 1993; Smith, 2012). Furthermore, the increasing adoption of psychiatric survivor discourse among networks and organizations of people who use drugs speaks to the real and symbolic violence inherent in the American-led "war on drugs," a stance that became closely mirrored in Canadian drug policy following the election of former Prime Minister

Stephen Harper's federal Conservative party in 2006 (Erickson, 1992; Hathaway, 2001; Hathaway & Erickson, 2003; VANDU, 2010).

**Background: Consumption, Survival, Dependence, and Autonomy Among People with Lived Experience of Substance Use and/or Psychiatrization**

As Speed (2006) has proposed, discourses associated with various forms of self-identification among psychiatrized groups can be conceived according to several primary types, each of which can be distinguished based on their relationship to notions of “acceptance, resistance and negotiation” (p. 29). In the first instance, psychiatrized factions who self-identify as “consumers” consist of individuals who “neither accep[t] (fully) nor rejec[t] (fully) their diagnosis,” instead oscillating between passive acceptance of the inbuilt relations of power inherent in the designation “patient,” and the antithetical discourse that has come to be associated with psychiatric “survivors,” entailing an explicit rejection of the ostensible expertise of biomedical authorities (Speed, 2006, p. 29). In this case, as Speed (2006, p. 30–31) has asserted, consumer groups are ultimately based on an acceptance of “the legitimacy of psychiatric knowledge.”

Psychiatric “survivor” groups, by contrast, explicitly reject “the legitimacy of psychiatric knowledge,” thus actively advancing an “agenda for social and political change” (Speed, 2006, p. 29). As Speed noted, one central distinction between these factions is that consumer groups generally “work with psychiatry,” whereas survivor groups typically “work against.” Analyzing the conflict-fuelled development and impact of “consumer” discourse over more than 30 years, Diamond (2013) noted that the term invokes mixed reactions:

With the development of government-funded consumer initiatives ... within mental health organizations, the term has become widespread.... Some psychiatric survivors are protective with respect to the use of language and are upset about how commonplace the term *consumer* has become within the community. They believe that the term fails to communicate the reality of psychiatric violence or coercion, but rather invokes notions of choice and freedom. On the flip side, some psychiatrized people ... resent the stance of some psychiatric survivors, which is perceived to be harsh and critical of those who identify as consumers within the community and who do not relate to the more radical terminology ... [yet] in practice, the meanings of the term are fluid and change in different contexts. (pp. 67–68)

Further detailing the various psychiatrized constituencies in Canada, Diamond (2013, p. 65) suggested that psychiatric survivors represent “those who are most deeply affected by the practice of biological psychiatry and sanism in dominant culture,” yet this group defies simplistic definitions because it is “not organized around a shared political ideology.” Instead, as Diamond explained, the psychiatric survivor movement is rooted in the central anarchist principle of mutual support, working not only to remedy the harms inflicted by traditional psychiatric services, but also to develop creative solutions to community needs. Furthermore, Diamond

identified peer support and anti-stigma as core elements of the psychiatric survivor constituency (p. 65).

Finally, representing one of the most radical factions of the psychiatrized community, Diamond (2013) suggested the “mad constituency” emerged from psychiatric survivors, but differs significantly due to its central emphasis on the challenges encountered by those who “have been oppressed as crazy,” encompassing a diverse spectrum of discourses concerning “madness and liberation” (pp. 65–66). Exemplary of the mad constituency, Toronto’s annual Mad Pride celebration unites a “multiplicity of different experiences and perspectives in celebration of a developing Mad culture” (Diamond, 2013, p. 68; Mad Pride Toronto, 2014; Reaume, 2008). As Diamond (2013) noted, despite these similarities, psychiatric survivor and mad constituencies differ in their shifting focus from “psychiatric oppression” to developing “positive understandings of Mad identity” (p. 66).

Similar to the case of psychiatrized individuals, autonomous organizing among people who use drugs ranges from conservative to radical, generally manifesting in three guises, each based on a number of factors, including (a) differing perceptions regarding the aetiology and prevailing pathology paradigm of ‘addiction’; (b) relationships to mainstream public health interventions relating to people who use drugs; and (c) relationships to biomedical authority. Closely paralleling the distinctions derived from an amalgam of Speed’s (2006) examination of Irish psychiatrized “service user discourses” in conjunction with Diamond’s (2013) typology of the psychiatrized constituencies within Canada, for the purpose of this analysis, drug/service user communities can be divided according to: (a) “client” groups, (c) recovery/support groups, and (c) drug/service user organizations. This parallel typology is, furthermore, corroborated by observations derived from the author’s cumulative ethnographic research among people who use drugs in Canada (Toronto) and the United States (Philadelphia and New York City).

Corresponding to Speed’s (2006, p. 30) analysis of discourses associated with “consumer[s] of psychiatric services,” drug/service user client discourse alternates between “acceptance and rejection” of the biomedical “brain disease” model of addiction. Effectively apolitical and with no agenda for structural transformation, the drug/service client constituency does not advance a critique of drug-related policy or practice, instead deferring to the supposed expertise of biomedical authorities. Moreover, as Smith (2012, p. 211) asserted, the designations *client* and *consumer* denote explicitly passive relationships to broader structural forms of power, resituating subjects in a “one-way relationship to capitalist forces.” Clients or consumers, in other words, can only “consume” and thereby play no role in the associated process of production. In this regard, the client constituency is generally not actively engaged in their own treatment/process, implicitly placing their unconditional trust in the hands of biomedical authorities.

Representing a highly diverse faction of drug/service users, recovery/support-based groups are, with few notable exceptions, traditionally abstinence based, effectively limiting their critique to the inaccessibility or inadequacy of drug/addiction treatment interventions. Such groups therefore strive for social

change from within the existing system, typically working in co-operation with policy officials and public health actors. In her discussion of the fluid, ambiguous, and highly contested “consumer” constituency, for example, Diamond (2013) argued that the impact of this faction on “radical political action” continues to represent a source of unresolved conflict for many Mad-identified activists and advocates owing to the belief that the very term *consumer* has effectively become associated with “notions of choice and freedom,” and thus “fails to communicate the reality of psychiatric violence or coercion” (pp. 68–69). Some individual psychiatric “survivors,” on the other hand, perceive consumer discourse

as an opportunity for survivors to influence change from within the system, while getting paid for their labour, by participating in forums where real policy, program and funding decisions are made. In this way, the consumer development is considered a step towards gaining power and influence in government and the psy complex where people can influence real change. (Diamond, 2013, p. 68)

The oldest and most popular examples of recovery-based groups in North America are those of the “12-step” family, including Alcoholics Anonymous (AA) and Narcotics Anonymous (NA). Not unlike Speed’s (2006) and Diamond’s (2013) analyses of “consumer” discourse among psychiatrized individuals, support/recovery-based groups among people who use drugs are largely characterized by tension, instability, conflict, and contestation, where public positions on issues such as abstinence, biomedical authority, and the reformation of current drug policies exhibit considerable variation.

Diamond’s detailed description of these variously (a)political factions among Canadian psychiatrized factions closely mirrors independent recovery/support communities among people who use illicit drugs, which are similarly focussed on the notion of mutual aid, yet lack a united political ideology. In the face of persistent, widespread stigma regarding people who use drugs, recovery/support groups therefore provide a forum for individuals with shared experiences under the prevailing pathology paradigm, where the very establishment and regular meetings common among such communities effectively serve as a means of combatting the cumulative stigma experienced by people with lived experience of substance use.

Moreover, the persistent emphasis on peer support initiatives among this community serves to elevate the value of users’ direct *experiential knowledge*, providing an active role for people who use illicit drugs in conjunction with traditional biomedical service delivery models. In such instances, Canadian recovery/support groups have been responsible for inspiring an emergent body of literature concerning the direct and active engagement of people who use illicit drugs in all aspects of the policies and practices ostensibly conducted in their interests (Albert, 2011; Allman et al., 2006; Balian & White, 2010; Belle-Isle et al., 2016; Bryant, Saxton, Madden, Bath, & Robinson, 2008; Canadian AIDS Society, 2015; Canadian Harm Reduction Network, 2008; Canadian HIV/AIDS Legal Network, 2008; Cheng & Smith, 2009; Coyle, Needle, & Normand, 1998; Crofts & Herkt, 1995; Friedman et al., 2004, 2007; Howard, 2015; Kerr et al., 2006; Latkin, 1998;

Mason, 2006; Orme & Starkey, 1998; Smith, 2012, 2016; Toronto Harm Reduction Task Force, 2003; VANDU 2004, 2010).

At what is perhaps the furthest end of the political spectrum, directly corresponding to what Diamond (2013, pp. 65–66) has identified as the “mad constituency,” independent organizations of people who use drugs have witnessed significant growth and political momentum over the past 20 years from local to national and international scales. Such groups are for the most part based on a complete rejection of traditional drug research and treatment paradigms, placing significant emphasis on autonomous, non-hierarchical, anti-authoritarian, and direct-action-based organizational models in their struggle to challenge prohibitionist-based drug policies and their correspondingly punitive, disciplinary practices (Albert, 2011; Day, 2004; Graeber, 2002; Smith, 2012; VANDU 2004, 2010). Incorporating an explicitly political critique of the structural forces that effectively produce and perpetuate harm, many autonomous drug/service user organizations actively resist the prevailing pathology paradigm for drug dependence (Alexander 2000, 2008; Smith, 2012). Returning to the original founding philosophy of harm reduction, such drug user organizations thus advance an explicitly political agenda that incorporates a direct critique of the structural factors that serve to perpetuate drug-related “harm” (Roe, 2005; Smith, 2012). It bears reiterating that, not unlike the psychiatric survivor movement that preceded it, drug user organizations throughout North America originated with the affinity-based direct-action tactics of people who use drugs, constituting a grassroots, community-based social movement (Crossley, 2002; Roe, 2005; Smith, 2012; Stoller, 1998). Conducting a critical review of the existing evidence concerning the fundamental importance of engaging people who use drugs in the policies and programs that shape their everyday lives, this paper thus continues to interrogate the points of intersection between various factions of the broader psychiatrized community and drug/service users, some of whom have reframed their individual and collective experiences in terms of *drug war survivors* (Smith, 2012; VANDU, 2010).

### **Literature Review:**

#### **Harm Reduction Policy and Drug User Organizations in Canada**

The 1987 publication of *Canada’s Drug Strategy* signalled the formal introduction of harm reduction in Canadian federal drug policy (Erickson, 1992; Fischer, 1997; Hathaway & Erickson, 2003). Despite appearing to constitute a departure from the American “war on drugs,” Hathaway and Erickson (2003) argued, the strategy embraced harm reduction in theory but not in practice, demonstrating “very little evidentiary progression of drug policy reform” (p. 476). As recent evidence suggests, after taking office in 2006, however, the Federal Conservative party attempted to affect a complete erasure of harm reduction from Canadian drug policy. In 2007, less than six months after taking office, for instance, former Prime Minister Stephen Harper unveiled the Conservative’s *National Anti-Drug Strategy*, serving to replace the previous 20 years of harm reduction policy promoted by *Canada’s Drug Strategy*. With the conspicuous absence of harm reduction, the new strategy thus consisted of little more than prevention, treatment, and most prominently enforcement. Moreover, signalling a clear ideological regression,



responsibilities for the Conservative's anti-drug strategy were shifted from Health Canada to the Department of Justice (Government of Canada, 2007).

As Canadian health care is provincially based, however, despite the disappearance of harm reduction in the *National Anti-Drug Strategy*, municipal and provincial public health bodies have retained an explicit harm reduction orientation. Nevertheless, similar to Hathaway and Erickson's (2003) assertions regarding Canada's federal adoption of harm reduction, this essay asserts that regional harm reduction strategies have often embraced service user involvement in theory but not practice, as evidenced in the following examples. Published in 2005, the municipal *Toronto Drug Strategy* was composed by a diverse spectrum of stakeholders—including drug/service users—and concluded by posing a series of policy recommendations. Emphasizing the importance of “involving people who use or have used substances in planning, delivering and evaluating policies and programs intended to serve them,” the *Toronto Drug Strategy* (City of Toronto, 2005) concluded that peer workers both “tend to be under-paid,” and require a “supportive work environment that enables them to continue sharpening their skills” (p. 54).

Detailing the significance of peer-based approaches, the *Toronto Drug Strategy* concluded with several explicitly peer-oriented recommendations, including: (a) “develop[ing] strategies to promote more opportunities for peer workers”; (b) “urg[ing] the provincial government to make funding available for on-going [peer] supervision, training and skill development”; and (c) “support[ing] the development of a ‘drug users group’ to undertake a range of activities” (City of Toronto, 2005, p. 55). Despite these recommendations, there have been few opportunities for peer work, no peer-based training, and no support for “drug user groups.” It is, however, relevant to note that in 2009, with little funding and limited support of any kind, a critical mass of drug user activists worked tirelessly to establish the Toronto Drug Users' Union (TODUU), a group that persists despite the issues of funding precarity and resource limitations. Although drug user organizations had previously existed in Toronto, by 2005 most had almost completely dissolved owing to similar challenges (City of Toronto, 2005, p. 54). TODUU can be seen as an example of a local drug user organization that serves to challenge the supposed expertise of biomedical authorities by elevating the value of users' lived experience and providing users with a forum for both mutual support and critical/creative expression.

Shifting from municipal to provincial levels, in 2008 the Ontario Ministry of Health called for the development of a 10-year mental health and addiction strategy for the province. Following over one year of consultations, the Ministry released a discussion paper (Ontario Ministry of Health, 2009) containing an overt emphasis on consumer involvement. As the document insisted, “People with lived experience have valuable skills and knowledge that can strengthen the system”:

When people with lived experience become partners in governing, planning, delivering and evaluating services, they can help develop effective services that meet needs [and] develop valuable skills that may help them gain work experience and participate more fully in their communities. (p. 36)

A subsequent document produced by a smaller group of senior policy actors appointed by the Ministry was even more unambiguous, stating “institutional and community-based service providers [should] actively seek to involve peer support workers in all aspects of service delivery” (Legislative Assembly of Ontario, 2010, p. 11). This recurrent focus on peers appeared to demonstrate increased receptivity for the direct engagement of drug/service users, yet as with the *Toronto Drug Strategy* (City of Toronto, 2005), such gestures in fact represented little more than a case of political posturing to foster the illusion of social responsibility and ethical best practices (Canadian HIV/AIDS Legal Network, 2008). In order to adequately assess the future potential for user-driven forms of harm reduction policy and practice, it is therefore necessary to investigate the current state of independent organizing among people who use drugs in Canada.

### **The Present State of User Organizing in Canada**

(Re-)mapping the Canadian landscape of drug user organizing provides a useful context both for identifying structural barriers and for exploring the similarities and contrasts between psychiatrized constituencies and (drug/service) user-based organizations (Diamond, 2013; Smith, 2012). This section thus begins by recounting an ethnographic vignette from a 2011 international conference in Vancouver concerning methadone maintenance treatment (MMT). Throughout the three-day conference, the small group of invited participants held several meetings with the British Columbia Association for People on Methadone (BCAPOM), a sub-group of the Vancouver Area Network of Drug Users (VANDU).

Representing perhaps the most notorious street-level drug scene in Canada, Vancouver’s downtown eastside (colloquially, DTES) is home to a high concentration of both injection drug users and, correspondingly, harm-reduction-oriented social services, including Insite, the first supervised injection facility in North America. The institutionalization of Insite was not, however, the result of a traditional top-down policy making process. Instead, this intervention was inspired by the underground implementation of an unsanctioned supervised injection facility established and operated by members of VANDU (Kerr et al., 2005, 2006; McNeil et al. 2013; Wild, 2002). Founded amid skyrocketing overdose rates and a declared public health emergency surrounding the rampant transmission of HIV/AIDS and hepatitis C among Vancouver’s injection drug user community in the late 1990s (Sommers & Blomley, 2002; Woolford, 2001), VANDU arguably represents one of the most accomplished, militant user-driven organizations in North America, constituting perhaps one of the only government funded drug/service users’ groups in either Canada or the United States (Kerr et al., 2001, 2006; VANDU, 2004, 2010; Wild, 2002).

During its more than 15-year history, VANDU has grown into an international model of user-driven organizing, responsible for reforming harm reduction policy not only in Vancouver, but also at the provincial and federal levels (Kerr et al., 2001, 2006; VANDU, 2004; Wild, 2002; Wood et al., 2003). As evidenced in VANDU’s (2010) *Manifesto for a Drug Users’ Liberation Movement*, the group continues to advance a radical political agenda, while simultaneously nurturing relationships of

*collaborative autonomy* with other grassroots community groups and institutional public health institutions (Cheng & Smith, 2009; Kerr et al., 2001, 2006; VANDU, 2004, 2010).

During each of the meetings between the conference participants and VANDU's methadone-specific sub-group (BCAPOM), a prominent non-drug-user VANDU member made repeated references to the fact that VANDU “*only* receives \$200,000 a year” in funding. After the third time this figure was invoked, one of the researchers interrupted the presentation to point out that VANDU was the only user-driven organization in Canada to receive any form of government support, emphasizing the fact that VANDU's annual \$200,000 budget was precisely \$200,000 more than any other independent organization of people who use drugs across North America.

Following the formal public health crisis among injection drug users in Vancouver's downtown eastside during the 1990s, Health Canada commissioned a formal study of VANDU (Kerr et al., 2001). Detailing the history, philosophy, governance, and activities of VANDU, the Lessons Learned contained in this report clearly emphasized the health promotion potential inherent in user-driven organizing, along with various other, less obvious benefits. As the report asserted, VANDU has:

demonstrated that drug users can organize themselves and make valuable contributions to their community ... Through years of advocacy work, [VANDU has] repeatedly voiced the concerns of drug users in the political arena ... [thus] perform[ing] a critical public education function by bringing various outsiders ... face to face with the realities of Vancouver's Downtown Eastside. (Kerr et al., 2001, p. 32)

Following publication of this report, Health Canada funded a team of VANDU members to hold a series of workshops among people who use drugs in 10 major cities across Canada, culminating in the publication of a final report (VANDU, 2004). “We embarked on a very ambitious National Capacity Building Project,” VANDU's (2004) report begins:

In other places in Canada, the voice of drug users has not been so clearly unified ... VANDU is perhaps then in a position to ... move the agenda forward for drug users across Canada ... so that they can get organized to stop the spread of disease. Most importantly, VANDU can let drug users everywhere know that they are citizens who deserve to be treated with dignity and respect by police, by hospitals and by service providers. (p. 4)

While it is important to acknowledge the contributions of early drug user organizations such as Toronto's Finally Understanding Narcotics (FUN; City of Toronto, 2005, p. 54), VANDU arguably continues to be the only government-funded user-driven organization in Canada, having established subgroups for different sub-populations of people who use drugs. In recent years, however, countless small, underfunded, regional drug user groups have cropped up across Canada, waging a continual struggle for funding, resources, and legitimacy. In response to this on-going struggle, VANDU's (2010) *Manifesto for a Drug User*

*Liberation Movement* asserted that the manner in which people who use drugs are “organized and represented ... is decisive”:

‘Representation’ of drug users has too often taken the form of below minimum wage jobs ... or ‘peer’ groups which are actually run by non-drug users and/or handpicked ‘peer’ representatives who have closer ties to research and service provider patrons than they do to the communities they purport to represent. (p. 2)

In an effort to avoid recuperation or co-optation, VANDU’s (2010) *Manifesto* asserted that such groups must insist that “people who use drugs are the ones to define the participation of people who do not use drugs in the organization” (p. 2). Resonating closely with descriptions of the psychiatric survivor constituency within the broader psychiatrized community (Crossley, 2004; Crossley & Crossley, 2001; Diamond, 2013; Reaume, 2002; Speed, 2006), the manifesto (VANDU, 2010) asserted “we are survivors of the drug war,” concluding with this explicit provocation:

We do not want to be used as cheap labour, we do not want to be studied while we die, or be turned into clients while resources are given to ‘service’ agencies. We will not tolerate actions that exploit the labour, activist work, or experiences of people who use drugs. (pp. 1–3)

In spite of their capacity-building efforts, VANDU remains the only government-funded user-driven organization in Canada (VANDU, 2004). Furthermore, despite numerous municipal and provincial policy references to increasing user/peer participation, to date none of these recommendations have been fulfilled (City of Toronto, 2005; Ontario Ministry of Health, 2009, 2010; Legislative Assembly of Ontario, 2010). Resonating with Hathaway and Erickson’s (2003, p. 476) assertion regarding harm reduction in Canadian drug policy, public health recommendations concerning consumer involvement thus represent little more than superficial gestures, enacted in theory but not in practice. In order to concretize these arguments, the paper thus shifts to examine a series of case studies interrogating existing drug/service user initiatives in Canada.

Established in 2003, according to its mandate, the College of Physicians and Surgeons of Ontario’s (CPSO) Methadone Patients’ Advisory Group is composed of a diverse, “representative” group of methadone maintenance treatment (MMT) service users from a variety of MMT service delivery models. Founded by a progressive CPSO staff member, the Patients’ Advisory Group was established with the supposed mandate of mediating between the CPSO’s Methadone Committee and Ontario’s wider methadone service user community regarding various elements of MMT policy and practice (CPSO, 2011). Facilitated by CPSO staff since its inception, the Patients’ Advisory Group appointed its first patient-elected chair in 2007. Over their 2-year term, however, the new chair was only permitted to attend a single 15-minute segment of one Methadone Committee meeting, ostensibly due to “confidentiality concerns.” Furthermore, the agenda for all Patients’ Advisory Group meetings continued to be composed by CPSO staff without any consultation with the Chair. Additionally, CPSO staff overtly discouraged Patients’ Advisory Group

members from undertaking any projects deemed “controversial,” including developing a methadone service user charter of rights.

Such examples provide tangible evidence that the Patients’ Advisory Group represented little more than a superficial, tokenistic form of institutionalized consumer involvement, a situation perhaps attributable to a distinct lack of what some Canadian psychiatric survivors have termed *collaborative autonomy* (Cheng & Smith, 2009). As Cheng and Smith (2009) wrote, the notion of collaborative autonomy directly invokes

the question of equitable engagement and/or collaboration between service providers and people with lived experience ... Here, it is understood that all parties respect the individuality, independence and autonomy of the user and/or user-run organization. This also directly underlines the importance of addressing systemic barriers and inequities such as resource allocation, and thus explicitly recognizes the value and importance of ... experiential knowledge. (p. 7)

Further demonstrating the advisory group’s tokenistic nature, subsequent events suggest its primary value may lie in its dual role as a consultancy body exploited by the CPSO for research purposes. This issue received significant media coverage in Ontario following the 2008 announcement that prominent Toronto physician and HIV/AIDS pioneer Dr. Phillip Berger had launched a formal complaint with the Ontario Human Rights Tribunal regarding what he perceived to be the highly restrictive, punitive, and disciplinary nature of Ontario methadone treatment policy. As Dr. Berger alleged that the CPSO had both (a) violated service users’ confidentiality by granting researchers unfettered access to the CPSO’s MMT client registry database and (b) effectively discriminated against addiction treatment service users resulting from the “heavy-handed” nature of the CPSO’s MMT *Guidelines* (Berger, 2009; CPSO, 2011; Hammer, 2008), members of the Patients’ Advisory Group were effectively caught in the cross-fire, as they performed extensive consultation with various research bodies as part of their “ordinary” responsibilities.

Since responsibilities for MMT were shifted from federal to provincial authorities in 1996, methadone service users were the only health care population monitored and regulated by the CPSO Client Registry. Although Berger’s Ontario Human Rights Tribunal challenge was ultimately unsuccessful, several years later the CPSO announced that the Client Registry would be dismantled:

The College believes methadone and all other narcotics prescribed by a physician require the same level of vigilance in prescribing. Specifically, professional judgment should ensure the risks and benefits for the patient as well as issues of public safety are considered. Therefore, the need for a specific registry for patients receiving methadone is not warranted. (CPSO, 2015, p. 1)

In spite of a pre-existing methadone service user group in Vancouver, by contrast, until very recently the College of Physicians and Surgeons of British Columbia (CPSBC) repeatedly refused this group’s requests for dialogue and direct involvement in MMT policy development. By ignoring recurrent requests for

dialogue from BCAPOM, therefore, the CPSBC thus neglected to take advantage of existing drug/service user networks to contribute invaluable experiential knowledge toward reforming MMT policy. Owing largely to the criminalization of illicit drug use, Allman et al. (2006, pp. 402–403) suggested, communities of people who use drugs often form organic self-governing networks of affinity and mutual aid, which can in turn be mobilized toward establishing formal user-driven harm reduction networks (Day, 2004; Smith, 2012). These sentiments are echoed in Friedman et al.'s (2004) contentions regarding the potential impacts of community-based *intravention*, defined as “prevention activities that are conducted by and sustained through ongoing actions of members of communities at risk” (p. 250).

The federal Conservative government's stance toward people who use illicit drugs—and harm reduction policy and practice more generally—is additionally revealing of the recent state of drug/service user organizing and activism in Canada. Beyond the effective erasure of harm reduction accomplished by the Conservatives' *National Anti-Drug Strategy* (Government of Canada, 2007), the former federal Conservative government also actively fought to close the first and only supervised injection facility in North America, taking their challenge all the way to the Supreme Court of Canada (Makin, Dhillon, & Peritz, 2011). In 2011, however, the Court delivered its ruling that Insite would effectively be institutionalized, eliminating the uncertainty that surrounded its status as a “scientific trial” (Makin, Dhillon, & Peritz, 2011).

### **Australia's Fictional “Liberal Paradise” and Canada's “Neoliberal Dystopia”: A Comparative Case Study of Drug User Organizing**

Problematizing popular perceptions of Australia as a “liberal paradise,” Treloar and valentine (2013) argued for the fundamental importance of critically interrogating structural barriers to services for people who use drugs. Drawing inspiration from Treloar and valentine's research, analysis of drug user organizing suggests that Canada may represent an increasingly dystopian socio-political landscape for people who use drugs. Above and beyond their commonwealth status, Australia and Canada share many similarities. Unlike the United States, for example, both countries followed the European “four pillar” model of drug policy, resulting in the widespread institutionalization of harm reduction during the mid- to late-1980s (Erickson, 1992; Fischer, 1997; Hathaway, 2001; Keane, 2003; Miller, 2001; Roe, 2005; Smith, 2012).

There is, however, at least one critical difference between the Canadian and Australian experiences of harm reduction: The Government of Australia's first *National HIV/AIDS Strategy* (1989) directly led to the institutionalization of state-supported drug user organizations, a strategy that is now widely recognized as having played an instrumental role in combatting the HIV/AIDS epidemic (Albert, 2011). State funding for regional drug user groups, coupled with the establishment of a national umbrella organization—the Australian Injecting and Illicit Drug Users' League (AIVL)—have been widely acknowledged as fundamental elements in Australia's effective response to HIV/AIDS, with such groups “successfully run[ning] a wide variety of programs” (Crofts & Herkt, 1995, p. 560; Toumbourou,

Hamilton, & Smith, 1994). Eventually coming to form a taken-for-granted “part of the backdrop,” as Crofts and Herkt (1995) remarked,

The active involvement of at-risk communities has been the hallmark of Australia's response in the AIDS epidemic ... Organizations of injecting drug users (IDUs) at state and national levels have been key in providing input to policy, program development, and delivery ... [and] their mere existence has had a profound effect on the nature of the response to HIV among IDUs. (p. 560)

By equitably engaging people who used drugs as partners, Australia's 1989 *Strategy* served to radically shift popular perceptions, effectively resituating users as “individuals with a capacity to educate and be educated, to form organizations, to manage funding, to represent their community, [and] to serve on governmental consultative committees” (Crofts & Herkt, 1995, p. 603). Growing directly out of Australia's *National HIV/AIDS Strategy*, AIVL was formed in 1988, working closely with the Australian Federation of AIDS Organizations (Crofts & Herkt, 1995). AIVL's constitution is revealing of the mainstream, institutionalized status of user-driven organizations in Australia, becoming the pre-eminent model of drug user organizing on the global stage (Albert, 2011). As their constitution (AIVL, 2009) begins, the league

represents issues of national significance for illicit drug users and people on opioid pharmacotherapies. The organisational philosophy of AIVL is user-centred and supports the right of people who use illicit drugs and people on opioid pharmacotherapies to self-organise and form peer-based structures and processes in order to reduce drug related harm. (p. 4)

Consisting of regional representatives from user-driven organizations across Australia, from its inception AIVL has placed considerable emphasis on change efforts for national policy in all areas affecting people who use drugs, adhering to the belief that “without good drug policy at the government level” there can be “no effective drug treatment” or harm reduction programming (Albert, 2011, p. 18).

Recent investigations have revealed how in areas such as North America, harm reduction emerged as an affinity-based, direct-action-driven social movement, where underground, street-level syringe exchange activists risked arrest and criminal persecution in an effort to reduce the spread of blood-borne infections such as hepatitis C and HIV/AIDS (Roe, 2005; Smith, 2012; Stoller, 1998). During the subsequent institutionalization of harm reduction practice as sanitized, “scientifically” justified public health policy, as this research has argued, the oppositional political origins of the movement—focussing not only on the reduction of drug-related harm, but also on the structural factors responsible for harm *production*—became obscured, resulting in the effective depoliticization of harm reduction theory and practice (Roe, 2005; Smith, 2012, 2016; Stoller, 1998). Such assertions therefore call for a critical reconsideration of the Australian experience, where harm reduction was conceived in institutionalized terms, and the ground-level experience of consumer participation was inseparable from the subtle expressions of governmentality inscribed in the

discourses surrounding “new” and/or “critical” public health (Fischer, Turnbull, Poland, & Hayden, 2004; Roe, 2005; Smith, 2012, 2016).

Drawn from ethnographic observations, the following vignette plainly illustrates how user-driven organizations occupy what Crofts and Herkt (1995) described as a “permanent feature” of Australian drug policy. During discussions regarding the incorporation of drug/service user participation at an international workshop conference concerning methadone treatment in Vancouver, Canada, during the spring of 2011, one of the Australian researchers in attendance innocently inquired: “Why don’t we approach the Canadian national drug user organization for consultation?” At this, the Canadian delegates in attendance—the author included—simultaneously hung their heads in silence until one individual gathered the nerve to admit that no such national body has ever existed, and moreover that the Canadian government has historically provided very little support to user-driven initiatives. However uncomfortable, this incident inadvertently brought to light the glaring disparity between Canada and Australia regarding the role of people who use drugs in harm reduction policy and practice.

Resonating with contemporary North American findings (Allman et al., 2006; Friedman et al., 2004, 2007), early research concerning the place of user-driven organizations in Australia’s highly successful National HIV/AIDS Strategy (Government of Australia, 1989) suggested that such groups “constitute[d] an elaborate social network linking active drug users and others in society” (Toumbourou, Hamilton, & Smith, 1994, p. 139). The first formal attempt to document the historical role and development of these organizations, however, concluded that such achievements had largely gone unrecognized, particularly on the international stage; “much has been taken for granted,” Crofts and Herkt (1995, p. 614) concluded, “and, because of this, user groups in Australia have rarely undergone systematic evaluation, and few lessons learned have been documented.” In contrast, more recent investigations conducted in collaboration with AIVL regarding active service user involvement in opioid pharmacotherapy programs revealed “considerable support for consumer involvement,” yet identified a clear need for training and capacity-building efforts to investigate “how consumer participation might work in practice” (Bryant et al., 2008, pp. 141–143). In spite of the virtual absence of state funding for user-driven organizations in Canada, it is relevant to note that an extensive body of community-based “grey literature” produced by grassroots, community-based, Canadian health and harm-reduction agencies has emerged concerning best practices and lessons learned for user/peer involvement in harm reduction policy and practice (see Balian & White, 2010; Belle-Isle et al., 2016; Canadian AIDS Society, 2015; Canadian Harm Reduction Network, 2008; Canadian HIV/AIDS Legal Network, 2008; Mason, 2006; Street Health, 2007; Toronto Harm Reduction Task Force, 2003).

As Treloar and valentine (2013) demonstrated in their critique of structural barriers to methadone treatment, even the “liberal paradise” of Australia continues to face significant systemic challenges in the struggle to reduce drug-related harm and increase human rights among people who use illicit drugs. In spite of a small number of recent promising developments—including the fledgling formation of the national



Canadian Association of People Who Use Drugs (CAPUD)—by comparison Canada’s recently conservative political climate has produced a distinctly dystopian environment for autonomous user-driven organizations. Effectively working to situate Australia as a global leader in public health and HIV/AIDS prevention policy, despite the persistence of structural barriers, in the highly successful Australian experience the state actively supported and facilitated the *empowerment* of users and the encouragement of community-based inter/intra-ventions toward the reduction of drug-related harm (Friedman et al., 2004).

From their initial election in 2006 to the end of their reign in 2015, Canada’s Conservative government, on the other hand, actively relegated people who use drugs to marginal, superficial, and/or tokenistic positions—if and when the notion of consumer involvement was even invoked—while still promoting a hollow policy discourse of support for more meaningful forms of engagement among people with lived experience (Cheng & Smith, 2009; City of Toronto, 2005; Legislative Assembly of Ontario, 2010; Ontario Ministry of Health, 2009, 2010). In other words, in spite of the promising momentum demonstrated by Heath Canada in 2001 (see Kerr et al., 2001; VANDU, 2004), the controversial Canadian policy shifts enacted by former Conservative Prime Minister Stephen Harper—namely the erasure of harm reduction from the *National Anti-Drug Strategy*, along with the shifting of responsibilities for drug policy from the Department of Health to that of Justice (Government of Canada, 2007)—signalled an unambiguous regression from biomedical to moral-criminological addiction paradigms.

### **Discussion: Structural Barriers to User Organizations in Canada**

Exploring notions of self-determination and/as empowerment in the psychiatric consumer-survivor movement, Cook and Jonikas (2002) identified three overarching structural barriers. Corresponding closely to the barriers faced by Canadian user-driven organizations, these barriers include (a) systemic stigma and discrimination, (b) the sometimes *destructive* nature of treatment regimes, and (c) inadequate training for service providers and professionals (Cook & Jonikas, 2002, pp. 90–91). In the first case, Cook and Jonikas (2002) asserted that beyond social stigma, “institutionalized discrimination against people with mental illness is one of the last socially acceptable, government-sanctioned threats to the rights of a large class of citizens ... mak[ing] the realization of self-determination a tenuous and challenging process” (p. 90).

In a similar manner, people who use (and particularly, inject) illicit drugs represent perhaps one of the most marginalized populations, whose popular and professional stigmatization has—since the social construction of the addict as a typology of moral-criminological deviance at the turn of the 20th century—been both socially and institutionally sanctioned (Alexander & Roberts, 2003; Brodie & Redfield, 2002; Sedgwick, 1993). In the second case, the lack of appropriate treatment services, coupled with their often coercive nature, bears startling similarity to contemporary addiction treatment services (Bourgois, 2000; Hunt & Stevens, 2004; Smith, 2011). Finally, the failure of conventional training and education programs, as Cook and Jonikas (2002) suggested, lies in the unwillingness or

inability of mental health service providers to “view clients as self-determining agents of their own change, capable of making informed choices about their treatment and recovery” (p. 91).

Existing literature concerning structural barriers to drug/service user participation commonly identifies several broad factors, including (a) stigma; (b) criminalization; (c) tokenism and superficial consultation; and (d) support, funding, and political issues (Canadian HIV/AIDS Legal Network, 2008; Greater London Alcohol and Drug Alliance, 2005; Mason, 2006; Toronto Harm Reduction Task Force, 2003). Similar to psychiatrized communities, drug/service users suffer from perhaps one of the highest levels of social stigmatization and marginalization. Resonating closely with Cook and Jonikas’s (2002) contentions regarding institutional authorities in the mental health sector, Mason’s (2006, p. 7) analysis, *Best Practices in Harm Reduction Peer Projects*, concluded that there is a direct correlation between institutional stigma and agency commitment to user-driven approaches. Among community-based organizations, the Canadian HIV/AIDS Legal Network (2008, p. 7) has suggested that in similar contexts, agencies should be eligible to receive government funding to both assess and implement the necessary steps for increasing meaningful forms of user/peer involvement.

Self-stigmatization among drug/service users is an additional consideration largely informed by agency support and capacity-building efforts prior to the commencement of user-driven programs or interventions (Cook & Jonikas, 2002; Mason, 2006). As the Toronto Harm Reduction Task Force (2003) *Peer Manual* asserted, “We often tend to define people by what we see as their weaknesses”:

Someone who uses drugs, therefore, becomes known as a drug user, a crack head, a junkie, rather than, say, someone with writing skills, a good listener, a problem-solver. By working with peers as individuals who possess wonderful gifts and a diverse range of skills and qualities, agency staff can help alleviate some of the stigma attached to using drugs, and contribute to peers’ sense of self-worth. (Toronto Harm Reduction Task Force, 2003, pp. 20–21)

Additionally, prohibition represents a seemingly obvious—yet often overlooked—structural barrier related to drug/service user engagement (Canadian HIV/AIDS Legal Network, 2008; Mason, 2006; Toronto Harm Reduction Task Force, 2003). Unlike a mental health condition, the typologizing diagnosis of ‘addiction’ is implicitly, if not overtly, illegal, owing not only to presumptions concerning the possession and consumption of “illicit” substances, but also assumed participation in the underground, black-market economy. Unlike the Australian context, therefore, in Canada the criminalization of people who use drugs undermines both public health efforts and human rights, representing a “barrier to their greater, meaningful involvement in the response to the HIV/AIDS epidemic” (Canadian HIV/AIDS Legal Network, 2008, p. iv).

Existing forms of institutional consumer involvement are not only often superficial but blatantly tokenistic (Canadian HIV/AIDS Legal Network, 2008); here, as Mason (2006, p. 7) revealed, barriers to meaningful drug/service user

participation identified by harm reduction service providers included a lack of stable funding, resource and staffing constraints, and the inability of authorities to relinquish control and enter into meaningful relationships of collaborative autonomy (Cheng & Smith, 2009). Extending from the forces of institutional stigma, the Canadian HIV/AIDS Legal Network's (2008) "Do's and Don'ts" rendered explicit both the tokenistic nature of present user engagement efforts, and the integral elements underlying meaningful collaboration with people who use illicit drugs:

**Do** ask us what we need

**Don't** be afraid to ask ...

**Do** acknowledge that you may have needs, too, and that unfamiliarity may make you uncomfortable

**Don't** assume that I am the problem and the only one who needs to learn ...

**Do** consider training for you and the other committee or board members specific to the issue of user involvement, and ask a user to participate

**Don't** think that you can't learn how to involve me better ... (p. 42)

While providing a clear illustration of the shallow, surface-level nature of consumer involvement that has come to characterize contemporary Canadian public health policy, the above guidelines also allude to the critical role of on-going communication, support, and user-centric training for all participating parties. Spanning social, material, financial, and political dimensions, the range of intersecting issues surrounding user-driven participation encompasses the training of service providers and drug/service users, resource allocation, and perhaps most importantly, the political will of policy actors and institutional authorities.

### **Conclusion: Institutional Collaboration, the "Right to Autonomy," and the Fundamental Value of Users' Experiential Knowledge**

In conclusion, it is relevant to further unpack the notion of collaborative autonomy that has been invoked throughout this paper. Directly invoking the question of equitable engagement between service providers and people with lived experience of substance use, the notion of collaborative autonomy emerged from Ontario psychiatric survivor initiatives (Cheng & Smith, 2009). Resonating with Szasz's (1992) "right to autonomy," in this case the strong emphasis on the notion of autonomy within the psychiatric survivor—and, increasingly, *drug war survivor* (VANDU, 2010)—movement(s) grows directly out of a longstanding history of institutional oppression and exploitation, in which the overwhelmingly quantitative and epidemiologically focused character of traditional addiction research functioned to frame research subjects as little more than laboratory rats, whose perceived criminal status transformed them into second-class citizens incapable of collaboration. As Cheng and Smith (2009) asserted, however, the notion of autonomy in relation to user-driven initiatives serves to "underline the importance of addressing systemic barriers ... and thus explicitly recognizes the value and importance of ... *experiential knowledge*" (p. 4).

Owing to the historical subordination, stigmatization, and systemic oppression of people who use drugs, the notion of autonomy is central to restoring the power imbalance between service users and providers and to reclaiming some degree of dignity by actively elevating the importance of experiential knowledge over the supposed expertise of biomedical authorities (Campbell, 1990; Cheng & Smith, 2009; Smith, 2012). In such cases, the development of autonomous user-driven organizations can serve to reintroduce the voices of drug/service users—voices that have been silenced and unacknowledged for far too long due to persistent stigma and systemic barriers—to debates concerning the policies and programs that affect their everyday lives (Canadian HIV/AIDS Legal Network, 2008).

In critically interrogating the notion of (collaborative) autonomy, however, it is relevant to address how this issue might translate in the Australian context, where user-driven organizations originated as a state initiative. Almost as if recounting the Australian experience, the Canadian HIV/AIDS Legal Network (2008) vehemently insisted that:

People who use drugs need to be meaningfully involved in consultative processes, as well as in decision-making or policy-making bodies and advisory structures dealing with issues related to HIV/AIDS, HCV, and illegal drugs. Such participation ... enables them to... foster genuine community participation in partnership with policy makers, researchers and service providers whose work significantly affects their lives. (pp. 58–59)

Local, regional, and national government bodies, the paper further suggests, need to overcome institutional stigma in order to actively “invite people who use drugs to participate in all consultations, committees, or fora where policies, interventions, or services concerning them are planned, discussed, researched, determined, or evaluated” (Canadian HIV/AIDS Legal Network, 2008, pp. 58–59). Although after more than 20 years of government-funded consumer participation such measures might be taken for granted in Australia, the question remains: Are state-conceived, institutionally supported, user-driven organizations in fact free to truly express oppositional, contrary, or dissenting ideas; or does their dependence on government funding and support effectively force them to practice self-censorship and/or behavioural self-policing?

Bureaucratic inconsistency has played a critical role in inhibiting the development of meaningful forms of user-driven organizing in Canada. The glaring disconnect between the conspicuous absence of harm reduction from the former Conservative government’s *National Anti-Drug Strategy* (Government of Canada, 2007) and various regional drug policies, for example, which contain a clear emphasis—at least in theory—on user/consumer participation and the deployment of peer-based approaches, represents a clear case in point (see City of Toronto, 2005; Legislative Assembly of Ontario, 2010; Ontario Ministry of Health, 2009, 2010). On a more profound level, it is also relevant to re-emphasize the fundamental disconnect between discourse and lived reality in relation to municipal- and provincial-level policy recommendations regarding user engagement in Canada.

The stark juxtaposition between thinly veiled utopian discourse concerning the direct involvement of drug/service users on one hand, and drug/service users' lived reality of superficial, tokenistic participation on the other, reveals a dramatic clash that is particularly evident in the province of Ontario. First applied to early psychiatric survivor activists by Chamberlin (1978), the phrase *nothing about us without us* was subsequently appropriated as the title of a 2008 position paper published by the Canadian HIV/AIDS Legal Network. Having appropriately morphed into one of the most common mantras of the global movement among people who use drugs, *nothing about us without us* thus represents a clear indication of the similarities and parallels between the struggles of people with lived experience of psychiatrization and those with lived experience of illicit substance use. Instead of a research culture based (from users' perspectives) on the principle of *nothing about us without us*, however, we have arrived at a critical moment when research is becoming (or perhaps, from the users' perspective, already has become) *about nothing without us* (Canadian HIV/AIDS Legal Network, 2008). As opposed to moving toward a research ethos in which the active inclusion of the voices of people who use drugs becomes a ubiquitous standard of practice, therefore, we have created an increasingly urgent state where research that neglects the perspectives of the subjects it purports to serve runs the inherent risk of becoming about—and by extension, *worth*—nothing.

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### Author Note

Conflict of interest: The author wishes to state that he was appointed to the Minister's Advisory Group on Mental Health and Addictions as a consultant for the development of a 10-year mental health and addiction strategy for the province of Ontario (2008–2010). In this capacity, the author furthermore became involved in the "consumer involvement" subgroup of the Minister's Advisory Group, where he was commissioned to co-author an evidence-based literature review concerning consumer participation in the mental health and addiction sectors (Cheng & Smith, 2009). Despite these involvements, the author believes his analysis to be impartial.

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