

Engaging People with Lived Experience for Better Health Outcomes:

Collaboration with Mental Health and Addiction Service Users in Research, Policy, and Treatment

*A Review of Literature Pertaining to
Peer / Consumer Involvement in Mental Health and Addiction Policy*

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Executive Summary

Over the past three decades, people with lived experience (PWLE) of mental health and substance use issues have begun to play an increasingly important role in the development and delivery of programs, interventions, and services designed to meet their needs. This paper investigates published literature from a variety of sources to critically explore the question of peer/consumer involvement in all areas of mental health and addiction policy and practice, including research and policy development, service delivery, social support, and evaluation and review. To date, there has been little research that addresses peer/consumer involvement in both the mental health and addiction sectors. Through a wide-ranging literature review, this paper presents a comprehensive portrait that spans the core issues underlying the question of engaging people with lived experience in the development and implementation of the policies and programs that affect their everyday lives.

With critical attention to the sensitive social and political implications of language, the introduction to the paper carefully works to define the notions of 'peer/consumer' and 'consumer involvement', before addressing the benefits and advantages of peer/consumer involvement that emerged as recurrent themes in the evidence base. After setting out the basic framework for the paper in the introduction, the first section examines the history and development of peer/consumer involvement initiatives, conducting a comparative analysis of such work in mental health and addiction policy, research and treatment. Having provided a sense of background and context to the question of peer/consumer involvement, the second section of the paper then proceeds into a formal literature review, which is complemented by a series of comparative case studies of consumer involvement in Canada and elsewhere.

The final sections of the report are devoted to exploring the structural, systemic, and socio-political tensions, challenges and barriers to peer/consumer involvement. Addressing the significant imbalance existing between the two sectors, this section moves from an investigation into the comparative lack of peer/consumer involvement among people with lived experience of substance use and mental health issues. From tensions surrounding institutionalization, to the issues of funding/support, stigmatization, and superficial consultation or 'tokenism', the primary barriers and challenges to consumer involvement are drawn and delineated directly from the evidence base. Growing out of the barriers and challenges identified in this analysis, the paper concludes by offering a series of tangible recommendations for increasing peer/consumer involvement among people with lived experience of mental health and substance use issues, in order to achieve better health outcomes for all Ontarians.

Central to the conclusions contained in this paper are the notions of *indigenous inclusivity* and *collaborative autonomy*. Indigenous inclusivity implies the mandated involvement of people who are indigenous to the specific communities that are being targeted for a given policy, research or treatment intervention. Demonstrating the ethical, public health and human rights imperatives of engaging and collaborating with people with lived experience of

substance use and mental health issues “nothing about us, without us” is an expression popularized by the Canadian HIV/AIDS Legal Network (2005) that points to the fundamental significance of indigenous inclusivity. Collaborative autonomy, on the other hand, speaks directly to the question of equitable engagement and/or collaboration between service providers and people with lived experience of substance use / mental health issues (PWLE). Here, the notion of autonomy with respect to users and user-run organizations serves to underline the importance of addressing systemic barriers and inequities such as resource allocation, and thus explicitly recognizes the value and importance of *lived experience* or *experiential knowledge*. The notion of collaborative autonomy also implicitly aligns with a recovery and wellness-based view of health.

In other jurisdictions, mental health and addiction policies have adopted bold and innovative new paradigms and approaches with an explicit focus on the direct involvement of people with lived experience. The unfortunate reality is that in the context of Ontario, however, peer/consumer involvement efforts are constrained by continuing stigma, lack of core funding and support, and systemic social inequity. The evidence base reviewed in this paper strongly asserts the overwhelming value and benefit of engaging people with lived experience and the potential for further integration and application of peer/consumer involvement when conducted in innovative, respectful, equitable, collaborative partnerships with service providers and the larger health care system.

Introduction

In recent years, the notion of consumer involvement has gained considerable currency in the areas of mental health and, to a lesser extent, addiction policy in Canada and elsewhere throughout the world. *Consumer/peer involvement* is a broad, umbrella term that describes “a range of approaches that engage members of a particular target group in delivering health promotion initiatives to their peers” (Mason, 2007: 4). It has been recognized as a potentially important contribution to all areas of mental health and addiction policy and practice, including:

- Research and policy development
- Service delivery
- Social support
- Evaluation and review

The fundamental significance of those individuals who self-identify as “peers”/“consumers” and the work that they are doing in Ontario cannot be overstated. Research suggests that how these terms are used and defined will raise financial and social implications in terms of issues of stigma, power sharing, and boundaries, among others (Mason, 2007: 6). Furthermore, the evidence base asserts the inherent values that come with these best practices, including the evident benefits of collaboration with institutional partners in the mental health and addictions systems.

The considerable expansion of consumer involvement in mental health service provision in Ontario over the course of the last two decades is significantly encouraging. Unfortunately, peer/consumer involvement in the area of addiction treatment, research and policy has not witnessed the same degree of integration and inter-professional collaboration. From this perspective, momentum and widespread acceptance in the Canadian context for addiction peer/consumer involvement has only just emerged from the shadows.

Reviewing the evidence base, this report details the benefits and inherent values of peer/consumer work, suggests reasons behind the relative lack of consumer/peer involvement in the area of addiction, and provides a series of clear recommendations to increase and expand peer/consumer involvement in the research, policies and treatment services that directly affect the lives of people with lived experience of substance use and mental health issues.

By contrast, peer and consumer involvement in mental health has gained widespread acceptance in recent years. In this enlightened context, the innovative evidence base for mental health consumers/survivors is examined in a wide-ranging literature review.

The evidence base for consumer involvement in mental health has had a longer period of development. Systematic reviews by Simpson & House (2002) and Doughty & Tse (2005) summarize the conclusions from the literature to this effect:

- “Users can be involved as employees, trainers, or researchers without detrimental effect.” (Simpson & House, 2002)
- “Involving users with severe mental disorders in the delivery and evaluation of services is feasible.” (Simpson & House, 2002)
- “Overall, research on consumer services reports positive outcomes for clients.” (Doughty & Tse, 2005)

Consumer-run services worldwide receive very limited funding from mental health budgets despite a growing trend that suggests they may represent an effective model of mental health service delivery. Furthermore, to justify their place in the array of services offered within the mental health sector, a strong case can be made that services should only be required to demonstrate equivalent effectiveness compared with traditional services rather than superiority in regard to outcomes for clients. (Doughty and Tse, 2005)

Informed by the literature review and subsequent analysis, this paper begins with a section devoted to highlighting the unique benefits and inherent advantages of engaging people with lived experience in policy, research and service provision initiatives. The report then follows by defining the notion of consumer/peer involvement, providing a brief history of the emergence and development of this policy initiative. Although there are many points of connection (namely in the area of ‘concurrent disorders’), this paper addresses the question of engaging people with lived experience of substance use and mental health issues separately.

The co-authors of this report then each conduct a brief review of the literature relating to consumer/peer involvement in both mental health (Cheng) and addiction (Smith). In both cases, the literature reviews synthesized academic analysis, relevant policy documents, public health reports and other ‘grey’ literature.

Closely following the evidence base, case study analyses of several exemplary peer-driven initiatives are presented in the areas of addiction and mental health respectively. With regard to the involvement of people with lived experience of substance use, the report conducts an examination of the *Crack Users Project* (CUP), a capacity-building, empowerment-based, peer-led project that provides training and education to crack smokers in downtown Toronto. Additionally on the addictions end of the spectrum, the paper chronicles the

Vancouver Area Network of Drug Users (VANDU), a user advocacy and activism group originating in Vancouver's Downtown Eastside (DTES). With regard to consumer involvement in mental health, on the other hand, the report details the use of innovative peer support models to divert emergency room use, along with several other examples of collaborative partnerships which have broad implications for the Ontario mental health system.

The CSI Builder Report "Consumer Survivor Initiatives: Building for an Equitable Future" went to press at the same time that this report was being finalized. It is gratifying that the Ministry of Health and Long-Term Care has invested wisely in a consumer-directed process of consultation within their community to find out what it took to restore equity within an important area of the mental health service and support spectrum. Given its outstanding breadth and summarization of the evidence base around consumer-run programs and peer supports, the CSI Builder Report is a document of seminal importance, forming a companion piece to this paper. The recommendations for action in the CSI Builder Report are closely aligned with the conclusions contained in this paper, reiterated at the end of this paper.

Emerging directly from this analysis, the paper then turns to suggest reasons why addiction research, policy, and treatment initiatives that leverage the expertise of people with lived experience (PWLE) are still highly stigmatized and undervalued. A synopsis of the mental health evidence base around collaborations reveals a more respectful acceptance of peers in institutional and community contexts.

The work concludes by proposing a series of concrete, evidence-based recommendations in the hope of initiating, developing, and sustaining equitable, inter-professional collaborations. When actively applied, collaborations between the healthcare system and people with lived experience of substance use and mental health issues will directly lead to better health outcomes for all Ontarians.

Based on the existing evidence base, two overarching paradigms serve to inform the recommendations and overall tone of this paper. The first concept is the idea of ***collaborative autonomy***, which speaks directly to the question of equitable engagement and/or collaboration between service providers and people with lived experience of substance use/mental health issues (PWLE). 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 *lived experience* or *experiential knowledge*. Problematic situations are critically assessed and analyzed, such as cases where users or service-user organizations face a power imbalance and are subordinated in an unequal "partnership".

Indigenous inclusivity, by contrast, suggests the mandated involvement of people who are indigenous to the specific communities that are being targeted for a given policy, research or treatment intervention. “**Nothing about us, without us**” is how this meme is popularly expressed when consumers talk about advocacy and self-determination (Canadian HIV/AIDS Legal Network, 2005).

The authors would like to share their perspective on the use of language. While we use consumer, consumer/survivor, people with lived experience (PWLE), and service user interchangeably throughout this paper, it is understood that in lived reality, none of these terms suffice to satisfy all parties. From this perspective, it is arguably not enough to 'consume', 'survive', 'use', or 'experience' "the system" if one aspires to lead a purposeful and wellness-based life. The question of language in relation to people with lived experience of substance use is explicitly taken up in Perry and Reist's (2006) Words, Values and Canadians: A Report on the Dialogue at the National Symposium on Language. As Perry and Reist assert, "[t]o call oneself a 'junkie' may be a liberating experience, but it also has the potential to be an act of self-deprecation that internalizes the very stereotypes and inequities we seek to dismantle" (2006: 2). In spite of the problems associated with appropriate use of language, however, it is clear that PWLE wish to join with others in their common journeys towards recovery and in that sense to be embraced wholeheartedly by the broader community, as fellow citizens with duly respected rights and aspirations. In this spirit, the co-authors of this paper intend for this document to inspire increased equitable dialogue and engagement to achieve better health outcomes for all Ontarians, particularly through the inherently unique, valuable and largely untapped knowledge base of people with lived experience of addictions and mental health issues.

1. Benefits and Advantages to Peer/Consumer Involvement

Published literature from a variety of sources, including academic, policy and ‘grey’ literature (namely reports published by grassroots agencies employing peer/consumer involvement initiatives) clearly demonstrates the benefits, advantages, and overall importance of engaging PWLE of substance use issues in all aspects of the services and policies that directly affect their everyday lives (Allman et al., 2006; Coyle et al., 1998; Freidman et al., 2004; GLADA, 2005; Health Canada, 2001; Kerr, 2006; Latkin, 1998; Mason, 2006; Orme and Starkly, 1999; Street Health, 2007; Toronto Harm Reduction Task Force, 2003; VANDU, 2004).

A similar examination of peer-reviewed literature regarding the role of consumer/survivors in mental health clearly demonstrates the same rationale (Simpson and House, 2002; Doughty and Tse, 2005; Crawford et al., 2002; Forchuk et al., 2005; Solomon, 2004; Cook et al., 2009; Lawn et al., 2008; Hardiman et al., 2005). Owing to the fact that peer/consumer involvement in the

mental health sector is considerably more advanced, the inclusion of peers and peer support organizations is additionally reinforced throughout “grey” literature.

Based on data collected through a web-based survey of almost 900 stakeholders prior to Canada’s first National Harm Reduction Conference, peer/consumer-based networking initiatives for the reduction of drug-related harm were seen as “effective, efficient health promoters” thus allowing for the “consolidation and sharing of information, skills and understandings” (Allman et al., 2006: 402). In this study, peer/consumer-based approaches to harm reduction among people with lived experience of substance use were seen to represent “a particularly community-based response to the need for education, prevention and harm minimization programmes”, and furthermore, “a form of response that is inclusive of the socially marginalized while promoting health” (Allman et al., 2006: 409).

Reducing the harms associated with drug use, including the transmission of blood-borne viruses such as HIV and HCV, represents perhaps the most considerable area where peer/consumer involvement has had significant, objectively measurable positive benefits among communities of people with lived experience of substance use. Directly supporting this finding, a review of published outcome data regarding peer outreach–based interventions in HIV risk behaviours in the U.S. demonstrated that peer-led community outreach efforts resulted in “significant follow-up reductions in drug injection, multiperson reuse of syringes and needles, multiperson reuse of other injection equipment (cookers, cotton, rinse water), and crack use” (Coyle 1998: 20). In conclusion, this report revealed that the vast majority of published literature “strongly indicate that outreach based interventions have been effective in reaching out-of-treatment IDUs, providing the means for behavioural change” (Coyle, 1998: 20). Similarly, other U.S. research has documented significant reductions in HIV prevalence rates among IDU communities following peer-based interventions, thus suggesting the importance of creating and propagating peer-based models to be used in regional contexts such as Ontario, where such programs remain underrepresented and underfunded, at best (Friedman et al., 2004).

Another U.S. study regarding the use of peer leaders for HIV prevention efforts among IDU discovered that both ‘peer leaders’ and the ‘risk network members’ in the target sample demonstrated significant reductions in HIV risk behaviours (Latkin, 1998: 155). Conclusions drawn from this study gesture towards several distinct advantages to peer/consumer involvement, including:

- “It may be more cost effective than traditional outreach”
- “[P]eer leaders may have a greater influence than professionals on the HIV-related behaviours of friends, relatives and sex partners”
- And the fact that peer leaders “are able to access a diversity of settings, some not readily accessible to nonindigenous professional outreach workers, across a wide geographic area” (Latkin, 1998: 157).

The emergence of the notion of ‘harm reduction’ policy and practice in the 1980s is undeniably indebted to the experiential knowledge base and active participation of PWLE of substance use. From its inception, harm reduction practice—from grassroots, bottom-up initiatives to institutionalized public health interventions—has relied heavily on the active involvement of PWLE of substance use in a diverse spectrum of capacities. Although this notion is defined and discussed in further sections of this paper, at this point it is suffice to mention that harm reduction policy and practice has benefited enormously from the direct involvement of PWLE as:

- (1) autonomous providers of informal, grassroots harm reduction education and services (the phenomenon of ‘secondary distribution’ of harm reduction equipment being a perfect case in point);
 - (2) service delivery partners with agencies and institutions, albeit in most cases in an underpaid and undervalued capacity;
 - (3) as sources of experiential knowledge and harm reduction education, networking, support and information-sharing,
 - (4) as active and engaged contributors not only in the areas of research, policy making, service delivery and social support, but also importantly in the realm of program development, and;
 - (5) as prominent voices in the ongoing ideologically-charged policy debates surrounding substance use and treatment, where PWLE have initiated and participated in important dialogues surrounding the right-wing, conservative moral-criminological perception of drug use and ‘addiction’, the politics of prohibitionism, and the acute lack of humane, ‘patient-centred’ forms of treatment and support.
- (Canadian AIDS Society / Canadian Harm Reduction Network, 2008).

As revealed in the Canadian AIDS Society / Canadian Harm Reduction Network (2008) report entitled *Learning from Each Other: Enhancing Community-Based Harm Reduction Programs and Practices in Canada*, clients of harm reduction services significantly value and benefit from the direct involvement of peers and ‘people who have been there’—that is *people with direct lived experience*. Based on focus groups with substance users, clients of harm reduction services, and service providers in nine small-to medium-sized cities from across Canada, this report highlights innovative harm reduction initiatives and the important benefits derived from the direct involvement of PWLE throughout the country. Copies of this report can be found at: http://www.canadianharmreduction.com/project/pdf/final_report_en.pdf

Finally, published literature suggests the inherent value of peer/consumer involvement among people with lived experience of substance use from the perspective of skills development, where peer educators in England reported skills development in five main areas, including:

“(1) interpersonal skills, including presentation and feedback skills, leadership skills and assertiveness. An increase in self-confidence and confidence working with other people as a result of the project was cited by many of the peer educators;
(2) increased knowledge about drugs and alcohol;
(3) increased awareness of harm minimization issues, and the importance of providing accurate and balanced information;
(4) groupwork skills, including working and talking in a group;
(5) task completion, including working to deadlines, organizing themselves, planning, decision making and reliability”
(Orme and Starkley, 1999: 10)

In conclusion, several grassroots health and harm reduction agencies, particularly in Toronto and Vancouver, have published literature on the successes and lessons learned from their ongoing peer-based initiatives. For an analysis of successful factors behind peer-based programming, and a summary of best practice recommendations, please see Mason, 2006, a summary of which can be found in the literature review tables contained in Appendix A.

By comparison, in the field of consumer/survivor empowerment in the mental health sector, there has been considerably more programming brought into practice. This area has witnessed a confluence between the development of consumer/survivor initiatives and the more recent evidence base of research. In Ontario, the presence of over 50 Consumer Survivor Initiatives (CSIs)— including peer support organizations, patient councils, and alternative businesses— speaks to an existing infrastructure that is capable of a wide range of supports to consumers. Simultaneous to these developments, individuals with lived experience and peer organizations have been able to exert their presence at decision-making tables.

The CSI Builder Report “Consumer Survivor Initiatives: Building for an Equitable Future” (O’Hagan et al., in press, 2009), is a comprehensive snapshot of peer/consumer involvement initiatives in the mental health sector. As such, this report both details consumer/survivor initiatives, and also conducts an extensive survey of the evidence base in support of peer/consumer-led initiatives and organizations. Owing to its specific focus on restoring equity to an important range of mental health services and supports in Ontario, the CSI Builder Report (2009, in press) represents an invaluable complement to this paper.

Another recent paper was produced in 2005 by the partnership of four mental health stakeholders in the Province of Ontario: CAMH; CMHA, Ontario; the Federation of Community Mental Health and Addiction Programs; and the Ontario Peer Development Initiative. Similar to the CSI Builder Report, this paper reinforced and highlighted the program strengths of CSIs, concluding with specific recommendations for action.

These two documents make the ongoing argument for peer support and CSIs even more compelling. In a slightly different trajectory, O'Hagan et al.'s "Consumer Survivor Initiatives: Building for an Equitable Future" (in press, 2009), has the broad-based consultative support of the consumer/survivor community, and thus presents tangible possibilities for new forms of political capital. Some of this report's recommendations inform the basis of the conclusions and recommendations detailed at the end of this paper.

A systematic scan of the literature regarding peer/consumer involvement in mental health reveals the existence of three predominant themes over the years. The first constitutes an initial view of research regarding how consumer participation can reduce hospitalization. The second theme emerging from this literature turns to query the effectiveness of services provided by PWLE, and critically interrogates the notion of collaborative partnerships between service providers and service users. The third theme reveals an emerging focus on research that has increased the stakes by considering the relative merits of consumer-led programs compared with those that strictly conform to the bio-medical paradigm.

An example of the first theme is an Ontario study that revealed significant improvement in quality of life through collaborative relationships between consumer survivor organizations and hospitals, leading to a stark positive impact on hospital care cost savings (Forchuk et al., 2005). In this study, positive outcomes were most apparent through a dual approach, involving volunteer peers from CSIs who partnered with discharged hospital inpatients to smooth the transition back into the larger community, while also providing extended in-patient care until a community-based partner can be found (ibid.). Findings from this study revealed that:

- Study participants left hospital 116 days sooner
- Study participants tended to need fewer hospital services after discharge
- Study participants felt better and were further along the recovery journey
- Factored on a daily rate of stay in a psychiatric ward, an estimated \$12.2 million of cost savings were generated in one year
- Collaborative partnerships work to save the system money, yet CSIs need more funding to be able to offer their volunteers (Forchuk et al., 2005)

A systemic literature review of the effectiveness of service user-run or service user-led mental health services in New Zealand (Doughty and Tse, 2005) reiterated several key rationales for supporting organizations driven by PWLE, including:

- Some studies confirm positive consumer outcomes in service satisfaction, general wellbeing, and quality of life
- Some studies show no significant differences between services offered by service users compared with traditional service providers
- No studies showed consumer services were less effective than those offered in a service provider setting (Doughty and Tse, 2005)

Interestingly, Doughty and Tse (2005) advise caution in interpreting the results of their meta-survey. They cite the fact that some of the user-run services cited worked in tandem with clinicians and other professionals, suggesting that the consequent outcomes might witness more significant improvements if consumers had greater autonomy, self-governance and increased control.

The mental health evidence base (both formal and informal) regarding peer/consumer involvement trends then turns towards interrogating the nature of collaborative relationships between consumers and service providers. This may involve a variety of approaches, detailed as follows:

- The Depression and Anxiety Consumer Research Unit (<http://cmhr.anu.edu.au/cru/>), is a unique part of Australia National University, runs an online website with access to a virtual “systemic review” of the body of evidence that points to where service users can play roles in research and evaluation. They also do research aligned with the priorities of mental health consumers.
- In “Emerging New Practices in Organized Peer Support” Campbell and Leaver (2003) describe the various types of peer supports and services available in the United States. Exploring the possibilities of integrating peer support within the continuum of community care and the potential of inter-agency collaboration that offers choices to consumers, this work suggests that such initiatives make hope a possibility within the system. They see ad hoc and informal relationships as being the norm of collaboration between autonomous peer support programs.
- Potter and Mulkern (2009) provide three commentaries that flesh out what policy makers can do to make peer services happen. This resource from the Clearinghouse for the Community Living Exchange Collaborative explains the difference between consumer-operated programs and peer providers (who have consumers on staff). Choosing a model, the challenges of integration, how traditional service providers can approach ways of making peer workers feel more inclusive, and pay issues are also examined.
- The US Substance Abuse and Mental Health Services Administration (SAMHSA, 2009) examines the possibility for consumer/peer engagement and integration in policy discussions in its series of publications on “Building Bridges” which are available online. These publications are derived from dialogue with stakeholders from areas such as concurrent

disorders, the forensic system, primary care, higher education sector, and the faith community. Broadly addressed are themes of consumer and service provider collaboration, identification of systemic barriers, and program development in heretofore unexplored settings.

Finally, Greenfield et al. (2008) conduct a direct comparison between the consumer model and medical models of care, revealing the existence of two diametrically opposite approaches:

- One model maintains an unlocked atmosphere; the other is more restrictive
- One is essentially a residential environment; the other is an inpatient setting
- One has consumer staff (including an addiction counsellor) who emphasizes client recovery and experiential understanding; the other is professionally managed
- The crisis residential program (CRP) used an assertive community outreach approach after service users had gone through the program (typically 8 days); there was no such follow-up in the traditional locked inpatient psychiatric facility (LITF) programme (Greenfield et al., 2008)

When comparative outcomes were analyzed, the less intrusive care program provided initially lower costs for participants measured against hospitalization; this was not sustainable because of the need to have potential research subjects using those beds. CRP graduates who required re-admission were admitted to the LITF facility (ibid.).

The study did discover nuanced interpretations regarding symptom reduction, but key differences in favour of the CRP model emerged in client satisfaction, while no appreciable differences in functioning were apparent. The authors found no measurable differences in psychiatric outcomes. As such, there is richness in this investigation's attempt to explore the consequences of research moving to make direct comparisons between two equally valid consumer treatment choices.

This synthesis of the above literature therefore reveals that PWLE are taken increasingly seriously in all aspects of involvement in the mental health system.

2. Background/Context: The History and Development of Peer/Consumer Involvement Among PWLE

a) Addictions

While there is a strong history of autonomous user-run organizations in Europe (notably Denmark, Switzerland, and the Netherlands), Australia and Western Canada (namely the Vancouver Area Network of Drug Users [VANDU], a group that is examined in detail in subsequent sections of this report) (Friedman et al., 2004; Health Canada, 2001; Kerr et al., 2006), there has been a notable lack of recent peer/consumer or ‘user’-led activism, advocacy, and education initiatives in the province of Ontario (Smith, 2008). Ontario does have some history of user-led advocacy, including Toronto-based groups that flourished in the early-mid 1990s such as *Finally Understanding Narcotics* (FUN), the *Drug Users Union of Toronto* (iDUUT), as well as two methadone activist groups (Walter Cavalieri, founder, Canadian Harm Reduction Network, personal communication, July 2009). An acute lack of funding and support, however, prohibited such groups from reaching their full potential, and most are no longer in existence today.

In recognition of the positive value of engaging/involving people with lived experience of substance use in the research, policy and treatment services that have a direct impact on their everyday lives, the Toronto Drug Strategy report (October 2005) clearly advocated in favour of establishing and supporting a users group in the City of Toronto:

Recommendation 62: The City of Toronto support the development of a “drug users group” to undertake a range of activities, including advocacy for the rights of people who use illegal drugs, harm reduction initiatives, education, community development and consumer representation. (p.55)

To date, this recommendation has not received any support or funding, although the beginning of an autonomous, grassroots user-organized advocacy group, the *Toronto Drug Users Union* (TODUU) was formed independently in 2008 (Zoe Dodd, personal communication, March 2009).

b) Mental Health

Initial investment in service user involvement in Ontario began in 1991 with the creation of the Consumer Survivor Development Initiative, and the subsequent establishment of 42 programs across the province. A second round of funding in 1996 helped to put even more consumer/survivor initiatives into play across Ontario (Ontario Peer Development Initiative, 2005). These early initiatives were and remain trailblazers and incubators of unique programs.

In the context of Ontario, each consumer/survivor initiative is a unique and distinct entity. As described in the CSI Builder Report (O'Hagan et al., 2009), a wide range of programming exists today in CSIs in Ontario and abroad, including:

- Recovery practice
- Advocacy
- Social-recreational activities
- Public education
- Wellness Recovery Action Planning (WRAP) training and other self-care activities
- Youth awareness
- Warm line
- Training for peer workers

Some of these programs and initiatives already take place in Ontario, while those that have not have potentially positive policy implications.

3. A Comparative Analysis of Consumer Involvement in Mental Health and Addiction Policy, Research and Treatment

The increasing interest and acceptance of service user participation in all aspects of the mental health system can be likened to viewing a thick soup of client satisfaction, visibly seasoned with consumer empowerment, and marketed as a long-term cost saver according to 'bottom line' fiscal analysis. Accompanied by the political will to invest in funding and scientific research to measure the impacts of these new programs, these are favourable times for PWLE in mental health. The present reality for substance users, however, is that the contested nature of the term 'addiction', which is variously positioned and understood according to moral, criminological and bio-medical ideological paradigms (Smith, 2008), results in problematic, ill-defined and often contradictory peer/consumer involvement initiatives among PWLE of substance use.

Another significant difference between peer/consumer involvement among PWLE of mental health and substance use lies in how attitudes have shifted towards a recovery-driven focus in the assessment mental health. The concept of chronicity in behavioural illness has been successfully overturned to a great degree; the norm has become that of staying well. The consumer/survivor learns to balance the individualism of self-care, and when that individual also takes the opportunity of joining a CSI, they often discover the benefits derived from systemic advocacy and peer support. As the evidence base suggests, there is also a broader choice of care, including less intrusive and potentially harmful programs run by and for PWLE, either established within consumer/survivor programs, or where peers have taken a staff role in more formal settings.

In the context of addiction research, treatment and policy development, the notion of 'harm reduction' takes on a more prominent and defined role. According to the Toronto Drug Strategy report (2005), harm reduction refers to:

interventions that seek to reduce the harms associated with substance use for individuals, families and communities. It can include, but does not require, abstinence. The focus is on the individual's behaviour, not on the substance use itself. Effective harm reduction approaches are pro-active, offer a comprehensive range of coordinated, user-friendly, client-centered and flexible programs and services and provide a supportive, non-judgmental environment. Examples of harm reduction include needle and condom distribution and maximum blood-alcohol limits for driving. (p. 6)

Another central tenet of harm reduction policy and practice is the idea of accepting and embracing PWLE of substance use where they are at, thus preventing active substance use from becoming a precondition for service access. Although harm reduction initially grew out of efforts to provide services to out of treatment injection drug users (IDUs), this principle has since been extended to other communities of people with lived experience of substance use, including programs such as TRIP and Dance Safe, which were established in order to provide relevant, up-to-date information regarding sex and drug use practices to the Toronto rave community (<http://www.tripproject.ca/trip/?q=node/7> accessed July 2, 2009).

Several significant, peer/consumer-led organizations among PWLE of substance use and recovery have emerged over the course of the last decade with an explicit harm reduction mandate. The *International Network of People Who Use Drugs* (INPUD) is perhaps the first truly global user-run harm reduction advocacy group, based on several core principles, namely:

- Pro drug user rights
 - Pro self-determination
 - Pro harm reduction and safer drug use
 - Remaining neutral on an adult's choice to take drugs or not
 - Anti-prohibitionist
 - Pro equality
- (<http://inpud.wordpress.com/about/>, consulted July 3, 2009)

From the perspective of treatment and recovery, the New York City -based *National Alliance for Medically Assisted Recovery* (NAMA) is a methadone advocacy group that has assumed a prominent position in US MMT treatment debates. According to NAMA's mandate, the group works to "dispel the ignorance regarding MMT which plagues both treatment professionals and the general public", fight against the "discrimination perpetrated against methadone maintenance patients" and promote "quality methadone maintenance treatment

as the most effective modality for the treatment of opiate dependence”
(http://www.methadone.org/library/what_is_nama.html, consulted July 3, 2009).

As discussed further in this paper, the very notion of harm reduction is not free from ideological conflict and debate, particularly surrounding the institutionalization of harm reduction as public health practice. In its most progressive forms (largely in Europe), harm reduction practice implies a broad range of services and programs, where ‘low threshold’ denotes forms of service that have little or no barriers to access. Recent policy shifts in the Canadian federal government, however, have systematically attempted to undermine and eliminate the notion of harm reduction as a central mandate of Canadian drug policy. Smith (2008) succinctly details this shift in his discussion of the emergence of ‘regulation’ regarding the question of substance use and this thing we call addiction, a movement that represents:

an oppositional stance to the prohibitionist discourse characterized by the American ‘War on Drugs’, a stance closely mirrored in Canadian drug policy until the 1980s (Fischer 1997, Erickson 1992). Regulation, in the form of the emergent notion of ‘harm reduction’, was first introduced in Canadian drug policy with the establishment of Canada’s Drug Strategy (CDS) in 1987 (Fischer 1997) ... Although on the surface this approach appeared to constitute a radical departure from the right wing, conservative, (and arguably profoundly unsuccessful) ‘War on Drugs’, scholars have suggested that Canada’s Drug Strategy embraced harm reduction in theory but not in practice, demonstrating “very little evidentiary progression of drug policy reform based on public health principles” (Hathaway and Erickson 2003: 476). More recent evidence suggests that twenty years after it was first introduced, the notion of harm reduction is being written out of Canadian drug policy altogether. In October 2007, Prime Minister Harper unveiled the Conservative government’s National Anti-Drug Strategy. Based on a three-prong approach that includes prevention, treatment and enforcement, the new Strategy did not incorporate the notion of harm reduction. Signaling a return to the moral-criminological approach to addiction, responsibilities for the new Anti-Drug Strategy were shifted from Health Canada to the Department of Justice (www.nationalantidrugstrategy.gc.ca , consulted Mar. 10, 2007)... While harm reduction ostensibly takes a ‘value-neutral’ stance regarding substance use, critics suggest that the “moral warrants behind the movement ... with their basic respect for human rights, are the very principles that have yet to be fully established”, leading to the fact that “the human rights of drug users are typically downplayed in favor of ‘cost-benefit’ analyses that are claimed to be morally neutral” (Hathaway and Erickson 2003: 484). Given the highly contested status of harm reduction policy and practice in North America today, continued recourse to ‘bottom line’ analyses can in many ways be understood as a strategic measure to appeal to fiscal conservatives. (p.34-38).

4. Literature Review

a) Addictions

Resulting from the ongoing lack of acceptance and/or stigma regarding consumer/peer involvement in research, policy development and service delivery for people with lived experience of substance use there is a scarcity of published academic literature that addresses this question, particularly in the North American context. The scant published literature that does examine the role and importance of peer involvement in addiction research, policy and treatment is focused on several prominent themes, including:

- the value of peer networking
- the positive role of peer support work and peer-based forms of outreach in HIV/AIDS education and prevention
- the role and importance of increasing equitable, grassroots, community-based forms of peer/consumer/user involvement

"[T]here is an informal network already established amongst drug users; the trick is how to formalize this process" (Allman et al. 2006: 405)

People with lived experience of substance use and drug dependency find themselves reliant on informal methods of networking on a day-to-day basis, whether it is 'hustling' to generate income or 'scoring' illicit drugs (Allman et al. 2006; Bourgois & Schonberg 2009). In this sense, people who use drugs demonstrate strong networking skills, suggesting that "what [is] required [is] to help bring these skills above ground" (Allman et al. 2006: 405). The establishment of peer-based networks or 'drug user groups' has been associated with reductions in drug-related harm, allowing for the "consolidation and sharing of information, skills and understandings" (ibid.: 402).

Research regarding networking within and between user-run organizations such as the Vancouver Area Network of Drug Users (VANDU) has demonstrated several strong positive outcomes, including:

- increased harm reduction education and skill-sharing
 - empowerment through activism
 - advocacy and peer-based social support
 - community care
- (Health Canada, 2001; Kerr et al., 2006; VANDU, 2004).

Given its recognition and relative success in the Canadian context, VANDU has attempted to build the capacity of other fledgling regional drug user groups in order to “educate and organize drug users to take action” in their local communities (VANDU, 2004: 5).

User-run education and capacity building efforts by autonomous peer/consumer-led initiatives/organizations has had a significant positive impact on HIV/AIDS and HCV (Hepatitis C) prevention initiatives (Health Canada, 2001; Kerr, 2006; Latkin, 1998; VANDU, 2004). Defining *community outreach* by its reliance on “peers and indigenous workers”, a review of the American evidence base in the literature revealed that “outreach-based interventions have been effective in reaching out-of-treatment injection drug users (IDU), providing the means for behavioural change” (Coyle et al., 1998: 20). Furthermore, U.S. research based on examining “users’ autonomous drive for self-care” demonstrated that contrary to popular perceptions, “drug injectors can and do react to HIV and other threats rationally and effectively” (Friedman et al., 2004: 252). This is generally accomplished through the establishment and development of consumer/peer-based organizations among people with lived experience of substance use to “represent and act on behalf of their interests and to conduct HIV and HCV risk reduction programs” (ibid.) Yet another U.S. study that provided HIV prevention promotion training to IDU peer leaders suggested that in the IDU community, “training peer leaders as HIV educators may promote HIV prevention among the leaders’ risk network members and others at risk of acquiring and transmitting HIV” (Latkin, 1998: 151).

Alongside peer networking and the hands-on commitment of people with lived experience of substance use engaged in HIV awareness and prevention, there is a small body of literature that critically examines the potential role and importance of increasing grassroots, community-based forms of user involvement. As well as addressing the positive value of user-led interventions and initiatives, this literature additionally examines some of the problems and challenges (both existing and potential) inherent in peer and consumer involvement among PWLE of substance use. Barriers and challenges to peer/consumer involvement in addiction research, treatment and policy development, along with recommendations for increasing consumer/peer involvement are further detailed in subsequent sections of this report.

The Canadian HIV/AIDS Legal Network (2005) argues that greater involvement of people who use illicit drugs is imperative from the perspectives of (1) ethics, (2) human rights, and (3) public health. In accordance with the UN General Assembly’s *Declaration of Commitment on HIV/AIDS*, “all people should have the right to be involved in decisions affecting their lives” as an ethical principle (Canadian HIV/AIDS Legal Network 2005: 4). Consumer/peer involvement also conforms to the United Nations *International Guidelines on HIV/Aids and Human Rights*, which urges governments to “involve representatives of vulnerable groups, such as people who use drugs, in

consultations and in the planning and delivery of services” (ibid.). This concept is generally understood through the mantra “*nothing about us, without us*” (Canadian HIV/AIDS Legal Network, 2005)

From a public health perspective, it has been further recognized that there is significant value in ‘insider’ or ‘indigenous’ understandings of local drug using communities (GLADA, 2005; Kerr et al. 2006; VANDU, 2004). In this sense, people with lived experience of substance use are themselves “often best able to identify what works in a community that others know little about” (Canadian HIV/AIDS Legal Network, 2005: 4). This literature therefore directly reinforces the ethical, human rights, and public health imperatives of *indigenous inclusivity* in the case of PWLE.

Broadly reflecting the different ideological commitments of users, research in the U.K. suggests the existence of two types of user involvement, namely *advocacy* and *activism* (GLADA, 2005: 9). Identified as **advocates**, the first group had an explicit “commitment to improving drug treatment services”, and emphasized their capacity for “understanding and empathy towards drug users” (ibid.). The second group tended to self-identify as **activists**, and was more committed to “affecting broader, systemic change” driven by user-run organizations, emphasizing their strengths in “organizational development, business management and consultation skills” (ibid.).

In some cases, consumer/peer involvement in the area of addiction research, policy and treatment has been advocated based on critiques of the traditional ‘provider-client’ service delivery model. These issues primarily include “the difficulty that service providers have in reaching drug users on their own turf, difficult communication between providers and clients, and fear among drug users that use of services may alert police to their activities” (Kerr et al., 2006: 61). At the same time, “street cred” necessarily drives any such organization’s ‘user-led’ or ‘user-run’ mandates. For this reason, a user group such as VANDU will have two types of group membership, where full membership with voting privileges is strictly reserved for “people who report using or formerly using illicit drugs intravenously” (ibid.).

“VANDU has, after years of activism, gained increasing recognition in the local community”; as one member stated, “If anything is happening, it seems that it is probably going to need VANDU’s okay. VANDU is always at the table.” (Kerr et al. 2006: 64)

Through analysis of the activist, advocacy and public education work undertaken by VANDU since its 1997 founding, Kerr et al. (2006) illustrate the diverse range of positive benefits derived from a well-supported, well-organized and cohesive user group, including:

- **Education** that is specific to groups living with Hepatitis C, people on methadone, and women living with HIV, for example
- **Alley patrols** in recognition of the “reluctance of many service providers to venture into alley-ways”
- **Syringe exchange and recovery** including the establishment of an unsanctioned, peer-run NEP (needle exchange program) in the heart of Vancouver’s open drug scene, as a response to the documented difficulties of syringe access during evening hours
- **A hospital program** where volunteers “make regular visits to hospitalized drug users for the purpose of providing support and encouraging them to stay in hospital”
- **Peer support and advocacy** involving helping other with “negotiating bureaucracies, completing applications, and overcoming legal hurdles... programme recipients emphasized the value they receive from peers, as peers are deemed to be the most knowledgeable about the experiences of drug users” (p. 65-66).

As people who use drugs, our organizations have an important role to play in advocating for our rights and for our health and well-being. Our organizations: need to work towards being governed, managed and run by people who use illegal drugs, with power and control held by people who use drugs; measurable progress towards control by people who use drugs must be demonstrated; are best placed to ensure appropriate representation to governments, non-drug user organizations and other relevant stakeholders; need to be recognized as valid and valued participants in any policies and programs dealing with drug use, including those aimed at reducing harms sometimes associated with drug use, such as HIV and hepatitis C; need to be recognized as participants in policies and programs dealing with other health and social issues that affect our lives, such as mental health, housing, welfare; must be treated with respect and as equals in all partnership arrangements with governments and other organizations; have a responsibility to the larger movement of people who use drugs and strive to empower and include people who use drugs; are committed to the principles of harm reduction, peer education and support, and community development; and fight for the health and human rights of people who use illegal drugs. (Canadian HIV/AIDS Legal Network, 2005: 21).

b) Mental Health

There is a wealth of both peer-reviewed and grey literature that suggests why collaborative partnerships between consumers and service providers are worth pursuing. The evidence base surrounding the question of peer support and peer-reviewed services has received an exhaustive analysis by Solomon (2004):

- a) *What is peer support?*
Peer support is a “system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful”.
- b) *What are the various kinds of peer support?*
Peer support can take many different forms, including self-help groups, internet support groups, and warmlines.
- c) *What types of peer delivered services exist?*
- **Peer run or operated services:** (consumers plan, operate, administer, and evaluate them) and which value freedom of choice and peer control; small staff and larger number of volunteers (examples include drop-ins, clubhouses, crisis services, vocational services, psychosocial educational services and peer-to-peer support programs)
 - **Peer partnerships:** shared control with non-consumers (financial, administrative and governance matters), but peers are primarily in charge
 - **Peer employees:** designated positions for consumers in traditional mental health organizations and also peers who happen to occupy traditional staff jobs
- d) Peer delivered services offer five characteristic benefits:
- Social support
 - Experiential knowledge
 - Helper-therapy principle
 - Social learning theory (“we are like one another; we are all OK”)
 - Social comparison (“I see positive role models I want to follow”)
- e) Benefits to recipients of peer-delivered supports
- No difference in outcomes compared with traditional services
 - No difference in outcomes compared with therapists
 - Synergies between peer provided services in crisis intervention, team care, post-discharge care, and vocational services
 - Identifiable and measurable outcomes such as shorter hospitalization, quality of life, improved social functioning, less substance use, higher employment
- f) Peers who provided services were themselves less likely to require hospitalization (Solomon, 2004)

Finally, Solomon (2004) summarizes the system-wide benefits of peer supports and peer-provided services:

- The peer-provided services have the potential to save the mental health system money
- Reducing hospital use as a result of peer supports and programs saves the system money
- The minimal costs of self-help groups is offset by far in savings to the system
- That is no excuse, however, for not keeping wage parity when a peer is hired into a traditional staff position
- Peer providers fight stigma by being there
- Peer providers know how to outreach and link hard-to-reach consumers to the professional services they needs
- Peer support meet the mental health needs of those in the community (ibid.)

Absent from Solomon's critique is an awareness of alternative businesses (i.e. those that are owned and run by consumer/survivors). To address this question, two sources offer critiques.

One Canadian study examined a traditional model of service delivery for individuals with disabilities which was grounded in receiving disability benefits and being professionally supported in looking for work (Neufeldt et al., N.D.). A second, more progressive model, by contrast, encouraged self-direction from those seeking work. The latter approach led to a higher income approaching self-sufficiency, although policies at that time posed systemic barriers such as loss of income supports and benefits clawback. This study is instructive in that these motivational barriers hinder PWLE from beginning as employees in an alternative business (Neufeldt et al., N.D.).

Another article reviewed six Community Economic Development (CED) organizations, two of which fit the definition of a consumer/survivor enterprise (Crawford et al., 2000). Here, further barriers emerged, namely the fact that funder guidelines for successful outcomes which guide people to full employment were at odds with more modest expectations of alternative businesses (whose other objective is to keep people in recovery) that cannot realistically expect all employees to be able to achieve financial autonomy. CEDs, through no fault of their own, generally have a small niche unless these regressive policies are addressed. Potential funders also have to acknowledge the indirect benefit of keeping people in recovery as well as the aspired goals of achieving some measure of economic success, whether it is the individual or the striving organization (Crawford et al., 2000).

The healthy presence of grey literature regarding peer/consumer involvement in the mental health sector speaks directly to knowledge exchange of best practices. For example, a recently published 110-page guidebook summarizes 10 peer support in-patient programs in the United States. Its user-friendly resource format combines narratives, job descriptions (of such innovative

positions as a “Director of Consumer Affairs” – a senior-management level position in an institution with a systems change mandate), program documentation, and a bibliography (Bluebird, 2008).

Chinman et al. (2008) similarly discuss implementation strategies to ease peer workers into traditional mental health service settings by examining issues relating to: (1) evolving from client to a consumer provider; (2) exploring what that role could be; (3) adopting staff culture and opportunities for management; and (4) ensuring that staff concerns are given their full due.

Through the use of an online survey, Schwenk et al. (2009) investigated the work of certified peer specialists. Highlights of the 275 responses are summarized as follows:

- Nearly 70% were female
- They averaged 24.6 months in length of employment and averaged close to a full work week (29.8 hours/week)
- Almost half reported being independent peer support workers or case managers
- A few were in senior management or were executive directors

This limited snapshot attests to success in the deployment of service users throughout the mental health systems (Schwenk et al., 2009). As this evidence suggests, the Canada mental health system would derive significant benefit from a similar synthesis and dissemination of best practices, along with profiling innovative forms of collaborative partnerships between service providers and peer support organizations.

5. Consumer Involvement Case Studies in Addiction and Mental Health

a) Two Consumer Involvement Case Studies Among PWLE of Substance Use

In order to clearly illustrate the value and effectiveness of successfully developed consumer/peer involvement initiatives, the paper now turns to profile two such Canadian peer-based projects, representing two different forms of engaging and involving of PWLE of substance use. The published literature regarding these ‘addiction’ consumer/peer initiatives suggests how a continuum of peer-based approaches can be applied in a harm reduction context to addiction research, policy-making, and treatment service delivery.

(1) The *Crack Users' Project (CUP)*, Street Health, Toronto

The Crack Users' Project (CUP) is an ongoing peer-driven capacity-building project established by Street Health, a community-based health care and harm reduction organization situated in east-central downtown Toronto, an area generally acknowledged as the epicentre of the city's urban core crack cocaine communities. Motivated by the goal of "reducing the harms associated with the use of crack cocaine among users" in the service area, the objectives of the CUP project were to "increase communication with and among marginalized crack users; build capacity among crack users to develop and implement peer-led, crack-specific harm reduction strategies; and to improve access to physical and mental health services for this group" (Street Health, 2007: 2). Crack smokers have been acknowledged as a particularly marginalized and hard-to-reach substance use community, and crack users are at increased risk for a host of health and social problems, including "violence, diseases like Hepatitis C and HIV, malnutrition, social isolation and mental health problems" (ibid.: 3).

The CUP project consisted of two main components, including (1) scheduled drop-ins specifically for crack users, and (2) a series of harm reduction training sessions for more involved CUP participants. Seamlessly integrated and interwoven into these two main components was the provision of a full range of services and supports designed to address the health needs of participants in a holistic and comprehensive way. This included providing primary health care, peer support, individual counselling, housing advocacy, and healthy food onsite, thus complementing core programming activities (ibid.).

The drop-in component of the CUP project is peer-led, and facilitated by a member of Street Health staff with direct lived experience of homelessness and crack use. During regular project evaluations, participants have clearly and repeatedly shared "how much they value having a stable peer attached to the project who can provide advice and information from a perspective of shared and similar experience" (ibid.: 4). Drop-ins are held at a local community health centre, provide harm reduction equipment, and participants are issued 'membership cards' that serve to remind participants of the drop-in schedule, and "help create a sense of belonging" (ibid.). Additionally, the program allocated resources for one women-only drop-in each week, given the fact that "women are disproportionately affected by the harms associated with crack use and poverty" (ibid.). The harm reduction training component of the CUP program is similarly peer-focused and peer-driven, involving specific activities oriented towards training relevant to peer outreach work, including an "introduction to harm reduction, communication skills, sex work, HIV and Hepatitis C basics" (ibid.: 6).

Overall, the success of the CUP project was attributed to "the crack-specific, non-judgmental, welcoming space that has been created for users, and the supportive environment that has been created around the project through the provision of services and supports, which address and improve all aspects of

participant health” in an integrated, comprehensive and holistic way (Street Health, 2007: 9).

(2) The Vancouver Area Network of Drug Users (VANDU), Vancouver

Established in 1997, VANDU is the oldest, largest and most well known advocacy and activism organization for people with lived experience of substance use in Canada. One of the most significant strengths of VANDU is the organization’s broad involvement across the policy landscape, spanning from advocacy, activism and public education to community care and support activities. Several prominent principles guide VANDU. They include:

- i. inclusivity of all current and former drug users
- ii. a militantly user-driven orientation
- iii. the maintenance of a peer mentorship policy that involves “pairing someone who has skills in a particular area with someone who is interested in acquiring those skills”

(Kerr et al., 2006: 63).

The experience of VANDU has clearly demonstrated the “unique and vital contribution” that can be made by engaging and involving people with lived experience of substance use. Here, the fundamental impact of user-run organizations “in preventing the spread of bloodborne infections, in particular HIV, and in advancing the rights of people who use drugs” had been distinctly highlighted (Canadian HIV/AIDS Legal Network, 2005: 6). Founded at the height of a public health crisis among injection drug users (IDU) in Vancouver’s Downtown Eastside, as overdose and HIV/HCV infection rates soared, VANDU’s early work focused on political activism, advocacy and awareness raising. With a mission statement to “improve the lives of people who use illicit drugs through user-based peer support and education”, VANDU’s activities grew more diverse as its capacity increased, encompassing public education efforts, participation in governmental and community research projects, and the establishment of support groups for various sub-populations of people with lived experience of substance use, including “persons with hepatitis C, women with HIV, and methadone users” (Health Canada, 2001: iv).

VANDU maintains a militant stance on drug user inclusion in every aspect of the service, policy and research initiatives that are ostensibly conducted in their interests. Additionally, all published research relating to the organization must conform to “VANDU’s philosophy and members’ demands that all projects directly involve them”, again reinforcing the notion of *collaborative autonomy*, popularly understood by the Canadian HIV/AIDS Legal Network’s (2005) mantra ‘*nothing about us without us*’ (Kerr, 2006: 62).

The notions of indigenous inclusivity and collaborative autonomy are raised again later on in the matter of peer mental health organizations. The fully realized state of membership within VANDU attests to their outsized impact on public policy discussion in western Canada. Persistent stigma and a lack of core funding/support for initiatives and organizations led by PWLE of substance use have prevented similar voices from emerging in Ontario.

b) Three Consumer Involvement Case Studies Among PWLE of Mental Health

As referenced earlier, the CSI Builder Report “Consumer Survivor Initiatives: Building for an Equitable Future” (O’Hagan et al., in press, 2009) provides a wealth of background on current literature regarding consumer / survivor involvement initiatives in the field. Given this existing research, this section of paper instead focuses on *transformative strategies*, sites where it becomes possible to leverage present activities into recovery-driven and person-centred models of care.

(1) The Emergency Room and Service Users

One way of re-interpreting the traditional dynamic of passive users of mental health services is to focus on one of the flashpoints of entry into the system – the emergency room. This locus is traditionally either the initial point of entry for a consumer or the “go-to” place in an institutionally-focused model of crisis care.

The emerging evidence base suggests that alternative approaches are gaining considerable currency. Common to each is a sincere effort to provide choices that will reduce the necessity of intrusive care. Examples of such approaches include the following:

- The Amistad Peer Center in Portland, Maine has innovatively conducted *inreach* through its peer supporters directly into the emergency department of the state’s largest psychiatric hospital (<http://www.amistadinc.org/programs.php>, accessed June 2, 2009). These peer supporters are able to work with those in crisis waiting in admissions in the emergency department and within each hospital unit, and are available on weekends and evenings. Peers also attend treatment meetings and can act as advocates, in addition to sharing experiential knowledge. In this program, peers also act as support group facilitators and wellness trainers inside the institution.
- Moving one step beyond the norm of repeated visits to the emergency department are the concrete combined goals of a focused discharge program model along with using peer support to reduce re-

hospitalization (whether in ER or inpatient units). This was discussed earlier through the transitional discharge study conducted by Forchuk et al. (2005). Lawn et al. (2007) examined a three-month project in Australia that employed a Peer Service (composed of a project manager, peer coordinator and 8 casual peer support workers). The aim was to create a service model that was “identified, planned, operated, administered and evaluated by people with mental health conditions, with fully negotiated input from mainstream mental health sectors and the primary health care sector” (ibid). Peer workers in this project required previous background in the field, specialized training, lived experience, and reference checks. Referrals from the health region (which could come either from hospitals or community agencies) were made, and peer workers were then tasked with providing a number of peer support hours over a one-to-two week period to the consumer in need. Such arrangements were negotiated before a given client was discharged from hospital. Likewise, if a service user felt in need of assistance to avoid rehospitalisation, similar referrals could be made for peer support. Over the three months of the study, 49 peer support allotments were offered, lead to 300 hospital bed days being saved at \$377 per day (Lawn et al., 2007). In stark contrast, the peer support package (an average of 8 hours of peer support) cost \$220. Moreover, instead of the expected 30% relapse rate, only 17% were readmitted to hospital (half of them for physical complications only) (ibid.). Positive feedback regarding the peer workers was received from, family members, professional referrers, general practitioners, and the concluding focus group. More impressively, since that initial 3-month project, 200 additional peer support referrals have been made with 900 hospital bed days diverted (ibid.).

- Another way of reframing the overuse of emergency rooms is to divert use through the creative programming of crisis services as discussed by Ashcraft and Anthony (2006) This project went beyond the de facto partnership of peer staff and service providers. Cleverly, it involved providing more resources to peer staff and asking them to design a peer-run crisis alternative adjacent to the regular service called the “Living Room”. This service operated with an emphasis on minimizing seclusion and restraint, and was staffed by PWLE around the clock. The characteristics of this facility were largely attributed to its success, including (1) peer staff receiving over 100 hours of training; (2) home-like characteristics (small rooms with futons leading out to a common area with sofas, a fridge and other amenities); (3) stays permitted ranging from 24 hours to 5 days; and (4) peer staff sharing their experiential knowledge with service users. Feedback was positive – so much so that one doctor was quoted as saying that peers wrote better discharge plans than the professionals (Ibid.). Feedback

showed that the success of this non-medical model relied on: immediate help, an holistic approach to crisis (not just illness and meds); a homelike atmosphere; accessible transportation with peer escort; access to visitors; and a nice, safe space that encourages autonomy and recovery (Ashcraft and Anthony, 2006).

- In their review of mental health clients' perspectives of the emergency department, Clarke et al. (2007) specifically cite clients' recurrent requests for other places to go to in the evenings and weekends when someone is having a hard time, given that community programs are generally oriented towards a Monday to Friday, 9 am to 5 pm working cycle. Pudlinski (2004) has researched the pros and cons of consumer-run warmlines, concluding that such programs (1) work well with callers who are not yet at the crisis level; (2) can create peer supports without physically being there one-on-one, and (3) have greater time flexibility. Among the three models examined, the one within a fixed site proved most inflexible in its ability to accommodate teamwork and transportation issues. Using a pager with a call-back number system balanced a lack of timeliness in returning calls with the benefit of caller identification and personalized support. The third method, involving call-forwarding to the staff member on duty, was seen to lead to role confusion (is it a friendly call or work-related?). In the case of the *Krasman Centre*, a CSI in Richmond Hill, Ontario, the call-forwarding warmline is a toll-free number that redirects the caller's number anonymously to the staff person on call, thus preserving confidentiality of the service (http://krasmancentre.com/?page_id=21, accessed June 3, 2009).

(2) The New Zealand Peer Support Employment Strategy

New Zealand arguably represents the pre-eminent human resource strategy for PWLE in mental health arguable. There, a national centre, *Te Pou* was entrusted with the objectives of organizing mental health research, information and workforce development (Te Pou, 2008a)

Fundamental to the idea of transformational change is the concept of trained consumer advisors. In order to ensure its development, Te Pou has designated a service user workforce development manager to be not only a support person to consumer staff, but also to serve as a liaison and champion with mainstream service providers. (Te Pou, 2008b)

Te Pou's resource base is both strategically compelling and comprehensively planned, include the following accessible online materials:

- *A consumer advisor resource kit* (Te Pou, 2008c)
- Discussion of the roles of consumer advisors documented in e-newsletters (see <http://www.mentalhealth.org.nz/newsletters/view/article/8/81/summer-06-07/>, accessed June 15, 2009)
- Competencies for Consumer Advisors in Mental Health Services (Te Pou, 2008d)
- The Blueprint Training Program (National Certificate in Mental Health Support Work) (<http://www.blueprint.co.nz/page/14-Welcome>, accessed June 1, 2009)
- Executive Leadership Training in Mental Health and Addictions (<http://www.blueprint.co.nz/page/12-Welcome>, accessed June 1, 2009)
- A wide variety of workshops with a wide range of topics including consumer partnerships (<http://www.blueprint.co.nz/page/20-Workshops+Blueprint-workshops>, accessed June 2, 2009)
- Finally, Te Pou supports The Auckland Peer Support Network, a support network for peer support workers that meets bimonthly at different locations, providing a forum for peer support workers to engage in information sharing, problem-solving, support and networking (Te Pou, 2008e).

Other electronic resources accessible through Te Pou include links to testimonials, as well as a certification program for qualified mental health and addiction workers (Te Pou, 2008f).

On the addictions side, there is a parallel organization in New Zealand, the National Addiction Treatment Workforce Development Program (NATWDP), where there is provision both for consumer advisor and consumer auditor (i.e. quality improvement) roles (<http://www.matuaraki.org.nz/index.php?id=75>, accessed June 3, 2009).

This evidence base suggests that meaningful resource allocation, a dedicated agency, and knowledge dissemination figure strongly in making meaningful and positive transformation happen for service users and PWLE.

(3) U.S.A. SAMHSA Transformation Grants

The notion that PWLE need direct investments to make their alternative mental health projects a reality gained traction in the United States with the introduction of Mental Health Transformation State Incentive Grants (Substance Abuse and Mental Health Services Administration, 2009b). Key to the success of these grants, the funds offered more flexibility, were be accountable to consumers and families, and offered increase choices of care.

Growing out of this initiative, a new website has been established as a knowledge exchange database to reveal the positive outcomes of such investments (<http://mhstgdata.samhsa.gov>, accessed June 3, 2009). Currently, this database tracks 967 projects, which can be retrieved by keyword classification and other categories. Because the public is permitted to comment on the projects, there is an opportunity to read the ostensible outcomes and hear the “ground floor reality”. One example of this public testimonial is a listing regarding the rating of the New Mexico Behavioural Health Planning Council, which is viewed as a strong consumer voice for mental health in that state (http://mhstgdata.samhsa.gov/tte_detail.asp?id=2275, accessed June 3, 2009).

This transparent evaluation of mental health reform could likewise be a valuable tool with implications for other jurisdictions such as Ontario.

6. Correcting the Balance: Reasons Behind the Lack of Peer-Driven Initiatives in Addiction Research and Treatment

Persistent stigma surrounding people with lived experience of substance use has been identified as one of the primary reasons behind the lack of peer/consumer involvement in Ontario. In the context of intra-agency conflict, ongoing stigma can result in peers being used as scapegoats (Mason, 2006: 6). The very term ‘peer’ itself is a double-edged sword, given the implicit assumption of past or current experience with substance use. In this case, agencies need to mitigate and dispel stigmatizing ideologies by clearly defining the role and scope of peer work, and acknowledging PWLE of substance use in their rightful experiential role as “specialist[s] in service provision to [their] communit[ies]” (THRTF, 2003: 21).

Lack of agency commitment to – and integration of – peer/consumer involvement (namely *peer support work*), in some cases on moral grounds, has also been identified as a significant challenge (Mason, 2006: 7). In such cases there is a clear and distinct imbalance in power and equality between ‘peers/consumers’ and staff, where in many cases peers are not seen as equal to other staff. This serves to limit the amount of agency support allocated to peers and peer-driven projects (ibid.). The positioning and integration of peer programs within an individual agency is critical to its success. In more general terms, agencies need to establish a clear, meaningful and safe *place* for the involvement of people with lived experience of substance use.

Related to a given agency’s commitment to and integration of peer/consumer involvement is the question of meaningful participation. Here, issues of power sharing, namely the (real and perceived) power imbalances existing between peers/consumers and health care providers are paramount (GLADA, 2005; Mason, 2006).

Moreover, the drug use history of active and potential peer support workers has been cited as a potential challenge to the establishment and day-to-day operation of peer programs (Mason, 2006; THRTF, 2003; Solomon, 2004). Along with the direct impacts of drug use among active peers, “related issues and harms associated with use, such as having to go to jail, or having to deal with a serious health issue” are additional considerations (Mason, 2006: 6).

A final issue that may influence the low level of involvement of PWLE in substance use around harm reduction and addiction treatment research, policy development and service delivery is the perceived tension surrounding institutionalization (GLADA, 2005; Mason, 2006; Smith, 2008). This has been characterized by a debate regarding the effectiveness of harm reduction peer projects in grassroots versus mainstream, institutionalized public health contexts (Mason, 2006: 7). Articulating the broader ideological tensions surrounding the institutionalization of harm reduction practice, Smith (2008) asserts that

[p]rior to being institutionalized as public health policy following the AIDS epidemic of the 1980s, harm reduction originated as a clandestine practice that existed in direct political opposition to the prohibitionist principle of criminalization. In other words, harm reduction began as an ‘illegal’ activity where activists and politicized front-line public health workers acted in defiance of the law, risking sharp penalties for distributing drug using paraphernalia such as clean syringes, thus constituting a kind of social movement or activist practice (Roe 2005). Some critics have argued that as it was institutionalized, the practice of harm reduction became sanitized, its oppositional political origins obscured. Here, Roe notes a historic tension between “those who see harm reduction primarily as a medical means of promoting health and mitigating the harm to individuals”, and a more political, activist- oriented faction who see it as “a platform for broader and more structural social change” (2005: 244)... Roe argues that institutional harm reduction advocates engage in cooperation and collaboration with state bodies at the expense of ignoring or overlooking the fact that “the health problems they address are substantially created by the ideology of the systems in which they work” (2005: 245). The more activist-oriented, explicitly politicized proponents of harm reduction, by contrast, tend to see the notion of harm reduction as “a political and moral commitment to altering the material and social conditions of drug users” by placing emphasis on a structural critique involving a “political analysis of ‘risk’ and ‘harm’ as by-products of social, economic, racial or political inequality” (ibid) (p. 37-38).

7. Acknowledging What We Know: Reasons Behind the Lack of Peer-Driven Initiatives in Mental Health Research and Treatment

The reality in Ontario is that the majority of resources are devoted to the most intensive and institutional-based form of care, 20 years after the Graham Report recommended the opposite. The CSI Builder report calculates that the percentage of community-based mental health budget allocated to CSIs is a mere 2% (O'Hagan et al., 2009: 66). From this perspective, there are no reasonable excuses, given the body of evidence to date, to deny further consumer involvement in improving the mental health system.

In addition to the other barriers that PWLE of mental health issues and substance use have in common (i.e. stigma, lack of commitment, meaningful participation, past history of individuals, and tension of being a consumer/survivor while working with the system), the human resources strategy surrounding the introduction of PWLE into unionized environments is another potentially problematic issue. Even when clinical and community services express interest in hiring peer workers, there may be overarching labour agreements that prevent the direct hiring of part-time or casual non-unionized staff from which PWLE are likely to be drawn. However, as Moll et al. (2009 in press) describe, the use of seconded peer workers in integrated community settings can circumnavigate these issues. This model has the advantage of shoehorning well-trained and experienced peer workers into more formal settings, and provides benefit from instant expertise and in-house training. This evidence strongly suggests that such an HR policy deserves further investigation and investment.

8. Barriers and Challenges to Consumer Involvement Among PWLE of Substance Use:

Involving people with lived experience of substance use in research, policy-making, social support and treatment service delivery is not without significant challenges. While some challenges are rooted in larger structural / systemic forces such as the availability and accessibility of resources (i.e. funding), other challenges relate to the micro-economies of power that shape and inform street-level drug using communities (GLADA, 2005; Canadian HIV/AIDS Legal Network 2005; Toronto Harm Reduction Task Force, 2003; VANDU 2004). For the purpose of this report, challenges to the involvement of people with lived experience of substance use can be organized into six main themes:

i. Tensions surrounding institutionalization

Many harm reduction activists and advocates who identify as people with lived experience of substance use share a strong sense of distrust and wariness regarding institutional public health programming (Allman et al., 2006; Smith, 2008). More specifically, the institutionalization of harm

reduction and user involvement is perceived as being sanitized and depoliticized, with harm reduction being divorced from its explicitly political origins (Smith, 2008: 37-38).

ii. Funding and support

Canadian research regarding peer networking for the reduction of drug related harm concluded that funding was seen as one of the primary issues prohibiting the establishment, development and growth of peer-based networks. While government funding was seen as a potential solution, there was significant distrust of government bodies by a faction of the user community (Allman et al. 2006: 406).

iii. Stigmatization and criminalization

Stigmatization and criminalization are systemic barriers to active participation. These issues also “impede effective public health responses to problematic substance abuse” (Canadian HIV/AIDS Legal Network, 2005: 5). Research has also identified the potential for stigma to be projected onto peer work. This can be overcome by a given agency by “talking openly about the possibility [of stigma], providing support and showing how much the peers are valued” (THRTEF, 2003: 20).

iv. Superficial consultation, or ‘tokenism’

People with lived experience of substance use are often highly wary of the potential for superficial, self-interested forms of consumer involvement on the part of agencies, in the form of ‘tokenism’. Moreover, “[t]he perceived rationale for drug user involvement in decision-making processes was essentially the ethical premise that users should have the right to be involved in the decisions effecting their lives” (GLADA, 2005: 7). This points to a pattern of *inoculation*, where research and service delivery institutions accommodate superficial forms of user involvement in order to protect themselves from critique by appearing to be ‘progressive’ and ‘ethically responsible’ (Smith, 2008). Interviews with drug user activists and advocates in the U.K. revealed the widespread belief that peer/consumer involvement “needed to go beyond being consulted in a tokenistic way [and] towards being more active in influencing decisions and policies” (GLADA 2005: 7, 29). In general terms, emphasis was placed on how it was necessary to shift the involvement of people with lived experience of substance use— more specifically the relationship between service providers and service users— from ‘tokenism’ to power sharing (GLADA, 2005: 29).

v. Equitable involvement across the policy spectrum

People with direct experience of substance use must be consulted and engaged across the landscapes of politics and policy. From this perspective, increasing the involvement of PWLE must be accomplished in a responsible and balanced manner involving a range of different forms and capacities, including “consultative processes [...], decision-making or policy-making bodies and advisory structures dealing with issues relating to HIV/AIDS, HCV, and illegal drugs” (Canadian HIV/AIDS Legal Network, 2005: 6).

vi. Boundaries and ethical issues

Peer/consumer involvement among people with lived experience of substance use presents unique boundary issues as peers “attempt to live and work in the same environment” (Mason, 2006: 6). The everyday realities of user involvement in the form of peer support work for example, involves a delicate balance of identity and responsibility, opening up a host of boundary issues and other ethical considerations. Boundary issues are thought to be especially acute with regard to peer work, owing to the fact that peers must “walk the finest line between ‘helper’ and ‘client’” (THRTF, 2003: 36).

9. Recommendations for Increasing Consumer Involvement Among PWLE in Mental Health and Addiction Policy / Research / Treatment

Above and beyond addressing systemic barriers such as stigmatization and criminalization, the most valuable and significant means of increasing the involvement of people with lived experience of substance use is through the establishment of organizations of people who use drugs, such as the Vancouver Area Network of Drug Users (VANDU). Defining *intravention* as “prevention activities that are conducted by and sustained through ongoing actions of members of communities-at-risk”, Friedman et al. (2004) suggest that further research is necessary in order to understand how to “create and diffuse” *communities of intravention*.

While there is an established tradition of user-run organizations in Europe, Scandinavia and Australia, (Friedman et al, 2004), the Canadian case represents a series of curious contradictions, particularly in the context of Ontario, which has little history of coherent, organized user-led advocacy or activism (Smith, 2008).

In spite of the Toronto Drug Strategy’s recommendation to “support the development of a ‘drug users group’ to undertake a range of activities, including advocacy for the rights of people who use illegal drugs, harm reduction initiatives, education, community development and consumer representation”, there has

been no government funding or support of any kind to execute this recommendation (City of Toronto, 2005: 55). Drug user groups have a long and active history in Europe and Australia, and these groups can provide a model for the establishment of similar organizations in Ontario. Although both British Columbia and Alberta have prominent, provincially funded user-led organizations, Ontario has fallen behind in supporting the establishment and development of similar advocacy groups among PWLE of substance use. In order to correct this balance, the allocation of core funding and support for an autonomous user-run organization in Ontario is of paramount importance.

Given these factors, the most significant and immediate means of increasing consumer/peer involvement among people with lived experience of substance use in the province of Ontario is therefore the establishment of a provincial drug user organization. Ideally, the establishment of such an organization should be guided by several key mandates, including “explicit recognition by Health Canada and the Public Health Agency of Canada, as well as by provincial/territorial and local governments, of the unique value of organizations of people who use illegal drugs; funding and capacity building initiatives for existing and new groups of people who use drugs; support for innovative and/or model projects and programs of groups of people who use drugs; and funding of a national group or network of people who use drugs” (Canadian HIV/AIDS Legal Network, 2005: 6).

Research in the U.K. context identified several key stages and components in the development of a user involvement strategy. In this model, the development of a user involvement strategy was expressed as a series of steps that could be adapted to local needs.

The first set of five steps is concerned with the *preparation* stages: they include mapping current user involvement; conducting awareness raising activities; securing buy-in from stakeholders; identifying a budget; and training. The second set of five steps applies to the *implementation* and *delivery* of the strategy: they include agreeing upon the plan (i.e. aims/objectives); action planning; agreeing upon structures and lines of accountability; implementation; and review. (GLADA, 2005: 22-23).

Given the networking skills inherent in the everyday lives of people with lived experience of substance use, Canadian research suggests that increasing user involvement can be accomplished by “discovering the networks that already exist and building on them” (Allman et al., 2006: 405).

"The Toronto Drug Users Union (TDUU), founded in 2008, consists of a membership base of people who use illicit drugs or those who use drugs illicitly. Our mandate is to be recognized as valued and valid participants in the development of policies and programs that affect our everyday lives. The vast majority of institutional user involvement in Ontario is tokenistic, superficial and in some cases even perpetuates the profound and persistent stigma surrounding people who use illicit drugs. In the absence of any formal means of funding or support, TDUU was established in the tradition of autonomous, user-led, user-governed organizations throughout the world, in hopes of inspiring increased capacity, consultation and user involvement in all areas, including research, policy development and treatment service delivery for people who use drugs. While there is a strong history of institutional, government support for user-run organizations in other parts of Canada (namely B.C. and Alberta), in Ontario there is a conspicuous lack of core support, funding and resources allocated to developing such initiatives. TDUU strives to correct this balance by re-establishing an independent voice for drug users throughout Ontario through capacity-building, skills development and empowerment projects, and hopes to inspire increased equitable partnerships."

(Zoe Dodd, Hepatitis C Peer Educator and Training Coordinator, South Riverdale Community Health Centre, Toronto and founding member of TDUU, personal communication)

The CSI Builder Report contains an extensive series of recommendations, and while all of the recommendations contained in the report are directly relevant to the context of this evidence paper, three citations are particularly salient, having broader implications beyond consumer/survivor initiatives and peer support organizations (O'Hagan et al., 2009: 47–50):

a) *2.4 Produce guidelines for LHINs and Health Service Providers on their relationships with CSIs, including:*

- *Protecting and restoring CSI organizational autonomy*
- *The development of MOUs for absorbed CSIs*
- *Sub-contracting CSI peer workers to work in mainstream services*
- *Understanding confidentiality issues within CSIs*

The evidence base suggests that with the variance of CSI governance models, the undertaking of establishing best practices will be difficult to reconcile with the LHINs focus on integration of independent organizations into networks within the mental health and addiction sector. Given that the most positive outcomes in consumer involvement are linked to self-governance, autonomy, and control by PWLE due caution is advisable (Doughty and Tse, 2005).

Extending the established evidence-based best practices throughout the field can be first accomplished by proactively addressing the issues of autonomy, organizational boundaries, and confidentiality in other areas of the mental health sector which employ self-identified consumer/survivors and peer support workers.

- b) *4.2 Promote CSI values, standards and measures through guidance on CSI strategy, planning, programming, funding applications and empowerment of members.*

As the evidence base clearly indicates, the importance of consumer-driven values cannot be understated. In this sense, consumer-led initiatives facilitate and give rise to new and innovative forms of ‘care’, with a focus on not only on preventing self-harm, but from the real possibility of being further harmed by invasive care. Over time, this would lead to a diminution of the practice of resorting to intensive and costly resources such as long-term hospitalization and emergency room use. These alternate levels of support represent a more appealing wellness and recovery-based approach to mental health that is infused by the value of hope. If this consumer-centred vision is supported and advocated by independent provincial infrastructure consumer/survivor organization(s), the overall healthcare system and its outcomes for Ontarians will be strengthened.

- c) *5.3 Develop curricula, standards, advice on educational accommodations and affordable opportunities for the education and possible credentialing for all CSI workforce roles.*

In assessing the integrated nature of the New Zealand human resources strategy surrounding service user roles in mental health and addictions, the parallel investment in education and training for future peer employees is clearly fundamental to the long-term success of a wellness-based, person-centred, recovery-driven system for mental health consumers. The same lesson is already being applied in a limited extent in Ontario, as individual peer organizations have taken on WRAP (Wellness Recovery Action Plan) and other forms of self-directed care training, and the Ontario Peer Development Initiative (OPDI) has embarked on the creation of a provincial Peer Support Toolkit. However, more inclusive partnerships between mental health service providers and CSIs, as well as the internal restructuring of these services themselves, have the potential to steer system realignment over time from a passive perspective of chronic illness to a proactive expectation of maintaining wellness. Here, the issue of collaborative autonomy bears reiteration, where the collective body of knowledge about peer support by the people who created peer support must necessarily be owned by consumer/survivors, because individual self-determination goes hand-in-hand with the understanding that “by helping each other, we help ourselves”.

Conclusion

The evidence base reviewed in this paper strongly asserts the overwhelming value and benefits of engaging people with lived experience and the potential for further integration and application of peer/consumer involvement when conducted in innovative, respectful, equitable, collaborative partnerships with service providers and the larger health care system. While in other parts of the world, mental health and addiction policy has adopted bold and innovative new paradigms and approaches with an explicit focus on the direct involvement of people with lived experience, the unfortunate reality is that in the context of Ontario, peer/consumer involvement has been highly limited, due to continuing stigma, a lack of core funding and support, and systemic social inequities.

In conclusion, the co-authors of this report wish to return to two notions introduced earlier in this paper. First, *collaborative autonomy* is a necessary precondition for any future policy interventions which truly aspire toward equality and dignity, reflective of the experiential knowledge derived from people with lived experience. Owing to the historical subordination and stigmatization of service users, whether in 'mental health' or 'addictions', the notion of *autonomy* is central to restoring equilibrium in the power balance between service users and providers. Here, the establishment, development and enhancement of autonomous peer/consumer-run organizations can serve to reintroduce the voices of service users in all aspects of the policies and programs that affect their everyday lives, voices that have been silenced, overlooked and unacknowledged for too long by systemic barriers and persistent social stigmas.

Collaborative autonomy only becomes possible through fundamental systemic restructuring, for example in the proven success of resource reallocation toward peer/consumer involvement initiatives. As demonstrated time and again in the progressive initiatives featured throughout this evidence paper, collaborative autonomy is integral to forming, developing and sustaining equitable, inter-professional partnerships between people with lived experience of substance use and mental health issues and the larger health care system.

From this perspective, the second key trope that emerged from this research, that of *indigenous inclusivity*, must be seen as an ethical, human rights and public health imperative, as encapsulated in the Canadian HIV/AIDS Legal Network's (2005) mantra, '*nothing about us, without us*'. Any health care intervention that strives towards *equity* must therefore work towards *inclusivity* by overcoming the stigmas associated with people with lived experience of substance use and mental health, and forming partnerships with those who are indigenous to the communities that such interventions claim to target and represent.

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**Literature Review of People with Lived Experience
in Substance Use**

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Bibliographic Citation	Description	Findings Relevant to Peer/Consumer Involvement Re. Addiction Research, Policy and Treatment
<p>Allman, D., Myers, T., Schellenberg, J. Strike, C., Cockerill, R., Cavalieri, W. (2006) Peer networking for the reduction of drug-related harm. <i>International Journal of Drug Policy</i> 17: 402-410.</p>	<p>Based on data collected through a web-based survey of almost 900 stakeholders prior to Canada's first National Harm Reduction Conference, "[p]eer based networks for the reduction of drug-related harm were seen to allow for the consolidation and sharing of information, skills and understandings".</p>	<ul style="list-style-type: none"> • "While the literature suggests networking for people who use drugs may be challenged by community context and social structure, findings suggest in Canada some harm minimizing subcultural change has, and can continue to occur, as a result of peer networking activities" • "Whether structurally envisioned as multiple interwoven communities, or one single community, facilitating interaction between people who use drugs to aid harm minimization, can benefit from a grassroots approach, one which values the relevance and utility of peer support in tandem with community development" • important to consider the diversity of drug user communities; therefore difficult to subsume all drug users into once single community • "while social networks of drug users can function as generators of harm, networks which share health and social care information and build social support can function to oppose the risks of drug-related harm" • regarding current peer networks such as VANDU (Vancouver Area Network of rug Users), respondents suggested that "[t]o get a really good network happening, it was believed, was not so much a question of creating a network but rather discovering the networks that already exist and building on them" (405) • survey participants suggested building upon existing formal and informal networks of drug users; here, people who use drugs were already seen as possessing certain networking skills (as demonstrated in the procurement of drugs), leading to the belief that the best place to start developing peer networks was to help users "bring these skills above ground". • "Peer based approaches were seen to complement rather than replace existing user networks. Creating effective peer-driven networks was be enhanced by strong input from established organizations such as needle exchange programs" (405) • funding was seen as one of the primary issues prohibiting the establishment, development and growth of peer-based networks; government funding was seen as a potential solution, although there was significant distrust of government bodies by a faction of the user community • dispersed geography and community diversity were cited as two reasons in support of developing electronic networking infrastructure • <i>Challenges:</i> "information-sharing networks could result in people using more drugs"; lack of organizational skills to sustain networks; resistance from the larger society; diversity of user communities leads to difficulties finding common objectives • "<i>peer</i>-based approaches to the reduction of drug-related harm are seen to embody a particularly community-based response to the need for education, prevention and harm minimization programmes—a form of response that is inclusive of the socially marginalized while promoting health" (409)

<p>Canadian HIV/AIDS Legal Network (2005) <i>Nothing about us without us; Greater, Meaningful Involvement of People Who Use Illegal Drugs: A Public Health, Ethical, and Human Rights Imperative</i>. Toronto: Canadian HIV/AIDS Legal Network.</p>	<p>A critical examination of the public health, ethnical and human rights imperatives regarding the involvement of "people who use drugs in the programs and services that affect their lives, as well as in broader policy and advocacy work on HIV/AIDS and HCV" (3).</p>	<p><i>Why is greater involvement of people who use drugs needed?</i></p> <ul style="list-style-type: none"> • Fulfilling the commitment to greater involvement of people living with HIV: because people who use drugs represent a significant fraction of those who contract HIV, "governments and organizations can no longer claim that they involve people with HIV adequately in their work on HIV/AIDS without meaningfully involving one of the most marginalized groups living with, or at great risk for, HIV" • Public health imperatives: "People who use drugs themselves are often best able to identify what works in a community that others know little about; they need to be involved if we want to create effective responses to the epidemic... People who use drugs have demonstrated they can organize themselves and make valuable contributions to their community, including: expanding the reach and effectiveness of HIV prevention and harm reduction services by making contact with those at greatest risk; providing much needed care and support; and advocating for their rights and the recognition of their dignity" • Ethical and human rights imperatives: "As an ethical principle, all people should have the right to be involved in the decisions affecting their lives"; consistent with UN General Assembly's <i>Declaration of Commitment on HIV/AIDS</i> and the <i>UN International Guidelines on HIV/AIDS and Human Rights</i>. <p><i>What needs to be done to increase involvement?</i></p> <ul style="list-style-type: none"> • Addressing systemic barriers to greater involvement of people who use drugs: stigmatization and criminalization create barriers to involvement and "impede effective public health responses to problematic substance use" • Organization of people who use drugs: organized user networks such as VANDU can "make a unique and vital contribution and play an important role in preventing the spread of bloodborne infections, in particular HIV, and in advancing the rights of people who use drugs"; necessity of supporting user organizations through recognition by Health Canada; need to increase funding and capacity building; establish funding for a national users group • Involvement of people who use drugs in consultations, decision-making or policy-making bodies, and advisory structures: "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 relating to HIV/AIDS, HCV, and illegal drugs" <p>*** Do's and Don'ts (p.15-16) *** "<i>Nothing About Us Without Us</i>": <i>A manifesto by people who use illegal drugs</i> (p. 19-21)</p>
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<p>Coyle SL, Needle RH, Normand J. (1998) Outreach-based HIV prevention for injecting drug users: A review of published outcome data. <i>Public Health Reports</i> 113: 19-30.</p>	<p>Based on a computerized literature search regarding outreach-based interventions in HIV-related risk behaviours among injection drug users. Two thirds of the 36 publications reviewed revealed that participation in street-based outreach interventions was followed with office-based HIV testing and counselling". In the context of this article, 'community outreach' is defined as being reliant on "peers and indigenous workers to identify out of treatment IDUs and initiate appropriate education and support" (20)</p>	<ul style="list-style-type: none"> • The majority of published literature demonstrated that "IDUs in a variety of places and time periods changed their baseline drug-related and sex-related risk behaviours following their participation in an outreach-based HIV risk reduction intervention • Most studies also pointed to "significant intervention effects in promoting entry into drug treatment and increasing needle disinfection" • The literature review discovered that peer-run community outreach efforts led to IDUs regularly reporting "significant follow-up reductions in drug injection, multiperson reuse of syringes and needles, multiperson reuse of other injection equipment (cookers, cotton, rinse water), and crack use" (20) • In conclusion, the article suggests that most published literature "strongly indicate that outreach-based interventions have been effective in reaching out-of-treatment IDUs, providing the means for behavioural change and inducing behaviour change in the desired direction" (20)
<p>Friedman, Samuel R., aslow, Carey, Bolyard, Melissa, Sandoval, Milagros, Mateu-Gelabert, Pedro, Neraigue, Alan (2004) Urging others to be healthy: 'Intravention' by injection drug users as a community prevention goal. <i>AIDS Education and Prevention</i> 16(3): 250-263.</p>	<p>In this article, <i>intravention</i> is defined as "prevention activities that are conducted by and sustained through ongoing actions of members of communities-at-risk". Based on data drawn from 120 IDUs in Brooklyn where HIV prevalence rates in that community declined significantly, this article calls for further research into the question of "how to create and diffuse" peer-based <i>communities of intravention</i>.</p>	<ul style="list-style-type: none"> • Contrary to the vast majority of research regarding addiction and drug users, which focuses on the "dysfunctional behaviours and personal attributes" of IDUs, the theoretical position of this paper is based on users' autonomous drive for self-care. While most research regressively investigates "how psychological traits of drug users and chemical traits of drugs lead to addiction and related problems", this article argues that this approach "by personalizing and medicalizing drug use and its associated problems, can lead to underestimating or even ignoring the ability of drug users to act collectively and respond to the dangers of the HIV epidemic as well as to other harms that threaten drug users. • In contrast to popular perceptions, research on IDUs during the HIV/AIDS epidemic "has in many ways shown that drug injectors can and do react to HIV and other threats rationally and effectively. For example, drug users have publically formed formal organizations in many countries, including the Netherlands, Denmark, Great Britain, Australia and Canada to represent and act on behalf of their interests and to conduct HIV and HCV risk reduction programs" (252)

Kerr, Thomas, et al. (2006) Harm reduction by a 'user-run' organization: A case study of the Vancouver Area Network of Drug Users (VANDU). *International Journal of Drug Policy* 17(2): 61-69. (1/2)

Given the “growing interest in drug user organizations” this article represents a community-based case study of the “genesis, structure and activities” of the Vancouver Area Network of Drug Users (VANDU), formed in 1997. Findings reveal that tireless activism, advocacy and public education has allowed VANDU to persistently voice “the concerns of drug users in public and political arenas”. The findings demonstrate that through years of activism, advocacy, and public education, VANDU has repeatedly voiced “the concerns of drugs users in public and political arenas”, performing a “critical public health function by providing care and support programmes that are responsive to immediate needs of their peers”. The report therefore concludes that “greater efforts should be made to promote the formation of drug user organizations” by exploring “novel methods for incorporating the activities of drug user organizations within existing public health, education, and policy making frameworks”.

- The vast majority of institutional services designed to meet the needs of IDU in Vancouver’s DTES operate under the highly limited ‘provider-client’ model, which has been critiqued based on “the difficulty that service providers have in reaching drug users on their own turf, difficult communication between providers and clients, and fear among drug users that use of services may alert police to their activities”
- This project was based on a community-based case study methodology, “in accordance with VANDU philosophy and members’ demands that all projects directly involve them”.
- The founding of VANDU was driven by the groups belief in “the importance of making public the suffering within the community”; As one founder stated, “There are so many institutions that privatize pain and keep it hidden, whether it is the psychiatrist’s office, the mental health system, or bars. Facilitating the public expression of pain was the most subversive thing we could do.”

Governance, Membership and Guiding Principles:

- VANDU’s constitution articulates two forms of group membership or affiliation, involving both *full* membership, “reserved for people who report using or formerly using illicit drugs intravenously” and *supporting* membership, “given to any person who has not formerly used illicit drugs”; while full members can both express views and vote at all meetings, supporting members can express their views but not vote.

Themes regarding the guiding principles of VANDU:

- (1) “the organization tries to be inclusive of all current and former drug users”; (2) “the organization is user-driven and makes all organizational decisions”; (3) “VANDU employs a peer mentorship policy that involves pairing someone who has skills in a particular area with someone who is interested in acquiring those skills”

Advocacy, activism and public education:

- “Some of the earliest work of VANDU focused on political activism and advocacy... the early organizers worked to bring the ‘voice of users’ into mainstream political discourse”; VANDU’s activist initiatives included public demonstrations, political disruptions, etc.
- “VANDU has, after years of activism, gained increasing recognition in the local community”; as one member stated, “If anything is happening, it seems that it is probably going to need VANDU’s okay. VANDU is always at the table”

Community care and support activities:

- VANDU has developed and implemented several member-led community education and harm reduction initiatives, including **education** specific to groups living with hepatitis C, people on methadone, women living with HIV, etc.; **Alley patrol**, in recognition of the “reluctance of many service providers to venture into alley-ways”; **Syringe exchange and recovery**, including the establishment of an unsanctioned, peer-run NEP in the heart of Vancouver’s open drug scene, as a response to the documented difficulties of syringe access during evening hours; a **Hospital program**, where volunteers “make regular visits to hospitalized drug users for the purpose of providing support and encouraging them to stay in hospital”; and **Peer support and advocacy**, involving helping other with “negotiating bureaucracies, completing applications, and overcoming legal hurdles... programme recipients emphasized the value they receive from peers, as peers are deemed to be the most knowledgeable about the experiences of drug users”

Kerr, Thomas, et al. (2006) Harm reduction by a 'user-run' organization: A case study of the Vancouver Area Network of Drug Users (VANDU). *International Journal of Drug Policy* 17(2): 61-69. (2/2)

Given the "growing interest in drug user organizations" this article represents a community-based case study of the "genesis, structure and activities" of the Vancouver Area Network of Drug Users (VANDU), formed in 1997. Findings reveal that tireless activism, advocacy and public education has allowed VANDU to persistently voice "the concerns of drug users in public and political arenas". The findings demonstrate that through years of activism, advocacy, and public education, VANDU has repeatedly voiced "the concerns of drugs users in public and political arenas", performing a "critical public health function by providing care and support programmes that are responsive to immediate needs of their peers". The report therefore concludes that "greater efforts should be made to promote the formation of drug user organizations" by exploring "novel methods for incorporating the activities of drug user organizations within existing public health, education, and policy making frameworks".

Broad spectrum of involvement:

- VANDU was noted by policy makers to engage in a broad spectrum of political and public commitments: "The beauty of VANDU is that it covers a lot of ground, from providing a place for the mentally ill drug user totally whacked out at a meeting to high level political activities on national committees"

Conclusions:

- "VANDU "demonstrated that drug users can organize themselves and make valuable contributions to their community ... Like many of the more powerful responses to the AIDS epidemic which were not based on expert-driven interventions but on mobilizing effected communities to resist oppression, VANDU has repeatedly voiced the concerns of drug users in public and political arenas, garnered political support, and performed a critical educational function by bringing outsiders face to face with the realities of Vancouver's DTES. VANDU has also engaged in activism that has focused public attention on the drug using community and ensured that drug users are more involved in decisions that affect them.
- "By virtue of its method of peer consultation, VANDU has often operated a step ahead of local health authorities who aim to monitor and respond to priority health issues ... it is clear that VANDU has addressed gaps in local public health efforts ... [and] also extended the reach of public health efforts by contacting drug users who may not be well served by traditional service delivery, and appears to be providing support that is more accessible for and acceptable to their peers"
- "drug user organizations have much to contribute to their immediate community and the community at large ... [and] greater efforts should be made to promote the formation of drug user organizations, and that health and policymakers should explore novel methods for incorporating the activities of drug user organizations within existing public health, education and policy making frameworks"

Latkin,C.A. (1998) Outreach in natural settings: The use of peer leaders for HIV prevention among injecting drug users' networks. *Public Health Reports*; 113(Suppl 1): 151-159.

In this study, HIV prevention promotion training was conducted among 36 Baltimore IDU peer leaders. Following training, the peer leaders reported a significant increase in condom use and the cleaning of used syringes with bleach. Correspondingly, the members of the leaders' risk network were "significantly more likely to report greater needle hygiene". "The results from this study suggest that, in the IDU community, training peer leaders as HIV educators may promote HIV prevention among the leaders' risk network members and others at risk of acquiring and transmitting HIV."

- "There is ample evidence that HIV risk behaviours among injection drug users (IDUs) are influenced by social factors... HIV prevention interventions have typically focused on the individual, often ignoring social determinants of HIV risk behaviours"
- "Although several studies suggest that street outreach is effective in reducing risk behaviours, some researchers have found that outreach is more effective for individuals who are at lower risk for HIV... despite the development of innovative outreach strategies, the full potential of outreach programs has not been realized."
- "In the present study, IDUs were recruited and trained to educate and influence their drug and sex network members about HIV-related behaviours... A secondary goal of the study was to provide a positive identity or role, for the peer leader, as health educator to individuals who were of low socio-economic status and often unemployed and who often has strained family relationships."
- **Peer Leaders:** Between baseline and follow-up, the leaders reported a significant increase in condom use (df= 24, t=3.38, P <0.01)... At baseline, there was no difference between the leaders and controls in self-reports of always cleaning used needles with bleach before injecting in the prior six months (16% vs. 17%). At follow-up, however, there was a highly significant difference, with 59% of the leaders and only 23% of the controls reporting that they always cleaned used needles with bleach before injecting ($X^2 = 14.25$, $P < 0.001$)
- **Risk Network Members:** "80% of the risk network members reported never sharing a needle without prior cleaning in the past six months, compared with 49% of the controls ($X^2=15.39$, $P<0.001$) Risk network members also were more likely than the ... study controls to report always cleaning used needles with bleach before injecting (41% vs. 17%, $X^2=13.24$, $p<0.001$). Eighty-six percent of the risk network members reported receiving written materials about HIV and AIDS in the prior two months, of whom 70% reported receiving the materials from the leaders. Of the 74% of the risk network members who reported receiving condoms in the prior two months, 58% reported receiving condoms from the leaders. Of the 65 risk network members who were current injectors, 92% reported receiving cleaning materials from the leaders" (155)
- "Although participants were not paid for conducting outreach, they remained enthusiastic about it. Participants reported several motives for conducting outreach. Both males and females reported that they were concerned about their community and children and other family members becoming infected with HIV. Another important motivational factor was the leaders' interest in maintaining their new status as an expert in HIV and other health-related issues ... Several participants stated that their outreach work altered their neighbors' and friends' perceptions of them and increased their respect among both drug users and nonusers"
- "The results of this study suggest that individuals identified as leaders among IDUs may be effective in promoting HIV prevention among their networks, drug users and other community members. There are several advantages to this approach. First, it may be more cost effective than traditional outreach... Second, peer leaders may have a greater influence than professionals on the HIV-related behaviours of friends, relatives and sex partners. Third, the leaders are able to access a diversity of settings, some not readily accessible to nonindigenous professional outreach workers, across a wide geographic area."

Martin, A. & P. Stenner (2004) Talking about drug use: what are we (and our participants) doing in qualitative research? *International Journal of Drug Policy* 15: 395–405.

"This paper considers the use of qualitative research in the drugs field ... Drugs research as both praxis and knowledge base may be seen as part of the machinery of advanced liberal government, which seeks to govern at a distance through the inscription of subjectivity. The drug user is produced and re-produced as a subject within research, always already positioned in relation to certain 'truths'. We need to conceive of qualitative research and what our participants tell us differently, such that the constructive and constructed nature of knowledge and talk becomes the focus of inquiry"

- "Rather than regress to one of the many forms of realism (scientific or otherwise) currently available, the challenge for poststructuralism is to engage with the full complexity of discursive mediation, including studies of the construction of reality specific to the social functions of law, economics, science, medicine, the mass media and so forth... Central to this is the recognition that in qualitative research we are dealing with complex forms of communication that both arise from and give rise to further communication. As such, our participants must be affirmed simultaneously as meaning-making beings and as beings who are made by meanings. These discursive activities are inseparable from relations of power. Our participants are—whether we are aware of it or not—reflexively aware of the ways in which they are constructed in the communications of others, and generate their own constructions accordingly ... any policy intervention is always also an intervention into these complex dynamics of discursively mediated mutual recognition." (403)

Mason, Kate (2006) *Best Practices in Harm Reduction Peer Projects*. Toronto: Street Health.

(1/3)

This report represents a review of literature regarding harm reduction peer projects, "based on a review of the literature and interviews with harm reduction practitioners across Canada" Additionally, the report "identifies challenges to developing and maintaining peer projects, the key factors influencing the success of these initiatives, and makes a series of best practice recommendations for service providers, policy makers and funders" (3).

- "Peer Education is often used as an umbrella term to describe a range of approaches that engage members of a particular target group in delivering health promotion initiatives to their peers... It is based on the belief that peers can be more successful than professionals in passing on information and sharing knowledge. **While peer education is often a passive process in which health professionals use members of the community to deliver professionally designed health education interventions, it can also refer to more participatory forms of engagement whereby community members not only deliver, but also develop responses to health and social issues"** (4)

Barriers and Challenges to Peer Programs:

- Who is a peer? There is the potential for conflicts to arise regarding the question of defining and qualifying the notion of 'peer', since "defining what makes someone a peer or whether or not to use the term has financial and social implications".
- Stigma: Persistent social stigma regarding drug use and dependence can result in peers being used as scapegoats in instances of conflict in the agency context.
- Boundaries: Living and working in the same environment carries unique challenges involving the transition between different roles; "Remaining part of the drug-using community can also mean that peers are at risk for being retraumatized or triggered" (6).
- Drug use: Drug use itself was cited as an occasional challenge and/or impediment to peer work, resulting in unreliability, inconsistent levels of commitment, inefficiency (i.e. slowing things down) and frustration. Issues related to drug use, including imprisonment and health concerns, also contribute to the potential difficulties of peer work.
- Lack of agency commitment and integration: Lack of agency commitment to peer work and/or harm reduction (in some cases on moral grounds) identified as a significant challenge that serves to limit the amount of support allocated to peers and peer-driven projects. Additionally, in some cases peers are not treated as equal staff. The positioning and integration of peer programs within an individual agency is also an important issue of consideration
- Grassroots / Mainstream Trade-off: [institutionalization = depoliticization] Developing and implementing peer projects is seen as being more conducive in grassroots organizations, as opposed to larger mainstream institutions, where the persistence of political sensitivities and/or moral-criminological ideologies regarding the issue of drug use create an apolitical atmosphere that is not always receptive to progressive peer-driven initiatives, as they are perceived to be too radical. In other cases, however, there was the belief that being part of more mainstream organizations with a "certain amount of 'public health' capital, equating to better funding and staff support, along with strong networking potential with related social service organizations.
- Meaningful Participation: Levels of participation vary widely within organizations, from a high level of user representation and involvement throughout all aspects of programming, to little or none whatsoever. Barriers to peer participation that have been identified include "not having enough funding, not having enough time, and not being able to relinquish power and control" (7) [ALSO, issues of tokenism; superficial consultation, etc.]
- Constant Conflict: Conflict within the project; between users/peers; projected the surrounding community (i.e. local residents and businesspeople).
- Supervision: "Being the 'boss' and support person for peer workers at the same time was identified as a challenge for several participants. Walking the line between flexibility and not being able to tolerate when drug use interferes with work responsibilities was highlighted as an issue" (8).
- Legal Framework: Police as both potential barrier and facilitator to peer work, particularly harm reduction outreach. Punitive drug laws still serve as a challenge that users and peers need to navigate.

Mason, Kate (2006) *Best Practices in Harm Reduction Peer Projects*. Toronto: Street Health.

(2/3)

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Barriers and Challenges to Peer Programs (cont.):

- *Funding*: Funding was consistently cited as one of the most significant barriers to successful peer work, at both the project and peer levels, where peers were often seen to be "too often unpaid, underpaid, not paid for training, or not given benefits" (8)
- *Political Context*: For the past two decades critics have accused Canadian drug policy as embracing harm reduction in theory but not in practice. Under the federal conservative government, however, the notion of harm reduction has been written out of Canadian drug policy altogether with the release of the National Anti-Drug Strategy.

Successful Factors:

- *Program Design and Underpinnings*: adopting alternatives to the traditional client-provider model was cited as a key success factor in peer projects, including non-hierarchical or collective run models; Re-orienting services to truly reflect a 'client-centred' approach; ensure that harm reduction principles run through all aspects of project delivery with an emphasis on non-judgemental attitudes; Explicit programming emphasis on empowerment; Central importance of consulting peers first; Incorporate informal and inclusive service delivery models such as schedule drop-in hours.
- *The role of staff*: Success is dependant on the skills of staff members, including facilitation, personal dedication, and conflict management; Additionally, managing expectations and providing balance were seen as key staff roles.
- *Peer Support*: "[A]dequate and effective training for peers was critical to a successful project", with an emphasis on communication and counselling skills; Using peers to conduct training for other peers is seen as an ideal model; Open and respectful communication is of central importance, and adequate supervision and assessment of peers was cited as a critical factor of success; Projects that incorporate "practices that help to protect peers from the stigma of both drug use and peer work" are deemed to be most successful; taking care of peers' basic needs is of critical, fundamental importance, and "rewarding peers both financially and with a sense of accomplishment" was identified as a best practice (11).
- *Agency Environment*: "Where peer or harm reduction programs are situated within larger organizations, ensuring that the program is truly integrated into the broader work of the organization was identified by many as central for effective and sustainable peer work" (12); Central importance of having supportive leadership in the organization (i.e., 'buy-in' from above); "smaller, independent, or 'grassroots' settings better facilitate best practices in peer work"
- *Social Context*: Confronting program adversaries through public meetings, open dialogue and community outreach are important considerations in developing, maintaining and managing projects; Trying to forge a working relationship with law enforcement officials, including inviting cops to sit on community advisory board etc.; Partnerships with other agencies are seen as a significant strength in project operation.

Mason, Kate (2006) *Best Practices in Harm Reduction Peer Projects*. Toronto: Street Health.

(3/3)

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BEST PRACTICE RECOMMENDATIONS:

For Service Providers:

- The issue of Language: Using terms other than 'peer' can provide greater professional credibility and avoid stigma.
- Diversify Peer Participation: Employing a variety of peer positions, of varying threshold and commitment) allows users to try on different roles in order to find aptitudes and affinities.
- Involve Users in Delivery AND Design: Bringing peers (and clients) into project planning as soon as possible ensures relevance and buy-in from important stakeholders.
- Provide Flexible Boundaries and Clear Policies: Clear policies and discussion around the expectations and limits of boundaries needs to take place with peers and at the agency level.
- Educate Staff and Board re. Harm Reduction and Peer Involvement: "Ensuring that you have a genuine commitment from larger agency management will avoid conflicts and tension as projects are developed and maintained" (13)
- Consider ALL Implications of Peer Involvement: "Benefits to peer involvement have been documented at a societal, organizational and individual level" (13)
- Consider the Social Determinants of Health: "The provision of other services and social programs (including counselling, advocacy and referrals) has been cited as a key to success for harm reduction programs... Helping peers to secure housing, a health care provider providing food at meetings, providing transportation, etc., will enhance their capacity to do peer work" (13).
- Don't Forget Training (and Retraining): "Do not assume that lived experience is, in itself, sufficient to take on the task of harm reduction outreach, advocacy or other peer roles. Peer work will be more effective and peers will feel more confident when training suited to their particular job is provided."
- Target the Broader Community: Projects need to "move beyond individual and group level programming to programming to explore how the improvement of their broader community context can help reduce drug related risks and harms... Join forces with other groups in your community who are working to make society more equitable"
- Quality Over Quantity: The least tangible aspects of service are seen as being the most critical for program success, therefore it's "as much *how* you do it as what you do" (14).
- Make Friends With Your Funders: "Personalizing your work will build empathy, understanding and create allies"

For Funders and Policy-Makers:

- Projects Must be Adequately Resourced: "The value of peers and of harm reduction will never realize its full potential unless adequate financial support is provided.
- Funding cycles Need to be made sensitive to the realities of peer projects: "Funders must be sensitive to the fact that the lives of drug users are sometimes unpredictable ... and that timelines may be effected as a result"
- Peer Pay Equity: "Honorariums are not enough ... Peers should be recognized for the work they do and paid equally for work of equal value" (14).
- Create Supportive Policy: Policy mandates are required to ensure that drug users are actively involved in policy, planning and decision-making in their health and social care provision.

Orme, Judy and Starkey, Fenella
(1999) Peer drug education: the way
forward? *Health Education* 1: 8-16.

"This paper discusses issues relating to the effectiveness of peer drug education with particular reference to two evaluations carried out recently in South West England; brings together the most recent literature on peer education; and considers the appropriateness of different approaches in schools and youth work settings"

- There are varying contextual definitions of the term 'peer', generally pointing to "peers as people of equal status in the sense of equal experiences"
- "All peer drug education initiatives share a common characteristic: the communication of information concerning drugs and drug use by peers (of equal age and/or similar experiences) to others, with the aim of educating them" (9)
- In this project, the majority of peer educators reported skills development in five main areas, including "(1) interpersonal skills, including presentation and feedback skills, leadership skills and assertiveness. An increase in self-confidence and confidence working with other people as a result of the project was cited by many of the peer educators; (2) increased knowledge about drugs and alcohol; (3) increased awareness of harm minimization issues, and the importance of providing accurate and balanced information; (4) groupwork skills, including working and talking in a group; (5) task completion, including working to deadlines, organizing themselves, planning, decision making and reliability"
- Findings in this study revealed several common assumptions regarding peer education, including "that peers are more credible than traditional authority figures; that peer education is an empowering process for those involved; that by tapping into the naturally occurring process of peer group information sharing and learning, peer education is also able to communicate drug education messages in a way which coincides with the value system and cultural norms of the peer group involved; that peer education is a more cost-effective method than other drug education approaches"
- "The most common argument used to justify the use of peer education as a drug education method is that peers are more credible than traditional authority figures such as teachers and police officers." However, "If the message being conveyed by a younger peer educator is perceived by other young people as being similar to that of a traditional 'adult' message (e.g. 'just say no'), or if the young peer educator involved is viewed as inexperienced and naive in relation to drug use, it is possible that this will reduce the impact of such peer drug education on the intended audience."
- "It could be argued that if young people are merely delivering messages agreed by adults, this is not necessarily peer education"
- If one of the assumption is that peer education taps into naturally occurring processes of information sharing and support between young people, it could be argued that the peer education model used must be informal enough to allow such processes to continue" (14)
- "While peer education seems to have potential as a drug education method, the research literature suggests that there is often an inadequate theoretical basis for peer education, for example in terms of its aims and methods, and inadequate consideration of key issues such as what constitutes a peer, particularly a credible peer. If peer education projects are to avoid some of the pitfalls highlighted, they should be: carefully set up, including the way peer educators are selected; thought through in terms of what they are trying to achieve and what messages they are trying to convey; and properly supported with training for peer educators and referral systems" (15)

Perry, Sara and Reist, Dan (2006)
Words, Values, and Canadians: A Report on the Dialogue at the National Symposium on Language. Victoria: Centre for Addictions Research of B.C.

Specific language and terms relating to drug use, users and dependence “may lend power to some persons while stigmatizing others; they may facilitate certain forms of public response to drug issues while hindering others; and they may enable particular individuals to communicate intelligibly together while leaving others uninvolved and arguably excluded” (1). This report constitutes a summary of the *National Symposium on Language*, a “dialogue on issues of language related to substance use”.

- “ultimately, everyone is using language to serve interests and establish some form of advantage. For example, certain people who use substances might call themselves ‘junkies’ in an effort to empower themselves, while the media might do the same in order to disempower ... To call oneself a ‘junkie’ may be a liberating experience, but it also has the potential to be an act of self-depreciation that internalises the very stereotypes and inequalities that we seek to dismantle ... While power relations will always be present in our discourses, we need mechanisms to create common frames within which to situate our various dialects” (2)
- On standardizing drug discourse/terminology: “Different people need to express themselves in different ways. Rather than seek to deny or eliminate these dialects, we need to encourage awareness of our linguistic diversity ... we actually do not have *enough* linguistic diversity around some of our substance-related issues (e.g. how we talk about people who use *illegal* drugs). This has contributed to a very limited and uninformed discourse.” (3)

MULTI-DIMENSIONAL CONTINUUMS

- “Recognition of the complex continuums of drugs and drug use is needed, with a commitment to addressing the full extent of each continuum without privileging one end over the other” (4)
- In order to address the specific contexts in which drug use is associated with harm, it is necessary to extend “our language of harm to address larger matters behind the substance use continua, including housing, nutrition, literacy, equity, justice, education and income security” (4)

LOCATING OUR IDEOLOGIES

- “It is our responsibility to ‘own’ our position— that is, to identify, up front, our point of view and how this point of view shapes or justifies the opinions, facts, narratives/agendas that we put forth ... [therefore] our ideologies should be made explicit, thereby giving others an opportunity to respond knowledgeably to their implications” (4)
- “Silence and fear of speaking forthrightly about drugs (including about their positive effects) inhibit the exploration of new and alternative responses to substance use issues... Our poverty of language is killing us”
- Recommendation #1: Use simple, general language whenever possible (“Efforts should be made to use common language and avoid the creation or use of technical terms or jargon that tend to be owned by particular interest groups”)
- Recommendation #2: Include a ‘glossary’ in all written documents intended for broad distribution (“Glossaries of terms should be added to printed documents to ensure clarity of meaning around specific or technical terminology, and to thereby facilitate understanding”)
- Recommendation #3: Articulate the cost-benefit nature of both substance use and our language choices (“By expressing awareness of how our substance use and our related discourse are inherently connected to beliefs and decisions about benefits or harms, the *Framework* documents could help set a context in which meaningful dialogue can take place”)
- Recommendation #4: Use language that is consistent with the common theme identified at the national symposium on language (“Greater emphasis needs to be placed on articulating these common themes and linking them, within public discourse, to issues related to substance use”).

Street Health (2007) *The Crack Users Project: A Manual*. Toronto: Street Health.

The Crack Users Project (CUP) is a "capacity-building initiative" with the aim of "reducing the harms associated with the use of crack cocaine among users in southeast downtown Toronto. Developed by Street Health, a community-based health care organization, the objectives of the CUP project included "increase[ing] communication with and among crack marginalized crack users; build[ing] capacity among crack users to develop and implement peer-led, crack-specific harm reduction strategies; and to improve access to physical and mental health services for this group". This manual was prepared in order to share experiences and lessons learned from the CUP project in order to "provide other community-based organizations who are working with marginalized drug users with a starting place from which to replicate this project" (2)

- " In 2005, Street Health conducted a needs assessment to find out if crack users were interested in crack-specific programming and, if so, what type of programs they would like to see in their neighbourhood. Crack users told Street Health that they wanted crack-specific, harm reduction information; that they wanted to learn from their peers and they wanted others to benefit from their own experiences and knowledge of harm reduction and crack use." (3)
- "For the most part, drop-ins are unstructured and simply provide a welcoming and non-judgmental space where crack users can come together, connect with each other and with service providers or other resources. Drop-ins are occasionally structured around informal discussions or activities of interest or relevance to participants. Drop-ins are **Peer-Led**. A member of the Street Health staff with past experience of crack use and homelessness manages the general drop-ins. This is an important component of the drop-in for CUP participants who have told us in evaluations how much they value having a stable peer attached to the project who can provide advice and information from a perspective of shared and similar experience"; *ALSO* women only drop in; membership cards create a sense of belonging; having food creates a warm and welcoming environment; harm reduction kits "act as a bridge that reconnects people with services again" (4)
- As part of the DROP-IN, a housing worker and community support worker are regular attendees, allowing participants to access key services in an informal, inviting, safe environment; Because the DROP-IN is held in a Community Health Centre (CHC), participants also have improved, 'barrier-reduced' access to primary health care, with two nurse practitioners and one registered nurse present during DROP-IN hours.
- Harm reduction training activities include Peer Outreach Training (which prepares participants to become peer outreach workers with specific content devoted to harm reduction, communication skills, sex work, HIV and HCV basics), Public Speaker Training, and Advanced Peer Training

BEST PRACTICES FOR HARM REDUCTION PROJECTS:

- Offer a variety of ways to get involved (of varying threshold and commitment); Get user input; Educate your board and staff about harm reduction and the value of peer work; Consider all the social determinants of health; Quality over quantity

Strike, Carol J., O'Grady, Caroline, Meyers, Ted, Millson, Margaret (2004) "Pushing the boundaries of outreach work: the case of needle exchange outreach programs in Canada. *Social Science and Medicine* 59: 209-219.

This article examines the "challenges of defining the boundaries of outreach work" through interviews with needle exchange program (NEP) outreach workers. Although not specifically devoted to the question of peer outreach, this article raises useful theoretical questions regarding the nature, challenges and 'boundaries' of outreach work among (injection) drug users, where "a variety of personal, social and socio-political forces encourage outreach workers to continually redefine the boundaries of their roles and service complements".

- "Drugs outreach work is diverse in terms of model (i.e., youth work, catching clients, self-help and public health), setting (i.e., street/community, homes and other organizations), objectives (i.e. abstinence or harm reduction) and the types of workers (i.e. professionals, peers and volunteers) who perform these services... [however] [r]egardless of the model, the goal of outreach is to bring workers and clients into contact" (209-210)
- "A core feature of outreach work is its highly unstructured and unpredictable nature... workers construct role boundaries that define the limits of what they will and will not do for clients. These boundaries help to provide structure to highly unstructured and unpredictable roles and define for clients what they can expect from the program" (212)
- "From the workers' perspective, doing too much for clients might be as detrimental as doing too little... From the workers' perspective, failure to define clear boundaries can create problems for clients and workers alike, particularly if clients become too dependent on the workers and/or become disillusioned with the needle exchange and stop using the service" (212)

SYMBOLIC AND PHYSICAL DISLOCATION FROM THE WORKPLACE:

- "Needles exchanges are often conceptualized to be separate entities within larger organizations ... due in part to the relative newness of the program for many organizations, their somewhat controversial identity and the stigma associated with their clients. As well, needle exchanges are often physically and socially disconnected from the parent organization"

CROSSING THE LINE:

- "According to workers, needle exchange work involves 'walking a fine line' between being a worker and being a friend... All workers go the extra-mile for clients but only a minority of workers (i.e. less than 10%) cross-the-line. Generally, these activities involve blurring the boundaries between private and professional lives, attempting to 'save' clients and engaging in illegal activities" (215)
- Formally expanding the definition of needle exchanges:
- "Pushing the boundaries of roles and programs is generally an informal process. However, several needle exchanges have formally expanded the definition of needle exchange work to include primary health care, methadone maintenance treatment and food and clothing banks."
- * "boundary crossing is sometimes necessary to improve the quality of service and this is clearly reflected in the efforts of outreach workers. However, this study shows that when workers push the margins, most do so with a clear idea of the limits of their roles"
- "The programmatic, contextual and/or social factors that influence boundaries are often overlooked. For example, poverty creates many needs among client groups which can in turn press on programmatic and interpersonal boundaries. Stigma can lead to exclusion from some social service settings and strain resources in other service settings. Needle exchange outreach work could be labelled as ad hoc case management because these activities are undertaken informally and in an unstructured manner. Generally, case management involves activities such as client assessment, service planning, referral to other service providers, monitoring client progress and advocacy for clients. However, the case management nature of some outreach work is not formally recognized. As such, workers are not provided with training or supervision about case management but would greatly benefit from this type of support" (217)

Vancouver Area Network of Drug Users (2004) "Creating Vectors of Disease Prevention: Empowering Networks of Drug Users," Vancouver: VANDU. Available online at <http://www.vandu.org/reportsmedia.html> (1/3)

This article summarizes the lessons learned from Vancouver Area Network of Drug Users' (VANDU) *Capacity Building Project*. Employing Peer Network Enhancers to travel to drug user communities outside the Vancouver context, the primary objective of the *VANDU Capacity Building Project* was to "educate and organize drug users to take action in their community much as VANDU members have in the DTES of Vancouver" regarding the spread of diseases prevalent among IDU such as HIV/AIDS and HCV.

- "drug users find each other and they find places to buy drugs quickly" regardless of where they are; this was recognized as a "remarkable networking skill" and " 'junkie' asset" and it was therefore believed that "public health interventions are wise to encourage these networks and use them to create networks of disease prevention"
- While "VANDU is seen as successful at pressuring government to open more appropriate harm reduction facilities ... [i]n other places in Canada, the voices of drug users have not been so clearly unified and heard"; Because of this imbalance, VANDU perceived itself as being "in a position to—even obligated to—move the agenda forward for drug users across Canada"
- The project was designed to "attract VANDU members who knew of communities where disease was spreading and who were willing to go to these communities as 'experts' in networking with users in their 'home' communities to build 'vectors of disease prevention'. These visiting VANDU members would educate and organize drug users to take action in their community much as VANDU members have done in the DTES of Vancouver"; Five regional committees were formed to engage communities across the country
- **Mission Statement:** "VANDU will use skilled peer educators from its membership to visit other communities across Canada with larger IDU populations to teach IDU's strategies to prevent the spread of Blood-Borne Pathogens (BBP). We will work to create several local networks of IDUs so that they can disseminate health promotion strategies and information amongst themselves. We will partner with local AIDS service organizations (ASO's) & other groups that provide HIV/AIDS and HCV prevention and support in order to increase their capacity to reach IDUs."
- The project succeeded beyond the initial objectives, visiting 10 cities across Canada to raise consciousness and encourage drug users to "expand their expectations of what they deserve from the health care system and their communities"; VANDU and it's local partners arranged for "users, health professionals, police and harm reduction service providers to participate in Community Forums to be conducted after key screenings in every community"
- The regional consultations revealed considerable differences between user communities across the country, although police harassment, social exclusion, and discrimination by the health care system were cited as common issues.
- One novel, peer-driven program that VANDU discovered was in Sydney, which uses a "natural' helper model where users who distribute needles and other harm reduction equipment carry business cards to show police if they are stopped and eyed with suspicion because of hanging around users and having many needles with them. This was an excellent way to begin to work with police and to educate them about harm reduction"
- Based on the findings from the regional consultations, VANDU discovered that it was "a mistake to assume that drug users in the DTES are the worst off", and that in spite of regional variation in local drug scenes, "people who use illegal drugs all across Canada are facing horrible odds; of getting Hep C and HIV, of having their children apprehended , of going to prison, of being illegally searched by the police, of being turned away from an emergency ward at a hospital, of living on less than \$200 / month, of smoking or injecting unknown poisons they bought as drugs on the illicit drug market, of being alienated from their family, of being denied pain medications, of being beaten or killed while selling sex to get money for drugs, of being ashamed and isolated even from other people who use illicit drugs and of dying of overdose. The conditions the marginalized drug users live in prohibit them getting organized without 'outside' facilitation and people who use illicit drugs who are not marginalized are unwise to 'out' themselves as hiding their drug use is often the reason they are not marginalized."

Vancouver Area Network of Drug Users (2004) "Creating Vectors of Disease Prevention: Empowering Networks of Drug Users," Vancouver: VANDU. Available online at <http://www.vandu.org/reportsmedia.html> (2/3)

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- **Why do we need user-run drug user groups?:** Harm reduction workers feel they are not in a position to actively politically lobby for safe injection sites, heroin prescription or even methadone programs or the funding to their own program may be cut or they may be fired. They worry that clients will not seek medical help for frighteningly serious abscesses for fear of losing their script for opiates and they fork over personal money so a sick client can 'score' to get on the methadone program, often driving them to a scoring corner. They come to know and care for 'clients' only to hear they have become HIV positive, died of a drug overdose or that they have been murdered or 'disappeared' from a stroll. This project revealed that HIV/Hep C prevention initiatives do reach drug users with needles, harm reduction equipment and pamphlets but are ineffective at doing what makes a more profound difference to people using illicit drugs. AIDS Service Organizations (ASO's) despite including people 'infected and affected by HIV/AIDS' do not see themselves as advocates for people who use illicit drugs specifically as they also work with other 'at risk' groups. They are loath to get involved in initiatives to stop the police from harassing and using inappropriate violence against people who use illicit drugs or lobbying for changes to Canada's drug laws so that addicts are no longer criminals. The people who use or used to use illicit drugs are perhaps more appropriate to lead this "Social Justice" movement and this is the role a user-run user group would have in enhancing HIV prevention. It is no longer true that people using drugs cannot get needles and are therefore becoming HIV positive (except in prison). What is true is that the squalor of their lives and the self-hatred that being criminalized by society creates, sets up the conditions in which people who use illicit drugs become HIV positive. Belonging to a user-run user group gives users a sense of themselves as responsible citizens who lobby for change because they begin to see themselves as deserving of proper and respectful treatment."

Recommendations:

- "Capacity building with people who use illicit drugs should include those that are "street involved" and the rigorous evaluation structures put onto projects by funders such as Health Canada need to respect that when coaxing frightened, criminalized, often very ill people into a "workshop" for capacity building the first thing you do NOT do is a "pre-workshop knowledge check." I recommend that capacity building projects that include "street involved" people negotiate a softer evaluation strategy and that we are not forced to pretend to use the usual methods.
- "The organizing of marginalized people who use illicit drugs is not just a good idea –it is essential to stopping epidemics of hepatitis C and HIV. This important work can be more generously funded either by making the funding allotted higher or by purposely networking between pots of money so that a national project receives funding from more than one program in a coordinated way

Vancouver Area Network of Drug Users
(2004) "Creating Vectors of Disease
Prevention: Empowering Networks of
Drug Users," Vancouver: VANDU.
Available online at
<http://www.vandu.org/reportsmedia.html>
(3/3)

This article summarizes the lessons learned from Vancouver Area Network of Drug Users' (VANDU) *Capacity Building Project*. Employing Peer Network Enhancers to travel to drug user communities outside the Vancouver context, the primary objective of the VANDU *Capacity Building Project* was to "educate and organize drug users to take action in their community much as VANDU members have in the DTES of Vancouver" regarding the spread of diseases prevalent among IDU such as HIV/AIDS and HCV.

- It may be helpful for Health Canada to provide optional contract guidelines or fill in the blank contracts for the subcontracting of evaluators so it is clear that the evaluator cannot copy write the evaluation and must return data.
- It is essential that a national group of people who use or formerly used illicit drugs be formed and funded to network users across Canada, to help seed user run user groups and to create and implement a strategy to demarginalize people who use illicit drugs so that the root causes of the epidemics of Hep C and HIV are solved.
- It may be possible to have Health Canada support people who are on methadone when they travel so that they can actually travel and are not humiliated by being given carries that do not cover the length of their trip putting them into methadone withdrawal. This could perhaps be negotiated with the body governing methadone prescription in each province. Not getting carries of adequate methadone to travel is a huge barrier to building the capacity of people who use illicit drugs.
- Health Canada can play an important role in brokering and facilitating entry into federal penitentiaries for groups like VANDU for the purpose of capacity building with users and former users of illicit drugs.

Literature Review of People with Lived Experience

in Mental Health

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Table 1 – Systematic Reviews

Bibliographic Citation	Description	Findings Relevant to <i>Peer/Consumer Involvement</i> Re: Mental Health Research/Policy/Treatment
<p>Emma L Simpson, Allan O House: Involving users in the delivery and evaluation of mental health services: systematic review</p> <p>http://www.bmj.com/cgi/reprint/325/7375/1265</p> <p>Summarized in:</p> <p>http://www.crd.york.ac.uk/CRDWeb/ShowRecord.asp?View=Full&ID=12003008052</p> <p>Related resource</p> <p>Online guidebook including a systemic review of literature and a 34-page bibliography</p> <p>Access at:</p> <p>http://www.leeds.ac.uk/hspbr/psychiatry/research/guidebook.htm</p>	<p>Systematic Review; world-wide English-language articles between 1996 -2001; service user delivery and evaluation of mental health services</p>	<p>Study selection</p> <p>“Systematic review of randomised controlled trials and other comparative studies of involving users in the delivery or evaluation of mental health services.”</p> <p>Data extraction</p> <p>“Patterns of delivery of services by employees who were current or former users of services and professional employees and the effects on trainees, research, or clients of mental health services.”</p> <p>Key Implications</p> <ul style="list-style-type: none"> • Five randomised controlled trials and seven other comparative studies were identified. Half of the studies considered involving users in managing cases. • Involving users as employees of mental health services led to clients having greater satisfaction with personal circumstances and less hospitalisation. • Providers of services who had been trained by users had more positive attitudes toward users. • Clients reported being less satisfied with services when interviewed by users. <p>Conclusions</p> <ul style="list-style-type: none"> • “Users can be involved as employees, trainers, or researchers without detrimental effect.” • “Involving users with severe mental disorders in the delivery and evaluation of services is feasible.”

Bibliographic Citation	Description	Findings Relevant to <i>Peer/Consumer Involvement</i> Re: Mental Health Research/Policy/Treatment
<p>Doughty, C., Tse, S. (2005) The effectiveness of service user-run or service user-led mental health services for people with mental illness: A systematic literature review. A Mental Health Commission Report; Mental Health Commission, Wellington, New Zealand.</p> <p>Accessed at: http://www.mhc.govt.nz/users/Image/Resources/2005%20Publications/SERVICE_USER_RUN.PDF</p>	<p>Systemic Review; International Evidence; New Zealand.</p>	<p>Please see p. 48 in "A Rapid Literature Review May 2009 PDF" for general comments.</p> <p><i>Conclusions</i></p> <p>"Overall, research on consumer services reports very positive outcomes for clients. This review of effectiveness found some studies that reported higher levels of satisfaction with services, general wellbeing and quality of life while others reported no significant differences between service user-run services and mental health services run by non-service user providers. No studies reported evidence of harm to service users or that consumer services were less effective than the equivalent services offered within a traditional setting.</p> <p>The evidence base supporting the effectiveness of service user-run services is gradually expanding. The findings to date have to be interpreted with caution as the majority of service user-run services identified by this review were operated alongside clinical staff, peer specialists on case management teams or crisis teams. This implies that the setting in which studies were conducted fulfils the definition of a consumer provided or partnership service but may not meet the more stringent operational definition of a consumer run service in terms of the level of autonomy, self-governance and the level of consumer control required. The positive effect on outcomes could potentially be greater for consumer run services than those with a participation model of consumer involvement. This is as yet unknown. Therefore it is vitally important that in the future effectiveness research measuring meaningful outcomes for service users is carried out on a wider range of different models or types of services in existence and that any differences in effect are formally evaluated.</p> <p>Consumer-run services worldwide receive very limited funding from mental health budgets despite a growing trend that suggests they may represent an effective model of mental health service delivery. Furthermore, to justify their place in the array of services offered within the mental health sector, a strong case can be made that services should only be required to demonstrate equivalent effectiveness compared with traditional services rather than superiority in regard to outcomes for clients. At present there is a mixed record of research on service user delivered services and more research on the effectiveness of these services is urgently needed to establish a broader evidence base for policy and advocacy. Despite a great deal of prior descriptive work that supports the feasibility of consumer provided services only a limited number of controlled studies have been published focusing on outcomes for people who participate in, or receive care or support from, these services. To date, there is very little evaluative work that has been done in this area in New Zealand.</p> <p>The potential already exists for New Zealand specific research and evaluation of service user-run, service user-led services but to achieve this goal, a full range of service user-run or led services, need to be developed, piloted and funded in a sustainable way."</p>

Bibliographic Citation	Description	Findings Relevant to <i>Peer/Consumer Involvement</i> Re: Mental Health Research/Policy/Treatment
<p>Systematic review of involving patients in the planning and development of health care</p> <p>Mike J Crawford, <i>senior lecturer in psychiatry</i>^a, Deborah Rutter, <i>research associate</i>^a, Catherine Manley, <i>research worker</i>^a, Timothy Weaver, <i>research fellow</i>^b, Kamaldeep Bhui, <i>senior lecturer in social and epidemiological psychiatry</i>^c, Naomi Fulop, <i>senior lecturer in health services delivery and organisation research</i>^d, Peter Tyrer, <i>professor of community psychiatry</i>^a.</p> <p>BMJ 2002;325(7375):1263 (30 November), doi:10.1136/bmj.325.7375.1263</p> <p>Accessed at: http://www.bmj.com/cgi/content/full/325/7375/1263</p>	<p>A systemic search to examine the effects of involving patients in the planning and development of health care using peer reviewed and grey literature written in English between 1966 and October 2000.</p> <p>Review changes to services, attitudes in organizations, and</p>	<p>Key Findings</p> <ul style="list-style-type: none"> • "Evidence supports the notion that involving patients has contributed to changes in the provision of services across a range of different settings." • "An evidence base for the effects on use of services, quality of care, satisfaction, or health of patients does not exist." <p>Other Conclusions</p> <ul style="list-style-type: none"> • Question of how healthcare providers demonstrate they involve patients in the planning process while being accountable for the decisions that they make • Better evidence base perhaps required • Authors found unpublished papers ("grey literature") to be some of the most informative • Speculation on whether articles that document successful involvement was likely to be peer reviewed and published

Bibliographic Citation	Description	Findings Relevant to <i>Peer/Consumer Involvement</i> Re: Mental Health Research/Policy/Treatment
<p>The Depression and Anxiety Consumer Research Unit is part of Australia National University.</p> <p>Access at: http://cmhr.anu.edu.au/cru/</p> <p>Researchers' publications available.</p> <p>Access at: http://cmhr.anu.edu.au/cru/publications/index.php</p>	<p>BrolgaNet is a network of people with an interest in: the involvement of consumers as active participants (not just passive 'subjects') in mental health research; and conducting research of high priority to mental health consumers</p> <p>An index of articles with summaries that relate to training, policy, and research by consumers is available here:</p> <p>Access at: http://brolganet.anu.edu.au/resources/index.php?action=rdocs</p> <p>English-speaking peer reviewed and grey literature up-to-date on the website with citations and hyperlinks for free Internet access</p> <p>Also access useful hyperlinks to research organizations here: http://brolganet.anu.edu.au/resources/index.php?action=rlinks</p>	<p>Key Findings</p> <ul style="list-style-type: none"> • A virtual "systemic review" online with summaries and hyperlink to articles • Collected body of evidence that points to the value of service users in research and evaluation, and supports greater collaboration Access at: http://brolganet.anu.edu.au/resources/index.php?action=rdocs • A more comprehensive "how to" database of sample documentation for consumer research and evaluation is available at the http://participateinhealth.org.au website Access at: http://www.participateinhealth.org.au/clearinghouse/ <p>Other Key Features for Consideration</p> <p>Online self-help and cognitive therapy programs (registration required) Access at: http://ecouch.anu.edu.au/welcome http://moodgym.anu.edu.au/welcome</p> <p>Also available an online discussion board. Access at: http://blueboard.anu.edu.au/</p>

Table 2 – Original Peer Reviewed Research

Bibliographic Citation	Description	Findings Relevant to <i>Peer/Consumer Involvement</i> Re: Mental Health Research/Policy/Treatment
<p>Forchuk, C., Martin, M.L., Chan, Y.L., and Jensen, E. (2005). Therapeutic Relationships: from Psychiatric Hospital to Community. <i>Journal of Psychiatric Mental Health Nursing</i>, 12 (5), 556-564. A similar report can be retrieved here: http://www.chsrf.ca/final_research/ogc/pdf/forchuk_final.pdf (the latter is used to cite findings)</p>	<p>“The transitional model focuses on interpersonal relationships. It includes two important elements: the first is peer support for one year from former clients of the mental healthcare system who promote friendship, provide understanding, teach community living skills, and encourage current clients in making a transition from psychiatric hospital to community. The second element is an overlap of in-patient and community staff in which the in-patient staff continued to treat clients until the clients have a working relationship with a community care provider, which can take up to one year.”</p>	<p>Research Highlights</p> <ul style="list-style-type: none"> • “ The pilot demonstrated significantly improved quality of life for nine participants who were given transitional support, while resulting in savings of \$496,862.55, during a one-year trial.” • “ Intervention participants were able to be discharged at an average of 116 days sooner than control ward participants.” • “At a rate of \$632.30 per day — the cost of a bed in a psychiatric hospital — the people in the intervention group consumed \$12,212,242 less in hospital costs than the group receiving regular, standard care, prior to discharge from the pre-enrolment admission.” • “In the first year after discharge, the intervention group consumed \$4,400 less hospital and emergency room services per person than the group receiving regular, standard care.” • “Despite the significantly shorter length of the Intervention group’s hospital stay, they did not need more services after discharge, and actually had a trend for fewer hospital services after discharge.” • “The people receiving usual care consumed a total of \$1,078,900 more hospital and emergency room services than the “lonely” people receiving support. <p>Key Implications</p> <ul style="list-style-type: none"> • “This new way of helping people with mental illness makes the difficult transition from hospital to community saved more than \$12 million through shorter hospital stays while improving how patients function. The savings were achieved through the early discharges of patients on 13 wards, in four cities, over the period of one year” • “Partnerships between mental healthcare consumer organizations and professional mental health services were crucial in yielding cost savings. Consumer organizations will need ongoing funding of peer support programs to continue offering these services.” • “Treating just one “lonely” person per year would pay for a part-time volunteer co-ordinator through reduced hospital and emergency room costs.” • “Patients getting help from community peer support groups reported improved social skills and feelings of well-being. They also appeared to be further along in the therapeutic recovery process than those getting the usual care.”

Bibliographic Citation	Description	Findings Relevant to <i>Peer/Consumer Involvement</i> Re: Mental Health Research/Policy/Treatment
<p>Solomon, P. (2004). Peer support/peer provided services: underlying processes, benefits, and critical ingredients. <i>Psychiatric Rehabilitation Journal</i>, 27 (4), 392-401. Retrieved online at:</p> <p>http://www.freedom-center.org/pdf/peersupportdefined.pdf</p>	<p>"The article defines peer support/peer provided services; discusses the underlying psychosocial processes of these services; and delineates the benefits to peer providers, individuals receiving services, and mental health service delivery system. Based on these theoretical processes and research, the critical ingredients of peer provided services, critical characteristics of peer providers, and mental health system principles for achieving maximum benefits are discussed, along with the level of empirical evidence for establishing these elements."</p>	<p>Key Definition of Peer Support</p> <ul style="list-style-type: none"> • Mead, Hilton, and Curtis (2001) have further elaborated that peer support is "a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful" (p. 135). Through the process of offering "support, companionship, empathy, sharing, and assistance," "feelings of loneliness, rejection, discrimination, and frustration" frequently encountered by persons who have a severe psychiatric disorder are countered (Stroul, 1993; p. 53). Peer support may be either financially compensated or voluntary. A peer in this context is an individual with severe mental illness who is or was receiving mental health services and who self-identifies as such (Solomon & Draine, 2001). <p>Definition and Delineating Categories of Peer Support</p> <ul style="list-style-type: none"> • Self-help groups: Katz and Bender (1976) defined self-help groups as "voluntary small group structures for mutual aid in the accomplishment of a specific purpose...usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life disrupting problem, and bringing about desired social and/or personal change." • Internet support groups: peer support groups not face-to-face (Perron, 2002); can be through e-mail, bulletin boards or "live" through software. "Internet support groups offer a high degree of anonymity, where confiding in others occurs without any social repercussions, given the lack of in-person contact among members (Davison, Pennebaker & Dickerson, 2000)." • Warmlines: "where peers offer support via the telephone. However, <i>warm lines</i> are one-on-one support, rather than having the group aspect of self-help groups. Also, warmlines may lack continuity with the same individual provider, therefore, limiting the ability to establish a relationship between peer and peer provider." <p>Delineating Categories of Peer Delivered Services</p> <p>Peer delivered services: defined as being one of three types (peer run or operated services, peer partnerships, and peer employees)</p> <p>Peer run or operated services:</p> <ul style="list-style-type: none"> • "services that are planned, operated, administered, and evaluated by people with psychiatric disorders (SAMHSA, 1998; Stroul, 1993). Individuals without psychiatric disorders may be involved in the service program, but their inclusion is within the control of peer operators (Solomon & Draine, 2001). These service programs are based on the values of freedom of choice and peer control.

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<p>Solomon, P. (2004). Peer support/peer provided services: underlying processes, benefits, and critical ingredients. <i>Psychiatric Rehabilitation Journal</i>, 27 (4), 392-401. Retrieved online at:</p> <p>http://www.freedom-center.org/pdf/peersupportdefined.pdf</p>		<ul style="list-style-type: none"> • “These programs have some paid staff and a significant number of volunteers. Generally, these services are embedded within a formal organization that is a freestanding legal entity. These programs vary greatly in terms of the size of the organization and they differ with regard to the nature of the services provided.” • “Examples of peer operated services include drop-in centers, clubhouses, crisis services, vocational and employment services, compeer, where volunteers are individuals with severe psychiatric disorders, psychosocial educational services (BRIDGES), and a peer support program such as Friends Connection in Philadelphia, where individuals with dual diagnoses are matched with peers in recovery.” <p>Peer partnerships: “Those service programs that are not freestanding legal entities and share the control of the operation of the program with others without psychiatric diagnoses”. Therefore, the fiduciary responsibility for the service program lies with a non-peer organization, and the administration and the governance of the peer program are shared mutually between peers and non-peers, but the primary control is with the peers (Solomon & Draine, 2001).</p> <p>Peer employees: “individuals who fill designated unique peer positions as well as peers who are hired into traditional mental health positions.”</p> <p>Benefits of Peer Support</p> <ul style="list-style-type: none"> • five theories that underlie peer delivered services, which include social support, experiential knowledge, helper-therapy principle, social learning theory (shared commonalities to achieve normalcy), and social comparison (interaction with peers likely to achieve change) theory. <p>Benefits to Individuals who Receive Mental Health Services</p> <ul style="list-style-type: none"> • Very high level of support for peer support regarding positive outcomes for service recipients • Research reviews find no difference in outcomes, or in a few instances, outcomes favor the paraprofessional • Also true when comparing self-help to therapists; • Peer provided services also useful in crisis intervention, team care (where they provide added value), post-discharge, and employment service • Many positive measurable indicators identified (improved social functioning, less substance abuse, improved quality of life, shorter hospitalization, higher employment rate, etc.) <p>Benefits to Providers</p> <ul style="list-style-type: none"> • A similar positive outcome to recipients was a reduction in hospitalizations for peer providers

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<p>Solomon, P. (2004). Peer support/peer provided services: underlying processes, benefits, and critical ingredients. <i>Psychiatric Rehabilitation Journal</i>, 27 (4), 392-401. Retrieved online at:</p> <p>http://www.freedom-center.org/pdf/peersupportdefined.pdf</p>		<p>Benefits to the Mental Health Service Delivery System</p> <ul style="list-style-type: none"> • One of the major benefits to the mental health service delivery system is the potential cost-savings that is likely to result to the system from peer provided services. • Given the consistency of the findings of decreased hospitalization or shortened length of hospital stay for both peer provided services and peer providers themselves, there is a translation of financial savings to the system, as hospitalization is one of the most expensive of mental health services. • Also, self-help groups generally do not cost the system very much in terms of dollars or resources, and therefore, any savings to the system are a total dollar savings. • Furthermore, self-help programs may reduce the utilization of the traditional mental health services, and as such may further reduce cost to the mental health system (Segal, Gomory & Silverman, 1998). • But one caution, dollar savings should not come to the mental health system from hiring individuals with psychiatric diagnoses into existing positions and paying them less for the same job. • Peer providers combat societal stigma against individuals with severe mental illness • Peer providers able to engage with individuals who are otherwise alienated from mental health system, more likely to do street outreach, and to encourage use of professional services • Peer support enhance ability of mental health system to meet community needs
<p>Judith A. Cook, Ph.D., Mary Ellen Copeland, Ph.D., Marie M. Hamilton, L.C.S.W., M.P.H., Jessica A. Jonikas, M.A., Lisa A. Razzano, Ph.D., Carol B. Floyd, Walter B. Hudson, B.S., Rachel T. Macfarlane, B.A. and Dennis D. Grey, B.A.(2009), Initial Outcomes of Mental Illness Self-Management using Wellness Recovery Action Planning</p> <p>Access:</p> <p>http://www.dbsalliance.org/pdfs/conference/2008/PTSD3.pdf</p>	<p>Objective. This study examined changes in psychosocial outcomes among participants in an 8-week, peer-led, mental illness self-management intervention called Wellness Recovery Action Planning (WRAP).</p> <p>Methods. Eighty individuals with severe mental illness at 5 Ohio sites completed telephone interviews at study baseline and one month following the intervention.</p>	<p>WRAP was delivered in 8 sessions, meeting for 2.5 hours each week and co-facilitated by two individuals in mental health recovery. Coursework included lectures, group discussions, personal examples from the lives of the educators and participants, individual and group exercises, and voluntary homework assignments.</p> <p>Results. Paired t-tests of pre- and post-intervention scores revealed significant improvement in self-reported symptoms, recovery, hopefulness, self-advocacy, and physical health; empowerment decreased significantly and no significant changes were observed in social support. "Those attending six or more sessions showed greater improvement than those attending fewer classes."</p> <p>Conclusions. These promising early results suggest that further research on this intervention is warranted"</p>

Bibliographic Citation	Description	Findings Relevant to <i>Peer/Consumer Involvement</i> Re: Mental Health Research/Policy/Treatment
<p>Mental health peer support for hospital avoidance and early discharge: An Australian example of consumer driven and operated service Sharon Lawn; Ann Smith; Kelly Hunter Journal of Mental Health, 1360-0567, Volume 17, Issue 5.</p>	<p>People with mental health issues are known to re-enter hospital periodically. Research shows that lack of community support (Davidson et al., 2001) is the primary factor. This is more relevant than the person's illness symptoms in re-admission.</p> <p>Moreover, the first three days after discharge requires monitoring to ensure that outpatients do not attempt suicide. Social support is critical.</p>	<p>A three month peer service project was undertaken to:</p> <ul style="list-style-type: none"> • Assess peer support effectiveness in providing early discharge and hospital re-cycling • Provide a recovery-based self-care service to offer consumers control of their mental health while changing the service delivery culture • Reduce re-admissions to inpatient beds • Reduce ER and crisis contacts by recently discharged outpatients • Assess peer supporters' role in helping family members • Assess staff acceptance • Review feedback <p>Delivery Model:</p> <ul style="list-style-type: none"> • Part-time project manager in regional health system (3 general hospitals with 105 psychiatric beds, community-based emergency team, and 3 multidisciplinary community mental health teams) • Peer coordinator • 8 peer support workers (paid on casual basis, previous paid or unpaid experience, formal training, six-week peer worker course, lived experience, medical, police, licence checks) <p>Results:</p> <ul style="list-style-type: none"> • Saved 300 bed days or \$113,100 AUS • Cost of intervention was \$19,850 AUS (project service delivery and administration costs) • Net savings of \$93,150 • In 9-month period, 900 bed days saved <p>Conclusions:</p> <ul style="list-style-type: none"> • Proof that peers "with adequate support, training and supervision" can provide important support that keeps people well and out of the ER room and inpatient unit • Peers have potential to "challenge and test the core value systems of service staff" • Support further integration of the peer role • Peers are "autonomous, independent, and clear in their role"

Bibliographic Citation	Description	Findings Relevant to <i>Peer/Consumer Involvement</i> Re: Mental Health Research/Policy/Treatment
<p>Evidence-Based Practice in Mental Health: Implications and Challenges for Consumer-Run Programs</p> <p>Hardiman, Eric R., Theriot, Matthew T., and Hodges, John Q.</p> <p>Best Practices in Mental Health, Vol. 1. No. 1. Winter 2005, Lyceum Books, Inc.</p> <p>pp. 105 - 122</p>	<p>Evidence-based practices are upheld and implemented in mental health service delivery because of its promise to improve both the consistency and quality of treatment.</p> <p>Consumer-run agencies remain an exception to the rule because they are different. Values, ideologies, and their service model of helping people make it a challenge.</p>	<p>Recommendations are suggested to address the evidence based practices (EBP) in consumer-run programs (p.116-117):</p> <ol style="list-style-type: none"> 1. Begin a dialogue internally and then with stakeholders to discuss EBP as it applies to the program (assumptions, evidence, knowledge) 2. Use a participatory action research approach to determine how best to develop EBP evidence (if desired) without compromising consumer values while validating their own body of work 3. Involve discussions with all levels of government about EBP 4. Look to access supports (education, implementation, research development, capacity for evaluation) 5. Work to define outcomes, how to measure outcomes, and ongoing outcome evaluation 6. Develop standards of care, success indicators, practice guidelines, and have appropriate training programs and staff supports in place to maintain them 7. Explore collaborations with traditional service providers 8. Seek assistance from other consumer-run programs and share resources and people as required 9. Use technical assistance from consumer advocacy groups as required 10. Advocate for more research funding and emphasis on peer-driven research and service delivery models 11. Be aware of new best practices In service delivery and evaluation to drive ongoing quality improvement <p>Advocates of EBP should be sensitive to PWLE needs by:</p> <ul style="list-style-type: none"> • Including them in all areas of planning and policy development (avoiding tokenism) • Allocate more research funding to consumer models of service delivery and supports • Promote and enhance ongoing consumer-run program funding • Educate service providers about the benefits of consumer programs • Collaborate with consumer organizations • Respect a broader definition of evidence and be sensitive to consumer values, knowledge, and barriers • Increase range of research designs and methods for consumer-run programs EBP research • Partner consumer researchers into the EBP process • Encourage consumers at doctoral research levels through graduate and postgraduate school recruitment • Prioritize the funding envelop for capacity and research building in consumer-operated programs

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<p>A Randomized Trial of a Mental Health Consumer-Managed Alternative to Civil Commitment for Acute Psychiatric Crisis</p> <p>Thomas K. Greenfield Beth C. Stoneking Keith Humphreys Evan Sundby Jason Bond</p> <p>American Journal of Community Psychology (2008) 42 (135-144)</p>	<p>"This was a study of nearly 400 individuals who were assigned to two types of programs. One was an unlocked, mental health consumer-managed crisis residential program (CRP). The other was a traditional locked, inpatient psychiatric facility (LIPF) for adults civilly committed for severe psychiatric problems"</p>	<p>Conclusions:</p> <ul style="list-style-type: none"> • Small and nuanced differences in outcomes • CRP program was more successful when statistically compared with LIPF (hospital-based model)
<p>Emergency Department from the mental health client's perspective.</p> <p>Clarke, Diana, Dusome, Debra, and Hughes, Linda. International Journal of Mental Health Nursing (2007) 16, 126-131</p>	<p>The authors surveyed client and family member perspectives of how general hospital emergency departments deal with individuals in crisis.</p>	<p>Findings:</p> <ul style="list-style-type: none"> • Focus groups wanted a better triage system, nurses with mental health training in the ER department, "safe spaces" and alternative resources outside of the M-F, 9 – 5 pm operating paradigm of community-based programs
<p>The Pros and Cons of Different Warm Line Settings.</p> <p>Pudlinski, Christopher. Psychiatric Rehabilitation Journal (Summer 2004), 28 - 1, 72-74</p>	<p>The author compared the benefits and disadvantages of three models of warm lines, which are run by peers and divert overuse of crisis hotlines.</p>	<p>Findings:</p> <ul style="list-style-type: none"> • Warm line teams working in pairs in a physical office setting, a beeper system where a caller left a number with a pager (to be called back), and a dedicated phone number each had pros and cons

Table 3 – Grey Literature

Bibliographic Citation	Description	Findings Relevant to <i>Peer/Consumer Involvement</i> Re: Mental Health Research/Policy/Treatment
<p>Potter, Deborah, MA, and Mulkern, Virginia, PhD. Consumer/Survivor-Operated Mental Health Services, in Vol.2, Iss. 2 of "Community Living Briefs".</p> <p>Access at:</p> <p>http://www.bcm.edu/ilru/html/publications/newsletters/Briefs/Vol2Iss2.pdf</p>	<p>A 12-page article that comprehensively studies the various types of peer supports and services offered by U.S. states at the beginning of the 21st century.</p>	<p>Key Findings</p> <ul style="list-style-type: none"> • Maps out process for planning and implementing a new peer-based service • Considers a framework of issues for consumers and for jurisdictions as development proceeds • How does organization and funder work together • How does capacity building take place (this need is moved up in the planning process) • Ultimately many options are possible <p>Key Examples</p> <ul style="list-style-type: none"> • Stepping Stone and Next Key program (New Hampshire) has peer support, warm line, and 2 respite beds http://www.steppingstonenextstep.org/ • The Friends Connection (Pennsylvania) which is a peer mobile psychiatric rehabilitation concurrent disorder team http://www.mhasp.org/friends/
<p>Campbell, Jean. PhD and Leaver, Judy, PhD. (2003) Emerging New Practices in Organized Peer Support</p> <p>http://www.nasmhpd.org/general_files/publications/ntac_publications/reports/peer%20support%20practices%20final.pdf</p>	<p>Describes the various types of peer supports and services available in the United States set against an uncertain funding climate.</p>	<p>Key Findings</p> <ul style="list-style-type: none"> • Recommends integration of peer support within the continuum of community care • Promote inter-agency collaboration to promote consumer choice • Peer support has a role to play – it brings hope to a mental health system with previously modest expectation around outcomes • "Most peer support programs still remain autonomous from professionally run organizations and are solely staffed by mental health recipients with decision-making and service delivery responsibility shared among the membership. However, they do enter into collaborative service relationships within the continuum of community care. In most instances, the partnering of peer-run support programs and professional services has not been formalized, but is maintained through ad hoc or informal relationships."

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<p>SAMHSA Consumer/Survivor Resources Access at:</p> <p>http://mentalhealth.samhsa.gov/publications/Publications_browse.asp?ID=4&Topic=Consumer%2FSurvivor</p> <p>Building Bridges - Co-Occurring Mental Illness and Addiction: Consumers and Service Providers, Policymakers, and Researchers in Dialogue (SMA04-3892)</p> <p>Access at:</p> <p>http://mentalhealth.samhsa.gov/publications/allpubs/SMA04-3892/</p> <p>Building Bridges Consumers & Representatives of the Mental Health & Criminal Justice Systems in Dialogue (SMA05-4067)</p> <p>Access at:</p> <p>http://mentalhealth.samhsa.gov/publications/allpubs/SMA05-4067/</p>	<p>Report <i>Building Bridges: Co-Occurring Mental Illness and Addiction: Consumer and Service Providers, Policymakers, and Researchers in Dialogue</i></p> <p>Report <i>Building Bridges: Consumers and Representatives of the Mental Health and Criminal Justice Systems in Dialogue.</i></p>	<ul style="list-style-type: none"> • “Dialogue participants identified and discussed the many longstanding systemic barriers to appropriate treatment and support services for people with co-occurring disorders, including separate administrative structures, eligibility criteria, and funding streams, as well as limited resources for both mental health services and substance abuse treatment. In addition, participants provided recommendations that support successful partnerships between the two groups, address the barriers to effective services, and promote recovery. The dialogue recommendations represent the united voice of those who receive services and those who provide them, build on the findings of the SAMHSA Report to Congress, and emphasize that people with co-occurring disorders can and do recover.” • Recommendations on justice diversion and peer support around these areas: policy, program development, training, and research <p>Policy: consumer/peer support services; peer specialist role and guidelines; training programs; recover-based service plans; include peer supporters who have experience with criminal justice system; provide services that sustain individual’s wish to recover in face of family cultures; hire consumer staff for jail diversion programs.</p> <p>Program Development: more integration and collaboration between peer organizations and criminal justice organizations/penal institutions/hospitals; offer employment alternatives; peer recovery units in prison</p> <p>Training: peer supporters train criminal justice system about recovery; peer support and forensic mental health issues become part of professional curriculum; mentoring program</p> <p>Research: engage in research that adds to the evidence base of peer support being helpful in forensic services</p>

Bibliographic Citation	Description	Findings Relevant to <i>Peer/Consumer Involvement</i> Re: Mental Health Research/Policy/Treatment
<p>Building Bridges Mental Health with Consumers and Primary Health Care Representatives in Dialogue (SMA06-4040) Access at: http://mentalhealth.samhsa.gov/publications/allpubs/SMA06-4040/default.asp</p> <p>Building Bridges Mental Health on Campus: Student Mental Health Leaders and College Administrators, Counsellors and Faculty in Dialogue (SMA07-4310) Access at: http://download.ncadi.samhsa.gov/ken/pdf/SMA07-4310/Building_Bridges_62p.pdf</p> <p>Building Bridges: Mental Health Consumers and Members of Faith-Based and Community Organizations in Dialogue (SMA - 3868) Access at: http://mentalhealth.samhsa.gov/publications/allpubs/SMA04-3868/default.asp</p>	<p>Report Building Bridges Mental Health Consumers and Primary Health Care Representatives in Dialogue</p> <p>Report Building Bridges Mental Health on Campus: Student Mental Health Leaders and College Administrators, Counselors and Faculty in Dialogue</p> <p>Guide Building Bridges: Mental Health Consumers and Members of Faith-Based and Community Organizations in Dialogue</p>	<p>Key Findings and Recommendations</p> <ul style="list-style-type: none"> • Broad themes around collaboration between consumer and service provider, education to employers about integrated care, payment incentives for primary care practitioners, and improved awareness of consumer involvement as being positive and the positive outcomes of peer-delivered and operated services • One recommendation was for development of a WRAP plan (Wellness Recovery Action Plan) program which includes elements of primary care, self-care, and self-management) • Highlight benefits of promotion and prevention <p>Key Findings and Recommendations</p> <ul style="list-style-type: none"> • “Campus as a safety net” when it comes to mental health and addictions” • “High incidence of substance use or abuse, binge drinking, and recreational use of prescription drugs, any of which may represent self-medication for mental health problems” • “Mental health policies driven by fears of malpractice suits, institutional liability, and adverse publicity, rather than focused on students’ success” • Counselling services if used by students offset by academic consequences of not completing schoolwork • “Offer peer education and supports, as well as peer training and peer-provided services.” • Includes recommendations for what should be featured on a campus website around mental health and addictions <p>Key Findings and Recommendations</p> <ul style="list-style-type: none"> • There are opportunities for collaborations between peer supporters and those in the faith community • There is no replacement for high-quality mental health services; using faith-based services is not an excuse to cut costs

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<p>Opening Futures: An Exploration of Community Economic Development For People with Disabilities. Authored by Cameron Crawford, Roehrer Institute CEO, Dena Maule, consultant, and Kathryn Church (section on A-Way Express) (2000)</p> <p>Private copy available through correspondence</p>	<p>Studies of six CEDs including A-Way Express (Toronto consumer/survivor courier company) and GROW (Waterloo garden and greenhouse that sells produce).</p>	<p>Key Findings</p> <ul style="list-style-type: none"> • Barriers to successful participation by individuals in CEDs explored, including: lack of coordination in public programs that results in conflicting criteria for eligibility; extreme requirements for program eligibility, unrealistic expectations of full economic independence; lack of seed capital investment, limited health insurance coverage especially for medications; and an emphasis on funding winning programs who “remove” people from public assistance • For effective CED partnerships, require policy and program harmonization to allow eligibility, maximize participation, and reconsider the idea of self-sufficiency as the ultimate goal • Various branches of government and stakeholders responsible for pooling of CED funds • Incentive for people to gather enough seed capital, rather than penalizing them for holding assets • Ongoing funding to support people whose businesses are not economically self-sufficient • Increased capacity building for funding to reach out to more people who are economically disadvantaged and wish to improve their situation

Table 4 – Other Literature

Bibliographic Citation	Description	Findings Relevant to <i>Peer/Consumer Involvement</i> Re: Mental Health Research/Policy/Treatment
<p>From HCBS (the Clearinghouse for Housing and Community Based Services website)</p> <p>http://www.hcbs.org/files/151/7505/winter2009.htm</p> <p>A sample inventory of articles around peer support is available here.</p>	<p>A short e-newsletter with links to a comprehensive list of documentation around peer providers in the U.S. Three articles are given special attention (dated July 2008).</p>	<ul style="list-style-type: none"> • Hyperlinks are provided to explain two types of peer support – COSP (consumer-operated service provider) and peer providers who work in more traditional mental health settings • Policy Issue #1 considers the organizational model for Peer Support; provides examples; suggests how models can fit the jurisdiction (in an American context); and asks questions regarding funding, fit, and evaluation about these models. They can be drop-ins, self-help groups, or multi-service agencies, or provide specialized services to populations operated independently. Specialists work within ACT and emergency room teams as practitioners. Conclusion: Diverse needs require different models; consider "fit" into system and consumer choice. Policy Issue #1: Organizational Models for Peer Support Prepared By: John O'Brien, M.A. Wendy White Tiegreen, M.S. Jean Campbell Ph.D. accessed at: http://www.hcbs.org/files/147/7309/PeerSupportsPolicyBrief1.pdf • Policy Issue #2 considers the multitude of issues involved in having peer providers put into traditional mental health settings and in particular barriers to integration. Conclusion: there should be guidelines defining who is a peer provider, role definition, day-to-day description, qualifications, process to become one, and who is eligible to benefit from access to a peer provider Policy Issue #2: Introducing and Supporting Peer Providers in Traditional Mental Health Provider Networks Prepared By: John O'Brien, M.A. Wendy White Tiegreen, M.S. Jean Campbell Ph.D. accessed at: http://www.hcbs.org/files/147/7316/Peer_Supports_Policy_Brief2.pdf • Policy Issue #3 considers how U.S. states can finance peer providers and other peer support programs. Conclusion: cannot be generalized compared with the Ontario experience. Policy Issue #3: Financing Peer Provided Services Prepared by: John O'Brien, M.A. Wendy White Tiegreen, M.S. Jean Campbell Ph.D. accessed at: http://www.hcbs.org/files/147/7317/PeerSupportsPolicyBrief3FINAL.pdf

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<p>Te Pou is New Zealand's National Centre of Mental Health Research, Information and Workforce Development.</p> <p>http://www.tepou.co.nz/page/63-Workforce-projects+Service-user-workforce-development</p> <p>Training is described here:</p> <p>http://www.tepou.co.nz/page/70-Workforce-projects+Service-user-workforce-development+Consumer-advisor-training</p>	<p>This website page hosts the service userworkforce development resources available for New Zealand including the unique concept of "consumer advisors", who have a specific role to play in mental health services.</p> <p>Addictions have their counterpart as well:</p> <p>National Addiction Treatment Workforce Development Program (NATWDP)</p> <p>http://www.matuaraki.org.nz/index.php?id=75</p> <p>Includes consumer advisor and consumer auditor (Quality improvement) roles</p>	<ul style="list-style-type: none"> • Consumer advisor resource kit Accessed at: http://www.tepou.co.nz/page/151-Workforce-projects+Service-user-workforce-development+Consumer-advisor-resource-kit Variety of roles of consumer advisor documented in this article in issue of e-newsletter Accessed at: http://www.mentalhealth.org.nz/newsletters/view/article/8/81/summer-06-07/ • Competencies for Consumer Advisors in Mental Health Services Accessed at: http://www.tepou.co.nz/file/PDF/publications/Competencies%20for%20Consumer%20advisors%202005.pdf • Blueprint Training Program (National Certificate in Mental Health Support Work) Accessed at: http://www.blueprint.co.nz/page/14-Welcome • Auckland Peer Support Network is a support network for peer support workers that meets bimonthly at different locations and where peer support workers share information, problem-solving, support and do networking Accessed at: http://www.tepou.co.nz/page/321-Workforce-projects+Service-user-workforce-development+Auckland-Peer-Support-Network • Executive Leadership Training in Mental Health and Addictions Accessed at: http://www.blueprint.co.nz/page/12-Welcome • A wide variety of workshops with a wide range of topics including consumer partnerships Accessed at: http://www.blueprint.co.nz/page/20-Workshops+Blueprint-workshops <p>Conclusions:</p> <ul style="list-style-type: none"> • New Zealand offers templates in its resource toolkit that describe how the organizational structure and job description is tailored for consumer advisor positions, who are typically described as being employed at management level and are charged with providing and facilitating effective consumer participation in the planning, delivery, and evaluation of services, and also a consumer role in training where applicable. • They can be: Consumer Advisers; Peer Support Workers; Policy analysts; Researchers; Auditors; Advocates; Consultants; Trainers; Board members; Managers; and Service Evaluators • Competencies for consumer advisors are documented. • New Zealand uses an independent agency to provide additional training in Mental Health Support Work (for either consumer or non-consumer staff), executive leadership training, and workshops that covers a wide curriculum of topics

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<p>SAMHSA's</p> <p>Mental Health Transformation State Incentive Grant (TSIG) program</p> <p>Access at:</p> <p>http://mentalhealth.samhsa.gov/cmhs/CommunitySupport/mentalhealth/default.asp</p> <p>Press release at:</p> <p>http://www.samhsa.gov/news/newsreleases/050928_StateIncentiveGrants.htm</p>	<p>U.S. federal agency program of grants to specific states to "transform state mental health service delivery systems – from systems dictated by outmoded bureaucratic and financial incentives to systems driven by consumer and family needs that focus on building resilience and facilitating recovery."</p>	<p>Key Findings</p> <ul style="list-style-type: none"> • Funding mechanism to selected states promote the principles of mental health recovery and meet consumer-based needs • Innovative funding use and flexible eligibility requirements compared with status quo • Increase accountability of levels of government towards consumers and families • Expand options for consumers and families <p>Action Plan</p> <ul style="list-style-type: none"> • Year 1 – each state completes needs assessment and inventory of mental health services • Year 2 – comprehensive mental health plan with transformation principles based on New Freedom Commission • Create a working group of stakeholders • Consider what technical assistance is needed to accomplish goals • Consider program directives <p>Results</p> <ul style="list-style-type: none"> • Transformation tracker website at: http://mhstsigdata.samhsa.gov
<p>Bluebird, Gayle. Paving New Ground: Peers Working in In-Patient Settings</p> <p>Access at:</p> <p>http://pamhi.wordpress.com/2008/03/28/paving-new-ground-peers-working-in-in-patient-settings/</p> <p>http://www.nasmhpd.org/general_files/publications/ntac_publics/Bluebird%20Guidebook%20FINAL%202-08.pdf</p>	<p>This is a 110-page guidebook that combines storytelling, job descriptions, program documentation, and concludes with a bibliography of research into the innovative approaches and lessons learned from introducing peer support into traditional service provider settings</p> <p>A must-read</p>	<p>Key Findings</p> <ul style="list-style-type: none"> • Summaries of 10 peer support in-patient programs in the United States • Many innovative job descriptions, including a senior management position in a long-term mental healthcare institution as "Director of Consumer Affairs" with a profile described as: " a member of the executive management team utilizes the full scope of management principles, organizational and communication skills to bring a consumer's point of view to all areas of program development, policy formation, program evaluation, quality assurance, system designs, education of mental health service providers, and staff providing direct services. Serves as a systems change agent." • Another is the role of Patient Liaison (entrusted originally with reducing the incidence of isolation or restraint in a hospital setting, but now more focused on critical incident prevention) • Demonstrates how the evolution of change can be successfully implemented

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<p>Mental Health Consumer Providers A Guide for Clinical Staff. Matthew Chinman, Alison Hamilton, Brittany Butler, Ed Knight, Shannon Murray, Alexander Young. A Report for the Rand Corporation (2008). Access at: http://www.rand.org/pubs/technical_reports/TR584/</p>	<p>This is a guide to the benefits of having Consumer Providers on staff, suggestions to facilitate the hiring of CPs, typical barriers to hiring CPs, components of a formal CP program that should be considered, and issues for the future of CP programs.</p> <p>The examples are U.S. jurisdictions.</p>	<p>Discusses implementation issues relating to the following themes:</p> <ul style="list-style-type: none"> • Transitioning from client to consumer provider • Peer support consumer provider • Integration of consumer provider into staff culture • Opportunities for management roles • Staff concerns <p>Barriers such as attitudes by other staff and organizational structures are also mentioned.</p>
<p>Economic Integration and Disability: A Baseline Benefits and Costs Study of Supported and Self-Directed Employment Initiatives in Canada. Alfred Neufeldt, Judith Sandys, Don Fuchs, Percy Paris and Martin Logan (2000)</p> <p>Available by private correspondence.</p>	<p>This is a Canadian study that reviews two models of employment support models in four provinces for persons with disabilities. Agencies were selected, and employees using self-directed means of employment and employment supports were studied. Natural benefits (income) and supports (from family and friends) were compared with "artificial" benefits (disability benefits) and professional support (job coach, counseling, etc.)</p>	<p>Key Findings</p> <ul style="list-style-type: none"> • Self-directed employees earned close to full time and close to \$16,000 a year • Supported employees worked about half-time and earned \$3,700 a year • Both expressed job satisfaction • Employers of supported workers expressed satisfaction with outcomes (citing personal growth), notwithstanding low incomes • Both types of employers were satisfied with the benefits of the programs • Provinces in which studies took place had varying disincentives to employment for people with disabilities such as benefits clawback and risk of losing income supports • more research is needed; however policy changes required to encourage economic integration of people with disabilities

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<p>Schwenk, E.B., Brusilovskiy, E., & Salzer, M.S. (2009). Results from a National Survey of Certified Peer Specialist Job Titles and Job Descriptions: Evidence of a Versatile Behavioral Health Workforce. The University of Pennsylvania Collaborative on Community Integration: Philadelphia, PA. Access at: http://www.upennrrtc.org/var/tool/file/213-FINAL%20CPS%20REPORT.pdf</p>	<p>"The purpose of this report is to present the job titles and descriptions that were provided by 275 respondents who responded to a brief online survey of certified peer specialists (CPS) working in paid positions in the US. The goal is to give peers and other stakeholders a sense of the wide variety of job titles that people have and the description of their jobs, in their own words."</p>	<p>Reviews the job descriptions as described by peer support specialists surveyed in 2008-2009:</p> <ul style="list-style-type: none"> • almost 70% female • CPS experience averaged 24.6 months and 29.8 hours/week of employment • Almost half of respondents were independent peer support workers or case managers • A few were in senior management or were executive directors <p>This report provides a limited but useful snapshot (as results were skewed by high participation rates from three states) as to how peer support can be deployed throughout mental health and addiction services.</p>
<p>Kathryn Power, SAMHSA Director, speech to the May Mental Health Commission of Canada Board Meeting Access: http://www.mentalhealthcommission.ca/SiteCollectionDocuments/Key_Documents/en/2009/Kathryn%20Power%20speech%20MHCC%20Board%20May%202009.pdf</p>	<p>"Recovery in Depth: Transforming Mental Health Care in Canada and the United States"</p>	<ul style="list-style-type: none"> • Healthcare goals and principles are to be: "safe, effective, patient-centered, timely, efficient, and equitable" • Transformed system is: "based on a belief in recovery, centered on consumer needs and preferences, grounded in evidence-based practice, and led by a culturally competent, technologically savvy workforce" • Role of consumers: "Consumers are no longer content to be at the margins of the mental health care system, and rightly so. They are the reason the system exists and they must be at the center of everything we do" • Described in DEPTH vision of recovery: Define recovery; Eliminate practices that are anti-recovery; Promote healthy behaviours; Train service providers about recovery; and Hold people accountable for transforming services to being recovery-focused • 55 – 99 percent of women in substance use programs and 85-95% in mental health programs report a history of trauma – acknowledgement and working in this area essential to helping these individuals to recover • Seclusion and restraint are but forms of re-traumatization – to be avoided and seen as treatment failures • "When it comes to mental health and well-being, there is no us and there is no them" • Consumers dying on average 25 years before their time is a "public health crisis" • Need to integrate primary care with psychiatric care • Self-directed care has better outcomes and does not cost any more than regular programs • Power of transformational grants for states noted – results summarized • Social inclusion is important to making consumers part of the community

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<p>Policy Title: Consumer Participation in Mental Health Services Planning, Implementation and Evaluation</p> <p>Access:</p> <p>http://www.cmha.ca/data/1/re_c_docs/898_consumerparticipation.pdf</p>	<p>Policy Category/Number HCS-210.2 Applicable to Regional Health Authorities and Selkirk Mental Health Centre</p>	<p>Policy Statement: "Consumers have the right to participate and have a direct and active role in all processes that affect their lives".</p> <p>Includes the fundamental principle regarding consumer involvement: "mental health consumers shall play an increasing role in the mental health system in terms of advising, planning, developing, implementing and evaluating mental health policies and programs".</p> <p>Core Values include: mutually respectful relationships; collaboration and participation; power-sharing (consumer empowerment and inclusion in decision-making); shared responsibilities; and equality</p> <p>Appendix explores consumer participation activities in other jurisdictions (British Columbia, Australia, etc.)</p>
<p>Nova Scotia Provincial Consumer, Family, Community Working Group Department of Health Mental Health Branch: Selection Criteria: Mental Health Consumer-Led Initiative Grants 2009-2010</p> <p>Access:</p> <p>http://www.gov.ns.ca/health/mhs/programs_strategies/consumer_involvement.asp</p>	<p>"The Mental Health Branch of the Department of Health is interested in supporting (one time) Mental Health Consumer-Led Projects that will be directed toward education, research to inform decisions, advocacy, or seed money to start self-supporting projects. These grants must not be used for operational expense of programs already in place. It is important to provide evidence that consumers support and are involved in all areas of the project".</p>	<p>Nova Scotia has also developed this template for a consumer participation evaluation tool online:</p> <p>http://www.gov.ns.ca/health/mhs/pubs/depression/ConsumerRatingToolSept2005.pdf</p> <p>This is a rare example of a funding mechanism in Canada that is respectful of meaningful consumer involvement in the mental health system through active investment funding.</p> <p>By comparison, in the United States, there is a wide range of funding mechanisms to effect system change.</p> <p>For example, SAMHSA is providing grants in 2009 to establish state-wide consumer networks:</p> <p>http://www.samhsa.gov/grants/2009/sm_09_014.aspx</p> <p>Other SAMHSA grants for the current year to bolster the transformation of substance use and behavioural care can be found at:</p> <p>http://www.samhsa.gov/grants/2009/fy2009.aspx</p>

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<p>OPDI Briefing Note: Peer Support Value to the Ministry's Healthcare Priorities (Sherman, 2008).</p> <p>Access</p> <p>http://opdi.org/images/uploads/08_06_05_Policy_Brief_E_RAccess_-_Final_submitted.pdf_.pdf</p>	<p>Briefly describes peer support in the Canadian context, the academic literature viewing it as a "best practice", and the various settings it is used in.</p>	<p>Findings:</p> <p>Peer support makes an impact because it relies on the informed perspective of people, uses a strengths-based approach and embeds the possibilities of hope and recovery as people help one another.</p> <p>Peer support is cited in the literature in crisis intervention, emergency departments, inpatient settings, discharge planning, case management, and other community mental health settings.</p> <p>System barriers faced by agencies offering peer support by and for consumers include: clinical programs introducing their own peer services; consumer/survivor organizations facing amalgamation; and uneven adaptations (role confusion, role dilution, etc.) of peer support work in the field.</p> <p>Two opportunities: use peers to guide clients through OCAN (Ontario Common Assessment of Need) and create collaborative partnerships between CSOs and mainstream organizations by using peer workers to share this work; also use secondments to provide mainstream agencies with instant expertise and internal training opportunities.</p>
<p>Consumer Survivor Initiatives in Ontario: Building for an Equitable Future (OFCMHAP, 2009).</p> <p>Report for CSI Builder Project</p> <p>O'Hagan, Mary, McKee, Heather, and Priest, Robyn.</p> <p>In press</p>	<p>Since 1991, when CSIs were founded in Ontario, they have become a "core service" in the mental health field provincially. The report examines why they continue to receive just 0.2% of the total community mental health budget 18 years and makes recommendations to improve the state of these type of supports given the international evidence base.</p> <p>A wealth of evidence on peer support and consumer-run organizations.</p>	<p>Recommendations (from Executive Summary of Report, p. 14-15):</p> <ol style="list-style-type: none"> 1. The provincial consumer/survivor leaders and MOHLTC, with involvement from LHINs, and the backing of the Minister's Advisory Group and the Select Advisory Committee, create new policy and funding frameworks for CSIs, using recovery and social justice principles. 2. The provincial consumer/survivor leaders and MOHLTC, with involvement from LHINs, create guidelines for the LHINS and others, to assist them develop a strong and equitable CSI presence in Ontario. 3. The provincial consumer/survivor leaders, with the involvement of MOHLTC and the LHINS, strengthen the provincial consumer/survivor development and advocacy role for CSIs. 4. The strengthened provincial development and advocacy structure/s offer opportunities and resources to CSIs to develop and evaluate their services. 5. The strengthened provincial development and advocacy structure/s offer opportunities and resources for the CSI workforce to be recruited, trained and educated. 6. Five other reports over the last 13 years have made recommendations on the development of CSIs. Little action followed these reports. Our overriding recommendation is that action must follow this report.

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<p>Work transitions for peer support providers in traditional mental health programs: Unique challenges and opportunities.</p> <p>Moll, Sandra, Holmes, Jennifer, Geronimo, Julie, and Sherman, Deb.</p> <p>(2009, in press).</p>	<p>Study explored peer provider integration into six community mental health programs. This was done through training, work placement, and feedback from all participants. Issues and challenges were discussed.</p>	<p>Conclusions:</p> <ul style="list-style-type: none"> • Challenges were: defining and establishing roles; negotiating the learning curve; balancing tensions between the peer versus staff role; negotiating the challenges of being a role model; transitioning identity from consumer to provider; and fitting in or being accepted in the workplace (p. 8). • Easing the transition: define work role for peer provider; consider the peer provider's needs; and consider the role of the workplace environment • Hiring the peer worker is only the beginning of the process
<p>Crisis Services in the "Living Room": An environment with peer supports helps people in crisis"</p> <p>July 2006, Tools for Transformation Ashcraft, Lori, and Anthony, W. A.</p> <p>Access: http://www.behavioral.net/ME2/dirmod.asp?sid=&nm=&type=Publishing&mod=Publications%3A%3AArticle&mid=64D490AC6A7D4FE1AEB453627F1A4A32&tier=4&id=3148AFFE6CE8472F877DAB4F8B9306F3</p>	<p>Peer staff was given two opportunities to design twp alternative crisis intervention milieus.</p>	<p>Intervention characteristics:</p> <ul style="list-style-type: none"> • Designed consumer-centred crisis intervention model • Staff required a minimum of 100 hours training • More home-like environment than standard ward • Immediate access to help • Less emphasis on seclusion and restraint • Peers shared experiential knowledge • Limited stays <p>Results:</p> <ul style="list-style-type: none"> • Reduced readmission state • Discharge planning deemed "better by at least one physician • Despite initial concerns by service staff, safe space issues did not emerge • In fact, tailored safe space for consumers more conducive to recovery • More referrals from professionals over time