"Nothing About Us Without Us"

Greater, Meaningful Involvement of People Who Use Illegal Drugs: A Public Health, Ethical, and Human Rights Imperative

Canadian HIV/AIDS Legal Network | Réseau juridique canadien VIH/sida

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This paper is dedicated to the memory of the many thousands of people who use drugs who have died of AIDS in Canada and internationally, often because proven prevention and care measures have not been implemented in a timely fashion, or because services have been denied to them because of stigma and discrimination.

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Executive Summary

This paper examines why it is important to increase meaningful involvement of people who use illegal drugs in the response to HIV and hepatitis C (HCV), and how this can be done.

Goals and objectives of the project

The *goal* is to promote respect for the human rights of all people living with or vulnerable to HIV/AIDS, and to promote and protect the health of people who use drugs.

The *objectives* are

- to increase *knowledge and understanding* of the issues related to greater involvement of people who use illegal drugs in Canada's community and government response to HIV/AIDS and HCV;
- to increase the *capacity* of non-governmental organizations and governmental stakeholders to involve people who use illegal drugs more often and more meaningfully;
- to increase *the involvement of people who use illegal drugs*, including in the development of better policy responses to HIV/AIDS and HCV in Canada; and,
- to increase *the involvement of people living with HIV*.

Epidemics of HIV and HCV among people who use illegal drugs: a public health and human rights failure

In Canada, prevalence rates of HIV infection among people who use illegal drugs by injection dramatically increased during the 1990s, reaching 25 to 30 percent in some areas. In 1996, it was estimated that about 47 percent of new HIV infections were among people who inject illegal drugs. Since then, the figure has decreased to about 30 percent of new infections, but HIV incidence and prevalence remain unacceptably high, particularly among women and aboriginal people who use drugs. HCV prevalence is even higher. Worldwide, there are more than 13 million people who

inject illegal drugs, and in some regions more than 50 percent of them are infected with HIV. Drug injecting with contaminated equipment is the major mode of HIV transmission in many countries and is the driver of the world's fastest spreading HIV epidemic, in Eastern Europe and Central Asia.

A growing number of HIV-positive people who use drugs are now developing AIDS. Their access to antiretroviral therapies is limited even in wealthy countries like Canada with universal public health insurance, and non-existent in many countries. The result is high rates of AIDS-related morbidity and mortality among people who use illegal drugs, particularly among those who are most socially and economically marginalized.

"Greater involvement of people living with HIV/AIDS" (GIPA) and the greater involvement of people who use drugs

The social and organizational response to the HIV/AIDS epidemic has been profoundly affected by the growth of a self-identified community of people living with HIV demanding a say in the development of policies and the delivery of services. Early in the history of the epidemic, those who were first associated with AIDS – gay men in North America and Europe – became actively involved in community-based education and support services, and challenged inadequate responses to their needs. Policy-makers began to recognize the importance and benefits of involving people living with HIV in formulating policy and delivering services. At the 1994 Paris AIDS Summit, 42 national governments, including Canada, formally recognized the principle of the "Greater Involvement of People Living with HIV/AIDS" (GIPA), declaring that GIPA is critical to ensuring that responses to the HIV/AIDS epidemic are ethical and effective.

Similarly, the HIV/AIDS epidemic has prompted the development of organizations of people who use drugs and a greater demand for the involvement of people who use drugs in HIV/AIDS policy, programs and services. Historically, people who use drugs have rarely been included in discussions of issues that affect their lives. Marginalized because of their drug use and other factors, such as homelessness, mental health needs, or social exclusion, they have often been distanced from mainstream services and structures. In the spirit of GIPA, it is time to consider 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.

Efforts to involve 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, are important for a number of reasons:

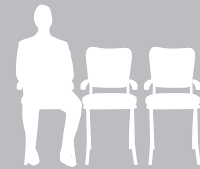
First, people who use drugs represent a significant proportion of the people in Canada and many other countries who contract HIV. This means that governments and organizations can no longer claim that they involve people with HIV adequately in their work on HIV/AIDS without meaningfully involving one of the most marginalized groups of people living with, or at great risk for, HIV.

Second, there are public health imperatives for involving people living with HIV/AIDS and those most at risk. 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 to create effective responses to the epidemic. People who use illegal 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.

Finally, there are ethical and human rights imperatives for the greater involvement of people who use drugs. As an ethical principle, all people should have the right to be involved in decisions affecting their lives. This fundamental requirement for meaningful involvement is consistent with the commitment made by the Government of Canada in 2001 when it endorsed the UN General Assembly's *Declaration of Commitment on HIV/AIDS*, which calls for the greater involvement of people living with HIV and of people from marginalized communities.

"It is our lives. We would like to take them into our hands."

– consultation participant



Such a commitment is consistent with the United Nations "*International Guidelines on HIV/AIDS and Human Rights*", which urge states to involve representatives of vulnerable groups, such as people who use drugs, in consultations and in the planning and delivery of services. An approach to HIV/AIDS informed by human rights principles is one that protects and promotes the rights of people living with or vulnerable to HIV, and ensures they are part of the design, development and implementation of programs responding to HIV/AIDS.

Conclusions and recommendations

It is time to move from supporting the meaningful involvement of people who use drugs in principle to ensuring their greater involvement in practice. There will be many opportunities to do so as Canada implements its new HIV/AIDS Action Plan (*Leading Together: Canada Takes Action on HIV/AIDS*), which explicitly affirms the importance of involving people living with HIV, and those vulnerable to HIV, in all aspects of the response to HIV/AIDS.

This paper makes several recommendations aimed at ensuring greater, meaningful, and sustained involvement *of people who use drugs* in all aspects of Canada's response to HIV/AIDS, HCV, and illegal drug use, 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 groups of people who use drugs;

- participation by people who use drugs in all consultations, committees, and fora where policies, interventions, or services concerning them are planned, discussed, researched, determined, or evaluated, with adequate support, training, and financial compensation;
- efforts to increase involvement of people who use drugs in community-based organizations.

The paper also makes recommendations aimed at greater, meaningful, and sustained involvement of *people living with HIV* in all aspects of Canada's response to HIV/AIDS; and recommends that Canada should promote greater involvement of both people living with HIV and people who use drugs at the international level.

For further information
about this paper and the project on greater involvement of people who use drugs, contact the Canadian HIV/AIDS Legal Network at info@aidslaw.ca.

Copies of this paper, an accompanying booklet and manifesto by people who use drugs, can be retrieved from the website of the Canadian HIV/AIDS Legal Network via www.aidslaw.ca/Maincontent/issues/druglaws.htm, or ordered through the Canadian HIV/AIDS Information Centre at tel +1 613 725-3434 (toll free from within Canada: +1 877 999-7740), fax +1 613 725-1205; e-mail: aidssida@cpha.ca, web: www.aidssida.cpha. All documents are available in English and French.

A Note About Terminology

People who use drugs

Many participants in the consultations that were part of this project rejected the terms "drug user", "injection drug user" or "IDU" as stigmatizing. They urged the use of a term that, instead of reducing people to the fact that they use or inject drugs, identifies them as people first and foremost, clarifying that drug use or injection drug use is just one aspect of their lives. After a review of documents by organizations of people who use drugs, the term "people who use drugs" was chosen as preferable.[1] Other terms, such as "drug user" or "injection drug user" are used here only when citing from other documents using these terms.

Similarly, people living with HIV have opted for terminology that identifies their disease as one facet of their lives rather than something that defines them entirely, to the exclusion of other aspects of who they are as people. The terminology that in the early 1980s labelled HIV-positive people as "AIDS victims" has been rejected because "it implies helplessness, and dependence upon the care of others."[2] With the new term "person living with HIV/AIDS," a "new social and/or political identity was born, stressing that people who are HIV positive or have AIDS are not dying; they are living and they are able to take care of their own lives."[3]

"Nothing About Us Without Us"

The motto "Nothing About Us Without Us" has been used by the international disability movement, and a search for it on the internet will reveal a great number of initiatives and even a book carrying this title. The motto is meant to encapsulate

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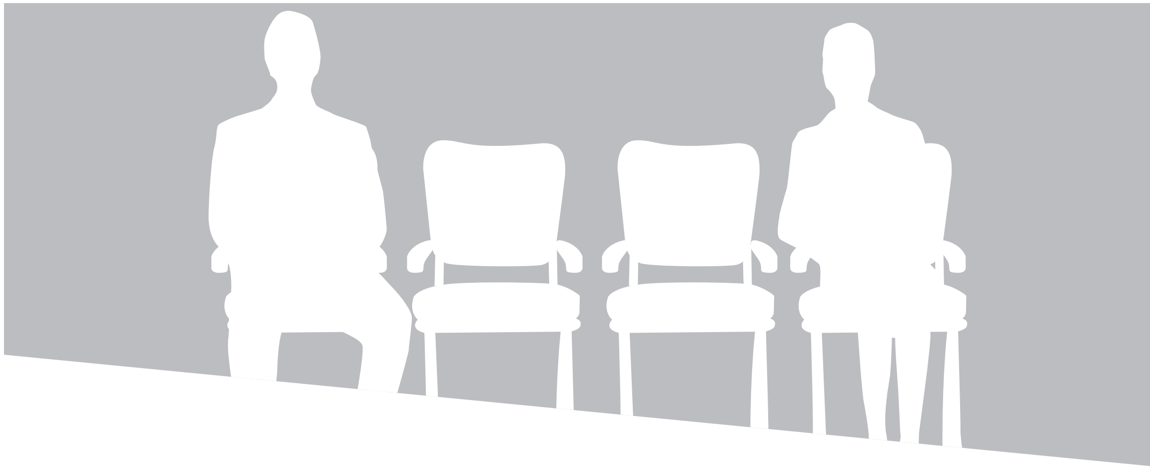
[1] This is similar to terminology used by the Australian Injecting & Illicit Drug Users League (AIVL). See, e.g., AIVL. *Policy Position: Discrimination.* Canberra: undated. Available via www.aivl.org.au (under "policy position statements").

[2] C Cornu, K Attawell. *The Involvement of People Living with HIV/AIDS in Community-based Prevention, Care and Support Programs in Developing Countries. A Multi-country Diagnostic Study.* Washington, DC, and London, UK: The Populations Council Inc and the International HIV/AIDS Alliance, 2003, at 22, with reference to the "Denver Principles." Available via www.aidsalliance.org/sw7442.asp.

[3] Ibid.

the "fundamental shift in perspective towards a principle of participation and the integration of persons with disabilities in every aspect of political, social, economic and cultural life." People who use drugs suggested that this motto be used for the title of this paper as well, symbolizing that no society can claim to be based on justice and equality as long as people who use drugs are not participating fully and meaningfully in shaping policy and developing and delivering the services that affect their lives.



Scope and Methods of the Project

Scope

This project was funded by the Public Health Agency of Canada under the Federal Initiative to Address HIV/AIDS and focuses on the involvement of people who use illegal drugs in *HIV/AIDS* policies, programs and services that affect their lives, and why this involvement is important. It is of equal relevance, however, to *hepatitis C* programs and services, since people living with or at risk of contracting HIV because of sharing drug injection equipment also often live with or are at risk of contracting HCV. In fact, prevalence of HCV is even higher among people who inject drugs than is prevalence of HIV.

The paper examines the greater involvement of people who use illegal drugs *whose drug use exposes them to the risk of contracting HIV and hepatitis C*. These are mainly people who inject drugs. However, certain other forms of drug use also expose people to the risk of HIV and HCV.[4] Therefore, the paper is concerned about the involvement of all people whose drug use exposes them to the risk of HIV and HCV, and uses the broader term "people who use illegal drugs."

Finally, the paper recognizes that many people who use illegal drugs face not only the risk of contracting HIV/AIDS and HCV, but also many other health issues, as well as structural issues that impact on their health. While dealing with these issues is outside the scope of the project, the paper acknowledges that there are many more reasons, beyond HIV/AIDS and HCV, why people who use illegal drugs need to be involved in social and political decision making on issues that affect their lives.

[4] For example, crack can increase sexual desire, which may lead to unsafe sex. Unprotected sex is also likely when sex is exchanged for crack. Crack smoking may also be a co-factor in transmission of HIV because it can cause severe burns or cuts on the mouth and lips, which can serve as a transmission site for HIV or other blood-borne infections during oral sex or when sharing pipes used for smoking crack. See: San Francisco AIDS Foundation. AIDS 101: Guide to HIV Basics, at www.sfaf.org/aids101/injection.html;. J Porter et al. Crack smoking methods as risk factors for HIV infection. 10th International AIDS Conference 1994; 10:391 (abstract no PD0170), at www.aegis.com/conferences/10wac/PD0170.html; S Faruque et al. Crack cocaine smoking and oral sores in three inner-city neighbourhoods. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 1996; 13: 87-92.

Methods

This project was undertaken in partnership with the Vancouver Area Network of Drug Users (VANDU, the largest Canadian organization of people who use drugs), CACTUS Montréal (which provides needles exchange and other services for people who use drugs and supports a local group of people who use drugs), and the British Columbia Centre for Excellence in HIV/AIDS (which has conducted several studies of organizations of people who use drugs and collaborates with VANDU on various projects).

At the outset of this project in early 2005, an advisory committee was established, with representation from the Canadian HIV/AIDS Legal Network, the project partners, AIDS-service organizations, and the federal and provincial/territorial governments. Nearly half the members were people who use drugs. The role of the committee was to:

- provide general advice regarding the project activities, methods and communications;
- review an outline of the paper and provide comments;
- review and comment on a draft of this paper, and the accompanying booklet and manifesto;
- provide input on the release and dissemination of these documents, and ideas for activities that could follow up on the recommendations presented here;
- champion the involvement of people who use drugs in responses to HIV/AIDS; and
- participate in the evaluation of the project.

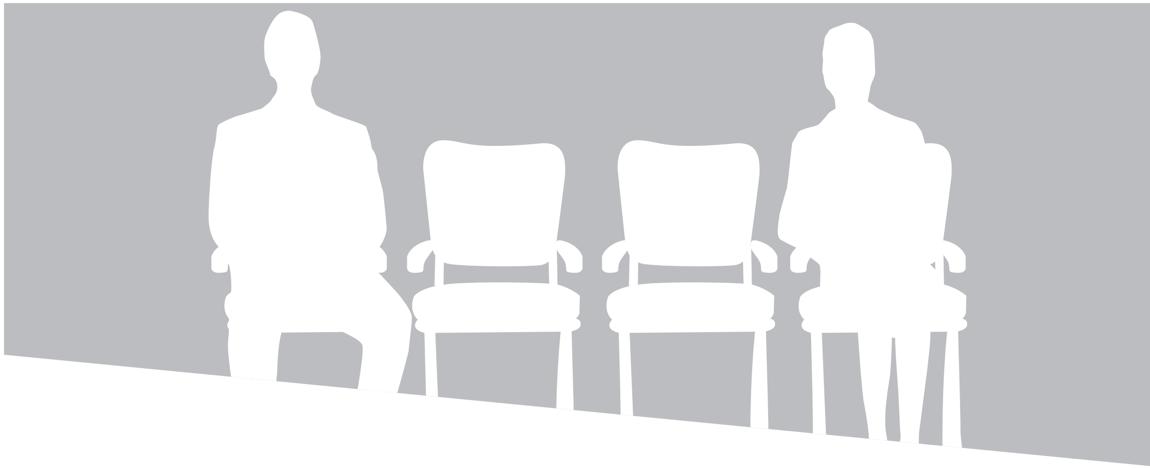
The author undertook a review of the literature (reports, journal articles, conference presentations, and government publications) on the involvement of people who use drugs. In addition to the input from the advisory committee, an extensive consultation process was undertaken, which included the following components:

- in-person consultations with people who use drugs in Vancouver, Montréal, and Toronto to obtain more input on what greater, meaningful involvement means and requires;
- in-person or telephone conference consultations with staff of organizations providing services to people who use drugs in Montréal and Peterborough;
- an in-person consultation with the Board of CACTUS Montréal, to obtain input from members of the Board of an agency providing services to people who use drugs;
- widely circulating a description of the project and a request for input, inviting individuals and organizations to answer a series of questions related to greater involvement of people who use drugs;
- distributing the project description and request for input to participants at the "National Forum on Crack Cocaine and HCV" (Ottawa, March 2005), and a meeting of harm-reduction professionals in Toronto;

- sending the project description and request for information and input to individuals and organizations internationally, to learn more about the experience in other countries;
- interviewing key informants, particularly from organizations of people who use drugs, at the 16th International Conference on the Reduction of Drug Related Harm (Belfast, March 2005) and soliciting feedback at a presentation of the project;
- presenting the project at a workshop with 60 participants from across Canada (Montréal, September 2005) and soliciting input from participants on a draft list of recommendations.

In total, nearly 100 people who use drugs from across Canada provided input during the consultations. Those who participated in consultations were offered a small honorarium to cover costs associated with attending, as well as food and soft drinks. Consultations lasted between 90 and 120 minutes, were conducted in English or French, and took place in agencies were people who use drugs regularly meet or access services. All participants provided informed consent to participate and to have the results disseminated in a variety of ways. The provision of informed consent was an active process achieved by discussing the research and consent process with participants, in order to ensure that all participants understood that their participation was wholly anonymous, and included participants' signature on an informed consent form. No identifying information was collected from any participant. In addition, 61 people responded by e-mail to the request for input, mainly on behalf of HIV/AIDS or other organizations providing services to people who use drugs. Fifteen addiction treatment or harm-reduction providers mailed in detailed responses to the request for input.

Before finalizing this paper, and the accompanying booklet and manifesto, the author obtained comments on drafts of these documents from members of the advisory committee and a group of peer reviewers. In addition, a number of the participants in the September 2005 workshop in Montréal provided comments on the recommendations in the draft paper. The author revised the documents taking these comments into account.



HIV and HCV among People Who Use Illegal Drugs: A Public Health and Human Rights Crisis

This section provides a brief overview of the extent of the epidemics of HIV and HCV among people who use illegal drugs. It shows that people who use drugs by injection continue to be over-represented among the people in Canada and many other countries who contract HIV and HCV. This not only represents a serious public health crisis, but also reflects the systematic failure to protect and promote the human rights of people who use illegal drugs.

Canada

> "Fundamental changes are needed to existing legal and policy frameworks in order to effectively address IDU as a health issue.… Injection drug use is first and foremost a health issue. Involving all Canadians in a just and compassionate response means that we must dig deep in our search for solutions and not stop until we find ones that work."[5]

The problem

In the early 1980s, the Canadian HIV epidemic was concentrated among gay men and other men who have sex with men. But by the early to mid-1990s there was an increase in the rate of transmission among people who inject drugs. As early as 1993, Canadian researchers warned that an explosive HIV epidemic among people

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[5] See, Health Canada. *Injection Drug Use and HIV/AIDS. Health Canada's Response to the Report of the Canadian HIV/AIDS Legal Network*. Ottawa: 2001 (www.aidslaw.ca/Maincontent/issues/druglaws.htm).

who inject drugs was looming.[6] Yet policy-makers and health authorities took little action. As a result, injection-related HIV and HCV transmission and overdose deaths reached epidemic proportions in many municipalities over the last decade. The prevalence of HIV infection among people who inject drugs increased dramatically, reaching 25 to 30 percent in some areas.[7] In 1996, it was estimated that 47 percent of new HIV infections were among people who inject drugs. Since then, this figure has decreased to about 30 percent.[8] But both incidence and prevalence of HIV remain unacceptably high among people who inject drugs, particularly among women[9] and Aboriginal[10] people. Prevalence of HCV is even higher. It has been estimated that injection drug use and needle sharing account for approximately 70 percent of all new HCV infections,[11] and that 240 000 to 250 000 people are infected with HCV in Canada.[12]

Access to highly-active antiretroviral therapies (HAART) for HIV-positive people who use drugs is a further challenge. The advent of HAART has led to substantial reductions in both AIDS-related morbidity and mortality, but inequitable access remains a challenge. People living with HIV who inject drugs have been found to have lower uptake of HAART compared to other HIV-positive people; one study in Vancouver found that only 40 percent of those eligible were receiving HAART in one population of people who use drugs.[13] Much more must be done to ensure that people living with HIV who inject drugs have equitable access to these life saving medications.

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[6] RS Remis, DW Sutherland. The epidemic of HIV and AIDS in Canada: current perspectives and future needs. *Canadian Journal of Public Health* 1993; 84: 34-38.

[7] See: Canadian HIV/AIDS Legal Network. Injection Drug Use and HIV/AIDS: The Facts. Montréal, 2005 (www.aidslaw.ca/Maincontent/infosheets.htm#isoidua); Public Health Agency of Canada. *HIV/AIDS Epi Updates, May 2005*. Ottawa: Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Public Health Agency of Canada, 2005 (www.phac-aspc.gc.ca/publicat/epiu-aepi/index.html).

[8] J Geduld et al. Estimates of HIV prevalence and incidence in Canada, 2002. *Canadian Communicable Diseases Review* 2003; 29(23): 197-206. See also Health Canada. *HIV and AIDS in Canada: surveillance report to June 30, 2003*. Ottawa: Health Canada, November 2003.

[9] PM Spittal et al. Risk factors for elevated HIV incidence rates among female injection drug users in Vancouver. *Canadian Medical Association Journal* 2002; 166(7): 894-899.

[10] KC Craib et al. Risk factors for elevated HIV incidence among Aboriginal injection drug users in Vancouver. *Canadian Medical Association Journal* 2003; 168(1): 19-24.

[11] Laboratory Centre for Disease Control. Hepatitis C prevention and control: a public health consensus. *The Canadian Communicable Diseases Report* 1999; 25 (suppl 1): 1-25.

[12] See the hepatitis C section of the website of the Public Health Agency of Canada: www.phac-aspc.gc.ca/hepc/hepatitis_c/index.html.

[13] E Wood et al. Adherence and plasma HIV RNA responses to highly active antiretroviral therapy among HIV-1 infected injection drug users. *Canadian Medical Association Journal* 2003; 169(7); E Wood et al. Prevalence and correlates of untreated HIV-1 infection in the era of modern antiretroviral therapy. *Journal of Infectious Diseases* 2003; 188: 1164-1170; E Wood et al. Antiretroviral medication use among injection drug users: two potential futures. *AIDS* 2000; 14(9): 1229-35.

Further Reading

For information about HIV/AIDS prevalence and incidence rates among people who inject drugs: Public Health Agency of Canada. *HIV/AIDS Epi Updates, May 2005*. Ottawa: Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control, Public Health Agency of Canada, 2005 (available via www.phac-aspc.gc.ca/publicat/epiu-aepi/index.html).

For a short overview of epidemiological data: "Injection Drug Use and HIV/AIDS: The Facts" (info sheet 1 in the Legal Network's series of info sheets on Injection Drug Use and HIV/AIDS), available at www.aidslaw.ca/Maincontent/infosheets.htm#isoidua.

For a 2-page summary of information about HCV among people who inject drugs: Health Canada. *Hepatitis C & Injection Drug Use*. Ottawa: 2001 (available via www.phac-aspc.gc.ca/hepc/hepatitis_c/library.html).

For more information about HCV and injection drug use: J Wiebe. *Profile of Hepatitis C & Injection Drug Use in Canada. A Discussion Paper*. Ottawa: Health Canada, 2000 (available at www.phac-aspc.gc.ca/hepc/hepatitis_c/pdf/careDiscCanada/).

What needs to be done?

> Despite the general insights provided by the Krever Inquiry, I see no reason to conclude that another preventable public health tragedy is impossible.... The same forces and ways of doing things that contributed to that tragedy are still deeply embedded in our public institutions, and in many of us. Indeed, another public health tragedy may now be underway.... A marginalized community (in this case injection drug users) is experiencing an epidemic of death and disease resulting not from anything inherent in the drugs that they use, but more from the ineffective and dysfunctional methods that characterize our attempts to control illicit drugs and drug users. There is the same unwillingness to carefully analyze the problem or to depart from traditional methods and conventional thought that was integral to the blood tragedy. There is a struggle for power and control over the issue between law enforcement and public health. There is a profound lack of understanding among decision-makers and many health professionals regarding the nature of the community and individuals at risk.[14]

There has been some recent progress in Canada in addressing drug-related harms. In particular, concerns about HIV among people who inject drugs led to the devolution of responsibility for methadone treatment systems to several provinces in the mid 1990s, resulting in an increase in the number of physicians prescribing methadone and the number of people receiving this treatment.[15] In addition, a

[14] J Skirrow. Lessons from Krever – A Personal Perspective. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 35-41, at 40-41 (www.aidslaw.ca/Maincontent/otherdocs/Newsletter/spring99/krever.htm).

[15] For more information please see: J Brands, B Brands, DC Marsh. The expansion of methadone prescribing in Ontario, 1996-1998. *Addiction Research* 2000, 8(5): 485-496; E McNinch. Bringing methadone treatment into the light. College of Physicians and Surgeons of Ontario, Members Dialogue 2000; Nov/December: 8-15; B Fischer et al. Methadone treatment in Ontario after the 1996 regulation reforms. Results of a physician survey. *Ann Med Interne* 2002; 153(7 Suppl):2S11-21; C Strike et al. Policy changes and the methadone treatment system for opioid dependence in Ontario, 1996 to 2001. *Journal of Addictive Diseases* 2005, 24 (1): 39-52.

medically supervised safer injecting facility has been in operation in Vancouver since September 2003,[16] and a trial of prescribed heroin has begun.[17] These measures were added to already existing needle exchange programs, which started in the late 1980s when the federal government, in collaboration with provincial and municipal governments, ensured that pilot projects would be funded.[18]

Nevertheless, Canada still lags behind countries such as the Netherlands, Australia, Germany, and Switzerland that have implemented an array of "low-threshold" harm reduction policies and programs.[19] Significantly, these countries have also worked to increase the meaningful involvement of people who use drugs in the response to HIV/AIDS, HCV, and injection drug use. In Canada, the full potential of harm reduction initiatives has not been realized because of restrictive policies, inadequate funding, the adverse effects of strategies focussed primarily on enforcing criminal laws prohibiting controlled drugs, and a lack of involvement of people who use drugs in shaping the policies and programs that affect their ability to protect their health.[20]

In 2001, the Auditor General of Canada reported that 95 percent of the federal government's expenditures related to illegal drugs was used for initiatives aimed at reducing the supply of drugs,[21] although it has been widely recommended that more money be spent on demand reduction and harm reduction initiatives. A great proportion of Royal Canadian Mounted Police (RCMP) expenditures on illegal drug issues are related to complex and resource-intensive operations aimed at reducing organized crime and the supply of illegal drugs.[22] Yet, a Canadian study found no evidence that large heroin seizures affected the price, purity, or perceived availability of heroin.[23]

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[16] E Wood et al. Changes in public order after the opening of a medically supervised safer injecting facility for illicit injection drug users. *Canadian Medical Association Journal* 2004; 171: 731 – 734; BC Centre for Excellence in HIV/AIDS. Evaluation of the Supervised Injection Site. Year One Summary. Vancouver: 17 September 2004; Vancouver Coastal Health and City of Vancouver. Vancouver Supervised Injection Site saving lives [press release]. Vancouver: 23 September 2004 (www.vch.ca/sis).

[17] S Brisette. Medical prescription of heroin – a review. *Canadian HIV/AIDS Policy & Law Review* 2001; 6(1/2): 1, 92-98 (www.aidslaw.ca/Maincontent/otherdocs/Newsletter/vol6nos1-22001/heroin.htm); Canadian Institutes of Health Research. North America's first clinical trial of prescribed heroin begins today [press release]. Vancouver, 9 February 2005 (www.cihr-irsc.gc.ca/e/26516.html).

[18] Canadian Public Health Association. Needle Exchange Programs in Canada. Savoir Faire: HIV Prevention News, 1994; CA Hankins. Syringe exchange in Canada: Good but not enough to stem the HIV tide. *Substance Use and Misuse* 1998, 33 (5): 1120-1146.

[19] B Fischer, J Rehm, T Blitz-Miller. Injection drug use and preventive measures: a comparison of Canadian and western European jurisdictions over time. *Canadian Medical Association Journal* 2000; 162(12): 1709-1713.

[20] The following analysis is, to a large extent, taken from T Kerr, W O'Briain. Drug Policy in Canada – The Way Forward. *Canadian HIV/AIDS Policy & Law Review* 2002; 7(1): 1, 27-32 (www.aidslaw.ca/Maincontent/otherdocs/Newsletter/vol7no12002/drugpolicy.htm). See also: E Wood et al. The healthcare and fiscal costs of the illicit drug use epidemic: The impact of conventional drug control strategies and the impact of a comprehensive approach. *British Columbia Medical Journal* 2003; 45(3): 130-136; T Kerr et al. Potential use of safer injecting facilities among injection drug users in Vancouver's Downtown Eastside. *Canadian Medical Association Journal* 2003; 169(8): 759-763; E Wood et al. The impact of a police presence on access to needle exchange programs. *J Acquir Immune Defic Syndr* 2003; 34(1): 116-118.

[21] Auditor General of Canada. *2001 Report of the Auditor General of Canada*, Chapter 11 – Illicit Drugs: The Federal Government's Role. Ottawa: Office of the Auditor General of Canada, 2001 (www.oag-bvg.gc.ca).

[22] Ibid.

[23] E Wood et al. Impact of supply-side policies for control of illicit drugs in the face of the AIDS and overdose epidemics: investigation of a massive heroin seizure. *Canadian Medical Association Journal* 2003; 168(2): 165-169. A recent Australian study showed that supply efforts may have some effect on the market: M Smithson et al. Impact of federal law enforcement on the supply of heroin in Australia. *Addiction* 2005; 100: 1110-1120.

Several experts have argued persuasively that the emphasis on prohibitionist drug laws, and the related law enforcement practices and incarceration, have exacerbated the problems of injection drug use and bloodborne diseases such as HIV/AIDS and HCV.[24] A criminalization response inevitably produces an illegal market, which results in increased crime, violence, corruption, and harm to individuals who use drugs and to the greater society.[25] The impact of incarceration on HIV/AIDS treatment and prevention has been demonstrated empirically. For example, incarceration has been found to be a statistically independent predictor of HIV infection and also a factor in the interruption of antiretroviral treatment.[26] With respect to HIV prevention, a Canadian study found police intervention to be a barrier to acquiring sterile needles – a disturbing finding, since difficulty obtaining needles has been found to be independently associated with sharing needles.[27] Another study found that a large police "crackdown" to control illegal drug use in Vancouver did not alter the price of drugs or the frequency of use, nor did it encourage enrolment in methadone treatment programs. It did, however, displace people who use drugs from the area of the crackdown into other areas of the city.[28] This study was followed by a qualitative study which found that the "crackdown" resulted in increases in 'rushed' injections, injecting in riskier environments, discouraged safer injection practices, and increased unsafe disposal of syringes. Because of the displacement of people who use drugs, the "crackdown" also impeded their contact with health workers and outreach services. Police activities also negatively influenced individuals' access to syringes and their willingness to carry syringes, and syringe confiscation was reported.[29]

Given the high rates of HIV and HCV infection among people who use drugs and the limited benefits and sometimes harmful consequences of an over-reliance on supply-control strategies, continuing to invest the vast majority of Canada's resources in such approaches is indefensible. As pointed out in a commentary in the *Canadian Medical Association Journal*, "these policies disregard the available scientific evidence, and in so doing directly contribute to the harms associated with illegal drug use, including the spread of HIV/AIDS. Moreover, they contravene human rights obligations under international law."[30]

In the age of HIV and HCV, governments must, first and foremost, promote public health approaches to dealing with problems of illegal drug use. This requires

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[24] S Brochu. Estimating the costs of drug-related crime. Paper prepared for the Second International Symposium on the Social and Economic Costs of Substance Abuse, Montebello, October 2-5, 1995. E Oscapella. *How Canadian Laws and Policies on "Illegal" Drugs Contribute to the Spread of HIV Infection and Hepatitis B and C.* Toronto: Canadian Foundation for Drug Policy, 1995.

[25] Kerr & O'Briain, supra, note 20, at 30.

[26] A Palepu et al. Adherence and sustainability of antiretroviral therapy among injection drug users in Vancouver. *Canadian Journal of Infectious Diseases* 2001; 12(Suppl B): 221B. MW Tyndall et al. Intensive injection cocaine use as a primary risk factor of HIV seroconversion among polydrug users in Vancouver. *Canadian Journal Infectious Diseases* 2001; 12(Suppl B): 70B.

[27] E Wood et al. Unsafe injection practices in a cohort of injection drug users in Vancouver: could safer injecting rooms help? *Canadian Medical Association Journal* 2001; 165(4): 405-410.

[28] Wood et al (2003), supra, note 20.

[29] W Small et al. Impacts of intensified police activity on injection drug users: evidence from an ethnographic investigation. *International Journal of Drug Policy* (in press).

[30] R Elliott et al. Reason and rights in global drug control policy. *Canadian Medical Association Journal* 2005; 172(5): 655-656.

acknowledging that supply-control strategies are limited and can sometimes be counter-productive, and that approaches to drug treatment based on abstinence are also limited. It requires a willingness to expand harm reduction programming as part of the continuum of services. For example, safer injection facilities are needed in other cities beyond Vancouver, prescription heroin should become accessible quickly after the conclusion of the trial currently underway, and prisoners need access to sterile syringes.[31] In addition, as recognized by Health Canada, "[f]undamental changes are needed to existing legal and policy frameworks in order to effectively address IDU as a health issue,"[32] rather than treating drug use primarily as a criminal law issue.

"It is not people who use drugs who are broken, but the system that fails to address their needs."

– consultation participant

People who use illegal drugs need to be meaningfully involved in all these initiatives, for the reasons outlined in the sections that follow – and this means challenging the dominant cultural attitude of stigma and discrimination that contributes significantly to many of the problems presently facing people who use drugs. In much of the world, people who use drugs are regarded as criminals deserving punishment.[33] This attitude has entrenched reliance on counter-productive and human rights-unfriendly law enforcement measures and prevented the implementation of harm reduction services of proven effectiveness.

Beyond this, much investment and coordination are needed to address the complex needs of people who use illegal drugs as well as the factors that lead to problematic substance use in the first place. To date, there has been little if any coordinated effort in Canada to address key determinants of problematic substance use such as poverty, homelessness, childhood abuse, mental illness, and cultural dislocation. Any meaningful change in drug use and patterns will necessarily require changes in social policy.[34] This in turn will require high levels of cooperation and coordination among federal departments. Until such action is taken, Canada's approach to illegal drug use will remain a "band-aid" approach.

Collectively, these changes will require increased funding, leadership, and coordination. An effective national strategy is needed, one that provides clear direction to all levels of government and other stakeholders, and incorporates

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[31] R Lines et al. *Prison Needle Exchange: Lessons from a Comprehensive Review of International Evidence and Experience.* Montréal: Canadian HIV/AIDS Legal Network, 2005 (www.aidslaw.ca/Maincontent/issues/prisons.htm); R Lines et al. Taking action to reduce injecting drug-related harms in prisons: The evidence of effectiveness of prison needle exchange in six countries. *International Journal of Prisoner Health* 2005; 1(1): 49-64

[32] Health Canada (2001), supra, note 5.

[33] A Wodak. Drug laws. War on drugs does more harm than good. *BMJ* 2001; 323(7317): 866.

[34] BK Alexander. The roots of addiction in free-market society. Vancouver: Canadian Centre for Policy Alternatives (www.cfdp.ca).

specific performance targets. And one that includes specific goals, objectives, activities and funding related to greater involvement of people who use illegal drugs.

Further Reading

For an assessment of what changes are needed to Canadian drug policy and practice in order to be better able to respond to the HIV and HCV epidemics: Canadian HIV/AIDS Legal Network. *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues*. Montréal: 1999. Available via www.aidslaw.ca/Maincontent/issues/druglaws.htm. At the same web address, see also: *Health Canada. Injection Drug Use and HIV/AIDS. Health Canada's Response to the Report of the Canadian HIV/AIDS Legal Network*. Ottawa: 2001. This is Health Canada's official response to the Network's report, which acknowledges that "injection drug use is first and foremost a health issue," and that "fundamental changes are needed to existing legal and policy frameworks in order to effectively address IDU as a health issue."

For a series of 13 info sheets with brief summaries of the key issues concerning HIV/AIDS, IDU, drug policy, and human rights: Canadian HIV/AIDS Legal Network. Injection Drug Use and HIV/AIDS: Info sheets (3rd, revised and updated edition). Montréal: 2005.

For a 17-page summary of drug policy developments in Canada: R Jürgens. Facing up to an epidemic: Drug policy in Canada. Montréal: Canadian HIV/AIDS Legal Network, 2004. Available via www.aidslaw.ca/Maincontent/issues/druglaws.htm

For a provincial harm reduction guide: BC Ministry of Health. (2005). *Harm Reduction: A British Columbia Community Guide*. Victoria: BC Ministry of Health. Available at: www.healthservices.gov.bc.ca/prevent/substance.html

Internationally

Worldwide, there are more than 13 million people who inject illegal drugs, and in some regions more than 50 percent of them are infected with HIV. Today, drug injecting with contaminated equipment (including needles, cookers, filters, water) is the major mode of HIV transmission in many countries in Europe, Asia and Latin America, and is a significant driver of the HIV epidemic in North Africa and the Middle East.[35] In recent years, unsafe drug injection has led to the world's fastest spreading HIV epidemic, in Eastern Europe and Central Asia.[36] HCV prevalence estimates range from 50 to 100 percent infection rates among drug injecting populations.[37] It is estimated that 170 million people are infected with HCV around the world.[38]

[35] C Aceijas et al. Global overview of injecting drug use and HIV infection among injecting drug users. *AIDS* 2004; 18: 2295-2303.

[36] S Strathdee, K Poundstone. The international epidemiology and burden of disease of injection drug use and HIV/AIDS. In: J Rehm, B Fischer and H Emma (eds). *Reducing the risks, harms and costs of HIV/AIDS and injection drug use (IDU): A synthesis of the evidence base for development of policies and programs*. Health Canada, 2003.

[37] E Finch. HCV policies – where to go? *International Journal of Drug Policy* 1998; 9: 1-2.

[38] For more information, see www.phac-aspc.gc.ca/hepc/hepatitis_c/index.html.

As in Canada, multiple factors impede effective responses internationally to the linked epidemics of injection drug use, HIV and HCV. Criminal prohibitions on drugs remain the dominant legal approach, as embodied in the three UN drug control conventions. The conventions themselves, and the views expressed by bodies such as the International Narcotics Control Board (the "quasi-judicial" body that monitors states' compliance with these treaties), are invoked, often inaccurately, by governments unwilling to implement sound harm reduction measures. Notwithstanding the documented health benefits of harm reduction measures, they remain contentious, and some powerful international actors actively oppose political or financial support for harm reduction. There has to date been little recognition of the human rights abuses faced by people who use drugs as a result of the "war on drugs" – abuses which are not only in violation of international law but have been shown to fuel the spread of HIV.[39]

At the global level, strong political leadership is needed both from states that have successfully implemented harm reduction, as well as from international organizations such as UNAIDS, the World Health Organization and the UN Office on Drugs and Crime, which should advocate for harm reduction measures and adopt official policy positions to this effect.[40] The UN Commission on Human Rights needs to affirm explicitly the human rights of people who use drugs, including the rights to access HIV prevention and care services. States that recognize the value of harm reduction approaches need to state their support officially and collectively in international fora. If necessary, they need to withdraw collectively their support for the international drug control conventions. The UN General Assembly Special Session on Drugs in 2008 will be a key moment for shaping global drug control policy. In the face of widescale human rights abuses, and the evidence that the overriding emphasis on prohibition is damaging to public health, there is a need for states, international organizations and civil society organizations to spur a fundamental re-orientation in global drug policy. The involvement of people who use drugs, including those living with HIV, will be critically important in this process.

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[39] E.g., see the reports by Human Rights Watch, available via www.hrw.org: *Not Enough Graves: The War on Drugs, HIV/AIDS, and Violations of Human Rights* [Thailand], 2004; *Lessons Not Learned: Human Rights Abuses and HIV/AIDS in the Russian Federation*, 2004; *Injecting Reason: Human Rights and HIV Prevention for Injection Drug Users*, 2003; *Fanning the Flames: How Human Rights Abuses are Fueling the AIDS Epidemic in Kazakhstan*, 2003; *Abusing the User: Police Misconduct, Harm Reduction and HIV/AIDS in Vancouver*, 2003.

[40] WHO has produced useful technical papers highlighting the evidence in support of harm reduction measures: e.g., *Effectiveness of Sterile Needle and Syringe Programming in Reducing HIV/AIDS Among Injecting Drug Users*. Geneva: WHO, 2004 (www.who.int/hiv/pub/prev_care/en/effectivenesssterileneedle.pdf).

Further Reading

For a discussion of the impact of the prohibitionist approach to illegal drug use and an assessment of strategies for reforming global drug policy: R Elliott. Drug control, human rights, and harm reduction in the age of AIDS. *HIV/AIDS Policy & Law Review* 2004; 9(3): 86-90 (www.aidslaw.ca/Maincontent/otherdocs/Newsletter/vol9no32004/bangkok04-08e.htm).

For an analysis of how the emphasis on prohibition, and the stigmatization and criminalization of people who use drugs, undermines effective responses to HIV/AIDS: D Wolfe, K Malinowska-Sempruch. *Illicit Drug Policies and the Global HIV Epidemic: Effects of UN and National Government Approaches*. International Harm Reduction Development, Open Society Institute, 2004. Available via www.soros.org/initiatives/ihrd/articles_publications/publications.

For a collection of essays by people working in the area of harm reduction, drug policy and human rights: K Malinowska-Sempruch, S Gallagher (eds). *War on Drugs, HIV/AIDS and Human Rights*. International Debate Education Association, 2004.

For a summary of evidence supporting harm reduction initiatives: N Hunt, M Trace & D Bewley-Taylor. *Reducing Drug Related Harms to Health: An Overview of the Global Evidence*. Beckley Foundation Drug Policy Programme, 2005 (www.internationaldrugpolicy.net/reports/BeckleyFoundation_Report_04.pdf).

AC Ogborne, V Carver, J Wiebe. *Harm Reduction and Injection Drug Use: an international comparative study of contextual factors influencing the development and implementation of relevant policies and programs*. Ottawa: Health Canada, 2001.Via www.phac-aspc.gc.ca/hepc/hepatitis_c/library.html.

Greater Involvement of People Living with HIV (GIPA)

The social and organizational response to the HIV/AIDS epidemic has been profoundly affected by the growth of a self-identified community of people living with HIV demanding a say in the development of policies and the delivery of services. Early in the history of the epidemic, those who were first associated with AIDS – gay men in North America and Europe – became actively involved in community-based education and support services, and challenged inadequate responses to their needs. Policy-makers began to recognize the importance and benefits of involving people living with HIV in formulating policy and delivering services. At the 1994 Paris AIDS Summit, 42 national governments, including Canada, formally recognized the principle of the "Greater Involvement of People Living with HIV/AIDS" (GIPA), declaring that GIPA is critical to ensuring that responses to the HIV/AIDS epidemic are ethical and effective.

In Canada, a draft "Canadian Declaration of Rights for People Living with HIV/AIDS" was developed by the participants in the 1996 HIV Forum of the Canadian AIDS Society and adopted in 1997.[41] GIPA is now firmly established, at least in principle, in Canada's response to the epidemic. This is reflected in government plans and in statements made by politicians and in the inclusion of people living with HIV in government consultations and on advisory committees. Canada was one of only a few countries to include a person living with HIV on its delegation to the United Nations General Assembly Special Session on HIV/AIDS in 2001. Community-based AIDS organizations also tend to have policies that guarantee that people living with HIV are represented on boards of directors and strive to include them in the development, implementation, and evaluation of most projects and programs.

While there is a strong commitment to greater and meaningful involvement of people living with HIV in the Canadian response in principle, in practice much

[41] Reproduced in the *Canadian HIV/AIDS Policy & Law Newsletter* 1996; 3(1): 9 (www.aidslaw.ca/Maincontent/otherdocs/Newsletter/October1996/07DECLARE.html).

remains to be done. Canada's new action plan on HIV/AIDS (*Leading Together*)[42] asserts this need in an implicit recognition that a relatively small number of people living with HIV are currently involved at policy- and decision-making levels, often without adequate compensation and accommodation of their needs. Despite Canada's stated commitments, too often "[p]rofessionals may retain control over decisions, and committees on which community representatives sit may not be given much decision-making authority.[43] Often the same people are involved in many different activities and on many committees, because of their skills, experience, and willingness to give a lot of their time and energy, but for a number of reasons few new faces are getting involved. In addition, there are few Aboriginal people, women, youth, and people who use drugs among those involved. And there still is no national organization of people living with HIV.

In many ways, the issue of greater involvement of people who use illegal drugs is connected to GIPA. In countries such as Canada, where people who use or have used illegal drugs represent a significant proportion of people living with HIV, one can no longer claim that the goal of greater involvement is realized without ensuring greater involvement of people who use illegal drugs. Efforts to ensure the greater involvement of people who use drugs therefore also need to consider the larger issue of involvement of people living with HIV.

Further Reading

For a copy of "The Denver Principles" (the first manifesto of people living with HIV/AIDS): www.aegis.com/pubs/bala/1998/Ba980509.html.

For a set of principles that community-based organizations should adopt to foster GIPA:J Cabassi. *Renewing our voice. Code of good practice for NGOs responding to HIV/AIDS*. Geneva: The NGO HIV/AIDS Code of Practice Project, 2004. Available at www.ifrc.org/what/health/hivaids/code/.

For more information on a study of involvement of people living with HIV, and recommendations about what to do to increase involvement: C Cornu, K Attawell. *The Involvement of People Living with HIV/AIDS in Community-based Prevention, Care and Support Programs in Developing Countries. A Multi-country Diagnostic Study*. Washington, DC, and London, UK: The Populations Council Inc and the International HIV/AIDS Alliance, 2003. Available via www.aidsalliance.org/sw7442.asp.

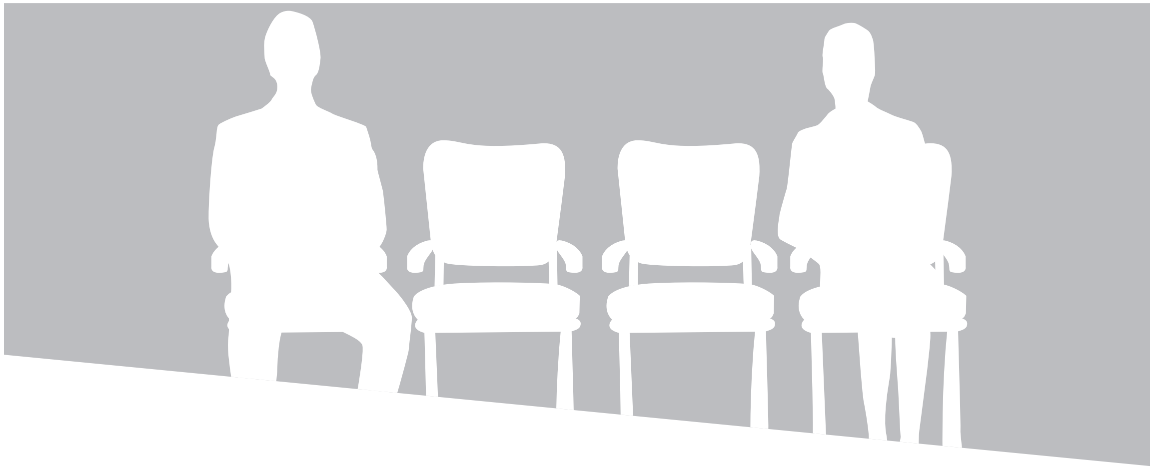
For the best Canadian study on GIPA: CM Roy, R Cain. The involvement of people living with HIV/AIDS in community-based organizations: contributions and constraints. *AIDS Care* 2001; 13(4): 421-432 (www.socsci.mcmaster.ca/healthst/emplibrary/roy_cain_involvement.pdf).

[42] *Leading Together:Canada Takes Action on HIV/AIDS.* Available via the website of the Federal Initiative to Address HIV/AIDS in Canada (www.phac-aspc.gc.ca/aids-sida/hiv_aids/)

[43] CM Roy, R Cain. The involvement of people living with HIV/AIDS in community-based organizations: contributions and constraints. *AIDS Care* 2001; 13(4): 421-432, at 423.

For a document addressing issues related to involvement of HIV-positive women: *Participation and Policy Making: Our Rights*. London: The International Community of Women Living with HIV/AIDS, 2004. Available via www.icw.org.

For a short presentation on the impact people living with HIV have had on the response to HIV/AIDS: John-Manuel Andriote. How people with AIDS changed the world. Closing keynote address. “Staying Alive” Conference, Denver, Colorado, 17 August 2003.
www.andriote.com/images/AIDS_and_Culture--Denver_Keynote.pdf



Greater Involvement of People Who Use Illegal Drugs

> Health developments in communities are made not only for but with and by the people.[44]

> There is very little IDU involvement in the overall response to the AIDS epidemic.[45]

> While some in the community may view people who use or have used drugs as having very little if anything to offer governments, services and the community, in reality, nothing could be further from the truth.[46]

This chapter provides a brief history of the involvement of people who use drugs in the response to HIV/AIDS, HCV, and injection drug use, in Canada and internationally. It then outlines why greater involvement of people who use drugs is important. This is followed by recommendations about what community-based organizations and governments in Canada should do to ensure that people who use drugs are meaningfully involved in all aspects of Canada's response to HIV/AIDS, HCV, and illegal drug use.

History of involvement of people who use drugs

> That IDUs were one of the last groups to respond to the community development model was perhaps a reflection of the degree to which they had been disenfranchised by the prevailing ethos of demonizing of drug use.[47]

In some countries, organizations of people who use illegal drugs have existed for some time and pre-date the HIV/AIDS epidemic. The 1970s saw the "spontaneous"

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[44] World Health Organisation. *Targets for Health for All.* Geneva: 1986.

[45] Declaration from "Injection Drug Use and HIV Meeting" at 29 of "The Dawn of New Positive Leadership Conference Report, 11th International Conference for People Living with HIV/AIDS, 2003.

[46] Australian Injecting & Illicit Drug Users League (AIVL), at www.aivl.org.au/about.html.

[47] N Crofts et al. A History of Peer-Based Drug-User Groups in Australia. *Journal of Drug Issues* 1993; 25: 599-616.

formation of two such organizations. The first was the "Junkie Bond" developed by people who use drugs in the Netherlands to lobby politicians and the media about the treatment and misrepresentation of people who use drugs. The second was the "Committee of Concerned Methadone Patients and Friends Inc." (CCMP), formed in 1973 by methadone patients who affirmed the importance of advocacy for those in drug treatment programs.[48] In Australia, a Self-Help and Substance Use group formed in 1986 around pre-existing self-help groups, just before HIV/AIDS emerged as an issue affecting people who inject drugs in that country.[49] But it was the HIV epidemic that led to the significant development of organizations of people who use drugs.

The HIV and HCV epidemics have highlighted the urgent need to involve people who use drugs, as well as the importance of "understand[ing] more about how the injecting drug user community functioned, in order to understand the nature of risk and to plan interventions."[50] In addition to forming their own organizations, people who use drugs have also been instrumental in establishing the first harm reduction programs in a number of countries, including the very first needle and syringe exchange program, which was set up as a hepatitis B prevention measure by people who use drugs.

Australia – A successful example of involvement

> The advent of HIV and the discovery of AIDS in the early 1980's meant that, in Australia, there was a radical rethinking of the concept of the Australian User. The Australian User was revealed as someone who was educatable, who lived in communities of like-minded individuals … who could play a role in Government policy, who could be profitably consulted and who could be employed through the state.… Australia is the only developed country to have avoided the so-called second wave of HIV infection. This is a result of a policy which allowed drug users to play a role in preventing the transmission of HIV infection. It was the result of policy that allowed drug users to become human again.[51]

In Australia, more so than in most other countries, groups of people who use drugs have received support and have been successful in having a say in the response to HIV/AIDS. A representative of people who use drugs was included on the advisory committee that developed a three-year National AIDS Strategy through 1988-89. The consultations that were arranged state-by-state during the development of this Strategy involved representatives of groups of people who use drugs as well, which by then were starting to achieve organizational prominence and an effective voice of their own. Australia's National AIDS Strategy recognized that no effective policies could be implemented by the government and medico-scientific community without the close and direct involvement of at-risk groups themselves; and that people who actively use drugs can form, manage, and staff viable organizations. It recommended

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[48] National Treatment Agency. *A Guide to Involving & Empowering Drug Users. Public Draft 2.* London (UK): no date, at 4.10. Available via www.canadianharmreduction.com/ readmore/facts_southwell.pdf.

[49] Crofts et al, supra, note 47.

[50] National Treatment Agency, supra, note 48, section 1.3, with reference to A Neaigus et al. The relevance of drug injectors' social and risk networks for understanding and preventing HIV infection. *Social Science Medicine* 1993; 38(1).

[51] The Australian Injecting & Illicit Drug Users' League. *Policy Position: Drug User Organisations.* Canberra: no date. Available via www.aivl.org.au/.

funding for such organizations at both the state and national levels. The Strategy redefined the relationship between government and people who use drugs, who were perceived by the Strategy to be individuals with a capacity to educate and to be educated, to form organizations, to manage funding, to represent their community, to serve on government consultative committees, and to be employable in a variety of roles as people who use drugs. According to Crofts et al, "[t]his perception, necessitated by the fundamental commitment to community involvement … was the basis for the success of the Australian National AIDS Strategy."[52]

In Australia, people who use drugs run a wide variety of programs themselves:

> They have had a real and often dominant influence on the development of policy in relation to harm reduction. User groups have run needle distribution and exchange programs that are among the best in the country; they have produced the most imaginative and appropriate educational material in this field; they have initiated and actively participated in research; they have provided structured access to informants for policy and program development; and have been active partners in this development…. User groups have been agents of social change who have altered the landscape in relation to every aspect of our perception of injecting drug use in Australia.[53]

There is also a national organization that represents the interests of state and territory organizations, as well as of people who use drugs on issues of national significance. The Australian Injecting & Illicit Drug Users League (AIVL) has developed a large number of ground-breaking policies on involvement of people who use drugs, and provided input on government policy on many occasions, consistently advocating for the rights of people who use drugs.

Crofts et al pointed out that groups of people who use drugs in Australia have not been without their problems. However, they add:

> [T]he majority of these problems are familiar to anyone who has worked with community development of any disenfranchised group, rather than being unique to IDUs. In examining the history and functioning of user groups, the fact that drugs are involved has continually blinded government leaders and concerned citizens from seeing the humanity of users, and the considerable civic responsibility and work they have successfully carried out.

These authors conclude that the existence of user groups in Australia has been a significant factor in the country's success in HIV prevention. According to them, these groups have been important at many levels, not the least of which has been in an advisory capacity to government, especially in the development of educational and harm-reduction programs. This success has been based on a willingness of government to be advised and to provide funding.

Similarly, Burrows observes that the "NSW [New South Wales] Users and AIDS Association "has been successful in helping achieve a low HIV infection rate for

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[52] Crofts et al (1993), supra, note 47.

[53] Ibid.

injecting drug users in Australia."[54] He gives the example of the public hearings evaluating the National AIDS Strategy: two people who use drugs advocated for the establishment of safer injection facilities, giving a "graphic account of scoring on the streets, grabbing a syringe and needle from the closest source, mixing up under a bush or in an alley, looking around constantly for the police, missing and finally hitting whatever vein could be found quickly, injecting, tidying up and disposing of equipment.… The evaluation panel may not have agreed with the views expressed at the meeting, but the existence of an organisation like the NSW Users and AIDS Association meant that the panel could hear first-hand about the effects of the national strategy and of national and state drug policies."[55]

Other countries

Since the beginning of the HIV/AIDS epidemic, people who use illegal drugs have formed formal organizations in many other countries.[56] By 1994, such organizations existed in at least 11 European countries (Germany, The Netherlands, the United Kingdom, Norway, Denmark, Slovenia, France, Belgium, Italy, Lithuania, and Spain), and in New Zealand and the United States.[57] As of 2005, such organizations existed on every continent with the exception of Africa.

In the **Netherlands**, people who use drugs have a long history of organizing to influence political and social decision-making.[58] The onset of HIV/AIDS resulted in government funding for groups for HIV/AIDS prevention work and for assistance with drug-related problems. In the 1990s, the National Interest Group of Drug Users (LSD) was formed with funding from the Ministry of Health, Welfare and Sport. LSD provides a national voice for people who use drugs to government, drug services, the judiciary, and the medical profession. As of 2001, there were about 20 local groups across the Netherlands initiated and supported by LSD. These groups have two major roles: the promotion of the interests of people who use drugs and the direct provision of services to them. The latter may include providing a drop-in service, outreach work, education about safe injecting and healthy behaviours, and services for specific target groups such as older people who use drugs or women.

In the **United Kingdom**, the existence of groups of people who use drugs remained somewhat haphazard for a long time, with individual groups coming and going. Today, however, service user involvement is understood to be a fundamental, underlying principle in the planning and delivery of public services to meet the needs of all sections of the community. It is a priority in all areas of health and

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[54] D Burrows. Choices for injecting drug users and changing drug policies. In: V Brown, G Preston (eds). *Choice and Change – Ethics, Politics and Economics of Public Health*. Public Health Association of Australia: Canberra, 1993: 219-223, at 219.

[55] Ibid.

[56] SR Friedman, W de Jong, A Wodak. Community development as a response to HIV among drug injectors. *AIDS 92/93 – A Year in Review* 1993; 7(Suppl 1): S263-S269; Wodak A et al. The global response to the threat of HIV infection among and from injecting drug users. *AIDS Targeted Information 1998*; 12(6): R41-R44.

[57] D Burrows. Establishing an international communications network for injecting drug user groups. *Health Promotion Journal of Australia* 1994; 4(1): 46-48.

[58] See AC Ogborne, V Carver, J Wiebe. *Harm Reduction and Injection Drug Use: an international comparative study of contextual factors influencing the development and implementation of relevant policies and programs*. Ottawa: Health Canada, 2001. Available via www.phac-aspc.gc.ca/hepc/hepatitis_c/library.html.

social care provision, and there are statutory requirements on agencies to ensure that users are actively involved in policy, planning and decision-making. Under the *NHS and Social Care Act 2001*, every National Health Services (NHS) body, including drug treatment services, has a statutory duty to consult and involve patients and the public in its activities. The National Treatment Agency for Substance Misuse (NTA) declares that it

> wants to build an equal partnership with drug users and treatment service users, because we recognise that users have the right to become involved in activities that affect their health and well-being. We also respect the unique expertise and experiences of drug users and know the health, esteem and other personal benefits which involvement can bring.[59]

The NTA is developing a guide for involving users[60] and is producing a strategy on how the NTA will involve service users. It has backed an initiative to rekindle the idea of a national forum – the so-called National User Advisory Group, and an increasing number of local user groups exist around the country.[61] In London, a "London Drug User Involvement Project" was aimed at "improved involvement of all drug users in planning, policy-making and decisions."[62] The project piloted, tested and outlined different approaches to improving the level and impact of user participation. It published a report that provides practical tools and approaches to inform the development of effective user and community participation.[63]

In **France**, an organization of people who use drugs (Auto-support et réduction des risques parmi les usagers de drogues, ASUD) was formed in 1992, with the main goal of changing drug policy and participation of people who use drugs in the development of drug policy.[64] Today, in addition to the main office in Paris, ASUD has a presence in at least eight other cities in France.

In **Switzerland**, self-help among people who use drugs is encouraged under the confederation's four-pillar drug policy.[65]

In the **USA**, extreme stigmatization and repression has made organizing of people who use more difficult, although it has nevertheless taken place.[66] In New York City, there is a "user union" doing advocacy around HCV, and a group of people who use drugs has also existed in Philadelphia for some time. Unlike in some other countries, the history of the harm reduction movement in the US is "bound up with

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[59] See the section on "service user involvement" on the NTA website: www.nta.nhs.uk/frameset.asp?u=http://www.nta.nhs.uk/programme/national/user.htm

[60] Correspondence received from Allan Johnstone, Programme manager - users and carers, NTA, on 5 September 2005 (on file with author).

[61] See the articles in the May/June 2005 issue of *druglink* (available via www.drugscope.org.uk/druglink/default.asp).

[62] *Lessons Learned; some approaches, tools and good practice for improving drug user involvement.* London: Greater London Authority, February 2005. Available via www.london.gov.uk/gla/publications/health.jsp#lessons.

[63] Ibid.

[64] See M Jauffret. *L'auto-support des usagers de drogues en France. Groupe d'entraide et groupes d'interêt.* Paris: Groupement de Recherche Psychotropes, Politique et Société, CNRS, n° 6, 2000 (via http://cesames.org/)for a detailed description of the history and activities of ASUD.

[65] Ogborne, Carver, Wiebe, supra, note 58.

[66] SM Friedman et al. Urging others to be healthy: "Intravention" by injection drug users as a community prevention goal. *AIDS Eduction and Prevention* 2004; 16(3): 250-263.

user participation" and has included user involvement.[67] People who use drugs have also been very much involved in needle exchange programs where they exist.[68]

In **Eastern Europe and Central Asia**, the International Harm Reduction Development program (IHRD) of the Open Society Institute has supported the development of organizations of people who use illegal drugs, through direct financial contributions, technical assistance, and other means. IHRD supports these programs

> because we believe that drug users are their own best advocates, and have a vital role to play in defining the health, social, legal, and research policies that affect them. Underlying this assumption is both a basic commitment to users' rights, and the visible success of user organizations in Asia, Australia, Eastern and Western Europe and North America in recent years.[69]

There have also been attempts to establish an **international communications network** for groups of people who use drugs. In March 1992, more than 50 participants from three continents attended the 1st World Meeting of Injecting Drug User Groups in Melbourne, held at the conclusion of the 3rd International Conference on the Reduction of Drug-related Harm. Participants agreed to set up the International Drug Users Network (IDUN), to assist groups of people who use drugs to exchange ideas, discuss effective strategies and programs and provide help to countries and regions attempting to set up groups of people who use drugs or needle exchanges. However, the problems of attempting to operate an international network without any funding soon became apparent. IDUN's activities continued for a number of years,[70] and people who use drugs have continued to meet informally on the occasion of the yearly International Conference on the Reduction of Drug Related Harm.

Canada: A slow beginning

In 1997, in response to the emerging health crisis among people who use drugs and government inaction, individuals gathered in Vancouver to form an organization run by people who use drugs. This group eventually became known as the Vancouver Area Network of Drug Users (VANDU). It is the most active and largest of a number of support and advocacy groups of people who use drugs in Canada. Its work was described extensively elsewhere[71] and summarized in the booklet published in conjunction with this paper.

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[67] Correspondence received from Matt Curtis, International Harm Reduction Programme, on 27 September 2005 (on file with author).

[68] AR Henman et al. Injection drug users as social actors: a stigmatized community's participation in the syringe exchange programmes of New York City. *AIDS Care* 1998; 10(4): 397-408; AR Henman et al. From ideology to logistics: the organizational aspects of syringe exchange in a period of institutional consolidation. *Subst Use Misuse* 1998; 33(5): 1213-1230.

[69] International Harm Reduction Development Program. Grant Program Announcement: Drug Users' Health and Rights in Eastern Europe and Central Asia. On file with author.

[70] Burrows (1994), supra, note 57, at 46-47; D Burrows. Towards an international union of injecting drug users. [Australian] *National AIDS Bulletin* July 1992: 29-31; D Burrows. Users unite: Injecting drug use research, reports and advocacy at Berlin. [Australian] *National AIDS Bulletin* July 1993: 14-17.

[71] T Kerr et al. *Responding to an Emergency: Education, Advocacy and Community Care by a Peer-Driven Organization of Drug Users. A Case Study of Vancouver Area Network of Drug Users (VANDU).* Ottawa: Health Canada, 2001 (www.phac-aspc.gc.ca/hepc/hepatitis_c/library.html).

In 2003, VANDU received funding from the HIV/AIDS Program of the Public Health Agency of Canada to build capacity in other communities across Canada to form and sustain organizations of people who use drugs.[72] As a result of this effort, for example, a group of people who use drugs has started to meet regularly in Montréal, but remains small and has no dedicated resources. In 2005, with funding from the Hepatitis C Program of the Public Health Agency of Canada, a task group of the Non Prescription Needle Use Consortium in Alberta concluded that local user groups should be established in Edmonton and Calgary and that a provincial user group should also be established and meet at least two times per year.[73] Funding has since been provided by the Hepatitis C Program for the formation of the two groups in Calgary and Edmonton, and for a meeting of a provincial group at the next Alberta Harm Reduction Conference in Lethbridge in February 2006.[74] A small number of other organizations, such as UNDUN in Kingston and the Kelowna Area Network of Drug Users (KANDU), have established websites to share information with and engage other people who use drugs, but have had little or no funding. An organization in Toronto that used to be very active (IDUIT), is no longer active – at least in part because of the lack of support that such organizations have traditionally received in Canada.

"We need an active user group in Toronto."

– consultation participant

[72] Creating Vectors of Disease Prevention: Empowering Drug Users. Vancouver: VANDU, 2004 (www.vandu.org/vreports.html).

[73] V Wheeler. User Network Development Project (UNDP). Final Report. NPNU Harm Reduction Programmers of Alberta, March 2005. For copies, contact Diane Nielsen at diane.nielsen@calgaryhealthregion.ca.

[74] Correspondence received from Virginia Wheeler on 11 October 2005 (on file with author).

Table 1:

List of groups of people who use drugs

The Canadian Harm Reduction Network will attempt to update the list on its website (http://canadianharmreduction.com/). If you are aware of a group that is not included in the list, please contact The Canadian Harm Reduction Network: 666 Spadina Avenue, Suite 1904, Toronto, Ontario, M5S 2H8 (tel: 416 928-0279; toll free: 1 800 728-1293; fax: 416 966- 9512).

British Columbia

BC Association of People on Methadone
Tel: 604 683-6061
E-mail: vandu@vandu.org
Website: www.vandu.org/vmethgroup.html
This group started in 1999 with the help of VANDU. It helps people who use methadone, "by providing the means and location to get together in order to support each other."

DTES HIV/IDU Consumers' Board
105 - 177 E. Hastings Street
Vancouver, BC V6A 1N5
Attn: HIV+ Chairperson
Tel: 604 688-6241
E-mail: cnsbd@direct.ca
A peer-driven intervention in the Downtown Eastside of Vancouver trying to prevent the spread of HIV/HCV and other bloodborne diseases among people who inject drugs.

IslandKidz Harm Reduction Society
6348 Somenos Rd
Duncan, BC V9L 4E9
Attn: Jessica Krippendorf
Tel: 250 746-7788
E-mail: jessi@islandkidz.org
Website: www.islandkidz.org
IslandKidz is a peer-based outreach service that provides health and safety information about drugs and other relevant topics to members of the rave and nightclub community.

Kelowna Area Network of Drug Users (KANDU)
E-mail: kandu@oaas.ca
Website: www.kandu.oaas.ca/
KANDU was established in 2004 and is modeled after VANDU.

Society of Living Intravenous Drug Users (SOLID)
c/o #307-2993 Tillicum Rd
Victoria, BC V9A 7L4
E-mail: solidones@hotmail.com
Website: http://groups.yahoo.com/group/solidones/
Established in Victoria, this group "challenges traditional client/provider relationships and empowers people who use drugs to implement harm reduction interventions."

Vancouver Area Network of Drug Users (VANDU)
2nd Floor, 50 East Hastings Street
Vancouver, BC V6A 1N1
Tel: 604 683-6061
Fax: 604 683-6199
E-mail: vandu@vandu.org
Website: www.vandu.org/
Canada's largest organization of people who use drugs.

Western Aboriginal Harm Reduction Society (WAHRS)
Tel: 604 683-8595
E-mail: livingstonechris@yahoo.com
Website: www.vandu.org/vwahrsgroup.html
WAHRS started in 2002 as a subgroup of VANDU, recognizing the need for an all-aboriginal group run by Aboriginal people.

Alberta

Two groups started meeting regularly in 2005, as a result of the recommendations in the report by the task group of the Non Prescription Needle Use Consortium.

Calgary User Group
This group may be contacted through
Virginia Wheeler, Safe Works, 323 7th Ave SE
Calgary, AB T2G 0J1
Tel: 403 944-7098 or 403 410-1180
E-mail: Virginia.Wheeler@CalgaryHealthRegion.ca

Edmonton User Group
This group may be contacted through
Marliss Taylor, Streetworks, 10116-105 Ave
Edmonton, AB T5H 0K2
Tel: 780 423-3122 ext 210
E-mail: mtaylor@boylestco-op.org

Saskatchewan

Saskatoon Area Network of Drug Users (SANDU)
c/o AIDS Saskatoon, 130A Idylwyld Dr,
Saskatoon, S7L 0Y7
Tel: 306 242-5005
Fax: 306 665-9976
E-mail: aids.saskatoon@shaw.ca
Website: www.aidssaskatoon.ca/
AIDS Saskatoon assisted its members who are using drugs with collecting donations for a group of people who use drugs and with filing a constitution and by-laws for their group.

Manitoba

There is currently no organization of people who use drugs in Manitoba, but Carrie McCormick at Kali Shiva AIDS Services was involved in VANDU's national capacity-building project and may be able to provide information.
Tel: 204 940-6000
Website: www.ninecircles.ca/kalishivaaidsservices.htm

Ontario

COUNTERfit Harm Reduction Program
an Initiative of South Riverdale Community Health Centre
955 Queen Street East
Toronto, ON M4M 3P3
Attn: Raffi Balian
Tel: 416 461 1925 ext 2
Fax: 416 469 3442
E-mail: rbalian@srchc.com
While this is not a group of people who use drugs, it is a harm reduction/needle exchange program operated primarily by people who use drugs. Its coordinator, Raffi Balian, was also involved in Toronto's user group, IDUUT, which is no longer active.

Unified Networkers of Drug Users Nationally (UNDUN)
E-mail: undun@sympatico.ca
Website: www.undun.mammajamma.org/index.htm
Based in Kingston, UNDUN is a coalition of users, ex-users, and allies who are committed to ongoing organizing of local user groups as the basis of an active national movement for harm reduction.

Quebec

Group of people who use drugs at CACTUS Montréal
Attn: Darlène Palmer
Tel: 514 847 0067
Fax: 514 847 0601
E-mail: tiburonne@hotmail.com
A group of people who use drugs has started meeting regularly at CACTUS-Montréal. Contact Darlène Palmer for more information.

Québec City
For information of activities by an informal group that meets in Québec City, contact:
Mario Gagnon, Point de Repères,
530, St-Joseph Est,
Québec, QC G1K 3B8
Tel: 418 648-8042
E-mail: pointderepere@qc.aira.com
Website: www.pointdereperes.com

Atlantic Provinces

There is currently no organization of people who use drugs in the Atlantic provinces, but the following organizations were involved in VANDU's national capacity-building project and may be able to provide information.

Halifax Direction 180 methadone clinic
Attn: Cindy MacIsaac, 2158 Gottingen St
Halifax, NS B3K 3B4
Tel: 902 420 0566
E-mail: CynthMacIsaac@aol.com

Sharp Advice Needle Exchange
150- Bentinck Street, PO Box 177
Sydney, NS B1P 6H1
Tel: 902 539-5556
E-mail: christineporter@accb.ns.ca; francesmacleod@accb.ns.ca

AIDS Saint John
115 Hazen Street
Saint John, NB E2L 3L3
Tel: 506-652-2437
E-mail: aidssj@nb.aibn

Territories

There is currently no organization of people who use drugs in any of the territories.

On World AIDS Day 1999, then Minister of Health Allan Rock stated that "people with addictions and HIV issues deserve to be heard."[75] In its response to the Legal Network's 1999 report on *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues*,[76] Health Canada committed to supporting a proposal to convene Canada's first national harm reduction conference,[77] which brought together people who inject drugs, service providers, and HIV/AIDS and HCV organizations in Toronto in November 2002. As part of the conference, peer networkers were recruited from across the country to ensure that the perspectives of people who use drugs would be included. More broadly, Health Canada committed to "both strengthening and expanding efforts with respect to IDU" and to focus on three areas of activity: reducing the harms associated with injecting drugs; providing care, treatment and support for people who inject drugs, including those with HIV/AIDS or HCV; and "ensuring that people who inject drugs can contribute to the development of policies and programs affecting their health."[78]

Since then, representatives of VANDU (and to a lesser extent, of other groups) have been invited participants in various policy planning meetings at the municipal, provincial/territorial and federal levels, including the consultations leading to the development of *Leading Together: Canada Takes Action on HIV/AIDS*, Canada's new action plan on HIV/AIDS.

However, meaningful participation of people who use drugs remains limited in shaping Canada's response to drugs and to HIV/AIDS. The challenge is to turn statements of principle into greater and meaningful involvement, and not just in the realm of HIV/AIDS policy, where the widespread acceptance of GIPA provides a precedent. For example, one of the "basic principles" of Canada's Drug Strategy, released in 1998 and renewed in 2003, is stated as follows:

> Involvement of target groups in research, program planning, development, and delivery is fundamental. Integral involvement of those who will be the ultimate recipients of programs, resources, and services is essential to appropriateness, relevance, and success.[79]

Health Canada's website also explicitly mentions "those who use drugs" among a long list of actors that "have a role to play in addressing problematic substance use."[80] Yet no groups of people who use drugs are listed as "partners" in Canada's Drug Strategy.[81]

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[75] Health Canada, supra, note 5, at 8.

[76] Montréal: 1999. Available via www.aidslaw.ca/Maincontent/issues/druglaws.htm.

[77] Health Canada, supra, note 5, at 8.

[78] Ibid, at 12.

[79] Canada's Drug Strategy. Ottawa: Minister of Public Works and Government Services Canada, 1998, at 3.

[80] Health Canada. *A National Framework for Action to Reduce the Harms Associated with the Use of Alcohol, Other Drugs and Substances in Canada*. At www.hc-sc.gc.ca/ahc-asc/activit/strateg/drugs-drogues/nfa-can/index_e.html.

[81] See the list of "partners" on the website of Canada's Drug Strategy via www.hc-sc.gc.ca/ahc-asc/activit/strateg/drugs-drogues/index_e.html (accessed 19 September 2005).

These formal commitments to involve people who use drugs in policy and program development are important. But the commitment in principle has not yet translated into concrete action to enable a sustainable and meaningful involvement of people who use drugs in Canada's response to HIV/AIDS, HCV, and drug use more generally. One of the first tests of this commitment is the implementation of the new "National Framework for Action to Reduce the Harms Associated with Alcohol, Other Drugs and Substances in Canada". This framework is being developed by the Government of Canada, in conjunction with the Canadian Centre on Substance Abuse. Actions to date include cross-Canada consultations and subsequent thematic workshops on priority issues with representatives from many sectors; there has been some involvement, although minimal, of people who use, or formerly used, illegal drugs. In June 2005, representatives from various sectors came together to review a draft of the National Framework. Encouragingly, the draft Framework firmly states that problematic substance use is first and foremost a health issue, and also identifies respect for human rights, including those of people who use drugs, as one of its principles. Noticeably absent, however, is any explicit reference to the meaningful involvement of people who use drugs. Once the National Framework is finalized, interested parties will move forward with an endorsement process to have it formally supported in principle by their respective boards, ministers or governing bodies. By 2007 all partners will meet again to discuss progress made in support of the Framework and to adopt a formal governance structure.[82] It remains to be seen whether this key opportunity to engage people who use illegal drugs, and the organizations that represent them, will indeed mark the start of a new approach to shaping Canada's response to illegal drug use in a way that meaningfully involves those with first-hand, lived expertise. Other opportunities for involvement of people who use drugs, and recognition of the importance of their contribution, are provided by the development of an umbrella policy on harm reduction by the Office of Canada's Drug Strategy, and by the development of a Policy Framework on Harm Reduction and Drug Use by the Public Health Agency of Canada.[83]

Further Reading

For a history of drug-user groups in Australia: N Crofts et al. A history of peer-based drug-user groups in Australia. *Journal of Drug Issues* 1993; 25: 599-616; A Wodak. Organizations of injecting drug users in Australia. *International Journal of Drug Policy* 1993; 4: 96-97.

For a documentation of the genesis, evolution, organizational structure, and activities of VANDU: T Kerr et al. *Responding to an Emergency: Education, Advocacy and Community Care by a Peer-Driven Organization of Drug Users. A Case Study of Vancouver Area Network of Drug Users (VANDU).* Ottawa: Health Canada, 2001. Available via www.phac-aspc.gc.ca/hepc/hepatitis_c/library.html. See also G Roe. *The VANDU Health Network Research Project.* Final Report, September 2001 (www.mydocsonline.com/pub/gwroe/VHNfinal.pdf)

[82] For more information, see www.hc-sc.gc.ca/ahc-asc/activit/strateg/drugs-drogues/nfa-can/index_e.html.

[83] Input received from Michael Smith, Public Health Agency of Canada, 6 October 2005 (on file with author).

For a report on efforts to build capacity in communities across Canada to form and sustain organizations of people who use drugs: Creating Vectors of Disease Prevention: Empowering Drug Users. Vancouver: VANDU, 2004. Via www.vandu.org/vreports.html.

For the report of the project aimed at assessing whether there is a need in Alberta for local groups and/or a provincial group of people who inject/use drugs: V Wheeler. User Network Development Project (UNDP). Final Report. Calgary: NPNU Harm Reduction Programmers of Alberta, March 2005. Copies available from Safeworks Calgary: diane.nielsen@calgaryhealthregion.ca

For a report (in French) about self-help among people who use drugs in France (and some other countries), comparing interest groups of people who inject/use drugs with self-help groups such as Alcoholics Anonymous: M Jauffret. *L'auto-support des usagers de drogues en France. Groupe d'entraide et groupes d'interêt*. Paris: Groupement de Recherche Psychotropes, Politique et Société, CNRS, n° 6, 2000. Via http://cesames.org/

What is meant by greater involvement of people who use drugs?

> Effective democracy ensures people affected by decisions have a voice in how these decisions are reached. This principle is so central to our culture that we often do not question it. So why then do we debate the idea of including drug users in decision-making when neglecting to do so would be alien in most other areas of society?[84]

Despite popular prejudice to the contrary, people who use drugs have proven, through their active involvement in the response to HIV/AIDS and HCV, that they can organize themselves and make valuable contributions to their communities. Table 2 shows how they can play a wide range of roles:[85] as contributors, speakers, implementers, experts, and participants in decision-making bodies.

They should be involved at all levels. Nevertheless, this paper recognizes that, because of the life circumstances of many people who use drugs, and because of the stigma and often hostility and hate they face, special efforts are necessary to make such involvement possible. Barriers to greater involvement, and ways to overcome them, are described below.

The paper focuses on three forms of greater involvement:

- organizations of people who use drugs;
- participation in consultations, decision-making or policy-making bodies, and advisory structures; and
- involvement in the work of HIV/AIDS (and other) organizations.

[84] Response to the request for input by Dr Peter Akai, 15 April 2005 (on file with author).

[85] Adapted from the GIPA pyramid of involvement in J Cabassi. *Renewing our voice. Code of good practice for NGOs responding to HIV/AIDS.* Geneva: The NGO HIV/AIDS Code of Practice Project, 2004. Cabassi's version of the pyramid was itself adapted from the pyramid in UNAIDS. *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA).* Geneva, UNAIDS/99.43E, 1999, at 3. See also S Arnstein. A ladder of citizen participation. *Journal of the American Institute of Planners* 1969; 35(4): 216-224.

Table 2:

A pyramid of involvement

This pyramid models the increasing levels of involvement, with the highest level representing complete application of the greater involvement principle.

Decision-makers: People who use drugs participate in decision-making or policy-making bodies, and their inputs are valued equally with all the other members of these bodies.

Experts: People who use drugs are recognized as important sources of information, knowledge and skills and participate – on the same level as professionals – in the design, adaptation and evaluation of interventions.

Implementers: People who use drugs carry out real & instrumental roles in interventions, e.g., as carers, peer educators or outreach workers. However, they do not design the interventions or have little say how they are run.

Speakers: People who use drugs are used as spokespersons, or are brought into conferences or meetings to share their views but otherwise do not participate. (This is often perceived as 'token' participation, where the organizers are conscious of the need to be seen as involving people who use drugs, but do not give them any real power or responsibility.)

Contributors: Activities involve people who use drugs only marginally, generally when the individual is already wellknown. For example, using a person who uses drugs on a poster, or having relatives of a person who uses drugs who died of AIDS speak about that person at public occasions.

Target audiences: Activities are aimed at or conducted for people who use drugs or address them en masse, rather than as individuals.

However, people who use drugs should be recognized as more than

(a) anonymous images on leaflets and posters, or in information, education and communication campaigns,
(b) people who only receive services, or
(c) as 'patients' at this level.

They can provide important feedback, which in turn can influence or inform the sources of the information.

Why is greater involvement of people who use drugs needed?

> Public health agencies, and even harm reduction, drug treatment, and drug prevention projects and agencies, though clearly important and necessary, are not the whole story. IDUs themselves are already actively playing roles in HIV prevention and care, in urging community members not to use drugs and in urging other drug users to seek treatment. IDUs are especially well placed to be health activists among other IDUs because they have insider knowledge and are often physically present when advice or assistance can usefully be provided.[86]

As Friedman et al have pointed out, "the common image of IDUs as being little more than sources of social and medical problems is inaccurate."[87] While it is "true that many IDUs do (at least in social contexts where drug use is illegal and highly stigmatized) commit crimes against persons or property … and that many become infected with HIV, hepatitis B or C, … there is another side to this story." Friedman's research has shown that a significant number of people who inject drugs act as volunteers or organizers of community-based events, and that a majority of them also actively urge other people to take actions that can protect themselves and others against blood-borne or sexually transmissible infections.

Other studies have also found that people who inject drugs are active participants in trying to reduce HIV transmission and other problems that afflict them and others.[88] Burrows identifies some of the contributions people who use drugs can and do make:

> At NUAA [the New South Wales Users and AIDS Association], drug users write, produce, develop messages, provide artwork, focus test, decide on printing priorities, carry out distribution, take photographs, are immersed in every step of the process to produce educational resources.
>
> Drug users also sift truckloads of information that stream in off the superhighway, judge the political environment, assess the latest scientific findings, grab for money when it's made available, and use this stew of information and resources to decide an official drug users' view on testing for Hepatitis C, on non-reusable syringes, on a third HIV/AIDS Strategy.
>
> Having decided on a direction, drug users approach skilled assistants, build coalitions, attempt to gain publicity or political or bureaucratic support for their work, hold meetings, attend meetings, sit on committees, walk off committees in disgust and on and on.
>
> In short, in Australia drug users try to play almost as great a role in the prevention of HIV among drug users as gay men play in the prevention of HIV among gay men.… Drug user organisations … have carried out HIV prevention campaigns of a quality and effectiveness that have made Australia's HIV prevention efforts among drug users the envy of the world.[89]

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[86] SR Friedman et al. Urging others to be healthy: "Intravention" by injection drug users as a community prevention goal. *AIDS Education and Prevention* 2004; 16(3): 250-263, at 259.

[87] Ibid.

[88] SR Friedman et al. Modulators of "activated motivation": Event-specific condom use by drug injectors who have used condoms to prevent HI/AIDS. *AIDS and Behaviour* 1999; 3: 85-98; SR Friedman et al. Networks, norms, and solidaristic/altruistic action against AIDS among the demonized. *Sociological Focus* 1999; 32: 127-142; Wodak et al, supra, note 56.

[89] D Burrows. Using the user: The future of user participation in harm reduction initiatives. Keynote address at the Mandurah Research Symposium. Mandurah, WA, 15-16 February 1995 (on file with the author).

Ethical and human rights imperatives

In addition to the practical benefits described in more detail below, there are ethical and human rights imperatives that require greater involvement of people who use drugs. The rationale for involvement is essentially the ethical premise that all people should have the right to be involved in decisions affecting their lives. As David Roy has stated, "[i]t is imperative that persons who use drugs be recognized as possessing the same dignity, with all the ethical consequences of this ethical fact, as all other human beings."[90]

"We use drugs, but we are still human beings."

– consultation participant

This fundamental requirement for meaningful involvement is consistent with commitments on the part of the government of Canada and most other countries:

- *The Declaration of the Paris AIDS Summit.* Canada, along with 41 other national governments, signed this declaration in 1994, and agreed to "support a greater involvement of people living with HIV/AIDS."[91]

- *The Declaration of Commitment on HIV/AIDS.* The Declaration, adopted in 2001 by the United Nations General Assembly Special Session on HIV/AIDS, calls for the greater involvement of people living with HIV and of people from marginalized communities and states that the "full involvement and participation [of these persons] in the design, planning, implementation, and evaluation of programmes is crucial to the development of effective responses to the epidemic" (Article 33).[92]

It is also consistent with the United Nations *International Guidelines on HIV/AIDS and Human Rights* which require that representatives of vulnerable groups, such as people who use drugs, be involved in consultations and in planning and delivery of services. Guideline 2, in particular, spells out the obligations of governments in this regard:

> States should ensure, through political and financial support, that community consultation occurs in all phases of HIV/AIDS policy design, programme implementation and evaluation and that community organizations are enabled to carry out their activities, including in the field of ethics, law and human rights, effectively. (Paragraph 24)

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[90] D Roy. Injection drug use and HIV/AIDS: An ethics commentary on priority issues. In: *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues. Background Papers.* Montréal: Canadian HIV/AIDS Legal Network, 1999, at B55. Available via www.aidslaw.ca/Maincontent/issues/druglaws.htm.

[91] Available via the UNAIDS website (www.unaids.org) by searching for the document "From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)" (UNAIDS/99.43E).

[92] The Declaration of Commitment is available on the website of UNAIDS via www.unaids.org.

The Guideline further states under paragraph 24(a) that "community representation should comprise … representatives of vulnerable groups." [93]

Greater involvement of people who use drugs is a specific expression of the right to participation – exemplified by the right to "take part in the conduct of public affairs" (International Covenant on Civil and Political Rights, Article 25) and the right to "take part in cultural life" (International Covenant on Economic, Social and Cultural Rights, Article 15). Both treaties highlight that such rights are to be enjoyed without discrimination (ICCPR, Article 2; ICESCR, Article 2), including discrimination based on "other status." It is well-established that this term includes HIV. It is also arguable that, as is the case under national law in some countries, drug dependence amounts to a disability and therefore discrimination on this "other status" is also contrary to international law. However, this legal understanding of dependence as a disability remains to be established as a matter of international law.

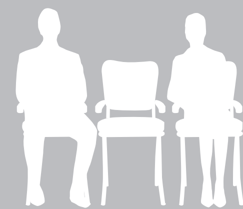
An approach to HIV/AIDS informed by human rights principles is one that protects and promotes the rights of people living with or vulnerable to HIV, and ensures they are part of the design, development and implementation of programs responding to HIV/AIDS.

Benefits of involvement

Benefits of involvement at societal level

At societal level, involvement sends a signal to society that people who use drugs have rights and claim their rights and can mobilize people into a potent political force for health and human rights advocacy. The example of VANDU is a good Canadian example of such benefits.

You always need loud, vociferous folks out there on the edge so the centre moves … and you can't ignore those guys. They're vocal, they're very passionate, and they are trying to hang on to the agenda until something significant occurs.[94]



Some of VANDU's earliest work focused on political activism and advocacy. The early organizers worked to bring the voice of people who use drugs into mainstream political discourse:

[93] Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS. *HIV/AIDS and Human Rights: International Guidelines*. New York and Geneva: United Nations, 1998.

[94] Statement from policy maker, as reported in Kerr et al, supra, note 71.

> The biggest obstacle to making the situation better was the marginalization of drug users, and the distance that addicts are from society. So the first thing we got involved in was the demarginalization of drug users.[95]

By organizing numerous public demonstrations, VANDU helped bring attention to the health emergency in the Downtown Eastside in Vancouver. Examples include:

- interrupting a Vancouver City Council meeting to present Council with a coffin in protest of a 90-day moratorium on the creation of services for people who use drugs;
- organizing events, referred to as 1000 and 2000 crosses, in memory of people who use drugs who died of overdoses (during these events, crosses were erected in a park, and residents were invited to write the names of friends who had died on the crosses); and
- opening a peer-run safer injection site, in response to a large-scale police crackdown and delays in the opening of Canada's first legally sanctioned safe injection site.

If it had not been for the unsanctioned safe injection site that we opened, it may have taken much longer for the official one to open.[96]

Benefits of involvement at the organizational level

> The users have more buy-in to the program. The program is able to stay current and relevant. The users' needs can be known and addressed.
>
> In essence, the services they help to design are the services they in turn are more likely to access.
>
> Benefits [of involving people who use] – service and program delivery and policies that are realistic, useful, client-friendly, and a sense of ownership and self worth for drug users who are consulted.[97]

Within organizations, such as community-based AIDS organizations that provide services to people living with HIV, working with a person who uses drugs can help people overcome their prejudices and change their perceptions about people who use drugs; it also helps create more effective and appropriate services for people who use drugs, who often comprise a large percentage of clients of these organizations.

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[95] T Kerr et al. Harm reduction by a "user-run"organization: a case study of the Vancouver Area Network of Drug Users (VANDU). *International Journal of Drug Policy* (in print).

[96] Comment by Ann Livingston at the consultation at the 2005 International Conference on Reduction of Drug-Related Harms.

[97] Samples of the responses to the question of what is gained by involving people who use drugs in services, provided in response to the call for input into the project.

Benefits of involvement at the individual level

> While being a drug user activist can be challenging and arduous,[98] there are also direct benefits for drug users themselves in becoming involved in drug user organising. Self-organisations may support people as they are trying to find stability with their drug taking, offer them purpose and direction in their life (if this is missing) and may offer them insight into new conditions such as Hepatitis C. In addition, drug user organising may act more fundamentally to raise the underlying sense of self-esteem and self-efficacy of drug users, which in themselves are important factors in the process change.[99] (Friedman and colleagues have described this last factor as 'redemption through social struggle.'[100])

Again, the experience of VANDU provides a good example of how greater involvement generates benefits for the individual as well. Consider the following comments from members of VANDU or people accessing VANDU programs:

> I've become more conscientious.... I'm more careful and health-conscious. I was pretty worn out there for a while and then I started hitting those meetings.
>
> You know I think it's [VANDU] changed a lot of people also, in the manner of how they conduct themselves out there. You know they're not just chucking their rigs as often as they were before.
>
> It made me feel really good about myself, it made me feel like I belonged to something. I was part of something even though I was still a drug user and people there were drug users, I felt part of a bigger thing.[101]

Kerr et al have urged that more research be undertaken to examine the effect of participation in a group of people who use drugs on individuals who are actively involved with such groups. They reported that incidents of fatal overdoses "are extremely rare among members of VANDU, whereas overdose deaths are commonplace among non-members". Furthermore, members of VANDU suggested that participation in VANDU helped them decrease behaviours that put them at risk of contacting blood-borne diseases."[102] Research would help further examine the link between participation and adoption of protective behaviours, and help identify the additional health and psychosocial benefits that people who are actively involved may enjoy as a result of participation.

"We know what we need."

– consultation participant

[98] A Efthimiou-Mordaunt. Spanner in the works – Obstacles to practical user involvement and pathways around them. *Druglink* 2002; 17(1).

[99] W Miller, S Roonick (1991). Motivational Interviewing: Preparing people to change behaviour.

[100] S Friedman, M Southwell et al. Harm Reduction: A perspective from the left. *International Journal of Drug Policy* 2000.

[101] Statements from members or program recipients of VANDU, as reported in Kerr et al, supra, note 71.

[102] Ibid, at 37-38.

Benefits of organizations of people who use drugs

Most health services initiated in response to HIV/AIDS among people who use drugs operate under the "provider-client" model, in which service providers strive to meet the needs of users. Notwithstanding the importance of such services, this model has its limitations,[103] including the difficulty that service providers have in reaching people who use drugs on their own turf, difficult communication between providers and clients, and fear among people who use drugs that using services may alert police to their activities.[104] In response to these concerns and the general lack of public health interventions for people who use drugs, organizations of people who use drugs have emerged throughout the world.[105] These organizations have generated considerable interest because of their potential to address the limitations of provider-client programs and to stem rates of overdose deaths and blood-borne diseases.[106]

People who use drugs themselves are often best able to identify what works in their community – a community that others know little about. Their voices need to be heard to ensure the shaping of effective responses to blood borne pathogen epidemics and other drug-related harms. Research, both in Canada and internationally,[107] has provided evidence of the benefits of greater involvement of people who use drugs. In particular, people who use drugs are able to expand the reach and effectiveness of HIV prevention and harm reduction services by making contact with people at greatest risk. For example, groups of people who use drugs can play an important role in reaching their peers with clean injection equipment.[108] More generally, as Southwell observes, such groups are a critical link for information and services:

> Given that drug patterns change and evolve in the illicit scene, then effective lines of communication are required if services are to be aware of changing trends and the need for new interventions.... Drug user self-organisations can have specialist insights and expertise that allow them to design and deliver specialist interventions within the illicit drug using community or may be able to respond rapidly to sudden health crises. Furthermore, peer leaders (including drug dealers) have been shown to be important referral routes from the illicit community into formal services where a trusting relationship can be established.[109]

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[103] RS Broadhead et al (1995). Drug users versus outreach workers in combating AIDS: preliminary results of a peer-driven intervention. *Journal of Drug Issues* 1995; 531-564; RS Broadhead et al. Harnessing peer networks as an instrument for AIDS prevention: results from a peer-driven intervention. *Public Health Reports* 1998; 113(Suppl 1): 42-57.

[104] Kerr et al, supra, note 71, with reference to Broadhead et al, 1998, supra, JP Grund et al. Reaching the unreached: targeting hidden populations with clean needles via known user groups. *Journal of Psychoactive Drugs* 1992; 24(1): 41-47; JD Rich et al. Obstacles to needle exchange participation in Rhode Island. *Journal of Acquired Immune Deficiency Syndromes* 1999; 21(5): 396-400.

[105] Broadhead et al, 1995; Grund et al, supra, note 104; N Crofts, D Herkt. A history of peer-based drug-user groups in Australia. *Journal of Drug Issues* 1993; 25: 599-616; R Power et al. Drug user networks, coping strategies, and HIV prevention in the community. *Journal of Drug Issues* 1995; 25(3): 565-581.

[106] Kerr et al, 2001, with reference to Broadhead et al, 1998; Grund et al, 1992; Power et al, 1995; CA Latkin. Outreach in natural settings: The use of peer leaders for HIV prevention among injecting drug users' networks. *Public Health Reports* 1998; 113(Suppl 1): 151-159; LB Cottler et al. Peer-delivered interventions reduce HIV risk behaviors among out-of-treatment drug abusers. *Public Health Reports* 1998; 113(Suppl 1): 31-41.

[107] Grund et al, 1992; E Wood et al.: An external evaluation of a peer-run "unsanctioned" syringe exchange program. *J Urban Health* 2003; 80(3): 455-64; Latkin, 1998; Broadhead et al, 1995; Broadhead et al, 1998; T Kerr et al, supra, note 95.

[108] Grund et al, supra, note 104. For a Canadian example, see: Wood et al (2003), supra, note 107.

[109] National Treatment Agency, supra, note 48, section 1.3.

Similarly, the Australian Injecting & Illicit Drug Users League argues that:

> drug user organisations are the only place from which peer driven initiatives such as peer education and peer support can truly be conducted. [D]rug user organisations have the capacity and right to be responsible for and provide broad harm reduction initiatives.... The successful role of drug user organisations as part of the national response to the prevention of HIV is unquestionable. The low number of infections of HIV amongst people who inject drugs is envied at an international level and it is impossible to not attribute this success to the crucial role of drug user organisations.[110]

Further Reading

For more information about the activities of one organization of people who use drugs (VANDU), and the benefits these activities have resulted in: T Kerr et al. *Responding to an Emergency: Education, Advocacy and Community Care by a Peer-Driven Organization of Drug Users. A Case Study of Vancouver Area Network of Drug Users (VANDU).* Ottawa: Health Canada, 2001. Available via www.phac-aspc.gc.ca/hepc/hepatitis_c/library.html.

Issues and Challenges

The review of government policy documents undertaken for this project, as well as the input received from community-based organizations and professionals across Canada shows that, at least in principle, governments and organizations understand the benefits of greater involvement of people who use drugs in Canada's response to HIV/AIDS and HCV, and have expressed commitment to increasing involvement.

The last years have seen some greater involvement. For example, as described above, a few people who use drugs were invited to participate in national consultation meetings about the Canadian Strategy on HIV/AIDS leading to the development of the nation-wide action plan *Leading Together* and the federal government's contribution to that action plan, the new Federal Initiative to Address HIV/AIDS in Canada.[111] During the development of the Action Plan, a separate consultation was held in Vancouver with people who use drugs. VANDU has received some funding from local and federal governments for the provision of services, but also to build capacity elsewhere in Canada among people who use drugs. The federal government also funded a small number of other initiatives in this area, such as the project undertaken in Alberta assessing the need for organizations of people who use drugs.

Many community-based organizations have recognized that, while people who use illegal drugs represent a significant number of those using their services, they are often not represented on their boards of directors or otherwise meaningfully

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[110] AIVL, supra, note 51, at 3.

[111] For more information, see www.phac-aspc.gc.ca/aids-sida/hiv_aids/.

involved. A few, such as CACTUS Montréal, have amended their by-laws to reserve seats on their boards to people who use (or have used) drugs. However, for most organizations translating their commitment to greater involvement into practice remains challenging and much remains to be done to ensure greater, ongoing, and sustainable involvement of people who use illegal drugs.

Involvement in consultations, decision-making bodies, and advisory structures

There are various challenges to greater involvement of people who use drugs in the consultations, decision-making bodies and advisory committees that shape the response to drug use and/or HIV/AIDS in Canada. These include:

- Few people have been involved, often as token representatives.
- Organizers have rarely taken the particular needs of people who use drugs into account, and have sometimes failed to provide adequate accommodation and/or compensation.
- Even when people who use drugs are invited to consultation meetings, most often one or two people must try to represent the views of people who use drugs among a large number of participants.
- In many cases, these people are hand-picked by meeting organizers rather than selected by the community they are supposed to represent.
- Many who are able to attend such meetings have ceased drug use and may be somewhat disconnected from the community they seek to represent.

During the consultation undertaken as part of the production of this paper, people who use drugs made a number of suggestions that would help overcome these challenges. They are summarized in table 3.

Table 3:

Consulting with people who use drugs: Do's and don'ts

Do	Don't
Do invite several of us	**Don't** invite just one of us
Do invite a user group to select representatives	**Don't** hand-pick always the same user you know and are comfortable with
Do invite an active user	**Don't** only always invite former users – it is OK to invite them and they have lots to offer, but they are not the same as I am, and I have a perspective that is valuable and needs to be heard as well
Do invite former users in addition to active users	**Don't** invite them instead of inviting active users
Do hold a meeting or consultation in a low-key setting or in a setting where users already hang out	**Don't** hold it in a government building
Do provide an honorarium – contrary to most people who attend your meetings, we are not paid to attend by our jobs, but still need to look after our needs	**Don't** assume that we don't need an honorarium or would just spend it on drugs (or that it wouldn't be justified even if we did)
Do give us money in cash	**Don't** write us a cheque or give us a coupon
Do come to us, if possible	**Don't** ask us to come and meet you in Ottawa
Do guarantee confidentiality	**Don't** identify what a particular user said in proceedings of the meeting
Do listen to our answers	**Don't** just ask the question because it is politically correct to ask us
Do show flexibility with meeting styles	**Don't** hold a meeting or consultation just the way you are used to
Do show flexibility with meeting times	**Don't** hold a meeting at 9 a.m., or on welfare cheque issue day

Do	Don't
Do ask us what we need	**Don't** be afraid to ask
Do acknowledge that you may have needs, too, and that unfamiliarity may make you uncomfortable	**Don't** assume that I am the problem and the only one who needs to learn
Do assign us a support person or provide training (if you ask us to be on a committee or board, not just a one-time event)	**Don't** run your committee or board meetings without acknowledging that it may be the first time for us to be on a committee or board
Do consider training for you and the other committee or board members specific to the issue of user involvement, and ask a user to participate	**Don't** think that you can't learn how to involve me better
Do protect confidentiality	**Don't** require disclosure of HIV or other health status
Do consider participation in consultations and meetings as a start	**Don't** think that we cannot do more, such as work for you in a paid position

In addition, if we have to travel:

Do	Don't
Do help with arranging methadone carries	**Don't** invite us at the last minute and assume we can deal with this alone
Do arrange for advice from a local person who uses drugs – drugs may be more dangerous in a different city and travelling puts us at risk	**Don't** just leave us on our own in cities we don't know
Do provide accommodation close to the meeting space	
Do have a physician on call	

Organizations of people who use drugs

With a few exceptions, little or no funding has been provided in Canada to organizations of people who use drugs, and there has not been a concerted effort to encourage and support their creation. Even VANDU has never received the support that one would expect to flow to such a successful organization. But other things are also needed.

Speaking on behalf of the Australian Injecting & Illicit Drug Users League (AIVL), Annie Madden identified some of the expectations placed on organizations of people who use drugs as well as the support they need:

> If we really want drug users to take a key role in responding to the hepatitis C epidemic then drug user organisations have to do more than 'just survive' – we have to grow and develop.... Everyone expects a great deal from drug user organizations in particular to do things that others can't do, reach people that others can't reach, but there is rarely consideration of how difficult it is to undertake the role they do. Most people in the audience would have no idea how difficult it is to work in and/or be part of a drug user organisation. Drug user organizations are one of, if not, the most marginalized type of organization in the community. The people who work in drug user organisations have to constantly justify the existence of the organisation, they represent people who are highly marginalised and are engaged in illegal behaviours and to top it all off they are frequently people who use drugs themselves. This means that the issues they are representing and fighting for are also personal issues including hepatitis C. It is not just a job or just another organization. When you are part of a drug user organization you don't get to leave the issues at work – you get to *live* the issues when you're not at work. So what do drug user organisations need to be able to play the role we want and need to play in relation to hepatitis C?
>
> - We need to be adequately funded and resourced to represent and address the needs of the majority of the estimated 242 000 people living with hepatitis C [in Australia] and the many thousands of current injectors not yet infected;
> - We need to be treated as equals and respected for the expertise and professionalism we bring to the hepatitis C and related areas;
> - We need to be supported (really supported, not just supported when things are going well but when things are tough and we are being attacked by the media and community merely because we dare not to be ashamed of who we are);
> - We need to be trusted that we know what needs to be done, that our interest is promoting and protecting the health of drug users, that we have expertise and that we take a particular approach for a reason rather than being seen as people who, if left to their own devices, would have *everyone* injecting drugs tomorrow;
> - We need to be supported to develop the skills and knowledge we need to be good peer educators and peer advocates and to run professional organizations; and
> - Finally, we need to feel like we are seen as part of the solution, not part of the problem – which we are so often made to feel.... If drug user organisations are to play an effective role in relation to such a massive issue as hepatitis C amongst people who inject drugs, drug user organisations must have complete and total support – not part time support. We need recognition for the enormous amounts of work that drug user organisations have done and continue to do.

AIVL adopted a "policy position" about involvement of people who use drugs and made a number of recommendations to the Australian federal and state/territory governments. Specifically, it called upon governments to "formally recognise the crucial and valid roles of drug user organisations within illicit drug and public health policy"; "all non drug using organisations within the alcohol and other drug

and communicable diseases sectors to immediately refrain from disempowering drug user organisations by accepting funding for projects and services that should be run by peers;" and government to support drug user organizations to meet the varying needs of people who use illegal drugs, such as: peer support, harm reduction initiatives, education, community development, lobbying, advocacy, and consumer representation.[112]

In addition, there is a need to develop a balance in the activities carried out by organizations of people who use drugs. Many groups have been overwhelmed by the demands from drop-in members. Moving to more structured approaches to providing direct client services has allowed some organizations more time for activities aimed at advocating for the interests of people who use drugs.[113] A related challenge is to find time, and gain acceptance for, an agenda that goes beyond HIV/AIDS and HCV, and to define the purpose of greater involvement of people who inject/use drugs beyond simply HIV and HCV prevention and access to treatment and care. As AIVL has stated:

> It is time for drug user organisations to be respected in their entirety. While the BBV [bloodborne virus] work that we do is of course important, our role and functions exceed this niche that governments have placed us in. The reality is that we do many other activities because we are human and we have many needs…. We are legitimate and accountable organisations that meet our outcomes and a whole lot more. Things would be a lot worse for people who inject/use illicit drugs if we did not exist.

[112] AIVL, supra, note 51.

[113] Ogborne, Carver, Wiebe, supra, note 58, at 32-33.

“Policy Position: Drug User Organisations”

Adopted by the Australian Injecting & Illicit Drug Users League (AIVL)

- Drug user organisations have a valid role and this needs to be validated by governments, policy makers and other individuals and organisations in the field.
- The role of drug user organisations is unique and is one that cannot be duplicated by other organisations.
- Drug user organisations are organisations that are governed, managed and run by people who use/inject illicit drug users. It is crucial that control and power is held by peers to ensure that the dilution of drug user self organising does not take place.
- AIVL recognises and supports the development of drug user self organising.…
- Drug user organisations have the responsibility to ensure the sustainability and development of the drug user’s movement and are expected to focus on the empowerment and inclusion of people who use illicit drugs that are interested in formalising their role within the movement. This includes developing and delivering training programs and initiatives that can introduce individuals to the roles and responsibilities of drug user organisations.
- Drug user organisations must be committed to the principles of harm reduction, peer education and support, community development and advocate for the health and human rights of injecting/ illicit drug users.
- Drug user organisations need to be sufficiently funded for all the initiatives and activities that they undertake. It is not acceptable for drug user organisations to carry out activities by default with no specific funding.
- Drug user organisations are the only vehicle from which legitimate consumer representation can take place.
- Working within the models of self determination and consensus, drug user organisations are best placed to ensure appropriate representation to governments, non drug user organisations and other relevant stakeholders.
- It is not appropriate for non drug user organisations to speak out or represent people who use illicit drugs.
- Drug user organisations recognise that their uniqueness is of great benefit to others and their expertise remains in great demand. As a result, drug user organisations are often approached to enter into partnerships. AIVL believes that within all partnership arrangements drug user organisations should be treated with respect and as equals. In addition, it is expected that drug user organisations be funded appropriately for their skills and experience. It is not acceptable for drug user organisations to be funded at lower rates than other partners or to have a lower level of power and recognition than others in the partnership.

Some insist that groups of people who inject drugs be staffed only by people who actively use,[114] arguing that only they can represent users and that, in addition, employment can provide them with a stepping stone to reducing drug use or getting off drugs and to social reintegration. Others, however, have pointed out that staff members who actively use experience the same problems as other users, such as needing to spend time acquiring drugs, dealing with fluctuations in drug supply or purity, or attending their methadone clinic.[115] Some organizations, such as VANDU, have employed a person who is neither a former nor an active user. Some have questioned the presence of a non-user in a purportedly user-run organization, but VANDU members have pointed out that they, and not the employee, run the organization, and that existing drug laws and policies are a factor in the selection of a non-user as coordinator:

> If I had to explain to Health Canada why [the coordinator] is in her position, I would say it's because drugs are still illegal. How can you run an organization when people are dying, being imprisoned, evicted, and hospitalized? You need someone there who is not subject to the same instability.[116]

There are, however, many examples of organizations that have successfully employed people who actively use drugs. AIVL has a "drug use in the workplace policy", while the New South Wales Users and AIDS Association (NUAA) decided in the early 1990s that an individual worker's drug use was of no concern to the organization's management. Instead, a workplace performance policy was adopted that, if an individual's work was suffering (from whatever cause) provided management with a way of dealing with the problem.[117]

The report of the London Drug User Involvement Project affirms that active users can be successfully employed, and focuses on training needs, noting that in this case people who used drugs belied the usual stereotypes and exhibited a wide range of skills and that training was needed for those not accustomed to working in organizations.[118]

For those wishing to become involved in the establishment of a group of people who use drugs, Burrows has provided a set of recommendations, in the form of steps, which are reproduced below in Table 4.[119] The VANDU case study by Kerr et al[120] also provides useful insight into how such an organization can start and successfully carry out activities.

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[114] See, eg, R Balian, C White. Defining the drug user (no date). Available via www.harmreduction.org/pubs/news/fall98/f98ballan.html.

[115] Ogborne, Carver, Wiebe, supra, note 58, at 33.

[116] Kerr et al, supra, note 71, at 21.

[117] D Burrows. Establishing and maintaining credibility as an injecting drug users group. In: AS Trebach, KB Zeese (eds). Strategies for Change – New Directions in Drug Policy. Drug Policy Foundation: Washington, DC, 1992, 363-371, at 366.

[118] Lessons Learned, supra, note 62.

[119] Burrows, supra, note 117, at 368-370.

[120] Kerr et al, supra, note 71.

Table 4:

How to become involved in the establishment of a user organization: 10 steps
(adapted from Burrows, 1992)

1 ***Gather a group of users, ex-users, and people interested in IDU issues.*** Discuss concerns about HIV and injecting and other issues that the group believes are of concern for users. This will provide an agenda for later meetings.

2 ***Attract people who use to a general meeting.*** This can be done by giving out leaflets, posters on walls or telephone poles. If the meeting needs to be clandestine due to police activity, use pocket-size cards with no details other than the date, time, place. When advertising the meetings, stress that they are an opportunity for users to get together to talk about issues which affect them.

3 ***Hold a series of meetings to determine the major issues affecting users in the local community.*** Some time will have to be given over to "bitch sessions" at these initial meetings in which people talk about how difficult it is to buy drugs, consume them without being busted, etc. The major issues from these sessions should be noted for future work, but the discussion should be directed towards HIV and safer using issues. It is in this health area that the group can have the most immediate effect. After all, if users die or are hospitalized, then no other issues are likely to be relevant.

4 ***Recruit articulate speakers and thinkers among the group.*** Try to talk to them after the meetings and tell them what the group is trying to achieve (better health for users, advocacy on user issues).

5 When the group seems ready, ***suggest that a committee be formed to work out what can be done in the area for users.*** Election of committee members from the floor or a call for volunteers can achieve this. Here, the role of outsiders begins to diminish. The group will begin to exert its own dynamics and the outsider will have less control over where the group goes next.

6

Assist in committee meetings. This may be as simple as suggesting a date and time and arranging a location, or it may be a more active role as either a committee member or minute-taker. Records should be kept of meetings (though not necessarily of names of those attending) so that the same ground is not covered each time. Achievable goals include realistic aims and objectives of the group, a name, and a set of priorities for activities. It is important to remember that, if the group explodes at this point (see next step), the group's organizers have still achieved a great deal. For many users, this may be the first time they have ever been asked their views, and the seeds of working together for change have been planted.

7

The cult of the personality will develop. One or more stronger committee members will begin to direct the group. If two or more relatively equal forces come into play, the group may explode, implode or simply collapse through inertia. Either one force will win and the organization can continue, or else the group will be abandoned. This should not discourage the group's organizers. In most cases in Australia, groups that have completely stopped functioning have eventually started up again. Also, one of the results of this process is often that the group moves away from one or two strong personalities and achieves a wider community base.

8

Structure peer education and discussion sessions. These sessions should be simple and modular (that is, they should give a package of information and skills on one topic) because turnover at these sessions can be very high, and people who come to today's session may not return next week. Other areas in which users may have great interest are: newsletters, research, and political work. Provide details of the latest research results that affect users. Ask their opinions; open up lines of communication between users and researchers studying user issues.

9

Encourage people who seem to have a long-term interest in the group to receive training. Try to get funding for the group or for an individual from the group to work with the local community. Start liaising with politicians and bureaucrats about issues of importance to the community. One factor that helps when dealing with hostile people in authority is to remind them that the group is a communications channel with users on the streets. This means that governments and researchers can learn much more about users' lives and behaviour (for policy-making, laws, etc.) and that they can provide more information directly to users (for health promotion campaigns).

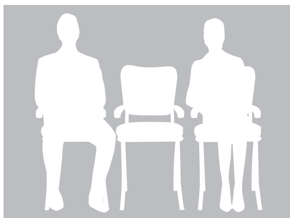
10

Wherever the group wants to go (longer opening hours for needle exchanges, safe injection sites, heroin trials, street drug testing, policing, improved health care and housing, positive images of users through art and media, education, job training), ***the group will choose the direction(s)*** and those working with the group can help them achieve their goals.

Community-based organizations

> Many fear that drug user organising will lead to increased conflict and confrontation between services and their service users. However, there may be benefits for both parties in a more mature engagement. Of course, to achieve these benefits both drug users and drugs professionals need to be willing to explore, debate, and probably redefine their working relationships. This is part of the journey towards a more open and effective engagement between drug users and their service providers.[121]

Community-based organizations struggle to make greater involvement of people who use a priority when funding remains insufficient to meet many of their needs and people often simply do not have the time and energy to take up new challenges. Little or no training has been provided to service providers to enable them to better involve people who use drugs, and little or no training has been provided to people who use drugs to enable them to participate more effectively. The London Drug User Involvement Project, while stressing the need for training of people who use drugs, emphasized the importance of "also investing in skilling up and equipping staff to work with users."[122]



"It is not the user's responsibility to get involved, it is the organization's responsibility to involve users."

– consultation participant

According to representatives of community-based organizations that provided input into this project, challenges include:

- educating board and staff of organizations about why involvement of people who use drugs is important, defining what involvement would look like, and considering its implications;
- incorporating the need for involvement into ongoing diversity training programs;
- incorporating involvement into organizational planning, including the recruitment of staff;
- changing indicators and outcomes used in evaluating the organization's work to gauge participation in the organization's activities by people who use drugs;
- honestly addressing addiction as a disability;
- tackling the stigma that surrounds illegal drug use and people who use drugs;
- defining what involvement would look like and explaining why it is valuable for the organization;
- needing a major shift in thinking in terms of organizational behaviour;
- being prepared to be flexible, such as by making changes to the hours of work;

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[121] National Treatment Agency, supra, note 48.

[122] Lessons Learned, supra, note 48.

- being prepared to foster the development of groups of people who use drugs;
- building cross-cultural awareness and filling the need to learn about people who use drugs and their life circumstances.

Further Reading

For a review of the history of an Australian group of people who use drugs, with recommendations for anyone wishing to become involved in the establishment of such an organization: D Burrows. Establishing and maintaining credibility as an injecting drug users group. In: AS Trebach, KB Zeese (eds). *Strategies for Change – New Directions in Drug Policy*. Drug Policy Foundation: Washington, DC, 1992, 363-371.

For a guide to user involvement: National Treatment Agency. *A Guide to Involving & Empowering Drug Users. Public Draft 2*. London (UK): no date. Via www.canadianharmreduction.com/ readmore/facts_southwell.pdf

For the report of the London Drug User Involvement Project: Lessons learned. Some approaches, tools and good practice for improving drug user involvement. London: Greater London Authority, February 2005. Via www.london.gov.uk/gla/publications/health.jsp#lessons

For a large number of useful documents on user organizing and involvement, see the website of The Australian Injecting & Illicit Drug Users' League (AIVL): www.aivl.org.au/

Conclusion and Recommendations

> Ultimately, it is the power of community to challenge and 'take charge' that, in many countries, has made the greatest headway against the [HIV/AIDS] epidemic.[123]

People living with HIV and people who use illegal drugs are central to the response to HIV/AIDS and HCV. There are ethical and human rights imperatives for involvement, but involvement is also required because it ensures a more effective public health response. In principle, Canada is committed to greater and meaningful involvement of *people living with HIV*, but this commitment must be matched by action.

With regard to greater involvement of *people who use illegal drugs*, even more needs to be done. There has been some greater involvement in government policy-making in recent years, but it has remained too limited. Some community-based agencies have also recognized that meaningful involvement of people who use drugs must go beyond simply providing services; it means involvement in other activities, including governance of the organization. Organizations of people who use drugs have not yet received the support they need to become an effective voice and force in Canada's fight against HIV/AIDS and HCV.

Canada strives to make a significant and original contribution to *global efforts to fight the epidemic and advance human rights*. This means that Canada can and should promote the greater involvement of both people living with HIV and people who use drugs at the international level.

Now is the time to move from principle to practice. In the next years, there will be many opportunities to do so, as Canada implements *Leading Together* and as the federal government implements its new Federal Initiative to Address

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[123] P Aggleton, R Parker. *A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination*. Rev. ed. UNAIDS/02.43E. Geneva: Joint Programme on HIV/AIDS and Human Rights, 2002, at 18. Available via www.unaids.org.

HIV/AIDS in Canada and a new *National Framework for Action on Substance Abuse.*[124] Accompanying the new Federal Initiative on HIV/AIDS is a new focus within the Public Health Agency of Canada on "vulnerable populations." As part of the dedicated attention to vulnerable populations, the federal government should demonstrate its commitment by increasing involvement of people who use drugs and, more broadly, people living with HIV in the fight against HIV/AIDS. Municipal and provincial/territorial governments should do the same, as they align their activities with Canada's new action plan on HIV/AIDS.

To take advantage of the existing momentum and commitment, the following recommendations therefore build upon Canada's new action plan on HIV/AIDS, and propose concrete ways to reach the goals and targets it sets out related to GIPA and to greater involvement of people who use illegal drugs.

Greater involvement of people living with HIV

These recommendations are aimed at greater, meaningful, and sustained involvement of *people living with HIV* in all aspects of Canada's response to HIV/AIDS.

Recommendation 1

Government action on GIPA

The Public Health Agency of Canada should provide funding for the development and implementation of a plan aimed at ensuring increased and sustainable involvement of people living with HIV in Canada's federal response to HIV/AIDS. The plan should be developed by and for people living with HIV, including a significant representation of people who use drugs. In addition, the Public Health Agency of Canada and/or the Canadian Institutes of Health Research should provide funding for a variety of other initiatives aimed at removing barriers to, and increasing, involvement of people living with HIV:

- model projects aimed at attracting, training, and retaining people living with HIV in various capacities in community-based organizations;
- establishment of a national organization of people living with HIV;
- developing good practice guidelines on the use of volunteers and employment of people living with HIV in community-based agencies;
- community-based action research aimed at providing further information, at a national, regional, and local level, on barriers to involvement and ways to overcome them; and
- projects aimed at promoting positive and non-discriminatory attitudes and policies towards people living with HIV.

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[124] See supra, note 80.

Provincial and territorial governments and municipalities should fund and otherwise support complementary efforts to ensure that elements agreed to in the federal plan can be put into place and that provincial and local realities can also be reflected.

Recommendation 2

Community-based action on GIPA

Community-based HIV/AIDS organizations across Canada should assess what steps they need to take to increase and sustain the meaningful involvement of people living with HIV at all levels of the organization, including people who use drugs. In addition, they should adopt the "Code of Good Practice for NGOs Responding to HIV/AIDS"[125] and, in particular, implement its component related to involvement of people living with HIV and affected communities. In fostering meaningful involvement, organizations should

- create an organizational environment that is premised on non-discrimination and values the contribution of people living with HIV and affected communities;
- foster the involvement of the diverse range of people living with HIV and affected communities;
- involve people living with HIV in a variety of roles at different levels within the organizations;
- define roles and responsibilities; assess what a particular role requires, and the capacity of individuals to fulfil the role; and provide the necessary support, including financial;
- ensure organizational policies and practice provide timely access to information to enable participation, preparation and input, before programmatic and policy decisions are made;
- ensure workplace policies and practices recognize the health and related needs of people living with HIV and affected communities and create an enabling environment that supports their involvement in the workplace;
- ensure, when seeking representatives of people living with HIV and affected communities, that these representatives have strategies for accountability to their members and processes for ensuring that the views put forward represent their members;
- support capacity-building within organizations and networks of people living with HIV and affected communities, including advocating for the necessary funding.[126]

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[125] Cabassi, supra, note 85.

[126] Cabassi, supra, note 85, at 41-42.

Greater involvement of people who use drugs

These recommendations are aimed at the greater, meaningful, and sustained involvement of *people who use drugs* in all aspects of Canada's response to HIV/AIDS, HCV, and illegal drug use.

"Drug users like all other men and women have a right to human dignity."

– consultation participant

Recommendation 3

Addressing systemic barriers to greater involvement of people who use drugs

The stigma that people who use illegal drugs face, as well as the fact that illegal drug use is criminalized rather than seen primarily as a health issue, create many barriers to involvement of people who use drugs and impede effective public health responses to problematic substance use.

Therefore, the federal and the provincial/territorial ministers of health should publicly state – and demonstrate leadership by discussing these issues with law enforcement agencies and with other government departments whose actions affect the response to problematic substance use (including those responsible for criminal justice, housing, and welfare) – that: (i) the response to illegal drug use in Canada is first and foremost a health issue and should be treated as such in Canada's laws and policies; (ii) the ongoing criminalization of people who use drugs is undermining public health efforts, including the response to HIV/AIDS and HCV among people who use drugs; and (iii) stigmatizing people who use drugs through criminalizing them undermines their human rights and is a barrier to their greater, meaningful involvement in the response to the HIV/AIDS epidemic.

Recommendation 4

Organization of people who use drugs – federal action

As experience in other countries has shown, organizations of people who use drugs, if properly supported, 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.

Health Canada and the Public Health Agency of Canada, through the Federal Initiative to Address HIV/AIDS in Canada, and the work of the HIV/AIDS and Hepatitis C divisions, as well as Canada's Drug Strategy, and the "National Framework for Action to Reduce the Harms Associated with Alcohol, Other Drugs and Substances in Canada" should explicitly and formally recognize the unique value of organizations of people who use illegal drugs. Working in close collaboration with representatives of people who use illegal drugs from across Canada, they should develop and rapidly implement a plan for the greater and meaningful involvement of people who use drugs in all aspects of Canada's response to HIV/AIDS, HCV, and illegal drug use. In particular, the federal plan should include:

- Support for existing groups of people who use drugs, including through funding and capacity building initiatives, to undertake a range of activities, including advocacy for the rights of people who use drugs, harm reduction initiatives, education, research, community development, and consumer representation.
- Funding, including longer-term, core funding in addition to project funding, in order to enable participation in government processes, capacity-building over time, and sustainability of groups.
- Support for innovative and/or model projects and programs of groups of people who use drugs, including for evaluation and documentation and dissemination of best practice.
- Support for initiatives aimed at assessing the needs for the creation of local and provincial/territorial groups of people who use drugs in cities and provinces/territories where such groups currently do not exist.
- Funding of a national group that can be a voice of people who use drugs at the national level and assist local and provincial/territorial groups.
- Funding the development of good practice guidelines on the employment of people who use drugs.

Recommendation 5

Organization of people who use drugs – Action by provincial/territorial and local governments

Provincial/territorial and local governments in areas in which a need exists for groups of people who use drugs, should also explicitly recognize the value of organizations of people who use illegal drugs. Working in close collaboration with representatives of people who use illegal drugs from their region, they should develop and rapidly implement action plans aimed at greater and meaningful involvement of people who use drugs in all aspects of the provincial/territorial and local responses to HIV/AIDS, HCV, and illegal drug use. These plans should be coordinated with the federal plan and include funding for local and provincial/territorial groups.

Recommendation 6

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 related to HIV/AIDS, HCV, and illegal drugs. Such participation (at the local, provincial/territorial, and federal level) enables them to:[127]

- Present the perspectives, needs, aspirations, and experiences of people who use drugs and thus better inform decision making that will affect their lives;
- Foster genuine community participation in partnership with policy makers, researchers and service providers whose work significantly affects their lives;
- Keep the communities of people who use drugs and their organizations informed of developments, initiatives, or changes in policy or service provision; and
- Develop skills and experience within the communities of people who use drugs, enhancing the capacity of individuals and communities to participate.

In practice, it is recommended that:

- People who use drugs be invited to participate in all consultations, committees, or fora where policies, interventions, or services concerning them are planned, discussed, researched, determined, or evaluated.
- Where organizations or networks of people who use drugs exist, they should be invited to nominate, according to the organizations' processes, appropriate representatives.
- A number of representatives, rather than just one, should be invited, recognizing that people who use drugs, because of their life circumstances, may sometimes not be in a position to participate or to participate continuously or regularly.
- Adequate support, training, and financial compensation be provided.

[127] Adapted from AIVL. Policy Position. Consumer Representation, at 4.

Recommendation 7

Involvement of people who use drugs in community-based organizations

Community-based organizations, in particular organizations providing HIV/AIDS and/or HCV-related services or other health or social services, need to increase involvement of people who use drugs at all levels of the organization. This is particularly true for, but not limited to, organizations whose clients comprise a large number of people who use drugs. Therefore:

- The Public Health Agency of Canada, under the "Federal Initiative to Address HIV/AIDS in Canada" should provide funding for a meeting of people who use drugs and representatives of community-based organizations to identify concrete actions for community-based organizations to better involve people who use drugs in all aspects of the organizations. The meeting should address hard issues that have made involvement more difficult, such as: managing tension between different "constituencies" using an organization's facilities and services; what can be done to make it possible for people who use drugs to participate in a meaningful, constructive way (e.g., when to schedule meetings, what needs to be on-site, how to handle the fact that some people will have unstable or chaotic periods in their lives and will not be able to participate, etc).
- Organizations should undertake an assessment of what they need to do in order to be able to increase involvement of people who use drugs at all levels of the organization, in a sustainable fashion. They should be provided with funding to allow them to develop and implement the steps that are needed.

The Public Health Agency of Canada should provide funding for projects aimed at improving involvement of people who use drugs in community-based organizations. The projects should pilot, test, and outline different approaches to improving the level and impact of participation. Their results should be published and include practical tools and approaches to inform the development of effective participation.

Providing international leadership on greater involvement

This recommendation is aimed at greater involvement of both people living with HIV and people who use drugs *at the international level*.

Recommendation 8

Providing international leadership on greater involvement

Consistent with its responsibility in the Federal Initiative to provide leadership in global efforts, the Canadian federal government should champion the rights of people living with HIV and of people who use drugs, including their right to actively and meaningfully participate in the response to the HIV/AIDS epidemic, in international fora. In particular, the Canadian federal government should:

- Speak out about the rights of people living with HIV and the rights of people who use drugs, including their right to actively and meaningfully participate in the response to the HIV/AIDS epidemic, as well as about the importance of harm reduction efforts, in statements to UN bodies and other international fora.
- Include action taken towards greater and more meaningful involvement of people living with HIV and of people who use drugs in reports about the progress achieved towards the commitments made in the "Declaration of Commitment on HIV/AIDS".
- Continue including people living with HIV on Canadian government delegations to high-profile international meetings such as the UN General Assembly Special Session on HIV/AIDS.
- Create the conditions under which people who use illegal drugs can safely be included on Canadian government delegations to international meetings, and include them on government delegations, particularly the UN General Assembly Special Session on Drugs scheduled for 2008.
- Provide funding for groups of people who use drugs, as part of development assistance.
- Use the leverage provided by Canada's contribution to the World Health Organization's 3 by 5 Initiative to (1) advocate within WHO and elsewhere in the UN system for the recognition of the important role that groups of people who use drugs can play in advocating for access to HIV treatment and in facilitating treatment rollout; and (2) ensure that evaluation of the 3 by 5 Initiative includes monitoring of efforts made to ensure that people who use drugs are included in an equitable scaling up of treatment.
- Provide dedicated funding for representatives of organizations of people who use drugs for the 2006 International Conference on the Reduction of Drug Related Harm and for the 2006 International AIDS Conference, as well as for fora on this topic organized at these conferences.
- Work with conference organizers to address the immigration policy and practice so that people who use drugs can effectively participate in these conferences by attending.

Appendix: The Project Partners

The **Canadian HIV/AIDS Legal Network**

The Legal Network is the only organization in Canada, and one of the few organizations worldwide, which focuses on legal and human rights issues related to HIV/AIDS. Our mission is to promote the human rights of people living with and vulnerable to HIV, in Canada and internationally. We accomplish this through research, policy analysis, education, advocacy, and community mobilization.

Vancouver Area Network of Drug Users (VANDU)

VANDU is the most successful example of an organization of and for people who use drugs in Canada. It has a unique experience of mobilizing people who use drugs and of participating in processes of other organizations, as VANDU is often called upon to represent the views of people who use drugs at meetings across Canada. To support VANDU's participation in the project, a contract was issued under which VANDU's contribution was clearly outlined and VANDU was paid for the services it rendered. These included participating in the advisory committee, providing general advice about project activities and methodology, providing input on draft documents, and organizing a consultation with drug users in Vancouver.

CACTUS Montréal

CACTUS Montréal is a community-based organization providing a needle exchange service and other programs for people who use drugs in Montréal. In recent years, the organization has increased its efforts to involve people who use drugs in all aspects of the services and on its Board. To support CACTUS' participation in the project, a contract was issued to outline clearly its contribution and CACTUS was paid for the services it rendered. These included participating in the advisory committee, providing general advice about project activities and methodology and input on draft documents, facilitating a consultation with its staff and Board members, and facilitating a consultation in Montréal with people who use drugs.

British Columbia Centre for Excellence in HIV/AIDS

The Centre has conducted several studies of organizations of people who use drugs and has successfully collaborated with VANDU on a variety of projects. The BC Centre for Excellence in HIV/AIDS contributed research expertise to this project and assisted the Legal Network in ensuring maximum involvement of people who use drugs in the consultation process.