



“Nothing About Us Without Us”

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



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Network

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Copies of this booklet and the paper on which it is based are available on the Canadian HIV/AIDS Legal Network website at www.aidslaw.ca/Maincontent/issues/druglaws/greater_involvement.htm and through the Canadian HIV/AIDS Information Centre (email: aidssida@cpha.ca).

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

This booklet summarizes the main issues addressed in the Canadian HIV/AIDS Legal Network’s paper on greater involvement of people who use illegal drugs. In particular, it explains why people who use illegal drugs must be meaningfully involved in Canada’s response to HIV/AIDS, hepatitis C (HCV), and injection drug use, and the benefits of greater involvement. The booklet also contains a manifesto written by people who use drugs, and describes the achievements of two organizations of people who use drugs, the Vancouver Area Network of Drug Users and the Thai Drug Users’ Network.

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 female and aboriginal people who use drugs. HCV prevalence rates are 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. Today, drug injecting with contaminated equipment 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. In recent years, it has led to 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.

What needs to be done?

There has been some recent progress in Canada in addressing drug-related harms. In particular:

- access to methadone maintenance treatment has increased significantly;
- a medically supervised safer injecting facility opened in Vancouver in September 2003;
- a trial of prescribed heroin has begun; and
- needle exchange programs have expanded, at least in some parts of the country.

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. 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 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 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, and greater access to measures that have been demonstrated to be successful in reducing the spread of infectious diseases in other countries. 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,” rather than treating drug use primarily as a criminal law issue.

People who use illegal drugs must be meaningfully involved in all these initiatives.

Why is greater involvement of people who use drugs needed?

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.

Fulfilling the commitment to greater involvement of people living with HIV

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.



“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.”

(Health Canada. *Injection Drug Use and HIV/AIDS. Health Canada’s Response to the Report of the Canadian HIV/AIDS Legal Network.* Ottawa: 2001)



“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.”

(Australian Injecting & Illicit Drug Users League)

Public health imperatives

Second, there are public health imperatives for involving people who use drugs. People who use drugs themselves are often best able to identify what works in a community that others know little about; they need to be involved if we want to create effective responses to the epidemic. Research, both in Canada and internationally, provides evidence of the benefits of greater involvement of people who use drugs. The limitations of the traditional “provider-client model,” in which service providers strive to meet the needs of people who use drugs, are increasingly recognized. 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.

In Australia, where groups of people who use drugs have received support and have been successful in having a say in the response to HIV/AIDS since the late 1980s, researchers concluded that the existence of user groups has been a significant factor in the country’s success in preventing further spread of HIV among people who use drugs, and in keeping prevalence at low levels.

Ethical and human rights imperatives

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; and
- 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.

It reflects the human rights to participation articulated in international treaties ratified by Canada. For example, the International Covenant on Civil and Political Rights (ICCPR) recognizes the right “to take part in the conduct of public affairs” (Article 25), while the International Covenant on Economic, Social and Cultural Rights (ICESR) recognizes the right of everyone “to take part in cultural life” (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,” which includes HIV or a disability such as drug dependence.

What needs to be done to increase involvement?

The last years have seen some greater involvement of people who use drugs in Canada’s response to HIV/AIDS and HCV. For example, a few people who use drugs were invited to participate in the consultations leading to the development of Canada’s new HIV/AIDS action plan, *Leading Together: Canada Takes Action on HIV/AIDS*. 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 a project undertaken in Alberta assessing the need for organizations of people who use drugs.

But much more must be done to give people who use drugs a stronger voice in the policies, programs and services that affect their lives. Because of the life circumstances of many people who use drugs, and because of the stigma, hostility and hate they often face, special efforts are necessary to make greater, meaningful involvement possible.

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 that:

- drug use is first and foremost a health issue and should be treated as such in our laws and policies;
- 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
- 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.

Organization of people who use drugs

As the experience of VANDU and that of many organizations in other countries has shown, organizations of people who use drugs 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.

They need to be properly supported through a variety of measures:

- explicit recognition by Health Canada and the Public Health Agency of Canada, as well as by provincial/territorial and local governments, of the unique value of organizations of people who use illegal drugs;
- funding and capacity building initiatives for existing and new groups of people who use drugs;
- support for innovative and/or model projects and programs of groups of people who use drugs; and
- funding of a national group or network of people who use drugs.

Involvement of people who use drugs in consultations, decision-making or policy-making bodies, and advisory structures

In addition to creating the conditions under which organizations of people who use drugs can fulfill their unique role in Canada, 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.

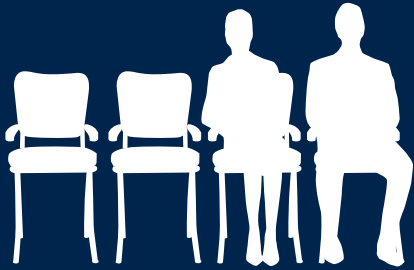


“Drug user organisations ... have carried out HIV prevention campaigns of a quality and effectiveness that have made Australia’s HIV prevention efforts among drug users the envy of the world.”

(D Burrows, 1995)

In practice,

- people who use drugs should 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 should be provided.



CACTUS Montreal, which provides needle exchange and other services for people who use drugs, recently amended its by-laws to reserve two seats on its board for people from the community of people who use drugs.

Involvement of people who use drugs in community-based organizations

Community-based organizations also 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.

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. They should be provided with funding to allow them to develop and implement the steps that are needed, as well as for projects to pilot and evaluate different approaches to improving the participation of people who use drugs in community-based organizations.

Providing international leadership on greater involvement

Consistent with Canada's commitment to provide leadership in global efforts to fight the HIV/AIDS epidemic, the Canadian federal government should champion the rights of people who use drugs, including their right to actively and meaningfully participate in the response to the HIV/AIDS epidemic, in international fora.

What else needs to be done?

Linked to the issue of greater involvement of people who use drugs is the issue of greater involvement of people living with HIV. In principle, Canada is committed to greater and meaningful involvement of people living with HIV. Canada's new action plan on HIV/AIDS, *Leading Together*, states:

More must be done to give people living with HIV/AIDS a strong voice in the programs and services that affect their lives. At the same time, the system must be careful not to expect more of people living with HIV/AIDS than it does of people with other life-threatening illnesses. It must also provide accommodations that take into account HIV-related disability and the side effects of medication.

This statement of the need for increased involvement is important; it now must be matched by action. Often, the same people are involved in many different activities and on many committees, because of their great 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. It is time to ensure that the principle of greater and meaningful involvement receives greater attention at both the governmental and community levels, and concrete goals, expected outcomes, targets and actions be set to move more decisively to involvement in practice.



For a list of do's and don'ts of consultation with people who use drugs, see the full paper on greater, meaningful involvement of people who use illegal drugs.

Public health and human rights in action : Organizations of people who use drugs matter!

This booklet and the paper on which it is based highlight the important contributions that organizations of people who use drugs have made, and recommend that Canada invest in such organizations, as one important part of efforts to increase the meaningful involvement of people who use drugs in Canada's response to HIV/AIDS and HCV.

The following text shows what two such organizations, one in Canada and one in Thailand, have achieved.



Vancouver Area Network of Drug Users protesting outside B.C. Legislature.

(photo: Elaine Briere)

Vancouver Area Network of Drug Users

In 1997, in response to the health crisis among people who use drugs and to government inaction, a group of individuals gathered in Vancouver to form an organization run by people who use drugs. The group felt that too little had been done in response to the well-documented health emergency among people who use drugs and that the voice of “users” had not been heard by those responsible for coordinating a response. This group eventually became the Vancouver Area Network of Drug Users (VANDU). With more than 1 500 members and a large number of peer volunteers, VANDU has since become one of the strongest associations of people who use drugs in the world. The organization maintains a 15-member board of directors consisting exclusively of people who use drugs, and a small staff.

During its formation, VANDU founders organized discussion groups of people who use drugs in the heart of the open drug scene. Within weeks, over 100 people were attending the meetings to discuss their concerns and plan user-based actions. All people who use drugs were encouraged to speak – no one was turned away. Through these early organizing efforts, VANDU founders ensured that users had a strong and united voice that could no longer be ignored. As one of the founders stated,

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.

The early work of VANDU focused primarily on political activism and advocacy work, but over time VANDU increased its capacity and expanded its activities. For many years now, while continuing its activism and participation on community and government task forces, VANDU has been engaged in public education efforts and the provision of various care and support programs for people who use drugs. Activities include support groups for women with HIV, persons with hepatitis C, and methadone users, as well as a syringe exchange and recovery program, alley patrols, and street, hotel, and hospital-based support programs.

In addition to promoting harm reduction initiatives, better housing and access to care, VANDU has consistently stood up in the face of power and authority to oppose measures that threaten the well-being of their members. One example occurred in 2000, following the Mayor of Vancouver’s call for a 90-day moratorium on the creation of health services for people who use drugs. Within days of the announcement, VANDU members erected dozens of crosses on the lawn of City Hall and then marched into council chambers carrying a coffin, demanding that people who use drugs have a say in discussions about their health.

In response to gaps in service delivery, VANDU has organized various support groups, expanded syringe distribution and recovery, and overdose prevention programs. The impact of VANDU on disease prevention and safety has been widely noted by local users, service providers and policy-makers, and documented by research.

When not exchanging syringes in the alleys and other locations where no health-care worker would dare venture, VANDU members can be found in the AIDS wards of the city’s hospitals, comforting those living with HIV. One VANDU volunteer described the program:

In the hospital program, we go up there ... to be there for our brothers and sisters and tell them not to leave early and to take all of their meds. We support them and tell them what is going on, on the street.

VANDU also advocates for their members in issues of fairness around methadone maintenance treatment, HIV medication access, and unfair law enforcement practices. As one funder noted:

They are seen as the voice of IDU, and that voice is being listened to because it is rational and passionate. If there was no VANDU, then how would the IDU community communicate? They would suffer a lot.



VANDU is dedicated to improving the lives of drug users, their families and our communities.

(VANDU mission statement)



It keeps us safe. It tries to bring down the risk of, like I've had HIV for years now. If VANDU had been going on back then, I probably wouldn't have it now, you know? Because there would have been somebody who gave a shit and I would have had a clean needle.

– Comment from VANDU member

VANDU has performed a critical public education function by bringing hundreds of policy-makers, health-care professionals, researchers, and others, face to face with the realities of the Downtown Eastside. Through public presentations and back alley tours, VANDU has actively countered dominant stereotypes that perpetuate the disabling stigmatization of people who use drugs.

VANDU has affected the culture of drug use in the Downtown Eastside by fostering a sense of mutual caring and responsibility among people who use drugs. This was done by promoting peer support, safer drug use, and participation in the local community.

Using limited resources and highly dedicated peer volunteers, VANDU has demonstrated that organizations of people who use drugs can focus the attention of policy-makers and the public at large on the ongoing public health and human rights crisis in their midst, while reaching those who are not being served adequately by health-care systems and delivering care to those whose rights are compromised by stigmatization and neglect.

Future directions for VANDU include influencing policy to ensure effective community consultation, building a national network of organizations of people who use drugs, and working with other organizations throughout the world to save lives and empower people who use drugs.



Thai Drug Users' Network Protest in Bangkok, Thailand.

Thai Drug Users' Network

Thailand was chosen to host the International AIDS Conference in Bangkok in July 2004, partly in recognition of its achievements in fighting HIV/AIDS. The country enjoys an international reputation as a “best practice” model in the fight against AIDS, principally because of its “100 percent condom” campaign the in 1990s. This campaign engaged sex workers with the clear recognition that they were part of the solution to a growing AIDS epidemic.

People who use drugs have not enjoyed the same recognition in Thailand. Although an estimated 30 percent of new HIV infections in Thailand are among people who use drugs, the government has never sought to provide services to prevent HIV in this population. As of early 2004, only one percent of people who use drugs in Thailand were receiving any HIV prevention services in a country upon which international praise has been heaped for its national AIDS program. As a result, an estimated 40 to 50 percent of people who use drugs in Thailand are HIV-positive. Very few of them have access to antiretroviral therapy.

The situation of people who use drugs in Thailand worsened sharply in early 2003 when Prime Minister Thaksin Shinawatra declared a “war on drugs” that gave local authorities and the police free reign, in Thaksin’s words, to deal in a “ruthless” and “severe” manner with persons charged with drug offenses. While the government’s official target was drug dealers, in many jurisdictions both small-scale users and dealers were targeted by the crackdown. The result of the first three-month phase of the crackdown was some 2 275 extrajudicial killings, which the government blamed largely on gangs involved in the drug trade; over 500 more killings are estimated to have occurred in subsequent weeks of the crackdown.



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A new voice for the most marginalized

The Thai Drug Users' Network (TDN) was formed in 2002 by a few people who use drugs who were moved to act by having seen so many of their peers die of AIDS and other drug-related harms. They began by documenting and analyzing the human rights abuses that not only impeded access to HIV prevention services and AIDS care for people who use drugs, but also forced them to live on the margins of society. TDN's documentation served to mobilize not only new members who sought advice and support from the growing network, but also attention within and outside Thailand to the plight of people who use drugs, and the absence of HIV/AIDS and other services for them.

TDN did not halt its activities in the face of the drug crackdown that began in early 2003. In April 2003, at a meeting of the International Harm Reduction Association in Chang Mai, Thailand, in spite of the danger to themselves, TDN members organized a peaceful public protest during a presentation by the Thai minister of health. Protestors stood with signs that read "Clean needles save lives" and "50% of Thai drug users = HIV+". This action helped bring international attention both to the killings in the anti-drug crackdown and to the absence of government attention to HIV/AIDS among people who use drugs.

The grounding of TDN's work in the reality of the lives of people who use drugs, its cogent analysis of drug policy and human rights issues, and its peaceful methods seemed to impress some policy-makers. Officials of the Ministry of Public Health and the Office of Narcotics Control who had never interacted formally with people who use drugs agreed to meet with TDN and continue to engage with the group on some issues. Among the achievements of this early collaboration was a change in the eligibility criteria for antiretroviral treatment that, in principle, allows people who use drugs to receive ARV therapy, though most of them still face extreme stigma and discrimination in the health system.

In spite of some collaboration with policy-makers, TDN was unable to persuade the Thai government to include HIV/AIDS services for people who use drugs among the activities proposed in the government's several applications to the Global Fund to Fight AIDS, Malaria and Tuberculosis. Taking advantage of a Global Fund provision that allows non governmental organizations to make their own applications when the official proposals of their government exclude important issues or the concerns of marginalized populations, TDN applied for and won a grant of US\$1.3 million to strengthen its policy advocacy work, expand services for people who use drugs, and build their capacity to advocate for their human rights.

TDN's work has also revitalized Thailand's National Harm Reduction Task Force, a body representing government, local and national NGOs and international agencies, with the mandate to review and recommend improvements for drug policy in Thailand.

In response to criticisms of the anti-drug crackdown, the Thai government, during the July 2004 International AIDS Conference, pledged to improve both HIV prevention services for people who use drugs and the availability of humane treatment for drug addiction, which has been virtually non-existent. TDN's monitoring capacity and its in-depth understanding of the reality of drug addiction in Thailand have made it a key player in ensuring accountability of the government with respect to these pledges, as well as representing people who use drugs in policy discussions.