

# “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

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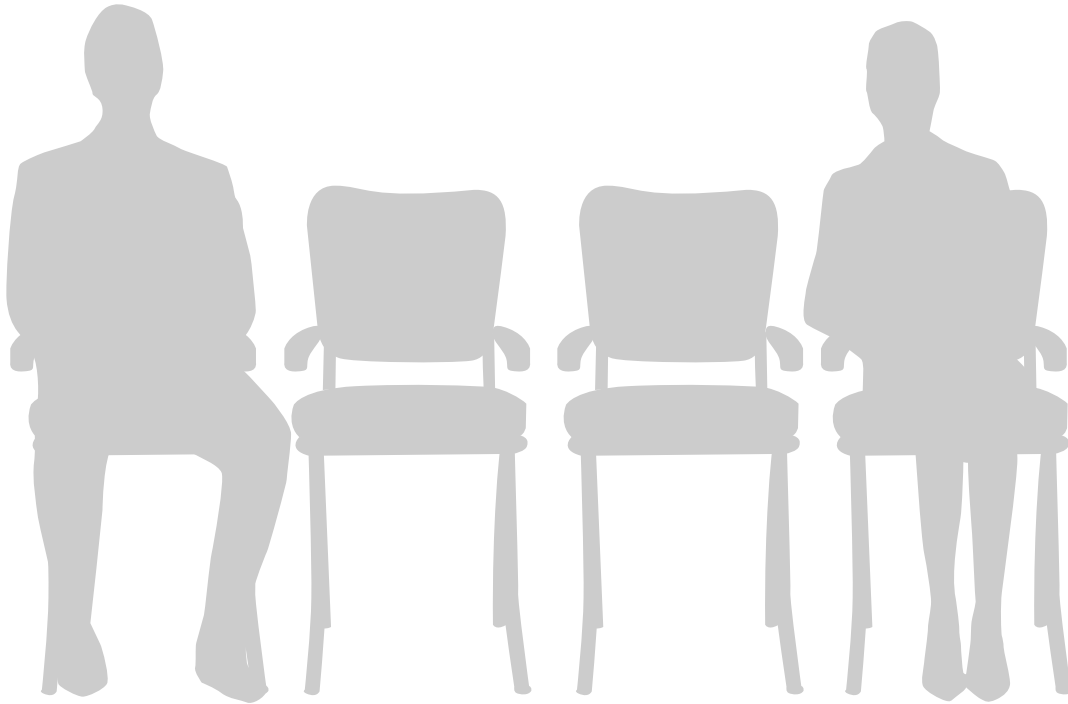
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### **Authorship note**

This report was researched and written by Ralf Jürgens.

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### **About the Canadian HIV/AIDS Legal Network**

The Canadian HIV/AIDS Legal Network ([www.aidslaw.ca](http://www.aidslaw.ca)) promotes the human rights of people living with and vulnerable to HIV/AIDS, in Canada and internationally, through research, legal and policy analysis, education, and community mobilization. The Legal Network is Canada's leading advocacy organization working on the legal and human rights issues raised by HIV/AIDS.

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### **About the International HIV/AIDS Alliance**

The International HIV/AIDS Alliance is a global partnership of nationally-based organisations working to support community action on AIDS in developing countries. To date the Alliance has provided support to organisations from more than 40 developing countries for over 3,000 projects, reaching some of the poorest and most vulnerable communities with HIV prevention, care and support, and improved access to treatment.

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### **About the International Harm Reduction Program of the Open Society Institute**

Founded in 1995, the International Harm Reduction Development Program (IHRD), a project of the Public Health Program of the Open Society Institute (OSI), works to reduce HIV and other harms related to injecting drug use, and to press for policies that reduce stigmatization of illicit drug users and protect their human rights. IHRD, which has supported more than 200 programs in Central and Eastern Europe, the former Soviet Union, and Asia, bases its activities on the philosophy that people unable or unwilling to abstain from drug use can make positive changes to protect their health and the health of others. Since 2001, IHRD has prioritized advocacy to expand availability of needle exchange, opiate substitution treatment, and treatment for HIV; to reform discriminatory policies and practices; and to increase the political participation of people who use drugs and those living with HIV.

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This report is dedicated to the memory of the many thousands of people who use drugs who have died of overdose and disease, particularly AIDS, often because proven HIV and HCV 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.



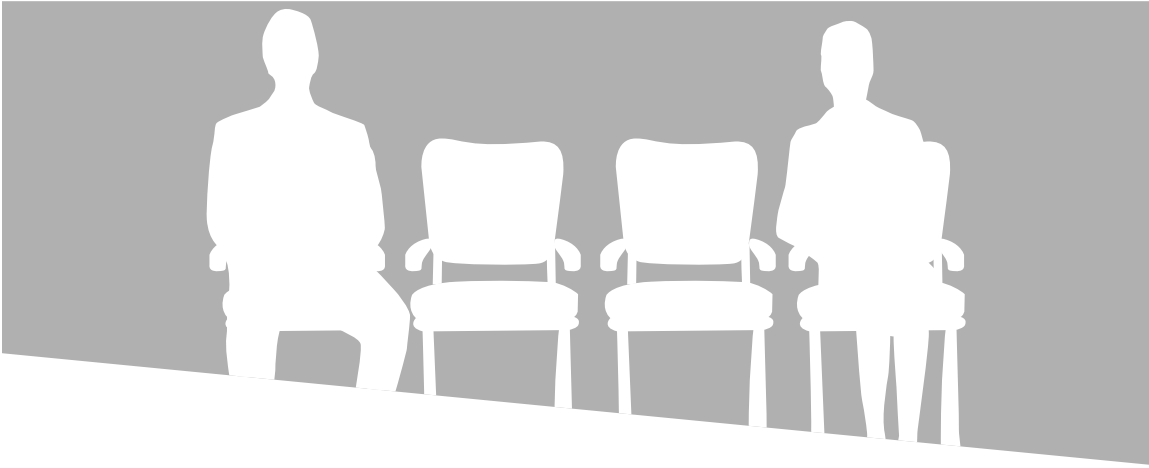
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# Executive Summary

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

## Goals and objectives

The *goal* of this report is to promote respect for the human rights of all people living with or vulnerable to HIV, 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 the response to HIV/AIDS and HCV by governments, funders, and non-governmental organizations in countries around the world;
- to increase the *capacity* of non-governmental organizations and governmental stakeholders to involve people who use illegal drugs more often and more meaningfully; and
- to increase *the involvement of people who use illegal drugs*, including in the development of better policy responses to HIV/AIDS and HCV.

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

Worldwide, there are more than 13 million people who inject illegal drugs. In some regions, more than 50 percent of them are infected with HIV and an even greater percentage are infected with HCV. 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. Other types of drug use also expose people to the risk of HIV and HCV.

In spite of the importance of addressing the needs of people who use drugs, estimates from 94 reporting low- and middle-income countries suggest that only eight percent of people who inject drugs receive some type of HIV prevention service. Even fewer have access to comprehensive services, including opioid substitution therapy and needle and syringe programmes. People who use drugs (or have used drugs in the past) also continue to have poor and inequitable access to anti-retroviral

treatment. For example, in Central Asia and Eastern Europe, where nearly 83 percent of HIV cases are attributed to injecting drug use, former or current injecting drug users only represented 24 percent of the people on anti-retroviral treatment at the end of 2004.

Everywhere, people who use drugs are among the most marginalized and discriminated against populations in society. Punitive approaches to drug use fuel stigma and hatred against people who use drugs, pushing them further into hiding and away from services to prevent, treat, and mitigate the impact of HIV and HCV.

## What needs to be done?

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 drug supply-control strategies are limited in their effectiveness 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 addition, fundamental changes are needed to existing legal and policy frameworks in order to effectively address drug use as a health and human rights issue, rather than treating it 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?

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 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.



“Most of the responses to drug related overdose, drug related crime, family breakdown, drug treatment, unemployment, etc, have been developed in isolation to people who use illicit drugs. We have been largely left out of responses to these issues because of a mistaken belief that we would be at best, disinterested, and at worst, incapable of participating in a meaningful dialogue on the issues that affect us.

While we cannot single-handedly address the issues associated with illicit drug use in the community, our involvement in the response is critical. We are the people who use illicit drugs, access drug treatment services and educate and support our peers - we have direct knowledge and experience to offer.”

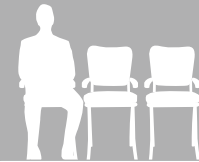
– *Australian Injecting & Illicit Drug Users League*

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 AIDS policy, programs and services. Historically, people who use or have used 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 or have used drugs in the programs and services that affect their lives, as well as in broader policy and advocacy work on HIV 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 and HCV, are important for a number of reasons.

**“It is our lives. We would like to take them into our hands.”**

– *consultation participant*



## **Fulfilling the commitment to greater involvement of people living with HIV**

First, in many countries, people who use drugs represent a significant proportion of the people 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 without meaningfully involving one of the most marginalized groups of people living with, or at great risk for, HIV.

### **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 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 governments in 2001 and 2006 when they endorsed the UN General Assembly’s *Declaration of Commitment on HIV/AIDS* and *Political*

*Declaration on HIV/AIDS*, which call for the greater involvement of people living with HIV and of people from marginalized communities;

- 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 most countries. 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 (ICESCR) 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.

## Recommendations: What needs to be done to increase involvement

The last years have seen greater involvement of people who use drugs in some countries’ response to HIV, HCV, and illegal drugs more broadly. 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 and often hostility and hate they 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, governments should acknowledge, and adopt policies reflecting 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 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.

In addition, governments should remove legal barriers to prevention and care for people who use drugs, and enact anti-discrimination or protective laws to reduce human rights violations based on dependence to drugs.

Where legal barriers exist to setting up organizations of people who use drugs, these barriers should be removed and efforts undertaken to ensure they can work effectively, without interference by law enforcement agencies, and guarantee the safety of participants.

### Supporting organizations of people who use drugs

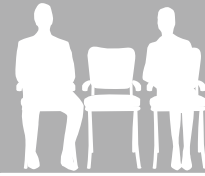
As the experience of many vibrant organizations of people who use drugs in countries around the world has shown, organizations of people who use drugs can make a unique and vital contribution and play an important role in preventing the spread of bloodborne infections, in particular HIV, and in

advancing the rights of people who use drugs. They need to be properly supported through a variety of measures:

- explicit recognition by national, regional, and local governments, as well as by international agencies, of the unique value of organizations of people who use illegal drugs;
- funding and capacity building initiatives for groups of people who use drugs; and
- support for innovative and/or model projects and programs of groups of people who use 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*



## **Involving 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, 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, HCV, and illegal drugs.

In particular,

- 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 (including women), 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.

## **Involving 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

Finally, governments and international agencies 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. International agencies should ensure that people who use drugs are invited to participate in all international consultations, committees, reference groups (such as the Reference Group to the United Nations on HIV and Injecting Drug Use) or fora where policies, interventions, or services concerning them are planned, discussed, researched, determined, or evaluated.

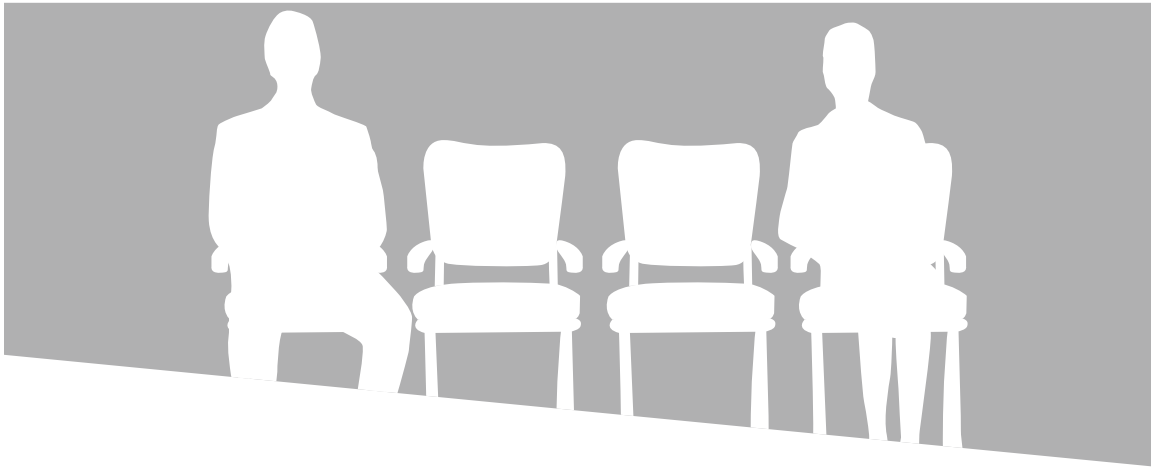


**CACTUS Montréal, which provides needle exchange and other services for people who use drugs, amended its by-laws to reserve two seats on its board for people from the community of people who use drugs.**

## For further information ...

about this report and the project on greater involvement of people who use drugs, contact the Canadian HIV/AIDS Legal Network at [info@aidslaw.ca](mailto:info@aidslaw.ca).

Further copies of this report and of a manifesto by people who use drugs developed in conjunction with this paper, can be retrieved from the websites of the Canadian HIV/AIDS Legal Network ([www.aidslaw.ca](http://www.aidslaw.ca)), Open Society Institute ([www.soros.org/initiatives/health/focus/ihrd](http://www.soros.org/initiatives/health/focus/ihrd)), and International HIV/AIDS Alliance ([www.aidsalliance.org](http://www.aidsalliance.org)).



# 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.<sup>1</sup> 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 HIV infection 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”<sup>2</sup> With the 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.”<sup>3</sup>

## “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 the “fundamental shift in perspective towards a principle

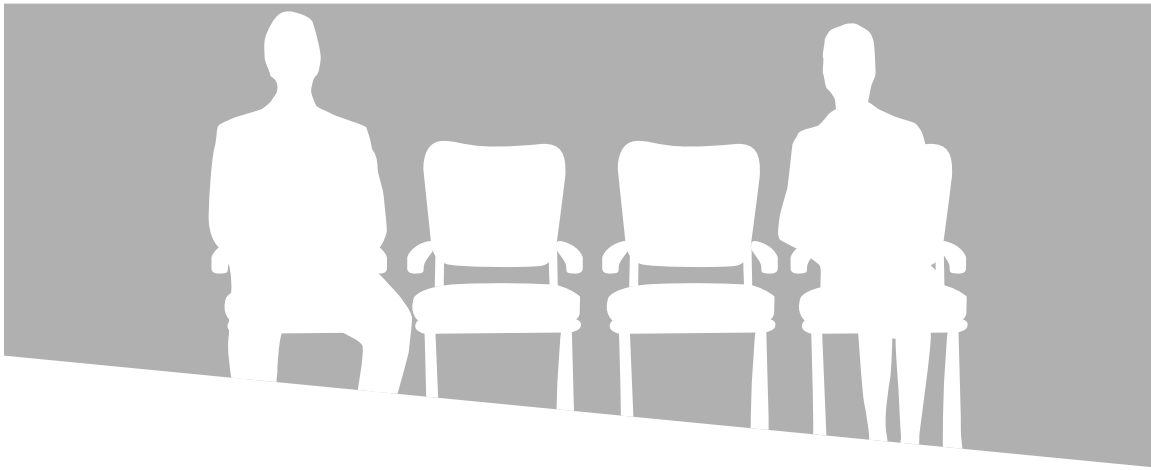
<sup>1</sup> This is similar to terminology used by the Australian Injecting & Illicit Drug Users League (AIVL) and by the International Network of People Who Use Drugs (INPUD). See, e.g., the INPUD website ([www.inpud.org](http://www.inpud.org)); AIVL. *Policy Position: Discrimination*. Canberra: undated. Available via [www.aivl.org.au](http://www.aivl.org.au) (under “policy position statements”). See also: N Stafford. Using words: The harm reduction conception of drug use and drug users. *International Journal of Drug Policy* 2007; 18: 88-91.

<sup>2</sup> 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](http://www.aidsalliance.org/sw7442.asp).

<sup>3</sup> Ibid.



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 report 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

## Scope

This report 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 report 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.<sup>4</sup> Therefore, the report 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.”

The report recognizes that many people who use illegal drugs face not only the risk of contracting HIV and HCV, but also many other health issues. As well, stigma and discrimination against people who use drugs is played out in public policies on crime, housing, welfare, access to healthcare, and education – all in ways which negatively affect the ability of people who use drugs to remain healthy. While dealing with these issues is outside its scope, this report acknowledges that there are many more reasons, beyond HIV and HCV, why people who use illegal drugs need to be involved in decision making on issues that affect their lives, and that the impact of all public policies related to drug use is inextricably linked to society’s ability to ensure the health of people who use drugs.

<sup>4</sup> 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](http://www.sfaf.org/aids101/injection.html); J Porter et al. Crack smoking methods as risk factors for HIV infection. 10<sup>th</sup> International AIDS Conference 1994; 10:391 (abstract no PD0170), at [www.aegis.com/conferences/10wac/PD0170.html](http://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; L Leonard et al. “I inject less as I have easier access to pipes”. Injecting, and sharing of crack-smoking materials, decline as safer crack-smoking resources are distributed. *International Journal of Drug Policy* (in press); J Porter, L Bonilla. Crack users’ cracked lips: An additional HIV risk factor. *American Journal of Public Health* 1993; 83: 1490-1491; J Porter, L Bonilla, E Drucker. Methods of smoking crack as a potential risk factor for HIV infection: Crack smokers’ perceptions and behavior. *Contemporary Drug Problems* 1997; 24: 319-347; S Faruque et al. Crack cocaine smoking and oral sores in three innercity neighborhoods. *Journal of Acquired Immune Deficiency Syndromes & Human Retrovirology* 1996; 13: 87-92.

Finally, while the report is primarily concerned with the involvement of *people who actively use drugs*, it acknowledges that *involvement of people who have used drugs in the past, or are on substitution treatment*, is also important. In this report, the term “people who use drugs” therefore includes people who currently use illegal drugs and people who have used illegal drugs in the past. This recognizes that, ideally, both active and former users should be involved, sometimes for the same, but sometimes for different, reasons. Active and former users share the experience of drug use and of the stigma and discrimination that people who use illegal drugs suffer. Involving both former and active users (and people on substitution therapy) in consultations and organizations of people who use drugs may also have practical advantages for people who use drugs, particularly in countries in which they are often victims of crackdowns and other forms of persecution, enabling them to speak for active and former users without necessarily self-identifying as an active user. Former users, or those on substitution treatment, may also find it easier to participate on committees and as staff in organizations and may be “better liked” by government officials, employers, and others who need to involve people who use drugs. In addition, involving both active and former users recognizes that many people who use drugs stop using drugs at certain points in their lives, but may start using drugs again.

However, former users may be somewhat disconnected from the community they seek to represent, may have other priorities than active users, may sometimes even have different and conflicting agendas, and may find it difficult to be around people who currently use drugs. For all these reasons, involving former users never can replace involvement of active users. In order to achieve the public health benefits of greater involvement of people who use drugs, and to fulfil the ethical and human rights imperatives for greater involvement, active users (and, sometimes, former users and those on substitution treatment) need to be involved.

## Methods

This report is based on a similar report produced in 2005 as part of a project undertaken in Canada by the Canadian HIV/AIDS Legal Network in partnership with the Vancouver Area Network of Drug Users (VANDU, the largest Canadian organization of people who use drugs), CACTUS Montréal (which provides needle 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). The project published three resources that make the case for greater involvement of people who use illegal drugs in the fight against HIV and HCV in Canada:

- a report exploring the practical, ethical and human rights reasons for greater involvement, along with tools (such as a list of “Do’s and don’ts” for consulting with people who use drugs) and recommendations to both community organizations and governments;
- a short booklet with key information from the report and stories of two organizations of people who use drugs engaged in advocacy and providing services (the Vancouver Area Network of Drug Users and the Thai Drug Users’ Network); and
- a manifesto by people who use illegal drugs demanding greater involvement.

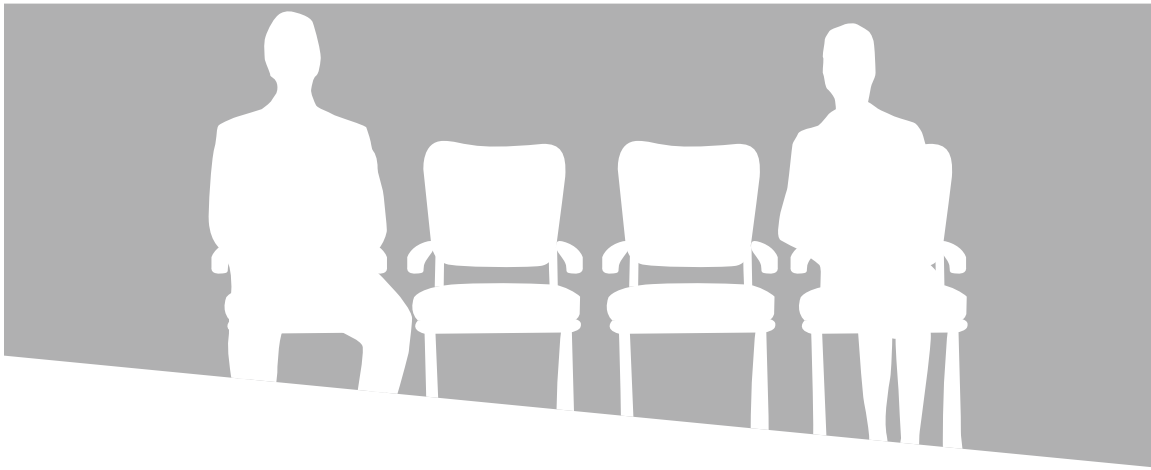
These materials were directed primarily at a Canadian audience. While they have been of some use to groups of people who use drugs, service-providers, advocacy groups and government decision-makers in other countries, a decision was taken to adapt them to the specific needs and realities of other countries and to produce an international version of the materials. At the same time, in a separate but related process, a version for Russian-speaking countries of the former Soviet Union was developed.

At the outset of the project to produce the international version, in early 2007, an advisory committee was established, with representation from the three project partners (Canadian HIV/AIDS Legal

Network, International HIV/AIDS Alliance, and Open Society Institute Public Health Program), representatives of organizations of people who use drugs from a number of countries, representatives of the Global Network of People Living with HIV/AIDS (GNP+) and the International Community of Women Living with HIV/AIDS (ICW), and selected experts. The role of the committee was to:

- provide general advice regarding the project activities, methods and communications;
- review the original Canadian documents and make suggestions about how they could best be adapted for international use;
- review and comment on a first draft of the international version of this report and the accompanying manifesto;
- provide input on the release and dissemination of these documents, and ideas for activities that could follow up on the recommendations presented here; and
- champion the involvement of people who use drugs in responses to HIV and HCV.

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. Groups of people who use drugs, service-providers, advocacy groups, and funders have been involved in the process of adapting the documents, not only to obtain their feedback, but also to increase their ownership of the documents and their commitment to greater involvement.



# 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 many countries who contract HIV and HCV, while receiving relatively little attention in many countries' efforts to scale up access to HIV prevention and treatment – despite governments' commitment “to pursuing all necessary efforts ... towards the goal of universal access to comprehensive prevention programs, treatment, care and support by 2010.”<sup>5</sup> 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.

## An epidemic of infection and of stigma and discrimination

People may have their property seized by the government, or be thrown in jail for possessing small amounts of illicit drugs, and then denied housing, jobs or voting rights after release. Worst of all, health policies are often constructed so that users are the first to be struck with the deadly HIV virus, but the last to receive the much needed treatment, care and support that non-users take for granted.<sup>6</sup>

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.<sup>7</sup> In recent years, unsafe drug injection has led to the world's fastest spreading HIV epidemic, in Eastern Europe and Central Asia.<sup>8</sup> Alarming, new epidemics of injection drug

<sup>5</sup> United Nations General Assembly. *Political Declaration on HIV/AIDS*, GA Res/60/262, 15 June 2006, paras 11 and 20.

<sup>6</sup> M Curtis. Drug user community organizing in harm reduction and the war on drugs. In: K Malinowska-Sempruch, S Gallagher (eds). *War on Drugs, HIV/AIDS and Human Rights*. International Debate Education Association, 2004, 284-304, at 284.

<sup>7</sup> C Aceijas et al. Global overview of injecting drug use and HIV infection among injecting drug users. *AIDS* 2004; 18: 2295-2303.

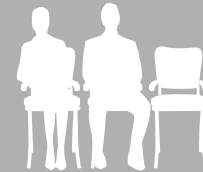
<sup>8</sup> S Strathdee, K Poundstone. The international epidemiology and burden of disease of injection drug use and HIV/AIDS. In: J Rehm, B Fischer and H Emma (eds). *Reducing the risks, harms and costs of HIV/AIDS and injection drug use (IDU): A synthesis of the evidence base for development of policies and programs*. Health Canada, 2003.

use are being witnessed in sub-Saharan Africa. HCV prevalence estimates are greater than 50 percent in over four out of five countries that have provided HCV infection estimates among drug injecting populations.<sup>9</sup> It is estimated that 170 million people (about 3 percent of the world's population) are infected with HCV.<sup>10</sup>

Once HIV enters a community of people who inject drugs, progress of the infection into the rest of the population can be very rapid if appropriate measures are not taken early. Yet in spite of the importance of addressing the needs of people who inject drugs, estimates from 94 reporting low- and middle-income countries suggest that only eight percent of people who inject drugs receive some type of HIV prevention service. Even fewer have access to comprehensive services, including opioid substitution therapy and needle and syringe programmes.<sup>11</sup> People who inject drugs also continue to have poor and inequitable access to anti-retroviral treatment.<sup>12</sup> For example, in Central Asia and Eastern Europe, where nearly 83 percent of HIV cases are attributed to injecting drug use, former or current injecting drug users only represented 24 percent of the people on anti-retroviral treatment at the end of 2004.<sup>13</sup>

**“Drug users are treated as criminals, as sub-human beings. For the past few years we have been hearing about [governments’ promise of universal access to prevention, treatment and care by 2010] – please, please don’t give us a false illusion of hope.”**

– Bijay Pandey, Nepal, speaking at the 1st Asian Consultation on Prevention of HIV Related to Drug Use, Goa, 2008



Everywhere, people who use drugs are among the most marginalized and discriminated against populations in society. Punitive approaches to drug use fuel stigma and hatred against people who use drugs, pushing them further into hiding and away from services to prevent, treat, and mitigate the impact of HIV and HCV.

Harsh drug laws effectively criminalize the status of being a drug user, leading police officers to extort bribes and confessions from vulnerable groups in order to meet arrest quotas. Many people who use drugs end up in prison or in a revolving door of ineffective and coercive rehabilitation programs, rarely receiving the HIV and/or HCV prevention and treatment they need.

## Country-level responses

A number of countries – ranging from high-income countries such as Australia, the Netherlands, Germany, and Switzerland to middle- and low-income countries such as Brazil and Indonesia – have implemented an array of harm reduction policies and programs to prevent the spread of infections

<sup>9</sup> C Aceijas, T Rhodes. Global estimates of prevalence of HCV infection among injecting drug users. *International Journal of Drug Policy* 2007; 18: 352-358.

<sup>10</sup> For more information, see the WHO hepatitis C factsheet at [www.who.int/mediacentre/factsheets](http://www.who.int/mediacentre/factsheets).

<sup>11</sup> WHO/UNAIDS/UNICEF. *Towards Universal Access: Scaling up Priority HIV/AIDS Interventions in the Health Sector*. Geneva: 2007. See also: Inter-Parliamentary Union/UNAIDS/UNDP. *Taking Action against HIV – Handbook for Parliamentarians*. Geneva: IPU/UNAIDS/UNDP, 2007. Available via <http://www.ipu.org/english/handbks.htm#aids07>.

<sup>12</sup> A Ball. Universal access to HIV/AIDS treatment for injecting drug users: Keeping the promise. *International Journal of Drug Policy* 2007; 18(4): 241-245; D Wolfe. Paradoxes in antiretroviral treatment for injecting drug users: Access, adherence and structural barriers in Asia and the former Soviet Union. *International Journal of Drug Policy* 2007; 18(4): 246-254.

<sup>13</sup> *Towards Universal Access*, supra, note 11.

among people who use drugs.<sup>14</sup> Significantly, some of these countries have also undertaken efforts to increase the meaningful involvement of people who use drugs in the response to HIV/AIDS, HCV, and injection drug use. But in the majority of countries around the world, 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.



**“Another issue of concern is equity, or should I say, the lack of equity, in access to HIV treatment by people who inject drugs. Of all injecting drug users receiving treatment globally, an astonishing 90% live in just one country, Brazil. Too often people who use drugs are denied the services that they need and have a right to. We hear that drug users are being told by physicians that “as long as you use drugs you cannot have ART”. Similarly, we have heard that drug users on methadone treatment have been denied access to ART. I find this situation unacceptable. Denial of treatment is a denial of basic human rights. But let us be clear, it is also bad practice. Current or past drug use cannot be used as a criteria for deciding who can and cannot access treatment. To curb and reverse the spread of AIDS, treatment needs to be provided based on clinical criteria, not on moral grounds.”**

– JVR Prasada Rao, UNAIDS, 2008

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.<sup>15</sup> 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.<sup>16</sup> 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<sup>17</sup> and also a factor in the interruption of anti-retroviral treatment.<sup>18</sup>

Researchers have reported numerous consequences of and responses to intensive drug policing that have a negative effect on HIV prevention and on access to other health services for people who use

<sup>14</sup> 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.

<sup>15</sup> T Kerr et al. The public health and social impacts of drug market enforcement: a review of the evidence. *International Journal of Drug Policy* 2003; 16: 210-220; Canadian HIV/AIDS Legal Network. *Legislating for Health and Human Rights: Model Law on Drug Use and HIV/AIDS. Module 1: Criminal Law Issues*. Toronto: 2006, at 6, with many references; D Wolfe, K Malinowska-Sempruch (2004). *Illicit Drug Policies and the Global HIV Epidemic. Effects of UN and National Government Approaches*. New York: OSI, 2004; 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 ([www.ccsa.ca/brochu.htm](http://www.ccsa.ca/brochu.htm)). E O'Scapella. *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.

<sup>16</sup> T Kerr, W O'Briain. Drug policy in Canada – The way forward. *Canadian HIV/AIDS Policy & Law Review* 2002; 7(1): 1, 27-32, at 30 (available via [www.aidslaw.ca](http://www.aidslaw.ca)).

<sup>17</sup> WHO/UNODC/UNAIDS. *Interventions to Address HIV in Prisons: Evidence for Action Technical Papers*. Geneva, 2007. Available via [www.who.int/hiv/idu/prison/en/index.html](http://www.who.int/hiv/idu/prison/en/index.html).

<sup>18</sup> 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.

drugs.<sup>19</sup> For example, studies have found that intensive police action or presence induces reluctance to carry syringes and other injection equipment on the part of people who use drugs, even where carrying syringes is not strictly illegal.<sup>20</sup> One study found that a large police crackdown to control illegal drug use in Vancouver, Canada, 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.<sup>21</sup> 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.<sup>22</sup> Studies of the impact of police crackdowns on HIV prevention in other countries found similar results.<sup>23</sup>

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 drug supply-control strategies are limited in their effectiveness and can sometimes be counter-productive, and that approaches to drug treatment based on abstinence are also limited.<sup>24</sup> It requires a willingness to expand harm reduction programming as part of the continuum of services. For example, needle and syringe programs, opioid substitution therapy, and other drug treatment programs need to be available (and often need to be vastly scaled up) in all countries experiencing injection drug use and related HIV and HCV epidemics. In addition, safer injection facilities may be needed<sup>25</sup> and access to substitution therapy<sup>26</sup> and to sterile injecting equipment is also needed in prisons.<sup>27</sup> Finally, “[f]undamental changes are needed to existing legal and policy frameworks in order to effectively address IDU as a health [and human rights]<sup>28</sup> issue,”<sup>29</sup> rather than treating drug use primarily as a criminal law issue.

<sup>19</sup> Canadian HIV/AIDS Legal Network. *Do not Cross: Policing and HIV Risk Faced by People Who Use Drugs*. Toronto, 2007 (available via [www.aidslaw.ca/drugpolicy](http://www.aidslaw.ca/drugpolicy)), with many references.

<sup>20</sup> L Maher and D Dixon. The cost of crackdowns: policing Cabramatta’s heroin market. *Current Issues in Criminal Justice* 2001; 13(1): 5-22.

<sup>21</sup> 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; 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; Canadian HIV/AIDS Legal Network. *Sticking Points: Barriers to Access to Needle and Syringe Programs in Canada*. Toronto, 2007 (available via [www.aidslaw.ca/drugpolicy](http://www.aidslaw.ca/drugpolicy)).

<sup>22</sup> W Small et al. Impacts of intensified police activity on injection drug users: evidence from an ethnographic investigation. *International Journal of Drug Policy* 2006; 17(2): 85-95.

<sup>23</sup> C Aitken et al. The impact of a police crackdown on a street drug scene: Evidence from the street. *International Journal of Drug Policy* 2002; 13(3): 189-198; H Cooper et al. The impact of a police crackdown on drug injectors’ ability to practice harm reduction: A qualitative study. *Social Science and Medicine* 2004; 61(5): 673-684.

<sup>24</sup> WHO. *Effectiveness of Drug Dependence Treatment in Preventing HIV among Injecting Drug Users* (evidence for action technical paper). Geneva: WHO, 2005; Canadian HIV/AIDS Legal Network. *Dependent on Rights: Assessing Treatment of Drug Dependence from a Human Rights Perspective*. Toronto: 2007.

<sup>25</sup> Canadian HIV/AIDS Legal Network. *A Helping Hand: Legal Issues Related to Assisted Injection at Supervised Injection Facilities*. Toronto, 2007 (available via [www.aidslaw.ca/drugpolicy](http://www.aidslaw.ca/drugpolicy)), with many references.

<sup>26</sup> WHO/UNODC/UNAIDS. *Interventions to Address HIV in Prisons – Drug Dependence Treatments* (evidence for action technical paper). Geneva: 2007. Available via [www.who.int/hiv/idu/prison/en/index.html](http://www.who.int/hiv/idu/prison/en/index.html).

<sup>27</sup> WHO/UNODC/UNAIDS. *Interventions to Address HIV in Prisons – Needle and Syringe Programmes and Decontamination Strategies* (evidence for action technical paper). Geneva: 2007 (available via [www.who.int/hiv/idu/prison/en/index.html](http://www.who.int/hiv/idu/prison/en/index.html)); R Lines et al. *Prison Needle Exchange: Lessons from a Comprehensive Review of International Evidence and Experience*. Montréal: Canadian HIV/AIDS Legal Network, 2<sup>nd</sup> edition, 2006 (available via [www.aidslaw.ca/prisons](http://www.aidslaw.ca/prisons)); 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.

<sup>28</sup> D Barrett et al. *Recalibrating the Regime. The Need for a Human Rights-based Approach to International Drug Policy*. The Beckley Foundation Drug Policy Programme, International Harm Reduction Association, Human Rights Watch, and the Canadian HIV/AIDS Legal Network, 2008.

<sup>29</sup> Health Canada. *Injection Drug Use and HIV/AIDS. Health Canada’s Response to the Report of the Canadian HIV/AIDS Legal Network*. Ottawa: 2001.



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.<sup>30</sup> This attitude has entrenched reliance on counter-productive and human rights-unfriendly law enforcement measures and prevented the implementation of harm reduction services that are proven to be effective.



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

*– consultation participant*

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 to address the key determinants of problematic substance use such as poverty, homelessness, childhood abuse, mental illness, and cultural dislocation. Any meaningful change in drug use patterns will necessarily require changes in social policy.<sup>31</sup> This in turn will require high levels of cooperation and coordination among various government departments. Until such action is taken, governments’ approach to illegal drug use will remain a “band-aid” approach.

Collectively, these changes will require leadership, resources and coordination. Effective national strategies are needed that provide clear direction to all levels of government and other stakeholders, and that incorporate specific performance targets. These strategies must include goals, objectives, activities and funding related to the greater involvement of people who use illegal drugs.

## Effective responses internationally

Multiple factors impede effective international responses 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 (INCB, the “quasi-judicial” body that monitors states’ compliance with these treaties), are invoked, often inaccurately, by governments unwilling to implement sound harm reduction measures. While many UN documents have emphasized the importance of programs that build on and reinforce human rights protections — including for people who use drugs — as a condition for effectively addressing HIV,<sup>32</sup> the INCB has been dismissive of this central tenet, reinforcing a disregard for the human rights of people who use drugs through errors of omission and commission. The Board’s annual reports refer regularly to “drug

<sup>30</sup> A Wodak. Drug laws. War on drugs does more harm than good. *British Medical Journal* 2001; 323(7317): 866 ; S Friedman. The political economy of drug-user scapegoating – and the philosophy and politics of resistance. *Drugs: education, prevention and policy* 1998; 5(1).

<sup>31</sup> BK Alexander. The roots of addiction in free-market society. Vancouver: Canadian Centre for Policy Alternatives (available via [www.cfdp.ca](http://www.cfdp.ca)).

<sup>32</sup> See *infra*, the section on ethical and human rights imperatives.

abusers”: since the UN drug conventions prohibit all but medical use, the report for 2001 noted, any illicit use is abuse.<sup>33</sup>

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.<sup>34</sup>

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.<sup>35</sup> 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. The political meeting at the 2009 Commission on Narcotic Drugs will be a key moment for shaping global drug control policy.<sup>36</sup> 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 and/or HCV, will be critically important in this process.

<sup>33</sup> J Csete, D Wolfe. *Closed to Reason: The International Narcotics Control Board and HIV/AIDS*. Toronto/New York: Canadian HIV/AIDS Legal Network & Open Society Institute Public Health Program, 2007, at 14, with reference to International Narcotics Control Board, *Annual report for 2001*, foreword by INCB President H. Ghodse, iii.

<sup>34</sup> E.g., see the reports by Human Rights Watch, available via [www.hrw.org](http://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. See also: R Lines and R Elliott. Injecting drugs into human rights advocacy. *International Journal of Drug Policy* 2007; 18(6): 453-457; D Barrett et al, *supra*, note 28.

<sup>35</sup> WHO (together with UNAIDS and UNODC) 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](http://www.who.int/hiv/pub/prev_care/en/effectivenesssterileneedle.pdf)). On 22 January 2008, UNODC released a discussion paper on “Reducing the adverse health and social consequences of drug abuse: A comprehensive approach” (available at [www.unodc.org/unodc/en/frontpage/reducing-the-harm-of-drugs.html](http://www.unodc.org/unodc/en/frontpage/reducing-the-harm-of-drugs.html)). While the paper still uses scare quotes around the term harm reduction and refers consistently to “drug abusers,” it is by far the clearest UNODC statement to date about the importance of needle and syringe programs, substitution treatment, overdose prevention, hepatitis vaccination, and quality drug treatment. See also the speech by UNODC Executive Director Antonio Maria Costa at the 51<sup>st</sup> session of the Commission on Narcotic Drugs on 10 March 2008 (available at [www.unodc.org:80/unodc/en/about-unodc/speeches/2008-03-10.html](http://www.unodc.org:80/unodc/en/about-unodc/speeches/2008-03-10.html)), explicitly acknowledging the importance of harm reduction and human rights approaches; and the statement by UNAIDS delivered at the Commission on 11 March 2008, urging those engaged in drug control efforts to, among other things, “allow people who use drugs or their representatives to participate in the design and delivery of HIV and harm-reduction services so that programmes will be as effective as possible” ([http://data.unaids.org/pub/BaseDocument/2008/20080311\\_statementunaids\\_cnd\\_en.pdf](http://data.unaids.org/pub/BaseDocument/2008/20080311_statementunaids_cnd_en.pdf)).

<sup>36</sup> International Drug Policy Consortium. *The United Nations Review of Global Policy on Illegal Drugs – An Advocacy Guide for Civil Society*. Witley (UK): IDPC, 2007 (available via <http://www.idpc.info/>).

## 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: D Barrett et al. *Recalibrating the Regime. The Need for a Human Rights-Based Approach to International Drug Policy*. The Beckley Foundation Drug Policy Programme, International Harm Reduction Association, Human Rights Watch, and the Canadian HIV/AIDS Legal Network, 2008. Available via [www.aidslaw.ca/drugpolicy](http://www.aidslaw.ca/drugpolicy). See also: R Elliott. Drug control, human rights, and harm reduction in the age of AIDS. *HIV/AIDS Policy & Law Review* 2004; 9(3): 86-90. Available via [www.aidslaw.ca](http://www.aidslaw.ca).

For an analysis of how the emphasis on prohibition, and the stigmatization and criminalization of people who use drugs, undermines effective responses to HIV: 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](http://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.

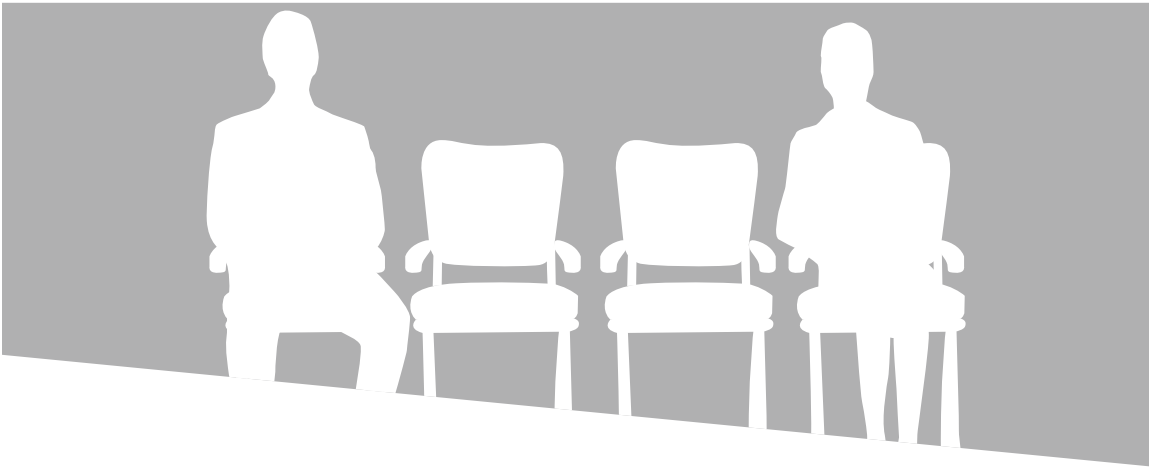
For a summary of evidence supporting harm reduction initiatives: N Hunt, M Trace & D Bewley-Taylor. *Reducing Drug Related Harms to Health: An Overview of the Global Evidence*. Beckley Foundation Drug Policy Programme, 2005 ([www.internationaldrugpolicy.net/reports/BeckleyFoundation\\_Report\\_04.pdf](http://www.internationaldrugpolicy.net/reports/BeckleyFoundation_Report_04.pdf)). See also: Institute of Medicine of the National Academy of Science. *Preventing HIV Infection among Injecting Drug Users in High Risk Countries*. Washington DC: National Academies Press, 2006.

For concrete examples of legislation and other action that advance evidence-informed and rights-based prevention and treatment for people who use drugs: Inter-Parliamentary Union, UNAIDS & UNDP. *Taking Action against HIV – Handbook for Parliamentarians*. Geneva: IPU/UNAIDS/UNDP, 2007. Available via [www.ipu.org/english/handbks.htm#aids07](http://www.ipu.org/english/handbks.htm#aids07).

For a comparative study of factors influencing the development of drug policies and programs at the national level: 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](http://www.phac-aspc.gc.ca/hepc/hepatitis_c/library.html).

For an analysis of the INCB's failure to address HIV in the context of drug use: J Csete and D Wolfe. *Closed to Reason: The International Narcotics Control Board and HIV/AIDS*. Toronto/New York: Canadian HIV/AIDS Legal Network and the International Harm Reduction Development (IHRD) Program of the Open Society Institute, 2007. Available via [www.aidslaw.ca/drugpolicy](http://www.aidslaw.ca/drugpolicy).

For a statement about the need to provide people who use drugs with equitable access to HIV treatment: Global Network of People Living with HIV/AIDS & International Community of Women Living with HIV and AIDS. *Position Statement: Injecting Drug Users and Access to HIV Treatment*. Amsterdam/London, October 2005. Available at [www.icw.org/tiki-download\\_file.php?fileId=181](http://www.icw.org/tiki-download_file.php?fileId=181).



## Greater Involvement of People Living with HIV (GIPA)

The response to the HIV/AIDS epidemic has been profoundly affected by the growth of self-identified communities 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 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.

GIPA is now firmly established, at least in principle, in most countries’ 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. A few countries included a person living with HIV on their delegations to the United Nations General Assembly Special Session on HIV/AIDS in 2001 and to the High Level Meeting on HIV/AIDS in 2006. 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.

**“Drug user organizing draws upon the work of other movements for social justice. Heavily influenced by the AIDS movement, drug user organizing carries forward the Denver Principles, which reject victimization.”**

*– Excerpted from: Jennifer Flynn, Drug User Organizing Training Manual*



While in many – but not all – countries there is a commitment to greater and meaningful involvement of people living with HIV in the response to HIV/AIDS in principle, in practice much remains to be done. A relatively small number of people living with HIV are involved at policy- and decision-

making levels, often without adequate compensation and accommodation of their needs. Despite countries' stated commitments, too often other "[p]rofessionals may retain control over decisions, and committees on which community representatives sit may not be given much decision-making authority.<sup>37</sup> 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, very often there are few women, youth, and people who use drugs among those involved.

In many ways, the issue of greater involvement of people who use illegal drugs is connected to GIPA. In countries where people who use or have used illegal drugs represent a significant proportion of people living with HIV, one cannot 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](http://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 ([www.ifrc.org/what/health/hivaids/code/](http://www.ifrc.org/what/health/hivaids/code/)).

For a policy brief with recommendations for governments, civil society and international donors on how to increase and improve the involvement of people living with HIV in global, regional and country AIDS responses: UNAIDS. *The Greater Involvement of People Living with HIV (GIPA). Policy Brief*. Geneva: UNAIDS, 2007 ([http://data.unaids.org/pub/BriefingNote/2007/JC1299\\_Policy\\_Brief\\_GIPA.pdf](http://data.unaids.org/pub/BriefingNote/2007/JC1299_Policy_Brief_GIPA.pdf)).

For a position paper on GIPA (including sections on: why we need GIPA; what GIPA really means; practical examples of GIPA activities; challenges to implementing GIPA; and suggested sources for further reading): Asia Pacific Network of People Living with HIV/AIDS. *APN+ Position Paper 2: GIPA*. January 2004 ([www.ahrn.net/library\\_upload/uploadfile/file1777.pdf](http://www.ahrn.net/library_upload/uploadfile/file1777.pdf)).

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. Via [www.aidsalliance.org/sw7442.asp](http://www.aidsalliance.org/sw7442.asp).

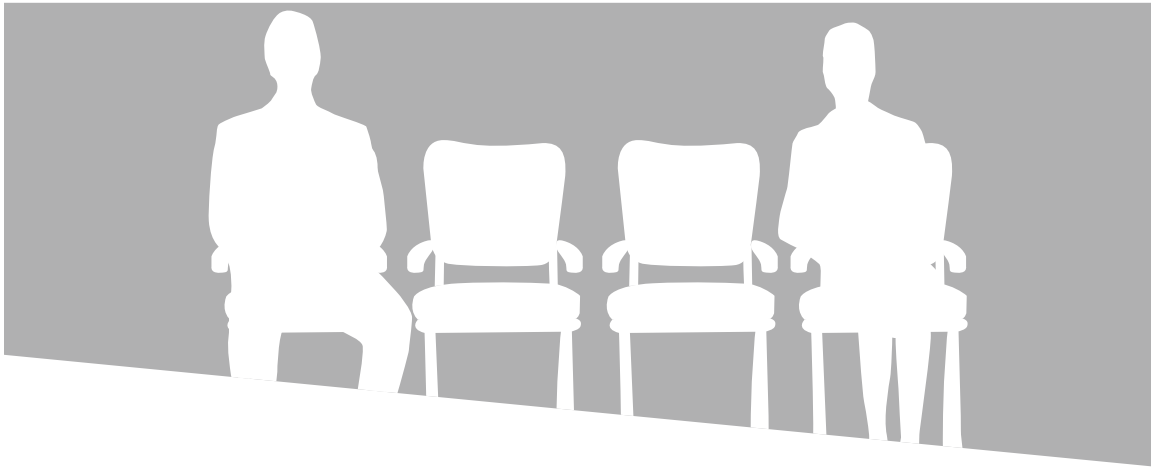
For a Canadian study on GIPA: CM Roy, R Cain. The involvement of people living with HIV in community-based organizations: contributions and constraints. *AIDS Care* 2001; 13(4): 421-432 ([www.socsci.mcmaster.ca/healthst/emplibrary/roy\\_cain\\_involvement.pdf](http://www.socsci.mcmaster.ca/healthst/emplibrary/roy_cain_involvement.pdf)).

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. Via [www.icw.org](http://www.icw.org).

<sup>37</sup> 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 number of documents aimed at enhancing the greater involvement of people living with HIV in community-based organizations, see the website of the International HIV/AIDS Alliance:  
[www.aidsalliance.org/sw7442.asp](http://www.aidsalliance.org/sw7442.asp).

For a manual on how organizations, particularly in resource-poor countries, can meaningfully increase involvement of people living with HIV: M Dylande, J Klinte, K Lund Africa. *Making a Difference – An NGO Guidebook for Facilitating the Involvement of PLWHA*. Copenhagen: AIDSNET, 2006. Via [www.aidsnet.dk](http://www.aidsnet.dk).



# Greater Involvement of People Who Use Illegal Drugs

Health developments in communities are made not only for but with and by the people.<sup>38</sup>

There is very little IDU involvement in the overall response to the AIDS epidemic.<sup>39</sup>

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.<sup>40</sup>

This chapter provides a brief history of the involvement of people who use drugs in the response to HIV, HCV, and other risks associated with injection drug use. 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 should do to ensure that people who use drugs are meaningfully involved in all aspects of the response to HIV, 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.<sup>41</sup>

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” 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 in the United States of America by methadone patients who affirmed the importance of advocacy

<sup>38</sup> World Health Organisation. *Targets for Health for All*. Geneva: 1986.

<sup>39</sup> Declaration from “Injection Drug Use and HIV Meeting” at 29 of “The Dawn of New Positive Leadership Conference Report, 11<sup>th</sup> International Conference for People Living with HIV/AIDS, 2003.

<sup>40</sup> Australian Injecting & Illicit Drug Users League (AIVL), at [www.aivl.org.au/about.html](http://www.aivl.org.au/about.html).

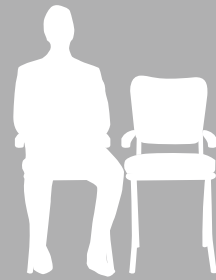
<sup>41</sup> N Crofts et al. A History of Peer-Based Drug-User Groups in Australia. *Journal of Drug Issues* 1993; 25: 599-616.

for those in drug treatment programs.<sup>42</sup> 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.<sup>43</sup> 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.”<sup>44</sup> 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.<sup>45</sup>

“We can’t know where we are going, unless we know where we’ve been. Therefore a key component of building membership or of getting people to be concerned about our issues is to clearly show people how small groups of others, working together, have made real changes in our society. This movement is linked to all other movements to create a more just society. The more someone understands this, the more they will visualize their own role in the movement. In your organizations, make sure you build community by **sharing our history. Put photographs of previous actions up in your office, start meetings by discussing the history, ask speakers who have participated in other drug user groups, fought for better AIDS policies, changed the political landscape to come and talk to your group. Remember, events with speakers are a great way to attract new people to your organization and they serve to connect your organization with others making history. More than that, they give the feeling to your members that their lives matter and once that happens, they will be able to achieve greatness.**”

– Excerpted from: Jennifer Flynn, *Drug User Organizing Training Manual*



Over the last 15 years, people who use illegal drugs have formed formal organizations in many countries.<sup>46</sup> 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.<sup>47</sup> As of 2008, such organizations existed on every continent, including in Africa.<sup>48</sup> They initially started in countries like Australia and the Netherlands where people who use drugs, “once organized, could relatively easily gain attention,

<sup>42</sup> J Byrne. Done To, Done Over, Doing it for Ourselves. The history of the Drug Users Movement. *Black Poppy* 2000; 3 ([www.blackpoppy.org.uk/highlights\\_ourselves.htm](http://www.blackpoppy.org.uk/highlights_ourselves.htm)). See also: National Treatment Agency. *A Guide to Involving & Empowering Drug Users. Public Draft 2*. London (UK): no date, at 4.10.

<sup>43</sup> Crofts et al, supra, note 41.

<sup>44</sup> National Treatment Agency, supra, note 42, 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).

<sup>45</sup> Curtis, supra, note 6, at 287.

<sup>46</sup> 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.

<sup>47</sup> D Burrows. Establishing an international communications network for injecting drug user groups. *Health Promotion Journal of Australia* 1994; 4(1): 46-48.

<sup>48</sup> In 2007, as part of the consultations undertaken for this project, the author met with a group of people who use drugs in Senegal.



build wider support, and find financial and other support,”<sup>49</sup> but have since become active also “in a number of countries where government policy is severely repressive of users, social stigma is deeper, or resources are lacking.”<sup>50</sup> The following text highlights examples of user involvement in various countries and regions.

## 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.<sup>51</sup>

The first peer-based<sup>52</sup> organizations of people who use drugs developed in Australia in the mid 1980’s in New South Wales, Western Australia, Victoria and Queensland as an ‘organic’, community-based response to the advent of HIV/AIDS in Australia and the transmission risk it posed to people who inject drugs. Since this time, Australia has continued to lead the world in peer-based organizing of people who use drugs and in recognizing the important role that people who use/have used illegal drugs have in addressing the health, social and legal issues that affect their lives.<sup>53</sup>

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, physicians, and scientists 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 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.”<sup>54</sup>

Australian organizations of people who use drugs strive to promote the health *and human rights* of people who use *or have used* illegal drugs, emphasizing that people who use or have used illegal drugs should be treated with dignity and respect, both as human beings and as consumers of health and social services. While the organizations educate and advocate on the broad range of issues that affect people who use illegal drugs, they have a primary focus on injection drug use and representing the

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<sup>49</sup> Curtis, *supra*, note 6, at 293.

<sup>50</sup> *Ibid.*

<sup>51</sup> The Australian Injecting & Illicit Drug Users’ League. *Policy Position: Drug User Organisations*. Canberra: no date. Available via [www.aivl.org.au/](http://www.aivl.org.au/).

<sup>52</sup> Peer-based organizations are organizations that involve people who use illegal drugs at all levels of the organization, including on Boards of Management, in management positions, as peer educators and project workers and as organizational members and volunteers.

<sup>53</sup> Part of the materials for this section were provided by Annie Madden from the Australian Injecting & Illicit Drug Users’ League.

<sup>54</sup> Crofts et al (1993), *supra*, note 41.

interests of people who inject drugs. The main rationale for this is a recognition that the vast majority of harms associated with illegal drug use, including the risk of HCV and HIV transmission, are experienced by the minority of people who inject drugs.

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.<sup>55</sup>

While rates of HIV among people who inject drugs in Australia have remained low, HCV rates are high, and organizations of people who use drugs provide many projects and services in relation to hepatitis C, including:

- hepatitis C peer education projects, including developing education resources
- operation of primary, peer-based needle and syringe programs
- peer support, information and referral for people living with and at risk of HCV
- information for people who inject and people on substitution therapy in relation to hepatitis C treatment, care and support issues
- representing people who inject on government hepatitis C related advisory committees and at national and local workshops, forums
- providing media comment on issues for people who inject in relation to hepatitis C
- providing input into government policy in relation to hepatitis C.

In addition to many organizations at the state and territory level,<sup>56</sup> 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. From the late 1980's to 1998, the Australian Injecting & Illicit Drug Users League (AIVL) functioned as an unfunded national organization with the exception of occasional one-off project grants.<sup>57</sup> Despite the lack of funding, "out of sheer determination and refusal to go away,"<sup>58</sup> AIVL developed into a strong, effective and accountable organization. In March 1998, AIVL received its first significant government funding for a two-year National Hepatitis C Education & Prevention Program for People Who Inject Illicit Drugs. The effectiveness and success of this program resulted in the organization receiving additional funding for a National Hepatitis C Policy Program in late 1999. These programs continued to be funded and allowed AIVL to establish an office and employ permanent staff members for the first time in the organization's history. Over the years, AIVL has developed a large number of ground-breaking policies on involvement of people who

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<sup>55</sup> Ibid.

<sup>56</sup> Including the NSW Users & AIDS Association (NUAA), Canberra Alliance for Harm Minimisation & Advocacy (CAHMA), Victorian Drug Users Group (VIVAIDS), South Australian Voice of Intravenous Education (SAVIVE), Western Australian Substance Users Association (WASUA), Network Against Prohibition (NAP), Queensland Health & Injectors Network (QUIHN), and the Tasmanian Council on AIDS, Hepatitis & Related Diseases (TASCAHRD) – Harm Reduction Program.

<sup>57</sup> See the brochures "Who is AIVL?" and "Why AIVL is important?", available via [www.aivl.org.au](http://www.aivl.org.au).

<sup>58</sup> Response to the request for input by Annie Madden, 16 March 2007 (on file with author).

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.<sup>59</sup>

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.

Similarly, Burrows observes that the organizations of people who use drugs have “been successful in helping achieve a low HIV infection rate for injecting drug users in Australia.”<sup>60</sup> 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 [New South Wales] 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.”<sup>61</sup>

Today, there can be no doubt that peer-based organizations of people who use drugs contribute a unique and crucial perspective within the Australian health context. They provide governments, services and the broader community with a unique perspective on a range of issues in relation to illegal drug use. In addition, these organizations and their employees and volunteers, as peers, also have the credibility and trust required to reach people who use illegal drugs who are often isolated and extremely marginalized within the community.



**“It occurred to me that without an effective users organisation there would be no effective response to the threat of HIV infection among injecting drug users.”**

*– Dr. Alex Wodak, Director of Alcohol and Drug Services, St. Vincent's Hospital, Darlinghurst, 1999*

Over the past 20 years, the Australian experience has reflected the value of involving people who use illegal drugs in the development of policy and programmatic responses. However, Australian organizations of people who use drugs have pointed out that they will require sufficient, dedicated funding and ongoing sector and community support in order to be able to continue to provide an effective voice for people who inject drugs into the future.

<sup>59</sup> Crofts et al (1993), *supra*, note 41.

<sup>60</sup> 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.

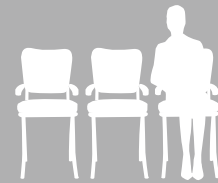
<sup>61</sup> *Ibid.*

## Eastern Europe and Central Asia: A promising beginning

In the countries of Eastern Europe and former Soviet Central Asia (EECA), the history of community mobilization by people who use drugs is largely bound up with the striking increase in the availability of heroin and other drugs, and the prevalence of injecting, that occurred after the collapse of communism.<sup>62</sup> Over the past decade – despite the fact that the funding, legal, and cultural environments are in many ways very different than in Australia or other western countries that have a longer history of user activism – the region has been a hotbed of organizing by people who use drugs, with several dozen groups active from the Balkans to Siberian Russia to the Tajik border with Afghanistan. These groups are now making important contributions to local and national debates on issues from human rights protections, drug treatment, drug policy reform, and HIV, tuberculosis and other medical care.

**“I think the more we attract international attention to the problems faced by drug users, and in Russia in particular, the sooner the situation will change for the better. The only context where the problems of drug users are discussed on the official level now in Russia is within the HIV and HCV epidemics. There is no comprehension of the rights of drug users as human beings, as members of society.”**

*– Masha Ovchinnikova, 2007*



**Russia** produced some of the first efforts at organizing. By the late 1990s, early harm reduction programs – notably the *Médicines Sans Frontières* needle exchange program in Moscow – were beginning to generate a cadre of people with a personal experience of drug use and an interest in bridging their growing public health expertise with a more activist and human rights-based approach. Kolodets, one of the first groups to form, quickly developed expertise on a range of matters central to the health of people who use drugs in Russia, and went on to play a key role in advocacy for reform of drug laws, introduction of opioid substitution therapy, and to introduce new tools for case management and HIV treatment support for people who use drugs. Activists from Kolodets have gone on to inspire change across Russia, serving as expert trainers to harm reduction and AIDS service organizations, chairing the board of the Russian Harm Reduction Network, and helping fund the national activist movement Front AIDS.

Elsewhere in the EECA region, people with the experience of drug use came together under a variety of circumstances. Some of the strongest community activist organizations, especially in Central and South-Eastern Europe, have been led by people receiving methadone therapy. In **Bulgaria**, the organization Hope-Sofia, originally founded by people in the capital city’s methadone program, has embodied a model of media savvy activism, building contacts with journalists and helping produce documentary videos exposing the country’s failure to provide sufficient treatment for hepatitis C and drug dependency. Hope-Sofia more recently has worked with the Bulgarian Helsinki Committee to document and publicize human rights and civil liberties abuses against people who use drugs. Other key organizations in the region that have grown out of methadone patient groups include Tavo Drugs in Lithuania, and Integration in Romania – both of which won new international funding for innovative peer harm reduction services in 2007.

In **Ukraine**, the location of perhaps the most intensive community organizing by people who use drugs in recent years, longer standing user and buprenorphine patient associations have been joined by

<sup>62</sup> The text for this section was provided by Matt Curtis from the International Harm Reduction Development Program of the Open Society Institute.

an emerging activist network founded on a 12-step recovery model, called Spilnota ('community' in Ukrainian). Although some of Spilnota's nearly two dozen member organizations focus exclusively on peer support, others – such as the Odessa organization Era of Mercy – are making important inroads toward improving Ukraine's TB, HIV and drug services, promoting community voices in government policy committees, and mentoring their peers. Moreover, Spilnota members and other likeminded activists are organizing new community groups in towns across the country, and, most importantly, seeking a broad base of participation from people with the experience of drug use, whatever their current relationship with drugs.

While **Central Asia** has a large population of people who use drugs, due to cultural and geopolitical specifics these communities are often more closed off than those in their neighbouring nations. In **Uzbekistan**, due to the government's restrictive policies towards non-governmental organizations, organizing of any kind has become practically impossible. Vast and remote mountainous regions in **Tajikistan** create an unfortunate physical barrier to communication between peers, and **Kyrgyzstan's** constant political upheavals have stifled the development of civil society groups. In the face of these and other difficulties, people who have previously used or are currently using drugs in Central Asia have nonetheless been active, particularly in Kyrgyzstan. For example, a group of individuals who run organizations delivering a range of services to people who inject drugs in Bishkek has been devotedly participating in local and national political and social debates. Talks of starting a Central Asian network of people who use drugs have been initiated. The next few years are to see cooperative projects between organizations from Kyrgyzstan and Tajikistan as well as a stronger, more numerous and active community of people who use drugs in Central Asia.

Though great progress has been made by people who use drugs in Eastern Europe and Central Asia in organizing, promoting change and winning recognition for their work, many challenges remain in the region. Compared to the size and resources available to harm reduction and AIDS service organizations, efforts to support organizing of people who use drugs remain small, underfunded, and to a certain extent isolated. Though harm reduction and other community health service organizations have become more accepting of involvement of people who use drugs, discriminatory attitudes persist strongly among a majority of government officials and medical personnel. Though there are now a number of effective activist groups and capable leaders, most organizations of people who use drugs in the region need to put a considerable amount of work into membership development, basic organizational management, and building capacity for advocacy and other activities. Nonetheless, the leadership and creativity shown by many people who use drugs, as well as new donor engagement and the increase in collaboration with natural allies in the movement of people living with HIV and in harm reduction organizations, have begun to entrench involvement of people who use drugs as a key part of the response to HIV and drug use in the region.



**“Even in progressive societies, the deep discrimination against people who use drugs and the tangible danger of going public in the name of user activism can act as a serious brake on organizing, an issue that is exponentially compounded in places with the harshest drug policies.”**

*– Matt Curtis, International Harm Reduction Development Program, 2004*

## Asia: Mobilization has started

Community mobilization of people who use drugs in Asia has grown at varying paces depending on national contexts.<sup>63</sup>

In **Thailand**, 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 "war on drugs"<sup>64</sup> 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 nongovernmental 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 U.S.\$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.<sup>65</sup>

In **Indonesia**, considerable investment in harm reduction programs since the late 1990s and a history of grassroots activism has helped create conditions for a wide group of individuals and organizations to engage in community mobilization work. Recent activities have included:

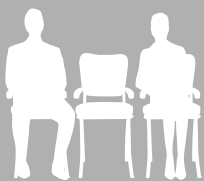
- The Jakarta network FORKON mobilized 200 people for a demonstration at the national parliament house demanding rehabilitation, not prison, for people who use drugs.

<sup>63</sup> Part of the text for this section was provided by Nick Bartlett and Matt Curtis from the *International Harm Reduction Development Program of the Open Society Institute*.

<sup>64</sup> The situation of people who use drugs in Thailand worsened sharply in early 2003 when then 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. For more information, see the report by Human Rights Watch, available via [www.hrw.org](http://www.hrw.org): *Not Enough Graves: The War on Drugs, HIV/AIDS, and Violations of Human Rights*, 2004.

<sup>65</sup> T Kerr et al. The Global Fund to Fight AIDS, Tuberculosis and Malaria. *Lancet* 2004; 364: 11–12.

- The user group Performa in Central Java undertook a successful campaign for access to antiretrovirals and humane treatment in prisons.
- A group of activists known as IKON put together a series of paralegal trainings and targeted campaigns to defend human rights of people who use drugs in Bali.
- A national network of people who use drugs, the Indonesian Drug User Solidarity Association (IDUSA), has engaged in international advocacy campaigns to increase the availability of generic HIV medications and has helped shape the national AIDS strategic plan.
- JANGKAR, the national network of harm reduction organizations, developed a national human rights database with over 1000 participants and is advocating to government stakeholders to address human rights violations.



“Since May 2003, Recovering Nepal has served as a strong network of committed people who are helping to address stigma and discrimination, raising our voices to promote basic rights, lobbying and advocating for policy change, and increasing quality access to affordable, comprehensive treatment and care for drug users who are living with HIV and hepatitis C.”

– Anan Pun, Chairperson of Recovering Nepal and Chair, INPUD, 2007

Community mobilization by people who use drugs in other countries in the region is still in its early stages. Over the past several years, **India** has seen activists from the North East India Harm Reduction Network (NEIHRN), Indian Harm Reduction Network in Delhi (IHRN), Social Awareness Service Organization (SASO), and other groups play an important role in the expansion and improvement of services for people who use drugs in different parts of the country. Recent positive changes in harm reduction policies in **China**, including the scaling up of a nation-wide opioid substitution program, are beginning to create opportunities for people with a history of drug use to pursue more active advocacy strategies. HuYangshu, a group of activists in Yunnan province, has been a pioneer in this arena, gathering nearly 500 signatures from methadone patients and community members in a successful drive to lower the price of government-supplied methadone. In **Nepal**, people with the experience of drug use have been at the forefront of efforts to develop harm reduction programs and protect the rights and health of people who use drugs, most noticeably through the organization Recovering Nepal, a founder of which – Anan Pun – was elected chairman of the International Network of People Who Use Drugs (INPUD) in 2007.

## Western Europe: Some success stories

### The Netherlands

In the Netherlands, people who use drugs have a long history of organizing to influence political and social decision-making.<sup>66</sup> 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 provided a national voice for people who use drugs to government, drug services, the

<sup>66</sup> See AC Osborne, 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/index\\_e.html](http://www.phac-aspc.gc.ca/hepc/index_e.html).

judiciary, and the medical profession, serving as an umbrella organization of local groups across the Netherlands. 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. Consistent government funding and cooperation from the police have allowed LSD and other groups in the Netherlands to flourish in ways that would not otherwise have been possible.<sup>67</sup>

## United Kingdom

User-led organizations were slower to start in the United Kingdom (UK) in comparison to the Netherlands or Australia.<sup>68</sup> This enabled UK activists to benefit from close contacts with user organizations in those countries.

By the end of the 1990s, there were several user-led organizations or full-time activists working in England, Scotland, Wales, and Northern Ireland. The first such organization to become a registered charity in the UK was the John Mordaunt Trust, named after a pioneering AIDS activist and drug user who died in 1994. Several other user-led organizations existed, some registered charities and/or limited companies and others more informal local groups, expressing the views of people who use drugs themselves about important health issues such as the quality of drug treatment available, the importance of harm reduction, the need for prevention of blood borne viruses, and the importance of user involvement in treatment and regulatory structures.

These groups benefited from a growing political recognition that public participation in the UK is a fundamental, underlying principle in the planning and delivery of public services to meet the needs of all sections of the community. Under the provisions of the Health and Social Care Act of 2011, 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. User involvement is a priority in all areas of health and social care provision, and there are statutory requirements on agencies to ensure that users are actively involved in policy, planning and decision-making.

**“For years, people in ... user groups have been covertly influencing policymakers, who phone us requesting information—data about, say, safer injection rooms. This is rare, but it does happen. Some of them surely care, and want to be advised from the horse’s mouth. They know we’re right.”**

*– Andria Efthimiou-Mordaunt, UK user activist, 2007*



Groups of people who use drugs also came together just as UK drug treatment services were about to change. Several high-profile public enquiries had been called to examine the quality of care in treatment centres. They confirmed what people who use drugs had been saying for years – that the UK treatment system was inadequate.

In 2001, treatment policy and practice in England became the responsibility of a new government agency - the National Treatment Agency for Substance Misuse (NTA). They set about trying to fix the problem of deficient services. The NTA recognized the importance of involving people using treatment

<sup>67</sup> For more details about user organizing in the Netherlands, see Curtis, *supra*, note 6, at 286-289.

<sup>68</sup> The text for this section was written by Bill Nelles.



services within their structure.<sup>69</sup> The first Board of Directors of the agency included an injecting drug user with many years of treatment experience. The agency also showed significant commitment to user and carer involvement. National and regional service user forums are regularly held. Most importantly, the NTA also set the quality standards for user involvement by treatment providers and local Drug Action Teams,<sup>70</sup> whose spending decisions directly affect the quality of life of people in treatment.

While much good work has been achieved within such relationships, there have also been tensions. The NTA is also tasked with the development of criminal justice initiatives such as compulsory treatment orders that many people who use drugs see as intimidating and oppressive. In addition, funding from the public purse has always come with the limitation that it cannot be used to promote anti-prohibition viewpoints, or used to campaign for drug law reform.

Thus the creation of user organisations seeking such goals has been challenging. In the last 10 years, several organizations have come and gone. The organizations have been hard to sustain because it has been very difficult to obtain adequate resources for their work. However, many of people who founded these groups are still active within the UK user movement. More recently, a National User Network was started.

There is also a well-developed structure of users and former users within England that are funded through The [Methadone] Alliance to provide advocacy and support services to people who use drugs needing treatment.<sup>71</sup>

Finally, the UK also has a thriving literary scene, with several user-produced publications and magazines that inform and invigorate the user community and counter stereotypical images of people who use drugs in the mainstream media.<sup>72</sup>



In ... Stockholm, Sweden, syringe exchange is illegal. On May 4, activists from the Swedish Users' Union turned themselves in to the police to assess what the penalty would be. "We are handing out syringes for purely humanitarian reasons," Berne Stålenkrantz, the union's national chairman, told *The Local*, an online Swedish news service. "And we are forced to do so since society is not providing this type of healthcare." INPUD's Stijn Goossens praises their efforts and adds, "We are in a lucky position in Europe, because the consequences for this type of activity aren't as severe as in the U.S. or Russia."

## Other countries

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

<sup>69</sup> The National Treatment Agency for Substance Misuse (NTA) declares that it "wants to build an equal partnership with treatment service users and drug users, because we recognise that those in treatment and those who have identified a need for treatment have the right to become involved in activities that affect their health and well-being. We respect the unique expertise and experiences of users and understand the health, esteem and other personal benefits that involvement can bring." For more details, see the section on "user involvement" on the NTA website: [www.nta.nhs.uk](http://www.nta.nhs.uk).

<sup>70</sup> National Treatment Agency for Substance Misuse. *NTA Guidance for Local Partnerships on User and Carer Involvement*. NTA: London, 2006. Available via [www.nta.nhs.uk](http://www.nta.nhs.uk).

<sup>71</sup> For more information, see [www.m-alliance.org.uk](http://www.m-alliance.org.uk).

<sup>72</sup> See, for example: *Black Poppy* ([www.blackpoppy.org.uk/](http://www.blackpoppy.org.uk/)); *The Users Voice*, a publication from the John Mordaunt Trust ([www.clubplan.org/CMS/page.asp?org=3460&name=home](http://www.clubplan.org/CMS/page.asp?org=3460&name=home)); and the *Heroin Herald* ([www.wiredinitiative.com/pdf/Heroin\\_Herald\\_autumn05.pdf](http://www.wiredinitiative.com/pdf/Heroin_Herald_autumn05.pdf)).

participation of people who use drugs in the development of drug policy.<sup>73</sup> Today, in addition to the main office in Paris, ASUD has a presence in other cities in France.

In **Switzerland**, self-help among people who use drugs is encouraged under the confederation's four-pillar drug policy.<sup>74</sup>

In **Denmark**, the Danish Drug Users' Union, BrugerForeningen (BF) was founded in November 1993, making it one of the oldest user organizations.<sup>75</sup> Methadone patients run BF's daily drop-in center. The 630 members pay \$18 in annual dues and can have free collective meals, laundry, vitamins, first aid and painkillers, and bicycle service. They also have access to computers and the Internet, physical workout equipment, musical instruments, video equipment, and copy and print services. BF members present preventive drug-education trainings to young people, nurses, journalists and other professionals. They also provide trainings to police cadets, substantially influencing the way police think of and treat people who use drugs. BF's Syringe Patrol clears the streets of used injecting equipment, picking up more than 200,000 syringes and needles a year, and gets paid by the city of Copenhagen to do so.<sup>76</sup>

In **Germany**,<sup>77</sup> a network of groups of people who currently use drugs, people who used drugs in the past, and people on substitution therapy ("Junkies, Ehemalige, Substituierte": JES) was created in 1989, with financial and logistical support provided by the Deutsche AIDS Hilfe, Germany's national coalition of AIDS-service organizations. Groups exist in cities across Germany, providing a variety of services ranging from needle and syringe programs to counselling to street patrols, and undertaking advocacy. The JES network has played an important role in the development of German drug policies and services over the last 18 years, and continues being engaged in the fight for a more humane drug policy and for the human rights of people who use drugs.

## North America

### 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.<sup>78</sup>

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

<sup>73</sup> For a detailed description of the history and activities of ASUD, see G Charpy. ASUD, 10 ans déjà ([www.asud.org/qui\\_sommes\\_nous/histoire\\_asud.php](http://www.asud.org/qui_sommes_nous/histoire_asud.php)); M Jauffret. *L'auto-support des usagers de drogues en France. Groupe d'entraide et groupes d'intérêt*. Paris: Groupement de Recherche Psychotropes, Politique et Société, CNRS, n° 6, 2000 (via <http://cesames.org/>).

<sup>74</sup> Ogborne, Carver, Wiebe, supra, note 66.

<sup>75</sup> S Subways. "Nothing about us without us". Drug users around the world organize for HIV and viral hepatitis prevention, healthcare, and human rights. *Solidarity Project 2007*; 5, 1-5, at 3.

<sup>76</sup> For more information about the history of the Danish Drug Users' Union: [www.brugerforeningen.dk/bfny.nsf/pagesUK/UK.html](http://www.brugerforeningen.dk/bfny.nsf/pagesUK/UK.html).

<sup>77</sup> The text for this section was provided by Dirk Schaeffer. For more information (in German), see: [www.jes.aidshilfe.de/index.php](http://www.jes.aidshilfe.de/index.php); Deutsche AIDS-Hilfe. *Zur Stellung der Drogenselbsthilfe der Junkies, Ehemaligen und Substituierten (JES) im Drogenhilfesystem: Leistungsangebote der regionalen Gruppen vor Ort im Jahr 1998*. Berlin: 1998; JES. *Profil und Selbstverständnis von JES, dem akzeptierenden arbeitenden Drogenselbsthilfe-Netzwerk der Junkies, Ehemaligen und Substituierten*. Berlin: 2003; Deutsche AIDS-Hilfe. *10 Jahre JES-Netzwerk*. Berlin: 2001.

<sup>78</sup> 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/index\\_e.html](http://www.phac-aspc.gc.ca/hepc/index_e.html)).

people who use drugs.<sup>79</sup> As a result of this effort, for example, a group of people who use drugs started to meet regularly in Montréal. 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.<sup>80</sup> A small number of other organizations, such as UNDUN in Kingston, have established websites to share information with and engage other people who use drugs, but have had little or no funding.<sup>81</sup>

On World AIDS Day 1999, then Minister of Health Allan Rock stated that “people with addictions and HIV issues deserve to be heard.”<sup>82</sup> 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 Canada’s action plan on HIV/AIDS.<sup>83</sup>

However, meaningful participation of people who use drugs remains limited in shaping Canada’s response to drugs and to HIV and HCV. The challenge is to turn statements of principle into greater and meaningful involvement, particularly in a political environment that has changed substantively in recent years under a Conservative minority government that has rejected harm reduction and turned its back to evidence-based drug policy informed by human rights principles.

### **United States of America: A difficult environment for user organizing**

Unlike in some other countries, the history of the harm reduction movement in the USA is “bound up with user participation”,<sup>84</sup> particularly with needle exchange programs where they exist.<sup>85</sup> This was especially so in the movement’s early activist-driven days, when many of the driving forces behind grass roots efforts to establish exchanges were injectors, or former injectors.

However, in the USA, extreme stigmatization and repression has made direct organizing of people who use more difficult,<sup>86</sup> although it has nevertheless taken place at various times over the past two decades in such disparate locations as New York City, Oakland (California), Philadelphia, and Denver (in the form of user advocacy groups) and Santa Cruz and San Francisco, California (in the form of user-run publishing collectives). In the late 1990s there was an attempt to create an umbrella network – the North American Users Union – to link US user activists with their Canadian counterparts. In New York City, VOCAL (Voices Of Community Advocates and Leaders) has organized since early 2005 for the education, prevention, and treatment of HIV and HCV, and for sound public policies affecting people who use drugs.<sup>87</sup> Most recently, VOCAL has campaigned for syringe access in the homeless shelter system and better access to buprenorphine and HCV treatment.

<sup>79</sup> *Creating Vectors of Disease Prevention: Empowering Drug Users*. Vancouver: VANDU, 2004 ([www.vandu.org/vreports.html](http://www.vandu.org/vreports.html)).

<sup>80</sup> V Wheeler. *User Network Development Project (UNDP). Final Report*. NPNU Harm Reduction Programmers of Alberta, March 2005.

<sup>81</sup> For more information about the situation in Canada, see the Canadian version of this report: Canadian HIV/AIDS Legal Network. *“Nothing About Us Without Us”: Greater, Meaningful Involvement of People Who Use Illegal Drugs: A Public Health, Ethical, and Human Rights Imperative*. Toronto, 2005 (available via [www.aidslaw.ca/drugpolicy](http://www.aidslaw.ca/drugpolicy)).

<sup>82</sup> Health Canada, *supra*, note 29, at 8.

<sup>83</sup> *Leading Together: Canada Takes Action on HIV/AIDS (2005-2010)*. Ottawa: Canadian Public Health Association, 2005.

<sup>84</sup> Correspondence received from Matt Curtis, International Harm Reduction Program, on 27 September 2005 (on file with author).

<sup>85</sup> 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.

<sup>86</sup> SM 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.

<sup>87</sup> Correspondence received from Paul Cherashore on 11 November 2007 (on file with author). See VOCAL’s website ([www.nycahn.org/nusersunion.htm](http://www.nycahn.org/nusersunion.htm)) for more information.

## Establishing an international network

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,<sup>88</sup> and people who use drugs continued to meet informally on the occasion of the yearly International Harm Reduction Conference (IHRC).

However, it was not until the 2005 IHRC in Belfast that the creation of a new network was highlighted as a priority, as a result of conversations between activists from many different countries, the International Harm Reduction Association (IHRA), and OSI's International Harm Reduction Development Program (IHRD). A core group of organizers was established, beginning a two-year process toward the founding of the International Network of People Who Use Drugs (INPUD).

In 2006, during the IHRC in Vancouver, Canada, the first International Drug Users Congress was held, marking the first major opportunity for activists to define the concept and goals of the network face-to-face. More than 120 activists participated in drafting INPUD's founding document, the Vancouver Declaration (reproduced below in textbox 1).

Following a second International Drug Users Congress held in Warsaw in 2007, INPUD was legally registered as an organization with a central office, an elected board, one paid staff, and an increasing number of members. Start-up funding came from IHRA, which secures the most basic needs of the network for a three-year period. Since then, INPUD has turned its attention to building regional sub-networks as a means of providing support to local members. INPUD-Asia was established in August 2007, an INPUD-Europe group has begun participating in European Commission bodies set up to involve civil society in drug policy making, and the first INPUD-North America meeting was held in New Orleans in late 2007, including some 40 activists from the USA and Canada, as well as counterparts from Europe, Latin America and Asia.

INPUD is the product of many years of work by activists demanding a voice in national and international responses to drug use. At a moment when the rights and contributions of people who use drugs appear to be gaining greater recognition, INPUD for the first time unites activists from every continent, promoting greater understanding of the experiences of people who use drugs and demanding human rights- and science-based approaches to health services and public policies affecting them.

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<sup>88</sup> Burrows (1994), *supra*, note 47, 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.

## Textbox 1:

### Why the world needs an international network of activists who use drugs

We are people from around the world who use drugs. We are people who have been marginalized and discriminated against; we have been killed, harmed unnecessarily, put in jail, depicted as evil, and stereotyped as dangerous and disposable. Now it is time to raise our voices as citizens, establish our rights and reclaim the right to be our own spokespersons striving for self-representation and self-empowerment:

- To enable and empower people who use drugs legal or deemed illegal worldwide to survive, thrive and exert our voices as human beings to have meaningful input into all decisions that affect our own lives
- To promote a better understanding of the experiences of people who use illegal drugs, and particularly of the destructive impact of current drug policies affecting drug users, as well as our non-using fellow-citizens: this is as an important element in the local, national, regional and international development of these social policies.
- To use our own skills and knowledge to train and educate others, particularly our peers and any other fellow-citizens concerned with drugs in our communities.
- To advocate for universal access to all the tools available to reduce the harm that people who use drugs face in their day-to-day lives, including, i) drug treatment, appropriate medical care for substance use, ii) regulated access to the pharmaceutical quality drugs we need ii) availability of safer consumption equipment, including syringes and pipes as well as iii) facilities for their safe disposal, iv) peer outreach and honest up-to-date information about drugs and all of their uses, including v) safe consumption facilities that are necessary for many of us.
- To establish our right to evidence-based and objective information about drugs, and how to protect ourselves against the potential negative impacts of drug use through universal access to equitable and comprehensive health and social services, safe, affordable, supportive housing and employment opportunities.
- To provide support to established local, national, regional, and international networks of people living with HIV/AIDS, Hepatitis and other harm reduction groups, making sure that active drug users are included at every level of decision-making, and specifically that we are able to serve on the boards (of directors) of such organizations and be fairly reimbursed for our expenses, time and skills.
- To challenge the national legislation and international conventions that currently disable most of us from living safe, secure and healthy lives.

Well aware of the potential challenges of building such a network, we aim to:

- value and respect diversity and recognize each other's different backgrounds, knowledge, skills and capabilities, and cultivate a safe and supportive environment within the network regardless of which drugs we use or how we use them;



- spread information about our work in order to support and encourage development of user organizations in communities/countries where there are no such organizations;
- promote tolerance, cooperation and collaboration, fostering a culture of inclusion and active participation;
- [respect] democratic principles and create a structure that promotes maximum participation in decision making;
- [achieve] maximum inclusion with special focus to those who are disproportionately vulnerable to oppression on the basis of their gender identity, sexual orientation, socioeconomic status, religion, etc;
- ensure that people who use drugs are not incarcerated and that those who are incarcerated have an equal right to healthy and respectful conditions and treatment, including drug treatment and access to health-promoting supplies such as syringes and condoms and medical treatment or at least equal to that they would receive outside;
- challenge execution and other inhuman treatment of people who use drugs worldwide.

Ultimately, the most profound need to establish such a network arises from the fact that no group of oppressed people ever attained liberation without the involvement of those directly affected by this oppression. Through collective action, we will fight to change existing local, national, regional and international drug laws and formulate an evidence-based drug policy that respects people's human rights and dignity instead of one fuelled on moralism, stereotypes and lies.

The International Activists who use drugs  
30 April 2006, Vancouver, Canada



## Further Reading

For a list of “user unions worldwide”, click on “useful links” on the website of the Danish Drug Users’ Union ([www.brugerforeningen.dk/bfny.nsf/pagesUK/UK.html](http://www.brugerforeningen.dk/bfny.nsf/pagesUK/UK.html)).

For a newsletter focusing on activism by people who use drugs from around the world, including articles on activism in Russia and Nepal: CHAMP. *Solidarity Project 2007*; 5 ([www.champnetwork.org/media/sp07No.5.pdf](http://www.champnetwork.org/media/sp07No.5.pdf)).

For a review of the history of user activism: M Curtis. Drug user community organizing in harm reduction and the war on drugs. In: K Malinowska-Sempruch, S Gallagher (eds). *War on Drugs, HIV/AIDS and Human Rights*. International Debate Education Association, 2004, 284-304.

For a more detailed history of groups of people who use drugs in Australia: N Crofts et al. A history of peer-based drug-user groups in Australia. *Journal of Drug Issues* 1993; 25: 599-616. See also A Wodak. Organizations of injecting drug users in Australia. *International Journal of Drug Policy* 1993; 4: 96-97; and the information available at [www.aivl.org.au](http://www.aivl.org.au).

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](http://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](http://www.mydocsonline.com/pub/gwroe/VHNfinal.pdf)).

For a documentation of a community-based care and support model for people who inject drugs living with HIV: *Breaking New Ground, Setting New Signposts: A Community-Based Care and Support Model for Injecting Drug Users Living with HIV (A SASO-Alliance Experience)*. Available at [www.aidsallianceindia.net/Main/ViewPublication.aspx?id=675](http://www.aidsallianceindia.net/Main/ViewPublication.aspx?id=675).

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](http://www.vandu.org/vreports.html).

For a report providing practical tools and approaches to inform the development of effective user and community participation, prepared by 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](http://www.london.gov.uk/gla/publications/health.jsp#lessons).

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'intérêt*. 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?<sup>89</sup>

Despite popular prejudice to the contrary, people who use drugs have proven, through their active involvement in the response to HIV 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:<sup>90</sup> as contributors, speakers, implementers, experts, and participants in decision-making bodies.

They should be involved at all levels. Nevertheless, this report 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 report 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.<sup>91</sup>

### Further Reading

For a report discussing another form of user involvement, namely in making decisions about their drug treatment: J Fischer et al. *Drug User Involvement in Treatment Decisions*. York (UK): Joseph Rowntree Foundation, 2007 (available via [www.jrf.org.uk](http://www.jrf.org.uk)). See also: National Treatment Agency for Substance Misuse. NTA Guidance for local partnerships on user and carer involvement. London: NTA, 2006 (available via [www.nta.nhs.uk](http://www.nta.nhs.uk)).

For more information about the “Treatment Service Users Project”, an Australian project aimed at increasing meaningful consumer participation in drug treatment agencies, see [www.aivl.org](http://www.aivl.org) (under “other projects”).

Phase 1 of this project looked at the existing levels of consumer participation in drug treatment services, identified gaps and provided recommendations that need to be addressed to increase these levels. It also looked to address the myths and misconceptions that exist in the sector about actively engaging consumers in drug treatment service delivery and planning. For example, a number of services felt that consumers are not really interested in such kind of participation. However interviews

<sup>89</sup> Response to the request for input by Dr Peter Akai, 15 April 2005 (on file with author).

<sup>90</sup> 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.

<sup>91</sup> Involvement in research and in drug treatment services is also essential, but could not be addressed as part of this project.



with consumers found a different response, where the majority of consumers of drug treatment services were very interested in such participation activities. In general, the project found that there is a significant amount of low-level consumer participation activities occurring in Australia, such as, feedback sessions and suggestion boxes. Though these activities are valuable, for a consumer they can be very tokenistic. Hence, Phase 2 is focusing on the development of projects where consumers of drug treatment services are more actively involved in decision-making processes, such as in staff recruitment, planning and delivery of services and membership on management committees. Five pilot projects will be established, where mid- to high-level consumer participation projects will be implemented. The pilot projects will then be evaluated and the lessons shared within the sector. After this, a framework for consumer participation in drug treatment agencies will be developed.

## Textbox 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.<sup>92</sup>

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.”<sup>93</sup> 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.<sup>94</sup> In particular, they are very effective in modifying group behaviours to instil disease prevention and social support standards.<sup>95</sup> 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.<sup>96</sup>

<sup>92</sup> Friedman et al, *supra*, note 86, at 259.

<sup>93</sup> *Ibid.*

<sup>94</sup> 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 46.

<sup>95</sup> See, e.g., 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; S Friedman. Going beyond education to mobilizing subcultural change. *International Journal of Drug Policy* 1993; 4(2); C Kaplan et al. The “boule de neige” project: Lowering the threshold for AIDS prevention among injecting drug users. *International Journal of Drug Policy* 1992; 3(4).

<sup>96</sup> 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.”<sup>97</sup>

This fundamental requirement for meaningful involvement is consistent with commitments on the part of governments:

- *The Declaration of the Paris AIDS Summit*. 42 national governments signed this declaration in 1994, and agreed to “support a greater involvement of people living with HIV/AIDS.”<sup>98</sup>
- *The Declaration of Commitment on HIV/AIDS and the Political Declaration on HIV/AIDS*. The Declaration of Commitment, 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” (para 33).<sup>99</sup> The Political Declaration, adopted in 2006, repeated the same principle (para 20).<sup>100</sup>

“We use drugs, but we are still human beings.”

– consultation participant



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).

The Guideline further states under paragraph 24(a) that “community representation should comprise ... representatives of vulnerable groups.”<sup>101</sup>

<sup>97</sup> 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](http://www.aidslaw.ca/Maincontent/issues/druglaws.htm).

<sup>98</sup> Available via the UNAIDS website ([www.unaids.org](http://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).

<sup>99</sup> The Declaration of Commitment and Political Declaration are available on the UNAIDS website via [www.unaids.org](http://www.unaids.org).

<sup>100</sup> UN General Assembly. *Political Declaration on HIV/AIDS*, June 15, 2006.

<sup>101</sup> Office of the United Nations High Commissioner for Human Rights (OHCHR) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). *International Guidelines on HIV/AIDS and Human Rights (2006 Consolidated Version)*. New York and Geneva: United Nations, 2006.

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 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. This has been recognized in the policy paper on intensifying HIV prevention approved by the UNAIDS governing board in June 2005, which noted that HIV prevention and treatment for people who use drugs should include peer outreach — that is, people who use drugs reaching out to other people who use drugs — and that HIV/AIDS programs “must be based on promoting, protecting and respecting the human rights of drug users.”<sup>102</sup> J.V.R. Prasada Rao, Director of the UNAIDS Regional Support Team, Asia Pacific, in major addresses in 2006 and 2008, recognized that respect by HIV organizations for the human rights of people who use drugs requires real participation and partnership with people who use drugs: “that doesn’t just mean polite meetings and shared recommendations; it means a real flow of resources to drug user networks . . .”<sup>103</sup> *Taking Action against HIV*, the Handbook for Parliamentarians issued by the Inter-Parliamentary Union, UNAIDS, and UNDP in 2007, also emphasizes the importance of “supporting community action among people who use drugs,” calling upon Members of Parliament to “consult with people who use drugs, support them in claiming their rights to prevention and care, and actively involve them in any initiatives related to AIDS and drug use”.<sup>104</sup>



**“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.”<sup>105</sup>**

## 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, can 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.

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:

<sup>102</sup> UNAIDS. *Intensifying HIV Prevention: UNAIDS Policy Position Paper*. Geneva: UNAIDS, 2005.

<sup>103</sup> JVR Prasada Rao. *From advocacy to implementation: challenges and responses to injecting drug use and HIV*. Plenary speech at XVII International Conference on the Reduction of Drug-Related Harm, Vancouver, 30 April 2006. See also the speech delivered by JVR Prasada Rao at the opening ceremony of the 1<sup>st</sup> Asian Consultation on the Prevention of HIV Related to Drug Use, 28 January 2008 ([www.unodc.org/india/prasadaraospeech\\_openingceremony.html](http://www.unodc.org/india/prasadaraospeech_openingceremony.html)).

<sup>104</sup> *Taking Action against HIV*, supra, note 11, at 183.

<sup>105</sup> Statement from policy maker, as reported in Kerr et al, supra, note 78.

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.<sup>106</sup>

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 1,000 and 2,000 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.

As described above, in the "History of involvement of people who use drugs," organizations of people who use drugs in many other countries have undertaken similar actions to bring attention to the serious issues and problems faced by people who use drugs, and to demand that they be listened to and action be taken to respect and promote their human rights and dignity.

### **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.<sup>107</sup>

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.

### **Benefits of involvement at the individual level**

There are also direct benefits for people who use drugs themselves in becoming involved in user organising. Self-organizations may support people as they are trying to find stability with their drug taking, and offer them purpose and direction in their life (if this is missing). In addition, user organising may act more fundamentally to raise the underlying sense of self-esteem and self-efficacy of people who use drugs.<sup>108</sup> (Friedman and colleagues have described this last factor as 'redemption through social struggle'.<sup>109</sup>)

<sup>106</sup> 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* 2006; 17(2): 61-69.

<sup>107</sup> 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.

<sup>108</sup> W Miller, S Roonick (1991). Motivational Interviewing: Preparing people to change behaviour.

<sup>109</sup> S Friedman, M Southwell et al. Harm Reduction: A perspective from the left. *International Journal of Drug Policy* 2000.

Consider the following comments from people who use drugs who are members of a user organization or access programs of such an organization:

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 [the organization] 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.<sup>110</sup>

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 such organizations, “whereas overdose deaths are commonplace among non-members”.<sup>111</sup> Furthermore, members of user organizations suggested that participation in them helped them decrease behaviours that put them at risk of contracting blood-borne diseases.<sup>112</sup> Additional 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.

At the same time, it can be challenging and arduous to be a user representative,<sup>113</sup> particularly an active user representative: “It can take an enormous personal toll on people depending on how ‘out’ their work makes them and can have extremely negative impacts on their lives in terms of discrimination, family problems, employment problems, housing problems, etc.” As a result, some people “are reluctant to come forward to get involved and represent users – it is not just about the demands of people’s own lives but is very much about the fear of what will happen if you come out as a drug user.”<sup>114</sup> This is particularly true for women who use drugs and have children, who may be reluctant to get involved for fear that their children may be taken away from them by the authorities if they are open about their status as a user.

Because the stigma around drug use, and of being a user, is so fierce, it can be equally challenging to be a peer worker. Participants in an evaluation of harm reduction peer projects highlighted how “drug use gets targeted when things go wrong and it becomes a license for others (staff, board members, police) to mistreat peer workers”.<sup>115</sup> One participant said:

When they know that we're community health nurses, our program gets incredible respect – when they think that we're just ex-users off the street who feel like doing this job because we want to give back to the community, we lose the respect for what we do. The community doesn't see a value in users being part of the program and they don't recognize that someone who is currently using has much to contribute.<sup>116</sup>

<sup>110</sup> Statements from members or program recipients of VANDU, as reported in Kerr et al, supra, note 78.

<sup>111</sup> Ibid, at 37-38.

<sup>112</sup> Ibid.

<sup>113</sup> A Efthimiou-Mordaunt. Spanner in the works – Obstacles to practical user involvement and pathways around them. *Druglink* 2002; 17(1).

<sup>114</sup> Correspondence received from Annie Madden, Australian Injecting & Illicit Drug Users League, 16 March 2007. See also: P Cherashore. Outlaws and activists. *Harm Reduction Communication* 1998, cited in Curtis, supra, note 6, at 293.

<sup>115</sup> K Manson. *Best Practices in Harm Reduction Peer Projects*. Toronto: Street Health, 2006, at 6 (available via [www.streethhealth.ca](http://www.streethhealth.ca)).

<sup>116</sup> Ibid.

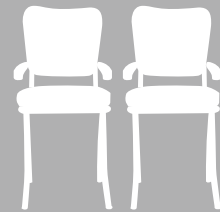
## Benefits of organizations of people who use drugs

Most health services initiated in response to HIV, HCV, or other health issues 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,<sup>117</sup> 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.<sup>118</sup> 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.<sup>119</sup> 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.<sup>120</sup>

“Through our direct experience we can provide governments, services and the broader community with the ‘drug user perspective’ on a range of issues in relation to illicit drug use. Equally, as ‘peers’ we also have the credibility and trust required to reach other people who use or have used illicit drugs who are isolated and extremely marginalised within the community.

While some in the community may view people who use or have used illicit drugs as having very little if anything to offer governments, services and the community, in reality, nothing could be further from the truth. In numerous important areas over the past ten years, the Australian experience has **reflected the value of involving people who use or have used illicit drugs in the development of policy and programmatic responses.**”

– *Australian Injecting and Illicit Drug Users League*



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 has provided evidence of the benefits of greater involvement of people who use drugs.<sup>121</sup> In particular, people who use drugs are able to expand the reach and effectiveness of prevention and harm reduction services by making contact with people at greatest risk. For example, groups of people who use

<sup>117</sup> Broadhead et al, 1995, supra, note 95; 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.

<sup>118</sup> Kerr et al, supra, note 78, 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.

<sup>119</sup> Broadhead et al, 1995, supra, note 95; Grund et al, supra, note 118; 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.

<sup>120</sup> 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.

<sup>121</sup> 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, supra, note 95; Broadhead et al, 1998; T Kerr et al, supra, note 95.



drugs<sup>122</sup> can play an important role in reaching their peers with clean injection equipment.<sup>123</sup> 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.<sup>124</sup>

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

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.<sup>125</sup>

## 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](http://www.phac-aspc.gc.ca/hepc/hepatitis_c/library.html).

For a short article by a health professional on why it is important to involve people who use drugs: A Wodak. Why deal with users? *User's News* 1999; 31. Available via [www.nuaa.org.au/nuaa/News/index.html](http://www.nuaa.org.au/nuaa/News/index.html).

<sup>122</sup> A Efthimiou-Mordaunt (What is a user group? *Solidarity Project* 2007; 5: 9) has defined user organizations as follows: "A group of ex/current criminalized drug users who try to improve the quality of their lives and if their wider communities by campaigning for local and/or national drug policies, which typically work towards reducing the death, disease and (where possible) crime, related to illicit drug use."

<sup>123</sup> Grund et al, supra, note 118. For a Canadian example, see: Wood et al (2003), supra, note 121.

<sup>124</sup> National Treatment Agency, supra, note 42, section 1.3.

<sup>125</sup> AIVL, supra, note 51, at 3.

## 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 show that most governments and organizations do not understand the benefits of greater involvement of people who use drugs in the response to HIV and HCV, and have not expressed commitment to increasing involvement.

Some 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 involved. But few have amended their by-laws to reserve seats on their boards to people who use (or have used) drugs. For most organizations greater involvement 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 and HCV. 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 report, people who use drugs made a number of suggestions that would help overcome these challenges. They are summarized in table 3.

### Textbox 3:

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

<b>Do</b> invite several of us	<b>Don't</b> invite just one of us
<b>Do</b> invite a user group to select representatives	<b>Don't</b> hand-pick always the same user you know and are comfortable with
<b>Do</b> invite an active user	<b>Don't</b> 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
<b>Do</b> invite former users and active users	<b>Don't</b> invite former users instead of inviting active users
<b>Do</b> hold a meeting or consultation in a low-key setting or in a setting where users already hang out	<b>Don't</b> hold it in a government building
<b>Do</b> provide a payment for our participation – 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	<b>Don't</b> assume that we don't need payment or would just spend it on drugs (or that it wouldn't be justified even if we did)
<b>Do</b> give us money in cash	<b>Don't</b> write us a cheque (many of us don't have bank accounts) or give us a coupon
<b>Do</b> come to our city or region, if possible	<b>Don't</b> ask us to come and meet you where you are
<b>Do</b> guarantee confidentiality	<b>Don't</b> identify what a particular user said in proceedings of the meeting
<b>Do</b> listen to our answers and take them seriously	<b>Don't</b> just ask the question because it is politically correct to ask us
<b>Do</b> show flexibility with meeting styles	<b>Don't</b> hold a meeting or consultation just the way you are used to
<b>Do</b> show flexibility with meeting times	<b>Don't</b> hold a meeting at 9 a.m., or on welfare cheque issue day – many of us won't be able to attend



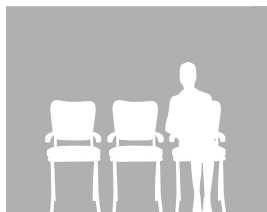
<b>Do</b> ask us what we need	<b>Don't</b> be afraid to ask
<b>Do</b> acknowledge that you may have needs, too, and that unfamiliarity may make you uncomfortable	<b>Don't</b> assume that I am the problem and the only one who needs to learn
<b>Do</b> assign us a support person or provide training (if you ask us to be on a committee or board, not just a one-time event)	<b>Don't</b> run your committee or board meetings without acknowledging that it may be the first time for us to be on a committee or board
<b>Do</b> consider training for you and the other committee or board members specific to the issue of user involvement, and ask a user to participate	<b>Don't</b> think that you can't learn how to involve me better
<b>Do</b> protect confidentiality	<b>Don't</b> require disclosure of HIV or other health status
<b>Do</b> consider participation in consultations and meetings as a start	<b>Don't</b> think that we cannot do more, such as work for you in a paid position
<b>Do</b> offer support to people after a consultation or meeting	<b>Don't</b> think we may not need additional information or access to support to help us process issues that the consultation or meeting raised
<b>In addition, if we have to travel:</b>	
<b>Do</b> help with arranging medical help and, if available, access to sterile injecting equipment and methadone carries or buprenorphine take away doses	<b>Don't</b> invite us at the last minute and assume we can deal with this alone
<b>Do</b> 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	<b>Don't</b> just leave us on our own in cities we don't know
<b>Do</b> provide accommodation close to the meeting space	
<b>Do</b> have a physician on call	



## Involvement in 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.<sup>126</sup>

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.”<sup>127</sup>



**“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 drug dependence 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;
- being prepared to foster the development of groups of people who use drugs;

<sup>126</sup> National Treatment Agency, *supra*, note 42.

<sup>127</sup> *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](http://www.london.gov.uk/gla/publications/health.jsp#lessons).

- building cross-cultural awareness and filling the need to learn about people who use drugs and their life circumstances.

Where peer projects are integrated into the work of larger organizations, lack of commitment to peer work and/or harm reduction from the larger agency can be a major challenge, limiting the amount of support peer projects and peers themselves are given. An evaluation of harm reduction peer projects showed that sometimes, peer workers felt that “workers in other programs didn’t consider peers to be equal staff and have difficulty seeing someone who used to be a client now as their a co-worker”. How well integrated a peer program is within a larger agency was commonly identified by participants in the evaluation as an issue. Some peers expressed that their program felt like an “add-on”, when it should be integrated more fully into an agency’s programs.<sup>128</sup>

## Organizations of people who use drugs

### The needs of organizations of people who use drugs

With a few exceptions, little or no funding has been provided in most countries to organizations of people who use drugs, and there has not been a concerted effort to encourage their creation and provide the support needed for longer-term sustainability. “Groups are often seemingly expected to operate flawlessly from the start. The absence of skills building, secure funding, and other management resources for any community organization ‘bereft of a history of self-management’ inevitably leads to problems.”<sup>129</sup> Coupled with other problems stemming from often high turnover in staff and from the chaos associated with drug use, these issues can be major barriers to a group’s efficacy and longevity. Very often, governments and other funders fail to invest in the building of lasting organizations that can withstand the transition of people coming and going, instead working with a limited number of individuals on a limited number of short-term projects. This highlights the need for funders and policy makers to:<sup>130</sup>

- adequately resource organizations, providing not only funding for specific projects, but also core funding that enables organizations to undertake longer-term planning, develop management and governance capacity, and invest in training
- adapt funding cycles to the needs of organizations, recognizing that it takes time to develop strong and sustainable organizations of people who use drugs – funding cycles ideally should be three to five years
- demonstrate flexibility and be sensitive to the fact that the lives of people who use drugs are sometimes unpredictable (because of ill health, unexpected time in prison, etc) and that timelines may be affected as a result
- invest in longer-term skills building activities
- create supportive policy or advocate for the creation of such policy, such as statutory requirements to ensure that users are actively involved in policy, planning and decision-making in all issues concerning them.

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:

<sup>128</sup> Best Practices in Harm Reduction Peer Projects, supra, note 115, at 7.

<sup>129</sup> Curtis, supra, note 6, at 290.

<sup>130</sup> Best Practices in Harm Reduction Peer Projects, supra, note 115, at 14.

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.<sup>131</sup>

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<sup>131</sup> AIVL, *supra*, note 51.

## Textbox 4:

### “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.



## Challenges for organizations of people who use drugs

It can be challenging 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.<sup>132</sup> A related challenge is to find time, and gain acceptance for, an agenda that goes beyond HIV 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.

Some insist that groups of people who use drugs be staffed only by people who actively use,<sup>133</sup> 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. There is also a risk that non-using professionals may build careers “on the backs of people who use drugs” by acting in their name without true user involvement.<sup>134</sup>

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.<sup>135</sup> Some organizations have employed people who are neither former nor active users. Some have questioned the presence of non-users in purportedly user-run organizations, but members of the organizations have pointed out that they, and not the employees, run the organizations, and that existing drug laws and policies are a factor in the selection of non-users as coordinators:

If I had to explain to [the funding agency] 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.<sup>136</sup>

There are, however, many examples of organizations that have successfully employed people who actively use drugs. A number of organizations, such as AIVL<sup>137</sup> and the New South Wales Users and AIDS Association (NUAA),<sup>138</sup> have developed workplace performance policies that treat drug use in the same way as any other work performance issue. Such policies provide management with a way of dealing with problems if an individual's work is suffering, from whatever cause.

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

<sup>132</sup> Ogborne, Carver, Wiebe, *supra*, note 66, at 32-33.

<sup>133</sup> See, eg, R Balian, C White. Defining the drug user (no date). Available via [www.harmreduction.org/pubs/news/fall98/f98ballan.html](http://www.harmreduction.org/pubs/news/fall98/f98ballan.html).

<sup>134</sup> Curtis, *supra*, note 6, at 286.

<sup>135</sup> Ogborne, Carver, Wiebe, *supra*, note 66, at 33.

<sup>136</sup> Kerr et al, *supra*, note 78, at 21.

<sup>137</sup> AIVL. Managing work performance policy. (on file with author)

<sup>138</sup> 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.

usual stereotypes and exhibited a wide range of skills and that training was needed for those not accustomed to working in organizations.<sup>139</sup>

A document on “user-friendly policies for harm reduction organizations” developed by Canadian user activists highlights that organizations that employ people who actively use drugs “need policies that take the conditions of their lived experiences into consideration” and suggests that, without training and supportive policies, both the organization and its employees who use drugs will be vulnerable to all kinds of problems.<sup>140</sup> Textbox 5 contains some excerpts of this document.

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<sup>139</sup> *Lessons Learned*, supra, note 127.

<sup>140</sup> Balian R, White C. User-friendly policies for HR organizations. (on file with author)

## Textbox 5:

### Excerpts from “User-Friendly Policies for HR Organizations”

#### **Inebriation During Business Hours**

*POLICY: Employees may not come to work showing signs of inebriation*

*POLICY: Management may not conduct witch-hunts to determine drug use by employees*

Employees are not to come to work inebriated. Employees should not come into work if they feel that they are “nodding” (excess tiredness or sleepy behaviours related to opiate, alcohol or sleeping pill “overdosing”), are unable to maintain an alert disposition throughout business hours, or, in the case of amphetamine and stimulant use, they are experiencing paranoid episodes. Other inappropriate or threatening physical or behavioural signs that cannot be tolerated include: incomprehensibly slurred speech, exaggerated or clumsy body movements, ie: “falling-down drunk behaviour”, verbal threats or generally unacceptable behaviours/statements for a work environment (ie: making inappropriate jokes, engaging in unwanted touching, and making discriminatory remarks, etc.). It does not matter whether management believes that these behaviours are caused by drugs or not. Management has to focus on behaviour and not drug use; focus on “perceived or assumed” drug use only serves to single out drug using employees (DUEs) and also sets the organization up to potential liability repercussions ... Management should be cognizant, however, of physical reactions that the DUE has no control over, and which do not, by themselves, compromise the job. For example, profuse sweating, pinned or enlarged pupils, itchy skin irritations and/or what might look like exacerbated scratching, or feeling tired or sleepy during methadone acclimation periods.

Drug witch hunts in a harm reduction based organization are always unacceptable. Some supervisors, board members, and colleagues have a propensity to attribute all “peculiar” and “unusual” behaviours to drug use. In their quest to establish a DUE’s drug-using habits, or whether a DUE is on drugs, a few supervisors go to extraordinary lengths including interrogating friends, family, and colleagues. There are even those who impudently demand to see the track-marks of a known DUE. The distrustful environment created from such speculative behaviour is very stressful for DUEs. It forces them to conceal their drug use and become as vulnerable to the harmful effects of criminalization as the population they are supposed to serve.

#### **Drugs and Drug Use in the Office**

*POLICY: Employees may not use drugs in the office except when prescribed by a physician*

The organization realizes that some DUEs may not be able to function and might also become extremely sick unless they were on certain drugs. For example, employees who are physically dependent on heroin have to ingest approximately every four hours (except for some opioids such as methadone, LAAM or ORLAM). However, drugs should not be ingested in the office, nor should they be stored within the geographical parameters of the organization unless they are legal and prescribed by a physician (ie: methadone, anti-depressants and other prescribed drugs ...

Shooting up, smoking, ingesting or inhaling in the washroom or anywhere else on the premises is forbidden.



## **Drug Use and Triggering Problems**

*POLICY: In an organization dedicated to HR, non-using employees who are triggered by drug users and drug use in general have the responsibility of finding coping mechanisms and a way to foster working relationships with their drug using colleagues and clients*

Some employees are negatively triggered by signs or even perceptions of drug use by colleagues and may complain to management. Employees who are former drug users may also complain to management that the presence of DUEs is a constant temptation for them to use drugs. However, management has to deal with this issue by recognizing that the problem is with these employees' reactions and not with the DUEs. Employees who are being affected by the presence of DUEs should be referred for counselling, at the organization's expense; in the meantime, these individuals should not work with the DUE(s) if possible, or their contact should be minimal. Under no circumstances should DUEs be reprimanded, singled out or made to feel responsible in any way for the triggering responses of others.

## **Drug and Dealer Referrals**

*POLICY: Employees may not violate the confidentiality of their clients. This policy includes referrals to and by drug users and dealers.*

Workers should never make referrals to drug users or drug dealers that are clients of the service.

## **Purchasing Drugs**

*POLICY: Except for emergency situations that are cleared by the program manager, employees may not purchase drugs from clients (including getting a non-dealing client to make a run for a DUE).*

*POLICY: If and when, in exceptional circumstances an employee is cleared to purchase drugs from a client, s/he may not do so on credit*

*POLICY: Employees may not receive free drugs or sex as tokens of appreciation from service users*

*POLICY: Employees may not use the office or office communication equipment, including the phone, fax machine, and E-mail to purchase drugs*

*POLICY: DUEs should make all efforts where possible (ie: in larger towns and cities) to secure a dealer(s) who does not access the service/organization*

It is very important for any illicit drug user to separate his/her drug purchasing activities from his/her professional life. ... [However, u]nder certain circumstances, with the permission and knowledge of a supervisor, an employee should be able to purchase drugs from a client. For example, scores of clients may be getting sick or overdosing because of the strength or the adulterants of drugs. In keeping with harm reduction objectives, to minimize the chance of overdosing or getting sick, questionable products should be tested whenever possible and the results should be shared with clients. Before an employee purchases drugs for testing purposes, management should be consulted and should look into the logistics of the transaction, perhaps consulting the organization's legal counsel to ascertain possible repercussions for the organization.

Another exceptional circumstance that may render it acceptable for a DUE to purchase limited amounts of drugs from non-dealing clients is when s/he is undergoing, or is about to go through involuntary drug withdrawal and is unable to purchase her drugs anywhere else due to a "dry



spell” (shortage of drug availability). In this case, if management has access to a doctor that can prescribe appropriate drugs, they should attempt to secure a supply for the DUE through this legal avenue. Barring that option, the DUE should be allowed to purchase opiates during the drought period only. Without violating the confidentiality of the dealer, the DUE should inform his/her manager regarding this transaction and should discontinue the activity when her/his regular supplier gets a new supply (also, the DUE should comply with policies regarding use on the premise, fronting the drug and inebriation while working).

In some cases, when a DUE is hired, s/he will find that some of her/his dealers are now his/her clients. In such cases, the DUE should make all attempts to find other suppliers as quickly as possible.

### **Selling Drugs**

*POLICY: Employees may not use the office or office communication equipment, including the phone, fax machine, and E-mail to sell drugs*

*POLICY: Employees may not sell drugs to clients under any circumstances*

### **Borrowing Money**

*POLICY: Employees may not lend or borrow money from clients*

DUEs can not borrow from or lend money to clients of the program.

### **Programs for DUEs**

*POLICY: The organization commits itself to allocate time off of work for DUEs who enrol in experimental or established drug-related programs (maintenance, tapering or abstinence). The organization will take a supportive position towards DUEs enrolled in these programs (i.e.: operating from a position of understanding regarding punctuality or absences from work)*

*POLICY: The organization commits itself to allocate time off (“withdrawal time”) of work for DUEs who are going through voluntary or involuntary withdrawal. The organization will only allocate one week during a calendar year for this purpose; however, if DUEs decide to come off drugs and have already used up their “withdrawal time”, the organization will be supportive and will not penalize these workers as long as they go through withdrawal on their own time (i.e.: using vacation, sick days, lieu or overtime hours).*

## **Assisting with the establishment of a group of people who use drugs**

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 Textbox 6.<sup>141</sup> The VANDU case study by Kerr et al<sup>142</sup> also provides useful insight into how such an organization can start and successfully carry out activities.

<sup>141</sup> Burrows, supra, note 138, at 368-370.

<sup>142</sup> Kerr et al, supra, note 78.

## Textbox 6:

### 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.

## Further Reading

For additional information for organizations of people who use drugs and organizations supporting the development of such organizations, aimed at helping with the step-by-step process of establishing and maintaining an organization of people who use drugs, see a series of upcoming short guidebooks being prepared by OSI's International Harm Reduction Development Program (IHRD). These documents are expected to become available via IHRD's website ([www.soros.org/initiatives/health/focus/ihrd](http://www.soros.org/initiatives/health/focus/ihrd)) later in 2008.

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/](http://www.aivl.org.au/)

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.

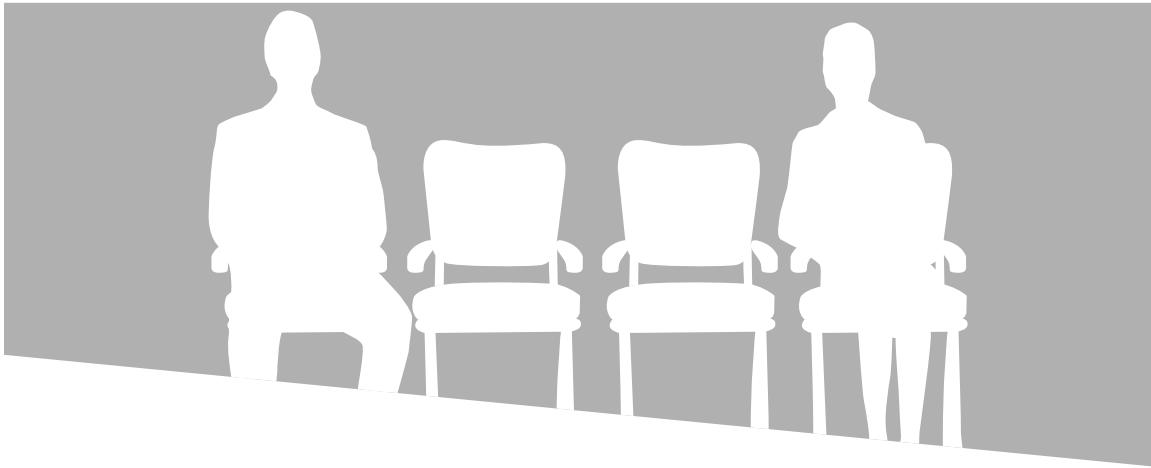
For the report of the London Drug User Involvement Project: *Lessons Learned. Some Approaches, Tools and Good Practice for Improving Drug User Involvement*. London: Greater London Authority, February 2005. Via [www.london.gov.uk/gla/publications/health.jsp#lessons](http://www.london.gov.uk/gla/publications/health.jsp#lessons).

For a report on peer involvement in harm reduction projects: K Manson. *Best Practices in Harm Reduction Peer Projects*. Toronto: Street Health, 2006. Via [www.streethhealth.ca](http://www.streethhealth.ca).

For a toolkit on involving people who use drugs in assessing HIV/AIDS and drug use issues at a particular site or location: *Developing HIV/AIDS Work with Drug Users, A Guide to Participatory Assessment and Response*. International HIV/AIDS Alliance, 2003. Via [www.aidsalliance.org/custom\\_asp/publications/view.asp?publication\\_id=88&language=en](http://www.aidsalliance.org/custom_asp/publications/view.asp?publication_id=88&language=en).

For a toolkit on community mobilization for HIV/AIDS, including mobilizing communities of people who use drugs: *All Together Now! Community Mobilisation for HIV/AIDS*. International HIV/AIDS Alliance, 2006. Via: [www.aidsalliance.org/custom\\_asp/publications/view.asp?publication\\_id=228&language=en](http://www.aidsalliance.org/custom_asp/publications/view.asp?publication_id=228&language=en).





## 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.<sup>143</sup>

People living with HIV and people who use illegal drugs are central to the response to HIV 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, most countries are committed to greater and meaningful involvement of *people living with HIV*, but this commitment must be matched by action (see recommendations 5 and 6 below).

With regard to greater involvement of *people who use illegal drugs*, even more needs to be done. In some countries, 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. In most countries, organizations of people who use drugs have not yet received the support they need to become an effective voice and force in the fight against HIV and HCV. Recommendations 1 to 4 below propose concrete ways to achieve greater involvement of people who use illegal drugs and of people living with HIV.

Finally, countries and international agencies can and should promote the greater involvement of both people living with HIV and people who use drugs at the international level (see recommendation 7).

### 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 the response to HIV, HCV, and illegal drug use.

<sup>143</sup> P Aggleton, R Parker. *A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination*. Rev. ed. UNAIDS/o2.43E. Geneva: Joint Programme on HIV/AIDS and Human Rights, 2002, at 18. Available via [www.unaids.org](http://www.unaids.org).

“We also know that in several countries drug users and positive people’s networks are still not allowed to organize themselves and that drug users and their networks are excluded from decisions that affect them. This needs to change. The stigma and discrimination associated with drug use and HIV need to go, communities and governments need to embrace the reality of what works in curbing the epidemic.

By treating drug users and their representatives as equals, by including them in consultative processes and the decision-making and policy-making bodies that shape the HIV, drug, and other relevant policies, we are more likely to succeed. We also need to support direct involvement of drug users in provision of services, such as outreach, substitution treatment, needle and syringe programmes, delivery of anti retro viral treatment, and prevention of overdose due to drug use. After all, who understands the health and social needs of drug users better than the drug user?”

– JVR Prasada Rao, UNAIDS, 2008



## Recommendation 1

### 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, **governments** should acknowledge, and adopt policies reflecting that:

- the response to illegal drug use is first and foremost a health issue and should be treated as such in laws and policies
- the ongoing criminalization of people who use drugs is undermining public health efforts, including the response to HIV and HCV among people who use drugs
- 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 and HCV epidemics.

In addition, as recommended by UNAIDS, UNDP and the Inter-Parliamentary Union,<sup>144</sup> **governments** should remove legal barriers to prevention and care for people who use drugs, and enact anti-discrimination or protective laws to reduce human rights violations based on dependence to drugs.

Where legal barriers exist to setting up organizations of people who use drugs, **governments** should remove these barriers and undertake efforts to ensure that these organizations can work effectively, without interference by law enforcement agencies, and without risks for the safety of participants.

<sup>144</sup> *Taking Action against HIV*, supra, note 11.

## Recommendation 2

### Supporting organizations of people who use drugs

As experience in many 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 HCV, and in advancing the rights of people who use drugs.

**National, regional, and local governments**, as well as funders, should explicitly and formally recognize the unique value of organizations of people who use illegal drugs. In particular, governments and funders should:

- support 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;
- provide longer-term, core funding (in addition to project funding) to organizations of people who use drugs, in order to enable their participation in government processes, capacity-building over time, and longer-term sustainability;
- support 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 initiatives aimed at assessing the needs for the creation of groups of people who use drugs where such groups currently do not exist;
- provide funding for a national group that can be a voice of people who use drugs at the national level and assist local and regional groups;
- fund the development of good practice guidelines on the employment of people who use drugs.

## Recommendation 3

### Involving 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, regional, and national level) enables them to:<sup>145</sup>

- Present the perspectives, needs, aspirations, and experiences of people who use drugs and thus better inform decision making that will affect their lives;

<sup>145</sup> Adapted from AIVL. Policy Position. Consumer Representation, at 4.

- Foster genuine community participation in partnership with policy makers, researchers and service providers whose work significantly affects their lives;
- Keep 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.

Therefore, **government agencies at the local, regional, and national level** should:

- invite people who use drugs to participate in all consultations, committees, or fora where policies, interventions, or services concerning them are planned, discussed, researched, determined, or evaluated;
- invite organizations or networks of people who use drugs to nominate, according to the organizations' processes, appropriate representatives;
- invite a number of representatives, rather than just one, 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;
- provide adequate support, training, and financial compensation.

#### Recommendation 4

### Involving people who use drugs in community-based organizations

Community-based organizations, in particular organizations providing HIV 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:

- **National, regional, and local governments and/or other funders** should provide funding for meetings 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 meetings 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).
- **Community-based 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.

**Governments and other funders** 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.

## Greater involvement of people living with HIV

In addition to taking action to ensure greater involvement of people who use drugs, governments need to continue to do more to ensure greater, meaningful, and sustained involvement of **people living with HIV** in all aspects of the response to HIV.

### Recommendation 5

#### Government action on GIPA

**National governments** should provide funding for the development and implementation of a plan aimed at ensuring increased and sustainable involvement of people living with HIV in the countries' 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, **governments and other funders** 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 organizations 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.

**Regional and local governments** should fund and otherwise support complementary efforts to ensure that elements agreed to in the countries' plans can be put into place and that regional and local realities can also be reflected.

## Recommendation 6

### Community-based action on GIPA

**Community-based HIV/AIDS organizations** 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”<sup>146</sup> 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.<sup>147</sup>

<sup>146</sup> Cabassi, supra, note 85.

<sup>147</sup> Cabassi, supra, note 55, at 41-42.

## Providing international leadership on greater involvement

These recommendations are aimed at greater involvement of both people living with HIV and people who use drugs *at the international level*.



**“We believe that the Commission and the other institutions of drug control would greatly benefit from the involvement of People who use drugs as part of the civil society engagement in the process of drugs policy making:**

- **To work together for improvement and to make more cost-effective the treatment and harm reduction measures for people who use drugs.**
- **To cooperate closely together in the global fight against AIDS, Hepatitis C and other blood born diseases.**
- **To avoid peoples unnecessary dying.**
- **To avoid the unnecessary, but socially harmful and expensive incarceration of people just because of the consumption of drugs that are considered to be illegal.**
- **To cooperate closely together in the fight against the criminalization, stigma, discrimination and marginalization of people who use drugs and to work together for social inclusion and health.**
- **And to avoid violations of the human rights of people who use drugs.”**

*– Stijn Goossens, INPUD Statement at the 51<sup>st</sup> Session of the Commission on Narcotic Drugs, 12 March 2008*

### Recommendation 7

#### Providing International Leadership on Greater Involvement

National governments and international agencies 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, **governments** 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 2001 “Declaration of Commitment on HIV/AIDS” and 2006 Political Declaration on HIV/AIDS;

- include people living with HIV on 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 government delegations to international meetings, and include them on government delegations, particularly the political meeting at the 2009 Commission on Narcotic Drugs;
- provide funding for groups of people who use drugs, as part of development assistance;
- advocate within 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 ensure that evaluation of initiatives to scale up access to antiretroviral treatment includes monitoring of efforts made to ensure that people who use drugs are included in an equitable scaling up of treatment.

**International agencies** should ensure that people who use drugs are invited to participate in all international consultations, committees, reference groups (such as the Reference Group to the United Nations on HIV and Injecting Drug Use) or fora where policies, interventions, or services concerning them are planned, discussed, researched, determined, or evaluated.



# Appendix 1: The Project Partners

## **The Canadian HIV/AIDS Legal Network**

The Canadian HIV/AIDS Legal Network ([www.aidslaw.ca](http://www.aidslaw.ca)) promotes the human rights of people living with and vulnerable to HIV/AIDS, in Canada and internationally, through research, legal and policy analysis, education, and community mobilization. The Legal Network is Canada's leading advocacy organization working on the legal and human rights issues raised by HIV/AIDS.

## **The International HIV/AIDS Alliance**

Established in 1993, the International HIV/AIDS Alliance ([www.aidsalliance.org](http://www.aidsalliance.org)) is a global partnership of nationally-based organisations working to support community action on AIDS. These national partners help local community groups and other NGOs to take action on AIDS, and are supported by technical expertise, policy work and fundraising carried out at the UK-based international secretariat and across the Alliance. In addition to community and country-based programmes, the Alliance also has extensive regional programmes and works on a range of international activities such as support for South–South cooperation, operations research, training and good practice development, as well policy analysis and advocacy.

## **The International Harm Reduction Development Program**

Founded in 1995, the International Harm Reduction Development Program (IHRD), a project of the Public Health Program of the Open Society Institute (OSI), works to reduce HIV and other harms related to injecting drug use, and to press for policies that reduce stigmatization of illicit drug users and protect their human rights. IHRD, which has supported more than 200 programs in Central and Eastern Europe, the former Soviet Union, and Asia, bases its activities on the philosophy that people unable or unwilling to abstain from drug use can make positive changes to protect their health and the health of others. Since 2001, IHRD has prioritized advocacy to expand availability of needle exchange, opiate substitution treatment, and treatment for HIV; to reform discriminatory policies and practices; and to increase the political participation of people who use drugs and those living with HIV. For more information, please visit our website: [www.soros.org/harm-reduction](http://www.soros.org/harm-reduction).

The following organizations participated in the original Canadian project:

### **Vancouver Area Network of Drug Users (VANDU)**

VANDU ([www.vandu.org](http://www.vandu.org)) 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 people who use drugs in Vancouver.

### **CACTUS Montréal**

CACTUS Montréal ([www.cactusmontreal.org](http://www.cactusmontreal.org)) 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 ([www.cfenet.ubc.ca](http://www.cfenet.ubc.ca)) is Canada's largest HIV/AIDS research, treatment and education facility. It has conducted several studies of organizations of people who use drugs and has successfully collaborated with VANDU on a variety of projects. The Centre contributed research expertise to this project and assisted the Canadian HIV/AIDS Legal Network in ensuring maximum involvement of people who use drugs in the consultation process.



Canadian  
HIV/AIDS  
Legal  
Network

Réseau  
juridique  
canadien  
VIH/sida



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