Chapter 12
User involvement and user organising in harm reduction

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Abstract

Within Europe, the active involvement of drug users in services and activities that affect their lives can be traced back to the Netherlands in the 1970s, pre-dating the development of harm reduction in response to HIV/AIDS. This chapter distinguishes involvement approaches, which typically focus on improving treatment and care, from user-led initiatives, where objectives are determined more autonomously. The chapter describes differences in user involvement and organising with respect to the preferred drugs of different populations (heroin and cocaine, 'party drugs' and cannabis). We also highlight the different aims and methods of user involvement and user organising initiatives. These also illustrate differences that are shaped by: the drugs used; the context of their use; and national contrasts in patterns of use and harm. In addition to noting some of the practical challenges linked to user involvement/organising, we also note potential tensions, most notably regarding disputes about the extent to which drug prohibition is construed as a cause of harm, and its reform seen as a legitimate target for drug users' activism. Finally, we summarise available evidence of the impact of user involvement and organising. We conclude that harms can best be reduced where affected people participate meaningfully in decisions concerning the systems and services that shape their lives. This requires clear commitment at every level and will frequently need corresponding resources, if its full potential is to be realised.

Keywords: harm reduction, user involvement, user organising, user-led, empowerment.

Introduction

Across Europe, patterns of drug use and their corresponding burden of harms differ considerably (EMCDDA, 2008). Such variations in drug use have implications for harm reduction responses. Variations in patterns of drug use are shaped by geographical factors, such as the suitability of the climate for drug production, or trafficking and transit routes. But they are also shaped by social factors, as are harm reduction responses. These include: the cultural and ethnic context; national legislation; the policies of the prevailing government; the influence of organised religion; national traditions concerning the role of civil society; and the economic situation. Social contexts thus shape patterns of drug use and harm, as well as its reduction, including the role of user involvement and user organising. As Friedman has commented, 'the structures of drug scenes affect what users' groups can do and how they can function' (Friedman, 1996, p. 212).

Harm reduction is grounded within a public health model, which primarily aims to improve the health and well-being of drug users alongside reducing community and societal level harms (Newcombe, 1992). As such, a desire to make the services user-friendly (i.e. providing

services that welcome and include drug users) and involving drug users is evident within formal definitions of harm reduction (Hunt et al., 2003) as well as within harm reduction practice. Yet the way that harm reduction is understood and translated into practice is variable, and this is reflected within drug user involvement and organising.

The geographical focus of this chapter is Europe. Nevertheless, some of the more relevant features of the international context are described. The main goal of the chapter is to describe and explain drug users' contributions to harm reduction, alongside the contrasting methods that comprise user involvement and organising. The constraints of a single, short chapter mean it is impossible to provide a comprehensive history of the drug user movement's contribution to harm reduction. Likewise, it is not feasible to provide a detailed, country-by-country account of all user involvement and organising. Some important features of this history are, nevertheless, included.

Within the drug user movement, there is ongoing debate about the language that should be used to refer to its participants. For example, some people readily describe themselves as 'addicts' or 'patients', whereas others resist such terms because of their implications regarding the legitimacy of medical power to shape their drug-using choices and the applicability of a disease model. Questions also arise as to who is a drug user and the role of non-drug-using supporters of drug user activists (Balian and White, 1998). While acknowledging the disputes surrounding these terms, we will largely use the terms 'user' or 'drug user', although even these terms are not without their critics.

History

The AIDS pandemic has clearly been a critical factor in the development of both the harm reduction movement and drug user organising (Crofts and Herkt, 1995; Zibbell, 2004). However, it is important to note that drug user activism does not relate purely to injecting, and it pre-dates the AIDS era. Theo van Dam credits Nico Adriaans as the founder and chairman of the first advocacy/activist group Rotterdam Junkie Union (RJB) in the Netherlands in 1977 (van Dam, 2008, p. 58). Around this time, van Dam and Daan van der Gouwe also started Landelijk Steunpunt Druggebruikers (LSD) to try to get the Dutch government to support users and user groups, reduce stigma and shape opinion around legalisation (Jezek, 2000; Tops, 2006; Museummouse, 2008). Initially, harm reduction was an offshoot of the drug users' movement, notably Dutch activists who established the world's first needle exchange programme, set up by the MDHG Belangenvereniging Druggebruikers (Interest Association for Drug Users) in 1984 (Tops, 2006).

Montañés Sánchez and Oomen define drug users' organisations as 'Organisations of users of prohibited drugs or organisations in which these people play an important role', and identify three types of organisations according to the profile of the users and the scene in which they use drugs: cannabis users; party drug users; and users of street drugs such as opiates and cocaine (Montañés Sánchez and Oomen, 2009, p. 213). Although our emphasis here is on user organising within the third group, we also include examples relating to cannabis users and 'party drugs'.

Drug user organising in Europe

Although there are publications that describe aspects of European drug users' activism, such as that of the Correlation Network (Bröring and Schatz 2008), accurately mapping the extent of drug users' organisations and their work is problematic. No survey has yet been undertaken across the whole of Europe using a consistent methodology. Any survey is also complicated because: activities are not necessarily publicly or well documented; some organisations have a short lifespan; and, stigma and the oppression of drug users mean that there are good reasons for organisations to avoid being too visible (Friedman, 1998). In addition, the work of some drug users is sometimes obscured, such as when drug user identities are not declared within services (Robbins, 2004). At the time of writing, the International Harm Reduction Association (IHRA) and the International Network of People who Use Drugs (INPUD) are developing a report describing the 'global state of drug user activism'. In time, this should provide a useful addition to what is currently known about the extent of drug user organisations.

Dolf Tops estimates that, at any one time, there are between 15 and 30 drug users' organisations in the Netherlands (Tops, 2006, p. 65). By 1994, such organisations existed in at least 11 European countries (Germany, the Netherlands, the United Kingdom, Norway, Denmark, Slovenia, France, Belgium, Italy, Lithuania and Spain) (Jürgens, 2008, p. 15).

In the Nordic countries, the first organisations for active drug users were formed during the 1990s in Denmark and Norway, and in Sweden in the early 2000s. In Finland, the first user-driven organisation was established in 2004. These drug user organisations were founded by heroin users, they are run by heroin users and users in maintenance treatment, and they also cater for active drug users, mainly heroin users (Anker et al., 2008, p. 18).

In France and Spain the first drug users' organisations started in the 1990s. Auto-support parmi les Usagers de Drogues (ASUD) was created in France in 1992 (Jürgens, 2008, p. 24). In 1996, the Spanish National Coordination for the Normalisation of Cannabis was born, largely comprising associations of cannabis users (Barriuso, 2003, p. 103); this developed into the Spanish Federation of Cannabis Associations (FAC, in Spanish) (Barriuso, 2007), and in 2003 the first national network of injecting drug users' organisations was created in Spain — the Spanish Nationwide Network of People Affected by Drugs and HIV (FAUDAS) (Pretel, 2007).

During 2003/4 the Central and Eastern European Harm Reduction Network (CEEHRN) assessed the needs of drug users' organisations across Central and Eastern Europe and Central Asia. Respondents came from 16 countries: Armenia, Belarus, Bulgaria, Croatia, Estonia, Georgia, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, former Yugoslav Republic of Macedonia, Moldova, Poland, Romania, Russia, and Ukraine. They identified 41 organisations, of which 15 were for drug users in general, 19 were for people living with HIV/AIDS (PLWHA), and six were for HIV positive drug users (CEEHRN, 2004; Canadian HIV/AIDS Legal Network, 2008).

Contribution of international networks to promoting user involvement

Developments in Europe need to be understood in the context of global networks. These have been important for enabling drug users to share ideas, knowledge and skills internationally — both into and out of Europe — and to provide structures within which drug users have begun to work internationally to identify and address common concerns.

The IHRA is a global organisation that promotes harm reduction. It seeks to involve drug users in its meetings and processes and has provided opportunities for drug users to network internationally, which has facilitated the development of international drug user networks.

The International Drug Users Network (IDUN) was initiated in 1992 at IHRA's Melbourne conference and was, arguably, the first network of its kind. Representatives from Germany, the Netherlands and the United Kingdom were among the seven countries represented at the inaugural meeting (Byrne, 2000). IDUN aimed to support injecting drug users to exchange ideas, develop drug user groups, and set up needle exchanges. However, a lack of funding and competing national and local demands for members' time meant that the network proved hard to sustain.

The Internet has enabled an electronic network for international drug user organising to be created, and after the IHRA conference in Geneva in 1998 a network of activists began an international discussion list hosted by the American Drug Policy Foundation, called Drug Policy Foundation — Users (DPFU) (Efthimiou-Mordaunt, 2005). This functions as a loose network of activists and facilitates ongoing discussion between drug users internationally.

In 2005, frustration at the poor facilities for drug users at IHRA's Belfast conference was a catalyst for an invigorated international network and led to the inception of INPUD. This formed around a statement that was endorsed at IHRA's 2006 conference — 'The Vancouver declaration' (INPUD, 2006). Although this was the product of many activists' efforts, the initial process of transforming INPUD into a legal entity was undertaken by a working group including representatives from Asia, Europe, Latin America, North America and Oceania. This was initially facilitated by Grant McNally (United Kingdom) with technical assistance from Stijn Goossens (Belgium), who subsequently became INPUD's director. Financial support was provided from the United Kingdom's Department for International Development (DfID) through IHRA. INPUD's early phase was marked by problems concerning who was/was not a member and associated constitutional problems. A subsequent crisis meeting was held at IHRA's Barcelona conference in 2008, which led to a successful re-foundation General Meeting held in Copenhagen at the end of October 2008, where a Consensus Statement and a clearer infrastructure were both agreed. Since then, a representative from INPUD was invited to give a formal address as part of the United Kingdom delegation to the United Nations' Commission on Narcotic Drugs (CND) in April 2009 and several other members attended as part of various NGO delegations.

International drug user activists, Vienna 2009

The networks and structures described so far are global and have clear, historical connections to the harm reduction movement and some emphasis on injecting drug use. By contrast, the ENCOD ([1]) (the European Coalition for Just and Effective Drug Policies) is a European network of 175 organisations and citizens affected by current drug policies, which also incorporates members with a more diverse range of concerns including all kinds of prohibited drugs. Created in 1994 by a group of European NGOs to work on drugs and development issues, it has become a drug policy reform network whose membership includes: drug users' organisations; harm reduction organisations; research groups; advocacy groups; and, individual members. Since its creation, ENCOD has advocated for drug policy changes at the European and UN level and for the participation of organisations and people affected by drugs/drug policies within the UN, the European Union and each country's government (ENCOD, 2006).

In 1998, a corresponding International Coalition of NGOs for Just and Effective Drug Policies (ICN) was founded by more than 200 organisations based on a 'Manifesto for just and effective drug policies', presented at that year's UN General Assembly Special Session on Drugs. Although less active than its European section (ENCOD), it appears to be the only formal international body where producers' and users' organisations can work together and pursue, among other things, the 'non-prosecution of drugs consumption while looking for means of regulation which are socially and culturally acceptable to those local populations involved, and the implementation of broad measures, including harm reduction, to prevent and treat the problematic consumption of drugs' (ICN, 1998). In 2004, ENCOD's General Assembly decided to adopt the title of the Manifesto in ENCOD's name, and signing it is one of the conditions of becoming a member.

([1]) The acronym ENCOD stood initially for European NGO Council on Drugs.

In 2005, the network Correlation: European Network Social Inclusion and Health was initiated to address health inequalities among marginalised groups. It has an extensive number of partners and receives financial support from the European Commission and the Dutch Ministry of Health. Within their work, HIV and Hepatitis C are specific concerns; drug users are one of their priorities and harm reduction and peer support are among the areas where they aim to promote effective practice. Their website provides extensive access to publications and other resources relevant to user involvement and organising (Correlation, 2009).

Forms of drug user involvement and organising

Actively involving people in decisions about their personal treatment and service provision is probably the most basic way by which user involvement can be said to take place. The literature shows that 'user involvement' is sometimes used to refer to the extent to which someone is involved in determining their own treatment or care from a service (Fischer and Jenkins, 2007). There are also other relatively passive ways of 'involving' drug users, such as the use of suggestion boxes or asking people to rate their satisfaction with the service. Whatever the merits of those activities, the focus of this chapter is on more active forms of drug user involvement and organisation within harm reduction. At the outset, we draw a distinction between involvement and organising.

User involvement

Some groups are keen to involve drug users within the systems and structures that affect their lives. In practice, involvement typically means giving a degree of power to drug users in ways that are managed and circumscribed, for example some form of consultation with individuals or groups who are deemed to represent the drug using population. Including service users within staff recruitment would be an example of user involvement that can directly benefit both the drug user and the organisation (Foster et al., 2007). Organisations in the drugs field often attempt to motivate their service users to set up user groups — a process that the Australian drug user activist Jude Byrne has termed 'contrived spontaneity' (Byrne, 2000). Results seem highly variable; many fail or flounder, others thrive and may occasionally lay foundations for more autonomous organisations to develop.

User organising

Organising implies more autonomous organisation by drug users to work across self-determined agendas affecting their interests. It is more directly linked to the 'empowerment' of the affected population. The term 'user-led' denotes this principle, yet allows a role for professionals too. In Canada, the term 'user-driven' is used (personal correspondence, Walter Cavalieri, 2009). Bröring and Schatz use the term 'self-organisations of drug users' (Bröring and Schatz, 2008). Again, this suggests the central importance of independence and autonomy. For brevity, we will use the term 'user-led' to refer to organisations of this type.

User-led organisations often differ from treatment or care services, within which involvement is encouraged. Although interests frequently coincide regarding threats to health, user-led

organisations may engage more actively with wider issues such as discrimination regarding their civil rights and the impact of legislation on their personal consumption choices. Methods may also differ; groups with more independence may be more prepared to use direct action to highlight an issue or effect change (Kerr et al., 2006).

In practice, these categories are often blurred. A drug user group that has been nurtured within a service as part of a process of involvement might reconstitute itself or progressively pursue a more independent, user-led agenda. Nevertheless, the distinction between systems that seek to consult or involve drug users in services, and those where power is asserted more directly in accordance with the concerns of drug users is an important one.

The 'JES network' — an example of user involvement in Germany (*Dirk Schäffer*)

Since its establishment in 1989, the JES network (Junkies, Ehemalige, Substituierte — Junkies, ex-users, substitution clients) users have been involved in its harm reduction initiatives at different levels.

An interesting and effective collaboration has existed for the past ten years between the 'AIDS Hilfe' NGO in Oldenburg and the local JES group, whose members provide safer use and safer sex education to prison inmates.

In some cities, such as Cologne, Bonn, Osnabrück, Braunschweig and Stuttgart, JES groups have become an integral part of the local network of drugs services and carry out important tasks, such as needle and syringe exchange.

The project 'JES-Seminars' is characterised by combining knowledge from self-help and acquired expertise. To promote the professionalism of activists in JES groups, the network conducts self-organised training sessions for users, in order to increase and expand the competencies of drug using people.

An impressive form of collaboration and cooperation between professional drugs service providers and user groups is in the preparation and implementation of a 'remembrance day' for deceased drug users, which has been held for over 10 years on 21 July in more than 40 cities in Germany. The event represents a great opportunity for users to discuss among themselves and with other citizens their vision for a progressive and liberal drug policy.

Of course, cooperation with the local drug services network is not always without problems. The role of JES as a component and at the same time critical counterpart of the drug system sometimes challenges the interests of aid agencies. However, in many cities successful collaboration between JES groups and the professional drugs help system has grown through mastering this challenge.

The particular strength of the JES self-help network lies in a specific approach to the problems of drug users, which has developed from personal experience, is orientated towards empowerment and aims at improving the skills of those seeking help. By developing and strengthening informal networks, new and qualitatively different resources and possibilities — beyond those accessible through the professional help system — can be opened up.

JES sees its offers of help and support, therefore, as a supplement to professional assistance and hence as increasing the effectiveness of such services. In this sense, JES offers of assistance are complementary rather than competing with the professional system of assistance.

Further reading: Schäffer and Hentschel (2004).

Aims and methods of intervention

In summarising the aims of user involvement and organising, several complications arise. Groups sometimes comprise loose associations, rather than being legally constituted organisations with a written statement of their aims. In some cases, aims also overlap or interact; for example, an aim of reducing stigma may affect an aim to improve treatment, or vice versa. This makes the production of any definitive list of aims problematic.

Aims relating to harm reduction that are readily identifiable within user involvement and organising include: responding to public health threats; improving the accessibility and quality of drug services; improving the accessibility and quality of other services to drug users; shaping and reforming drug policy; reducing stigma and increasing public understanding; improving the quality of life for drug users, their families and local communities; knowledge production; and drug law reform.

A recent typology of the methods used to achieve such aims derives from the categorisation of activities reported from an online, international survey of drug users' organisations, conducted in 2007 by the International Network of People Who Use Drugs (INPUD) in cooperation with the European Correlation Network (Goossens, 2008). Based on a sample of 38 organisations from 21 countries, Goossens grouped the activities into eleven major categories:

1. Advocacy and health/drug policymaking.
2. Peer support for people living with HIV/AIDS (PLWHA).
3. Peer support for drug users.
4. HIV and other blood-borne disease (BBD) education and prevention.
5. Issue/publish electronic and printed magazines and newsletters.
6. Producing other types of informational material.
7. Organise, conduct, moderate training, workshops, seminars, peer meetings.
8. Educational and peer support work in the party scene.
9. Run accommodation projects.
10. Drop-in centres with various services.
11. Raise public awareness about the main problems in the drug using community.

As with the classification of aims, some of these categories could easily be merged or subdivided, while others might be added. The review undertaken for this chapter suggests that additional categories of 'research' and 'user-driven market interventions' might also be added.

With the same reservations that apply to classifying aims, this list of methods is best viewed as provisional. It nevertheless provides a framework for some illustrative examples from the work of different organisations and activists across Europe. The criteria used to select the examples we provide included: geographical diversity;

innovative or leading practice; high quality; impact; and, inevitably, our greater personal knowledge of some examples.

Advocacy and health/drug policymaking

At the European level, ENCOD is the network with the longest experience of participating in consultation and dialogue, including: the Civil Society Forum on Drugs; conferences of the European Commission and its sections; hearings and conferences with the European Parliament; and submitting proposals to the European Commission (ENCOD, 2006). In 2007 INPUD also began to participate actively in the Civil Society Forum on Drugs, which was made possible through the allocation of seats for drug user representatives by IHRA and the Central and Eastern European Harm Reduction Network (CEEHRN). These are the only two participating organisations with drug users as open members.

An ENCOD study of drug users' organisations and drug policy dialogue found that most organisations had experience of dialogue and consultation with local and national authorities. These included one-off or time-limited formal meetings and, in some cases, more structured, ongoing participation (Montañés Sánchez and Oomen, 2009).

In Russia, where the context of drug user activism includes some of Europe's harshest policies and laws, drug users' advocacy contributed to the amendment of more than 200 articles of the Penal Code that had effects such as: decriminalising some possession offences; distinguishing manufacture for personal use and commercial distribution (unlike Western Europe, home production is common among drug users in Russia); and, abolished compulsory detention and treatment for the treatment of alcoholism and drug addiction (Canadian HIV/AIDS Legal Network, 2008).

The Alliance (originally the Methadone Alliance) is a user-led organisation in the United Kingdom, founded in 1998 by Bill Nelles and other supportive professionals. The Alliance provides advocacy for people receiving drug treatment with an aim to improve the quality and availability of treatment in the United Kingdom. It has trained advocates across most of England who mediate between services and drug users. The Alliance also trains other advocates and has contributed extensively to conferences, national consultations, guideline and policy development and other activities, such as steering groups for research projects.

Aupa'm (Spain) is an informal group of active/ex-drug users and professionals who meet at a weekly assembly to plan work focusing on increasing injecting drug users' inclusion as citizens in their community. It has an allied, NGO partner, Asaupam, whose members also includes active/ex-users and which manages the agreed projects. Asaupam has participated in the design and implementation of local community programmes in two cities of Catalonia, and manages and coordinates the local plans on drugs (including harm reduction, prevention and socio-labour incorporation) in three cities. Asaupam is one of many members of FAUDAS, a state federation of people affected by drugs or HIV/AIDS (personal communication, Carmen Romera and Xavier Pretel, 2009; FAUDAS, 2003).

Peer support for people living with HIV/AIDS

In Ukraine, the All Ukrainian Network of People Living with HIV is an umbrella organisation for eight Ukraine-based organisations with drug user members, within which peer support is one important activity (CEEHRN, 2004). It is also illustrative of the way organisations often pursue a range of aims using different methods, as they have also: made prominent national and international contributions to combating stigma and discrimination; campaigned for more humane and effective HIV/AIDS policies/treatment; and been influential in campaigns to pilot methadone and buprenorphine programmes and their subsequent expansion (Canadian HIV/AIDS Legal Network, 2008). In these respects they have also contributed to the areas of health/drug policymaking, discussed earlier, and to raising public awareness (discussed below).

Peer support for drug users

Peer support can be interpreted in numerous ways. Local support groups for specific concerns other than HIV, such as hepatitis C, are now common, as are Internet-based support groups. The impact of peer-driven interventions and peer-based groups has been noted with reference to Europe and Australia (Crofts and Herkt, 1995; Grund and de Bruin, 2007).

Within residential rehabilitation programmes that typically operate on some form of 'therapeutic community' model there is a tradition of involving ex-users to deliver programmes because they can sometimes relate to drug users in a way that professional staff cannot, and their presence demonstrates that a drug-free life can be achieved (Mold and Berridge, 2008).

In Italy, Pazienti Impazienti Cannabis (PIC — Cannabis Impatient Patients) provides a contrasting example (Barriuso, 2001). Starting in 2001, as a group for mutual self-help, its members include people who experience legal or economic problems associated with their use of cannabis as a medicine. Beyond providing mutual self-help its aims are to claim the rights of patients, and to promote cannabis as part of the botanical heritage of mankind along with other prohibited plants. As part of its pursuit of practical solutions for access to cannabis as medicine, they use methods including information provision and advocacy. Their work has included the clarification of procedures which patients have to follow regarding the importation of medicinal cannabis and cannabis-derived medicines ([2]), such as those produced by the Dutch Health Ministry, and their provision through pharmacies, subject to medical prescription. Under specific circumstances this is paid for by the local health system (Personal communication, Alessandra Viazzi, 2009).

HIV and other blood-borne diseases (BBD) education and prevention

According to Tops (Tops, 2006), the world's first needle exchange programme was started in Amsterdam in 1984 by the MDHG Belangenvereniging Druggebruikers (Interest Association

([2]) The legal framework is Article 72 of DPR 309/90, Decree of the Ministry of Health 11/2/1997, Modalita' di importazione di specialita' medicinali registrate all'estero, (G.U. Serie Generale n. 72 del 27 marzo 1997), http://www.normativasanitaria.it/jsp/dettaglio.jsp?attoCompleto=si&id=20747 and D.Lgs 24 April 2006 n 72 paragraph 6.

for Drug Users). Many users' organisations across Europe now distribute syringes, other paraphernalia for sterile injecting, and condoms. These include most of the associations involved in the Spanish federation FAUDAS, some Akzept members in Germany, the Danish Drug User Union (BrugerForeningen or BF), and Blue Point in Budapest. Details vary considerably in the specific roles, extent and formality of these arrangements and whether organisations receive payment.

Issue/publish electronic and printed magazines and newsletters

Drug users' organisations produce publications in print and, increasingly, on the Internet. There are numerous examples, some very local and others that address national and international issues. Production standards, editorial quality, style and tone also vary considerably. Whereas some have a more mainstream harm reduction emphasis, focusing on risks, harms and their avoidance, others are more overtly politicised and celebrate positive features of a drug-using lifestyle. At IHRA's conference in 2008, a new international network was announced that aims to support drug user organisations with their own publishing projects — the Drum Alliance (IHRA, 2008).

Publications often operate on multiple levels: support; information provision; initiating or publicising campaigns to change policy, etc. In France, ASUD, a national drug users' organisation that has existed for 15 years, has published 39 editions of its magazine at the time of writing (Olivet, 2009). The magazine has a distinctly political edge, focusing on the marginalisation, discrimination and lack of rights faced by the majority of French drug users. ASUD has branches in most major French cities and regularly participates in or organises forms of direct action, such as the recent construction of a symbolic safe consumption room in its Paris office.

In England, *Black Poppy* (O'Mara, 2008) is a widely distributed 'drug users' health and lifestyle' magazine, founded and edited by Erin O'Mara. It includes health and harm reduction information alongside articles on cultural and historical aspects of drug use, user activism, personal stories and information about services. Individuals and many treatment agencies subscribe to the magazine and distribute it among their service users. Its prominence has also enabled its editor to present drug users' perspectives at parliamentary advisory committees and national radio, television and the press.

Producing other types of informational materials

Beyond harm reduction's early focus on HIV prevention among IDUs, users' organisations have produced a wide variety of information on: the effects, risks and reduction of harms from specific drugs; the prevention and management of specific hazards, such as overdose or hepatitis C; sexual risks and protection strategies for drug users in general, commercial sex workers or targeting gay drug users; legal rights if arrested; gaining access to welfare benefits; and the presence of contaminated batches of drugs. In addition to leaflets or posters, these are disseminated in a range of ways that overlap with the other activities we describe elsewhere.

Organising, conducting and moderating training, workshops and peer meetings

Activities in this area span highly structured training provision through to informal education within peer meetings. Training was one of the main activities reported among the 16 countries surveyed by the Central and East European Harm Reduction Network in 2004 (CEEHRN, 2004), and training, workshops, seminars and peer meetings with an educational component of some sort are an almost universal feature of groups' activity. Content is diverse, reflecting people's needs and concerns, such as: health, harm reduction and treatment information; explanation and skills development to increases users' capacity to influence local and national policy processes; and topics such as fund-raising and organisational management.

The Spanish Nationwide Network of People Affected by Drugs and HIV (FAUDAS) illustrates this work. Periodical seminars and formative courses for and, in some cases, by its member associations address topics such as computer skills, communication skills, fundraising, harm reduction or the development of harm reduction materials by and for users. There is also a permanent working group on gender and drugs focusing on the situation of female drug users and most member organisations implement local training for drug users on assorted harm reduction topics (Pretel, 2004).

Educational and peer support work in the party scene

The impact of ecstasy, alongside the wide range of other legal and illegal drugs used by party-goers, has triggered numerous peer-based initiatives across Europe that focus on the constantly evolving, free-party, festival and club-based electronic music scenes. Harm reduction activities include: creating and distributing information; providing or assisting in chill out areas; conducting drug checking; and, crisis intervention and support. A useful guide to peer-based work in this area comes from the Basics Network, which provides an online guide to organisations across Europe and an extensive downloadable library of information. At the time of writing, they list 22 organisations from 10 countries across Europe (BASICS, 2009).

Running accommodation projects

In Spain, Anydes and Comité Ciudadano Antisida de Ourense, both members of the Spanish Nationwide Network of People Affected by Drugs and HIV (FAUDAS), run what have been termed 'casa de acogida' (shelters), which are places where people who use drugs can stay for a certain time and get access to services.

Drop-in centres with various services

Drug users' organisations have been extensively involved in initiating, developing and delivering interventions at many levels. Goossens' (2008) category of 'drop-in centres with various services' reflects some of these but does not fully indicate the breadth of work that is undertaken.

Naloxone distribution

In Catalonia (Spain), Asaupam provide training courses for drug users on how to use naloxone to as part of efforts to reduce overdose deaths. As part of this, they distribute naloxone to the users participating in the training courses.

Methadone distribution

'Guerrilla' methadone distribution by users' organisations can be traced back to work in the 1980s by the Rotterdam Junkiebond, which led to improved formal methadone maintenance (Grund, n.d.). Today, various users' organisations within FAUDAS participate in the distribution of methadone at the local level (La Calle, Comité antisida de Ourense). This is done informally as, legally, the formal dispensing of methadone is only possible through health centres. In practice, one person from the association collects the drug in the health centre, and takes responsibility for dispensing it to the registered clients in their own premises.

Drug consumption rooms

In the role of 'experience experts', members of drug users' organisations have contributed to policies that underpin 'using rooms' (safer injecting rooms/drug consumption rooms) in the Netherlands (Tops, 2006). Elsewhere, users' groups have sometimes implemented clandestine and less formal users' rooms to provide their community with a more hygienic and safer place.

Drug dealing controls on quality and value for money

In the Netherlands, a users' group identified an inconsistency between providing hygienic equipment and space to users when the quality and purity of the substance they are using varied, with a potential for harm to arise. This led to the introduction of an 'in-house dealer' initiative to guarantee the availability and quality of the drug sold and ensure fair prices (Tops, 2006). In the United Kingdom, a peer-led group — The Crack Squad — introduced a 'dealer's charter' with similar aims (Carty, 2002).

Community reintegration

In Spain, almost all users' organisations have programmes assisting drug users in treatment programmes to access the labour market. One example is Engánchate al trabajo (Get hooked by work), run by two FAUDAS member organisations (Asaupam and Arpa ONG). Active drug users engage in community work such as repairing and maintaining urban spaces or taking care of public gardens. The programme's goals are to provide work experience, improve active users' quality of life and promote more responsible use of drugs. Participants set their own rules to organise and fulfil the work and solve the conflicts that can arise during the implementation. The programme is now in the process of external evaluation and a pilot programme will be implemented in other Spanish cities.

Raising public awareness about the main problems in the drug using community

Some of the earliest work in the Netherlands during the late 1970s was concerned with raising public awareness of problems experienced by drug users (Jezek, 2000), and from 1982 the Rotterdam Junkiebond presented an hour-long radio show on a popular national radio station every Friday evening (Grund, n.d.). We noted above the media work of Erin O'Mara (O'Mara, 2008), and in 2001 Mat Southwell produced a television programme 'Chemical Britannia', which was broadcast nationally by the BBC (Browne, 2001).

Such examples are numerous, but one further example seems especially worthy of mention. In a growing number of countries, users' groups hold an annual remembrance or memorial day for deceased drug users on 21 July (see also box on p. 339). This originated in Germany more than ten years ago when the mother of a heroin user who had recently died wanted to draw attention to the poor condition in which many drug users live. In Copenhagen, Denmark a similar event has been held for the last seven years and the United Kingdom also followed suit in 2008. In Australia, similar events are organised to coincide with 'International Drug Users' Day' on 1 November.

Often, remembrance events draw attention to issues that contribute to 'drug-related deaths', such as deficiencies in service provision, but also the impacts of drug prohibition. They also provide an opportunity for drug users to mark the deaths of friends; this is especially important as so often drug users die alone and their drug using friends are excluded from family burial services. In this respect the day can serve to raise the consciousness of the drug using community as a group. As an example, in Copenhagen, after many years of negotiations, the city council gave the Danish Drug Users' Union (BrugerForeningen) permission to install a permanent stone inscribed with the words 'In memory of dead drug users' beside a paradise apple tree. This site acts as a permanent place for users to remember lost friends. As drug policies have sometimes been described as a 'war on drugs', many in the user community regard these memorials as remembering those who have died as the unintended casualties of policies that have exacerbated rather than reduced harm.

User-driven market interventions

The Italian group PIC has already been discussed as a form of peer support for medical cannabis users, addressing availability and distribution. Initiatives to influence quality and value for money of drug purchases through dealers have also been mentioned. Since 2003, ENCOD and the Spanish Federation of Cannabis Associations (FAC) have proposed a much wider user-driven, market-level approach: a model for the production and distribution of cannabis for adults' personal use (ENCOD, 2007; Barriuso, 2007). ENCOD uses the Cannabis Social Club (CSC) model within the wider campaign 'Freedom to Farm', which seeks the decriminalisation of the three forbidden plants (opium poppy, coca leaves and cannabis). Originating in Spain, CSCs are non-profit associations whose members are adult cannabis users, most of whom use it recreationally but with others who do so medicinally. People who enter the club have to fulfil certain conditions in order to avoid the risk of selling or passing on to third persons or to minors. The CSC members organise a professional, collective cultivation of limited quantities of

cannabis to cover the personal needs of their club members and the system is regulated by security and quality checks (Barriuso, 2003, 2005a, 2005b, 2007).

The first CSC started in Barcelona, Spain in 2001 (Barriuso, 2005a, p. 163), followed by others in Catalonia and Basque Country. Further clubs now operate in Spain and another in Belgium. According to Martin Barriuso, president of FAC, this system contributes to the reduction of both risk and harm, since:

> the uncertainty is often about the quality and possible adulteration of the product purchased on the black market. In a production system in closed circuit, the partner/s know the quality of what they consume, to which variety it belongs, how it has been cultivated, and so on. Furthermore, the association can serve as a point of advice and exchange of information, helping to create a new culture of use, which … is essential for true normalization.
>
> (Barriuso, 2005a, p. 165)

He also claims that this system prevents minors from accessing the substance and avoids the possibility of so-called 'cannabis tourism' (personal communication, 2009).

Research

Knowledge production, and its use, is often an explicit or implied aim of drug users' organisations. This production of knowledge on and by drug users reflects the approach taken by many other groups seeking civil liberties and human rights historically; notably, women's studies, black history, and queer studies. Much research is conducted on drug users. An increasing amount takes place with drug users. Research by drug users, who shape or decide the questions and methods used and are involved at every stage, is the most empowered position possible. Internationally, work by the Australian Injecting and Illicit Drug Users League (AIVL) has been at the forefront of discussions about the terms on which drug users are involved in research and their guidance is a valuable point of reference (AIVL, 2003).

ENCOD has made submissions and undertaken surveys that support drug users' roles, as members of civil society, to be participants in all aspects of policymaking that affects their lives — including research. The report *Green Pepper* was submitted as a response to the European Commission Green Paper on the Role of Civil Society in Drugs Policy in the European Union, with an historical analysis of the participation of drug users and their role in the drug policy debate at the European Union level (ENCOD, 2006). A recent survey on the participation of drug user organisations in the design of drug policies at local and European Level recommended ways to improve drugs users' participation and a proposal on how to structure the Civil Society Forum on Drugs of the European Commission (Montañés Sánchez and Oomen, 2009).

In the United Kingdom, a number of user activists with academic and other backgrounds have either initiated or been invited to be directly involved in research including: the causes and definitions of drug related deaths; the Randomised Injectable Opiate Treatment Trial (RIOTT); factors that promote and hinder successful user involvement in drug misuse treatment services; and user involvement in efforts to improve the quality of drug misuse services. There is also a

drug user-run research and training company that only employs ex- or current drug users to undertake research on, and of benefit to, the drug using community (led by Mat Southwell).

Discussion

Although drug user involvement and organising seems increasingly widespread, we have noted some of the obstacles facing attempts to document it. Stigma, and the consequences of the criminalisation of drug use means that many drug users have reason to remain invisible (Robson and Bruce, 1997). The scarcity of resources to support activism itself means that archiving and preserving its history is often a subordinate concern, at best. Many key participants, such as Nico Adriaans, have died prematurely, taking personal knowledge of this history with them (Grund, n.d.). Nevertheless, one of the clearest messages is that drug users' organisations have multiple aims, and use many methods to engage with harm reduction; spanning mainstream public health work, through to efforts to amend drug control systems. Although there is ongoing debate about the place of drug law reform within harm reduction (see Reinarman, 2004), for many drug users' organisations drug prohibition is without doubt seen as a cause of drug-related harms. The pursuit of drug law reform with the aim of achieving some form of regulated drug market is therefore perceived as a legitimate harm reduction activity.

Besides bringing benefits, user involvement and organising are not without their challenges, including internal conflict (Kerr et al., 2006; Osborn and Small, 2006). Marginalised groups do not necessarily possess good knowledge of the way that systems they seek to influence work or the skills needed for establishing and operating their own organisations, especially early in the process. Expectations can also greatly exceed what is deliverable, although Crofts and Herkt suggest that these problems are no greater than those found within community development work with other disenfranchised groups (Crofts and Herkt, 1995).

Resources commonly fall short of needs, and in many countries funding for drug users' organising is not readily available. One indication of this comes from the CEEHRN needs assessment where drug user groups had noticeably less funding and had access to a smaller range of donors than people living with HIV/AIDS (CEEHRN, 2004).

The extent and nature of state support differs considerably across Europe. For example, England has seen a serious commitment to develop 'user involvement' through its National Treatment Agency (NTA). User involvement is expected at all levels within treatment systems and resources are provided to support it. Yet, this has produced tensions that have been noted elsewhere. For example, critics of the English system, such as the (now defunct) National Drug Users Development Agency (NDUDA), received little support. In just the same way, Crofts and Herkt have commented on the 'tension between the funding agencies (state and federal health departments) for AIDS prevention activities, and the community development agenda of the funded groups, which often includes criticism of the policies of the funding agencies, especially in relation to drug policy and enforcement' (Crofts and Herkt, 1995), and Byrne has referred to the problems that can follow groups that develop through 'contrived spontaneity' (Byrne, 2000).

Impacts

Setting aside any values-based arguments for thinking it right to properly include affected populations in the decisions and processes that shape their lives, policymakers or others may ask, what is the impact, outcome or benefit of involving drug users and their organisations in the reduction of drug-related harm? In an analysis of impacts within Europe, Grosso (Grosso, 2008) concludes that drug users' organisations have produced impacts through peer support in three areas:

- personal change, such as more prudent consumption and risk reduction;
- the social normalisation of drug use, by which they mean 'treating the phenomenon of drug use as any other socio-sanitary problem that society takes care of', and avoiding 'rigid and dichotomous interpretive categories that adopt binaries such as on/off, dependency/abstinence (where) drug use becomes identified totally with "hell" and abstinence with "salvation"', because 'scientific evidence has difficulty making headway with public opinion and consequently with the institutions that should support it and which instead remain paralysed by the generalized opinions of the people they represent'; and
- the modification of services, where drug users' organisations have 'managed to influence services and to make them — at least in part — closer to the needs of their clients, more receptive to their requirements and more contractual.'

The ENCOD survey on the participation of drug user organisations in the design of drug policies at local and European level also appraises the impacts of drug users' organisations on harm reduction as follows:

> Drug user organisations have contributed with methods to reduce harms and risks from their origin. Many of the programmes that are currently carried out by official state programmes (like drug testing, syringe exchange, opiate prescription, user rooms etc.), form part of claims that have surged from these organisations themselves, and in some cases, these programmes are being elaborated by drug user organisations, who have become more professional by converting themselves in service providers. This professionalization has helped to get rid of the stigma on drug users, demonstrating the fact that they can represent themselves.
>
> (Montañés Sánches and Oomen, 2009, p. 220)

In Canada, Thomas Kerr and his colleagues have described the development and impact of the Vancouver Area Network of Drug Users (VANDU), and concluded that:

> Through years of activism, advocacy, and public education, VANDU has repeatedly voiced the concerns of drugs users in public and political arenas. VANDU has also performed a critical public health function by providing care and support programmes that are responsive to immediate needs of their peers. This study indicates that greater efforts should be made to promote the formation of drug user organizations, and that health authorities and policy makers should explore novel methods for incorporating the activities of drug user organizations within existing public health, education, and policy making frameworks.
>
> (Kerr et al., 2006, p. 61)

In Australia, Crofts and Herkts' analysis of peer-based groups concluded that:

> IDUs have organized and, from that, they now successfully run a wide variety of programmes themselves. IDUs 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. In general, this has been done with minimal funding and support, and often in an unsympathetic if not hostile environment. 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.
>
> (Crofts and Herkt, 1995, p. 614)

Finally, in the report *Nothing about us without us* (Canadian HIV/AIDS Legal Network, 2008), which focuses on the meaningful involvement of people who use illegal drugs in public health, the authors conclude:

> People living with HIV and people who use illegal drugs are central to the response to HIV/AIDS and HCV. There are ethical and human rights imperatives for involvement, but involvement is also required because it ensures a more effective public health response.
>
> (Jürgens, 2008, p. 56)

Conclusion

Key messages

- The way that harm reduction is translated into practice is variable, and so is user involvement and user organising.
- User organising implies more autonomous organisation by drug users to work to self-determined agendas affecting their interests, whereas user involvement implies less autonomy.
- In Western Europe, the first drug user advocacy/activist group was the Rotterdam Junkie Union, founded in 1977 by Nico Adriaans.
- The aims and methods of user-led initiations are multiple and variable, and include: peer support; advocacy and lobbying for improved services and policies; provision of helping services; health promotion and user representation; and raising public awareness.
- User organising occurs in a climate of limited support and resources, yet has had a significant role in generating and sustaining harm reduction responses.
- Research and evaluation on the impacts of user involvement and organising is in its infancy, but is much needed, including through user-led research projects.

We have described the aims and methods evident within drug users' involvement and organising, and some evidence of its impact (see box on p. 339). For current and former drug users to make their full contribution to harm reduction an enabling environment is required, in which their capacity to contribute can develop. The challenges of achieving this in a context where having a drug user identity is, in effect, criminalised and certainly highly stigmatised, are hard to overstate. Nevertheless, there are two clear ways by which this can be directly helped.

First, any authority that is making decisions or shaping services that affect drug users' lives can introduce policies that promote or require the meaningful involvement of drug users at all relevant points, that is, from the very beginning of planning, through to monitoring and evaluation. This has implications at all levels of society, ranging from central government to local services. Most obviously, it relates to the planning and delivery of harm reduction and drug treatment services, but it also relates to the likes of research bodies, housing services, criminal justice services and so forth.

The second requirement is for the resources to support this and a corresponding readiness to alter systems in ways that enable drug users' participation. Becoming 'involved' often generates direct costs to the drug user, such as time and travel. It also implies the provision of the drug user's hard-won expertise. These costs should be fairly met. Likewise, systems need to be sensitive to ways they may need to adapt for this to occur successfully. At the same time, drug users need to recognise that accepting state or other official forms of funding/support may have a real impact on what they can or can't do, and the way that priorities for action may be affected.

In conclusion, we have tried to illustrate the need for a more nuanced appreciation of the contribution of drug user involvement and organising to harm reduction and its greater potential. In setting out many of its assorted aims and methods, we have also acknowledged that there are areas where consensus does not exist among drug users and within the harm reduction movement. Finally, we have highlighted ways that user involvement and organising can be nurtured, with an expectation that this will support wider efforts to reduce drug-related harms across Europe.

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