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Drug user participation and European cities

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European network of partnerships between stakeholders at frontline level responding to drug problems providing experience and assistance for inter-sectoral cooperation

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Summary

Like every citizen, drug users have the right to get information and access to the adequate services and treatments they need. They have the right to influence the policies which relate to them.

The European local authorities have the duty of making the citizens' rights respected and promoted, especially in the framework of participative democracy.

Cities can support drug users' participation at three levels:

- By supporting the self-organisation of drug users;
- By promoting the involvement of the drug users in the drug services;
- By integrating drug users in local and integrated partnerships responding to the issue of drugs.

At the European and global level, drug users' networks, networks from the harm reduction fields and city networks are able to help cities to improve drug users' participation by providing expertise and practice sharing.

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Introduction

According to the Ottawa Charter for Health Promotion¹:

- *Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities - their ownership and control of their own endeavours and destinies.*
- *Health promotion supports personal and social development through providing information, education for health, and enhancing life skills. By so doing, it increases the options available to people to exercise more control over their own health and over their environments, and to make choices conducive to health.*

But the level of implementation of these health promotion rules is very low in the field of drugs: Traditionally users of illegal drugs do not have their voices heard in the matter concerning with them. Policy makers, service providers, health authorities, police and judges usually discuss drug policy and establish the legal and treatment system around drug use. They make decisions about drug users without taking their voices seriously into account. For many years, users of illegal drugs developed different methods to get organized and to influence policies and treatment. They fight for the right to get information and the

medication they need, for adequate treatment and decriminalisation. They aim to get treated with respect and dignity like every other citizen².

The development of the drug user participation in the drug policies and services is closely linked to the development of the harm reduction movement. The harm reduction strategies necessitate a Community dimension because they are possible only through an alliance between professionals and drug users. This alliance stems from the call for drug users' to be responsible for active collaboration in order to make possible, on the one hand, the production of good prevention messages and, on the other hand, the diffusion of these messages to the good target groups.

In this context, due to their role of coordinating the various local responses, participative democracy is a relevant lever on which the European municipalities can rest to promote the drug user participation in the local policies and practices. Indeed, the local elected officials are called upon to lead participative democracy at the city level and in this way should guarantee the participation of all citizens, including those who use drugs.

¹ First International Conference on Health Promotion - Ottawa, 21 November 1986 - WHO/HPR/HEP/95.1

² *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008



Different levels of drug user participation

Drug user participation is a complex issue including many different realities and methods: peer support, peer education, peer projects, self-organised groups, user-led groups, community-based groups, drug user councils, drug user focus groups, etc.

To understand the situation, two levels can be identified:

- the organisations and services level;
- the drug policies level.

The level of the organisations (empowerment) and services (involvement)

“The distinction between a) systems that seek to consult or involve drug users in services [involvement] and b) those where power is asserted more directly in accordance with the concerns of drug users [empowerment], is an important one³.

The history of drug user involvement/empowerment shows a process going from strong empowerment (pioneers) to low involvement (generalization). Indeed, the first practices were the most empowering ones: Self-organised drug user groups appeared to combat for their rights. Community-based and

3 Neil Hunt, Eliot Albert, Virginia Montañés, ‘User involvement and user organising’ in Rhodes, T. (ed.), 2009, *Harm Reduction: Evidence, Impacts and Challenges*, European Monitoring Centre for Drugs and Drug Addiction, Scientific Monograph Series No 10, Office for Official Publications of the European Communities, Luxembourg.

drug user organisations are described in the chapter p. 7. Then, after this first step, the development of the drug user involvement within the services became possible and is presented in the chapter p. 12.

The level of drug policies (participation)

The influence of drug users on drug policies can be observed:

- At the global level, for example through the civil society consultation carried out by the UNODC⁴. The International Network of People who Use Drugs (INPUD) takes part in this consultation to improve quality of the services;
- At the European level through the EU Civil Society Forum on Drugs (see p. 30);
- At the National level, for example the French national addiction commission in which drug users’ organisations are represented to express their points of view on treatments;
- Finally at the city level, through their participation in the local drug policies.

The drug user participation in local drug policies is described in the dedicated chapter starting p. 17.

Drug user organisations (DUO)

Why drug users create self-organised groups?

This occurs at a local level rather than at the national level, with the aim of protecting themselves against discriminatory practices, carried out by policies, institutions, society and services. These groups arise in a manner totally external to services. Most users in these groups are not clients of therapeutic programmes.⁵

The type of organisations and actions are different in each country according to the cultural, political and social context. Moral perception, pattern of drug use, the Welfare state model, the national drug policies (such as the availability of substitution treatments) have an impact on the resources, the opportunities and the barriers drug user groups have to tackle with.

4 United Nations Office on Drugs and Crime

5 *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008

Actually, mainly two types of drug users have organised themselves:

- The street drug users of heroin or crack, to face the HIV/AIDS epidemic and the conflicts related to public nuisances;
- The drug users issued from recreational settings.

This is due to the fact that these two situations are both linked to open drug scenes, so making possible the meeting between drug users and, consequently, their mobilisation.

History of drug user organisations

Four different phases can be identified:

1. The social peace and human rights phase (Nordic countries): Before the HIV/AIDS epidemic, the first activists fought for their rights and were sometimes supported by local authorities (Amsterdam) in order to manage at best the problems related to public nuisances. The first group was the Rotterdam Junkie Union, created in 1977;
2. The HIV/AIDS phase (Latin countries): Injecting drug users' groups were created to face the epidemic among them, as ASUD (Auto-Support des Usagers de Drogues) created in France in 1992;
3. Patient-oriented phase: Mobilisation of vulnerable groups in order to improve quality of services and treatments such as the Methadone Alliance created in UK in 1998;
4. Recreational settings phase: mobilisation among the party scenes since the 90s⁶.

During 2003/4, the Central and Eastern European Harm Reduction Network (CEE-HRN) assessed the needs of drug users' organisations across Central and Eastern Europe and Central Asia. Respondents came from 16 countries. They identified 21 drug user organisations⁷.

⁶ See *Safer Nightlife in Europe*, Thierry Charlois, Council of Europe COOP (2009) 4

⁷ Neil Hunt, Eliot Albert, Virginia Montañés, 'User involvement and user organising' in Rhodes, T. (ed.), 2009, *Harm Reduction: Evidence, Impacts and Challenges*, European Monitoring Centre for Drugs and Drug Addiction, Scientific Monograph Series No 10, Office for Official Publications of the European Communities, Luxembourg.



Community-based organisations

A part from the strictly drug user organisations (DUO), community-based organisations are also places for drug user empowerment. Two different situations are observed regarding community-based organisations:

- The organisations in which drug users and professionals are equal partners. This is the case of the MDHG, the Medical-social service for heroin users, initiated in 1977 in Amsterdam and gathering drug users, parents of drug users, social workers and other interested people;
- The organisations in which people are from the same community. This is the situation of the gay organisations fighting against HIV/AIDS. This is also the case of the organisations issued from the party scenes in which members identify themselves first as sharing the same musical and cultural movement before being drug users. In addition, some of the members are both partygoers and students or young professionals from the social and care field.



Priorities and activities

According to research conducted in 2007 by INPUD⁸ and the Correlation Network among 38 DUO from 21 countries worldwide, the main priorities and activities of the drug user organisations are:

- advocacy and health/drug policy making;
- raising public awareness about the main problems in the drug user community;
- peer support for drug users and people living with HIV/AIDS;
- HIV education and prevention;
- producing e- and printed magazines and newsletters as well as other types of informational materials;
- organizing, conducting, moderating training sessions, workshops, seminars, peer meetings;
- educational and peer support work in the party scene;
- running accommodation projects;
- drop-in centres with various services;



Strengths and weaknesses

From the point of view of a city, the main strengths of DUO or community-based organisations are their high level of empowerment and their legitimacy to represent efficiently drug users in a local and integrated partnership. In terms of empowerment, some of the DUO members have become professionals and so are available and look as credible in relation to the other partners.

On the other hand, the major risk for the life of the “self-made” group is represented by the danger of isolation, often the result of the assumption of hard and radical positions and the determined willingness to refuse almost any negotiation with institutions, which in turn precludes the possibility of confrontation and constructive exchange⁹.



8 International Network of People who Use Drugs

9 *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008

Drug services and user involvement

Deciding to work with the resources a client has to offer and not just the “pathology” that has brought them to the drug services, is a choice that hardly needs mentioning and that today concerns a consistent minority of professionals¹⁰.

Why involve drug users in the services?

Drug users, like most people, would like a greater say in the services they receive:

- *Services will be more efficient and effective if they listen to the views of their service users;*
- *Purchasers and planners will make more informed decisions if effective user involvement structures are in place;*
- *User Involvement groups can assist in changing public attitudes towards people who use drugs and encourage a more informed response from the general public;*
- *User Involvement can also be a way of actively channelling the skills of drug users¹¹.*

How is drug user involvement initiated?

Mixed groups

The “mixed groups” are conceived by operators [...] through which pre-chosen users are called up to undertake some kind of already determined activity. Instead they are the outcome of an invitation to participants to develop together with the services a debate, a reflection of joint interest, at times a research project, an experiment, or whatever initiative that could be of interest and useful [...]. This happens on equal terms with a combined participation that brings together different points of view, different knowledge and competences, and is not characterised by the asymmetry of a relationship that is generally found in the therapeutic setting¹².

Spontaneous client groups

These are client groups that, finding themselves in therapeutic programmes run by drug services, decided to autonomously agitate regarding a number of issues: improvement of the allocation of services that regarded them; the request for a space not strictly rehabilitative; the need to be protagonists, but not rigidly confined to the role of user. The involvement of users in group initiatives was more or less the consequence of good clinical practices but also the establishment of accessible services, open and negotiable, aimed at not focalising only

¹⁰ *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008

¹¹ Ibid

¹² Ibid



on the problematic aspect of who had made a request for help, but on valuing the resources, the knowledge and the competencies present¹³.

How to involve drug users?

Focus groups

A focus group is a form of qualitative research, in which a group of drug users are asked about their practices, their needs, their opinions, etc. Questions are asked in an interactive group setting where participants are free to talk with other group members.

Focus groups can be organised easily and are less expensive than individual interviews. This method is more efficient than survey questionnaires to get qualitative information. It is thus a good method to involve drug users in assessment and evaluation actions at the level of a service or at the one of a local drug strategy.

The disadvantages of such a method are:

- *Results from focus groups can not always be used to make statements about the wider community;*
- *For various reasons, participants may agree with responses from other group members. Caution is required when interpreting the results;*
- *A moderator who is not-well trained may influence the participants to answer questions in a certain way;*
- *Focus groups have limited value in exploring complex beliefs of individuals; for this purpose, in-depth interviews are a more appropriate method¹⁴.*

¹³ Ibid

¹⁴ *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008



Drug user Council

A user council is a democratic forum where users and staff and/or management within a treatment institution can work together to discuss and make decisions on various factors concerning treatment. A user council can be set up in different ways. Users can be elected or selected to sit alongside staff representatives and managers. User councils can also be open to all users who wish to participate along with staff members or managers¹⁵.

The French public health law imposes on the services to set up such consultative councils¹⁶ in order to express the users' opinions on service operating and organisation, activities, treatment services, prices of services, etc. The members of the councils are elected by the users. The Dutch regulation imposes as well "client boards" within the drug services.

This method is huge to carry out but present a high level of participation from a democratic point of view. However it is a method hard to transfer into a local drug strategy because it is impossible to organise an election among drug users in a city.

15 Nr 49 *Drug Users and Spaces for Legitimate Action*, Eds. Jørgen Anker, Vibeke Asmussen, Petra Kouvonen & Dolf Tops, Nordic Centre for Alcohol and Drug Research

16 Conseil de la Vie Sociale – Loi du 2 janvier 2002

Peer intervention

This includes the notion of peer support, peer education, peer operators, etc. *The peer approach is a broad definition that includes all interactive education strategies through peer-led groups. It assumes that experiences lived with others or through models of others can effect changes in behaviour and, like the general health promotion model; it may include elements such as knowledge, resistance skills and social support for non-use.*

Peer-led approaches aim to use the interactions between peers, and the associated socialisation and influence, to promote health-related behaviours and reduce drug use. This method makes use of the fact that messages (information, norms, attitudes, behavioural models) are better and more credibly delivered by trusted sources, i.e. peers¹⁷.

The practice of involving users to manage or co-manage certain harm reduction interventions, as peer-operators, is a very useful opening, both for the contribution of new competencies for services and for placing value on the user as a protagonist¹⁸.

Concretely, a service can involve peer operators as volunteers or by integrating them in their staff as outreach workers. This can also be done at the level of a local drug strategy. For example in Paris, the local partnership for prevention in recreational settings (Fêtez Clairs) is currently recruiting peer educators as volunteers among the clients of the Parisian night clubs.

Obviously as peer intervention involves active drug users; it presents some risks in terms of behaviour which need to be reduced by setting up a clear framework of involvement including peer training and supervision.



17 <http://www.emcdda.europa.eu/html.cfm/index10872EN.html>

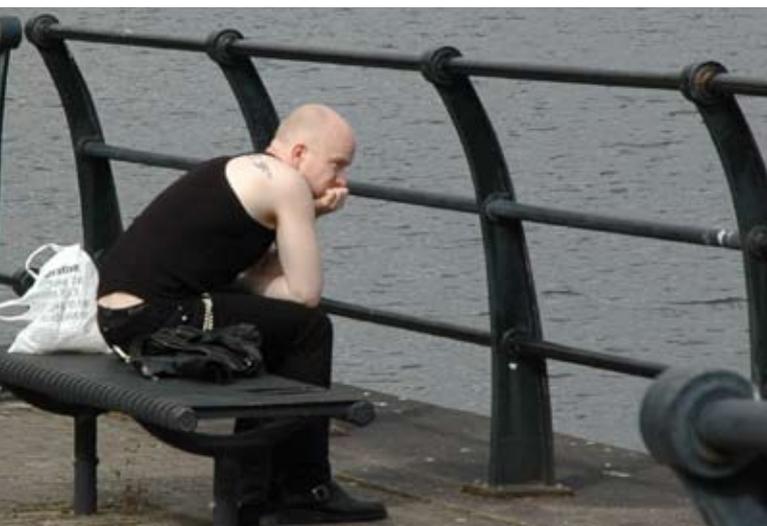
18 *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008

Cities supporting drug user empowerment and involvement

The involvement of drug users is critical in reaching the hidden population of users because they already have access to that world. Drugs are hidden from anyone on the outside. The alliance with drug users is not only useful for reaching other users but is also important for understanding their needs in terms of health protection. Users have personal knowledge about the drugs they are taking, how to take them, and what the risks of consumption are. Personal decisions are made about using condoms or sterile syringes, or whether to stop injecting altogether and seek treatment. Finally, drug user involvement improves the quality of specialist drug services.

Some experiences of cities initiating and supporting the development of drug user organisations (DUO) have been identified. Generally it aims at:

- getting representatives of drug users into local partnerships led by the cities (i.e. in the Dutch cities);
- Improving access and quality of the services;
- Developing prevention in recreational settings (i.e. Paris or Barcelona).



This support can be done either directly by providing funding, premises, training, etc. or indirectly through umbrella organisations. *The umbrella organisations, both public and private or voluntary, can be defined on the basis of their willingness to offer refuge and support to all mutual self-help groups and local initiatives that have as protagonists the same people who directly live and experience the problems. The material resources and the institutional credibility that the umbrella organizations benefit from enable them to undertake two fundamental functions: trampoline and protection*¹⁹.

Cities also initiate and support drug user involvement within the local services. This can be done by providing funding, organising training and practice sharing between drug services. Indeed, *the formation of professional operators as facilitators of the empowerment process becomes the characteristic of an essential and priority practice to favour and extend the opportunity for user involvement [...]. In addition, to sustain the diffusion of empowerment strategies, it is essential to exploit [and share] good practices in order to make use of experiences already put to the test and to avoid repeating errors or making unsuccessful directions [...]. The implementation of focus groups has proven to be particularly productive for starting up mixed working groups of users-operators in diverse and multi-task services. These groups have enabled the involvement of users, the acquisition of user points-of-view and knowledge, the sensitisation of operators and the establishment of new ways of relating and collaborating*²⁰.

¹⁹ *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008

²⁰ Ibid



The Scottish Drug Forum experienced the development of a Drug user involvement model among several drug services. The lessons learned from this model are:

- The volunteers have to be clear on why they have been recruited and what the purpose of the project is. They have to be trained and supported;
- The group develops a representative overview, rather than individual perspective, of issues facing problem drug users;
- User Involvement Group members develop and build a range of skills and self-esteem, which assists members to move onto education, training or employment and benefits other aspects of their personal lives;
- Drug agencies can be ambivalent about - or in some cases, hostile to User Involvement because they may perceive user opinions' as a threat to their vision of the structure and/or operation of the services offered or as a threat to their reputation²¹.

21 *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008

Participation of drug users in partnership-based local drug policies

Why cities support drug user participation?

Integrated local drug policies bring institutions and organisations involved in reducing local drug problems together at one table to discuss the drug related problems in communities and their possible solutions. Drug users, drug treatment services, the health system, the police, judges and other community representatives work together to develop a local drug policy and strategies to improve the situation where they live. This participative process strengthens the ability of communities to manage their own affairs on a sustainable basis and creates consensus.

Any authority that is making decisions or shaping services which affect drug users' lives can introduce policies that promote or require the meaningful involvement of drug users at all relevant points i.e. 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 has relates to the likes of research bodies, housing services, criminal justice services and so forth²².

How to manage the drug user participation?

The partnership

No one is more concerned than the drug users themselves, but their participation appears to be difficult to achieve. Drug users are seen as people who have lost control of themselves, although, faced with the threat of AIDS, they have been able to protect their health. Drug users are not only responsible for themselves; they also often play an important role in projects that impact on drug use as well as on drug-related public nuisances.

22 Neil Hunt, Eliot Albert, Virginia Montañés, 'User involvement and user organising' in Rhodes, T. (ed.), 2009, *Harm Reduction: Evidence, Impacts and Challenges*, European Monitoring Centre for Drugs and Drug Addiction, Scientific Monograph Series No 10, Office for Official Publications of the European Communities, Luxembourg.

Different means of drug user participation have been identified among European cities:

- by inviting a local drug user organization (DUO) into the partnership;
- by inviting a national DUO or a local DUO from another city as experts. It is also possible to invite experts from a European drug user network (see chapter p. 22);
- by consulting or including in the partnership services involving drug users. Drug services are concerned but also other social and health services.

Assessment and evaluation

The first source of information is the experience of each partner. Professionals know what problems arise from dealing with drug users. Drug users know why they use or refuse to use a service. Residents know what they fear. The partners know what the relationship between the services is. It is thus important to be sure that the drug users' voices are heard in order to guarantee the effectiveness of the assessment phase. Drug users must be involved in the assessment of the risks linked to drug use as well as on the public nuisances. They must be consulted on defining their own needs. They must also be consulted, as service users, to evaluate the quality of initiatives provided for them²³. The participation of the drug users in shared assessments and evaluations can be done by the drug services or by autonomous operators (researchers or focus group mediators).

However, there are many barriers to effective information sharing. The aims of monitoring have to be discussed and agreed with each partner. Ethical rules need to be defined: drug users have to be considered as any other citizen; their human rights have to be respected.

Partners and clients (drug users, families and residents) have to be informed of the data collected, who has access to the information, and how the data will be used.

Local strategy

Programmes have to take into account the effects and impacts of health and law enforcement issues on social cohesion. The aims of social cohesion policies have been defined by the Council of Europe with the following indicators: an equal access to available resources, a respect for diversity, autonomous groups and citizen participation²⁴.

²³ *Drug use, front line services and local policies - Guidelines for elected officials at the local level*, Anne Coppel, European Forum for Urban Safety, 2008

²⁴ See publication Pompidou Group, *Concerted development of social cohesion indicators - Methodological guide*, 2005



Networking among partners, including drug users, is an effective strategy for action because it creates a common culture among partners. This can be improved by organising common training sessions with all key partners.

In this way some cities organised meetings between problematic offending drug users and inhabitants. Involved drug users and inhabitants better understood each other and disseminated new behaviours within their respective communities. It raises public awareness about the main problems in the drug-using community. It raises drug users' awareness about the impact of their behaviours on the citizens' daily life.

This cultural change affects every one: professionals, drug users, families and the wider community. The local and integrated drug policies brings change when it takes into account all the different needs and calls upon every one to be responsible and promotes social cohesion through negotiation between different parties.

Here is an example of drug user participation in Spanish cities: *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, formally constituted, 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/AIDS²⁵.*

²⁵ Ibid



European networks of drug users' participation

International drug user networks are linked to the international HIV/AIDS and harm reduction networks. They are also linked to the anti-prohibitionist movement.

The International Network of People Using Drugs (INPUD²⁶)

This network was created in 2006 at the time of an International Harm Reduction Conference and is supported by the International Harm Reduction Association (IHRA, see below). This is a network of individuals and organisations. The European INPUD members intend to create a sub-European network in the framework of a European project conducted by IHRA.

The INPUD activities are:

- International advocacy for drug users' rights;
- Influence on regulation;
- Promotion of harm reduction services and treatments adapted to the drug users' needs.

²⁶ <http://inpud.wordpress.com/>

Experts from INPUD are called up by NGOs or authorities over the world for supporting local advocacy or to improve quality of services and drug user involvement in the responses. In the future, INPUD intends to support the emergence of drug user-led projects.

INPUD works with UN bodies such as UNAIDS and UNODC as well as the EU Civil Society Forum on Drugs (in this case through harm reduction networks) and the International Drug Policy Consortium.

Basics Network “for dance culture and drug awareness”

Founded in 1998, the *Basics Network*²⁷ gathers peer projects issued from party scenes among 12 European countries.

In 2001-2002, the member NGOs developed a project in order to share practices and promote safer clubbing.

Since 2005, the Basics Network has been leading a working group on safer nightlife in the framework of the *Democracy, Cities & Drugs* projects²⁸ (DC&D).

Finally the Basics Network submitted a proposal in April 2009 to the Drug Prevention and Information Programme to share practices on new technologies, research, training and to organise common interventions in big European events.

Correlation - “European Network for Social Inclusion & Health”

The Correlation²⁹ network develops projects funded by the European Public Health Programme with the aim of improving the access to services for the marginalized and excluded people.

In the framework of the Correlation II project (2009-2012), an expert group called “peers support” aims to improve Peer Education (HIV & HCV) by:

- ⊙ identifying existing peer education strategies;
- ⊙ discussing existing practices during national debates;
- ⊙ developing and implementing a training manual.

²⁷ <http://www.basics-network.org>

²⁸ <http://www.democitydrug.org>

²⁹ <http://correlation-net.org>



The International Harm Reduction Association³⁰

IHRA is the leading organisation in promoting evidence based harm reduction policies and practices on a global basis for all psychoactive substances (including illicit drugs, tobacco and alcohol). It seeks to involve drug users in its meetings and processes and has provided opportunities for drug users to network internationally that have facilitated the development of international drug user networks. IHRA organise every year the International Harm Reduction Conferences.

The European Coalition for Just and Effective Drug Policies (ENCOD³¹)

ENCOD is a platform founded in 1993 by European citizens affected and/or concerned with the current international war on drugs. ENCOD members unite representatives of drug consumers, their relatives, health workers, experts, entrepreneurs and activists from the whole of Europe. ENCOD advocates for drug policy changes at the European and UN level. ENCOD is member of the EU Civil Society Forum on Drugs.



³⁰ <http://www.ihra.net/>

³¹ <http://www.encod.org>

Drug users' participation and policies at the EU level

The EU Drug Policy

The EU Drug Strategy 2005-2012 and the EU Drug Action Plan 2009-2012 invites the member states to improve access to the services, to develop an alliance between citizens and institutions but there is no reference to drug user empowerment and involvement.

However, the Council Recommendation of 18 June 2003 on the prevention and reduction of health-related harm associated with drug dependence invites member states to «*encourage, when appropriate, the involvement of, and promote training for, peers and volunteers in outreach work, including measures to reduce drug-related deaths, first aid and early involvement of the emergency services*».

There is no drug user organisation among the members of the EU Civil Society Forum on Drugs but drug users are represented through the *European coalition for just and effective drug policies*, the *Correlation network* and the member organisations from the harm reduction field: The *International Harm Reduction Association*, the *Eurasian Harm Reduction Association* and the French and Romanian harm reduction associations.



The EU Programmes

The Work Plan 2009 of the Public Health Programme gives priority to projects *developing, implementing and evaluating drug demand reduction activities* but there is no focus on drug user involvement or empowerment.

However, this programme has supported some projects in this field, as for example:

- ⊙ 1996: *The European Peer Support Project: Encouragement, development and support of peer support aiming at harm reduction in IVDU communities.* Dutch National Institute for Alcohol and Drugs.
- ⊙ 2001-2002: *European strategy by the peer education associations within the Techno movement for harm reduction in consumption of synthetic drugs linked with the Techno/House scene* (BASICS network)
- ⊙ 2005-2008: *Promoting health and prevent disease through addressing health determinants across all policies and activities* (Correlation Network)
- ⊙ 2006-2009: *PEER - education-project for young drivers to prevent alcohol and drugs in connection with road use - Drive Clean!*

There is no reference to drug user involvement and empowerment in the Drug Prevention and Information Programme but in 2009 an application was submitted by the IHRA in which INPUD intends to create a European drug user network.

Conclusions

The World Health Organization (WHO) has more than once affirmed the importance for achieving changes – in particular regarding a series of questions where health issues are grounded in social problems – by working simultaneously on three aspects:

- *lifestyles of individuals or groups;*
- *the environmental context that induces this;*
- *and the current health and social system.*

The work of peer support, activation and self-help between users, meet at the crossroads of the three areas for change identified as strategic by the WHO:

- *There is the “community” that learns to protect itself, to produce behaviour change and self-propose a lifestyle that is safer and compatible with social integration.*
- *There is the “initiative group” that tries to have impact through a different social representation of the problems surrounding drug use in terms of the environmental context.*
- *Finally, there is the “peer-operator” who has influence regarding better access and relevance to needs from the specific socio-health services, modifying work methods and organization³².*

European cities have demonstrated that they can play an important role to support these changes:

- by helping drug user organisations;
- by promoting drug user involvement in the services;
- by including drug users within the local and integrated drug policies.

Finally, the European cities get the opportunities to improve their responses in this field by sharing practices with and using expertise from existing related European networks.

³² *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008



Resources

Publications, documents, magazines

Empowerment and self-organisation of drug users, Foundation Regenboog AMOC – Correlation Network, 2008

Neil Hunt, Eliot Albert, Virginia Montañés, 'User involvement and user organising' in Rhodes, T. (ed.), 2009, *Harm Reduction: Evidence, Impacts and Challenges*, European Monitoring Centre for Drugs and Drug Addiction, Scientific Monograph Series No 10, Office for Official Publications of the European Communities, Luxembourg.

Drug Users and Spaces for Legitimate Action, Eds. Jørgen Anker, Vibeke Asmussen, Petra Kouvonen & Dolf Tops Nordic Centre for Alcohol and Drug Research publication 49, 2006

Drug use, front line services and local policies - Guidelines for elected officials at the local level, Anne Coppel, European Forum for Urban Safety, Paris, 2008

Encouraging peer support for risk reduction among injecting drug users, National Committee on AIDS Control, Amsterdam, 1993

Safer Nightlife in Europe, Thierry Charlois, Council of Europe COOP (2009) 4

Asociaciones de usuarios de drogas y grupos afines, Coord. Maria Dolores Rodriguez, Fundación CREFAT, Madrid, 2000

Continuité et rupture dans l'histoire de l'auto-support des usagers de drogues en Europe, Abdalla Toufik, CRIPS-IDF, Paris, 1997

ASUD Journal, FR – www.asud.org

Black Poppy, UK - <http://www.blackpoppy.org.uk/>



European institutions

European Commission – EU Drug Policy:

http://ec.europa.eu/justice_home/fsj/drugs/fsj_drugs_intro_en.htm

Public Health Programme:

http://ec.europa.eu/health/ph_programme/programme_en.htm

Drug Prevention and Information Programme:

http://ec.europa.eu/justice_home/funding/drugs/funding_drugs_en.htm

EU Civil Society Forum on Drugs:

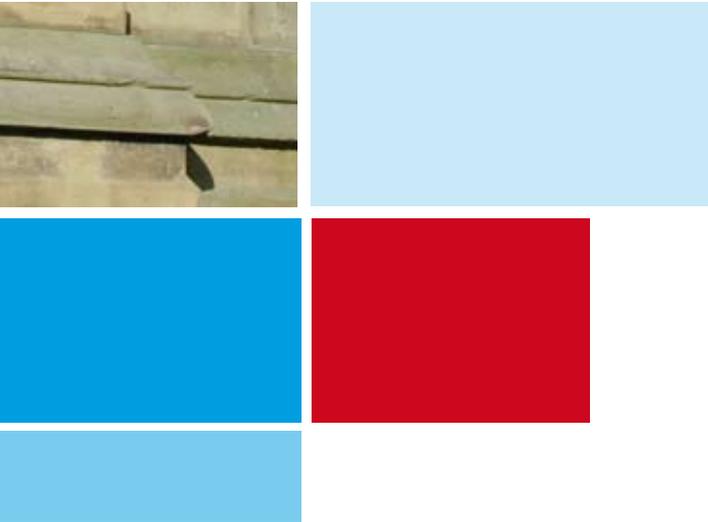
http://ec.europa.eu/justice_home/fsj/drugs/forum/fsj_drugs_forum_en.htm

European Monitoring Centre for Drugs and Drug-Addiction:

<http://www.emcdda.europa.eu>

Council of Europe – Pompidou Group:

<http://www.coe.int/T/dg3/pompidou/>



International and European networks

International Network of People who Use Drugs:

<http://www.hardcoreharmreducer.be/>

Basics Network for dance culture and drug awareness:

<http://www.basics-network.org>

International Harm Reduction Network:

<http://www.ihra.net/>

Eurasian Harm Reduction Network:

<http://www.harm-reduction.org/>

International Drug Policy Consortium:

<http://www.idpc.net/>

European Coalition for Just and Effective Drug Policies:

<http://www.encod.org>

Correlation Network (Peer support group):

<http://www.correlation-net.org>

Democracy, Cities & Drugs:

<http://www.democitydrug.org>

Example of drug user organisations across Europe

Auto-Support des Usagers de Drogues, France:

<http://www.asud.org/>

Danish Drug Users' Union:

<http://www.brugerforeningen.dk/>

Swedish Drug Users' Union:

<http://www.svenskabrukarforeningen.se/>

Croatian Drug User Union:

<http://www.uho.hr/>

Krakov association of substitution patients, Poland:

<http://wyzwolenie.weebly.com/>

Bolton User Group Service, UK:

<http://www.serviceusers.org/>

M.o.r.p.h, UK:

<http://www.morph-uk.org/>

The Alliance, UK:

<http://www.m-alliance.org.uk/index.html>

Drug Users RU, Russia:

<http://www.drugusers.ru/>

Federación estatal de Asociaciones de Personas afectadas por las drogas y el VIH, Spain:

<http://www.faudas.org/>

Landelijk Steunpunt Druggebruikers, The Netherland:

<http://www.lsd.nl/>

Doelstelling Belangenvereniging Druggebruikers MDHG, The Netherland:

<http://www.mdhg.nl/>



Example of safer nightlife peer projects across Europe

Technoplus (Paris):

<http://www.technoplus.org>

Keep Smiling (Lyon):

<http://www.keep-smiling.com>

Le Tipi (Marseille):

<http://www.letipi.org>

Prev'En Teuf (Louvier, FR):

<http://www.preventeuf.org>

Spiritek (Lille):

<http://spiritek.free.fr>

Energy Control (Barcelona):

<http://www.energycontrol.org>

Modus Fiesta (Brussels):

<http://www.modusvivendi-be.org/modusfiesta>

Raid Blue (French-speaking Switzerland):

<http://www.raidblue.ch>

Crew 2000 (Edinburgh):

<http://www.crew2000.co.uk>

Drogart (Ljubljana):

<http://www.drogart.org>

Drug scouts (Leipzig):

<http://www.drugscouts.de>

Eve & Rave (Berlin, Zurich):

<http://www.eve-rave.net>

Eclipse (Berlin):

<http://www.eclipse-online.de>

Party project (Breme):

<http://www.party-project.de>

Unity (Amsterdam):

<http://www.unitydrugs.nl>

Blue Point (Hungary):

<http://www.kekpont.hu>

CheckIt! (Vienna):

<http://w3.checkyourdrugs.net/checkyoursite/index.html>

Check In (Oporto):

<http://www.apdes.net/> (see Unit 1)



Drug user participation and European cities

Internet guide prepared by Thierry Charlois

Introduction

This Internet guide aims at providing links to relevant websites and downloadable documents related to the following topics. It is issued from the [background document *Drug user participation*](#) written for the [EXASS-Net Amsterdam seminar](#) organised on October 19-21, 2009.

The issue of drug user participation is related to the [Ottawa Charter for Health Promotion](#) (see. articles *Strengthen Community Actions* and *Support Personal Skills*).

Different levels of drug user participation in the responses

Drug user participation is a complex issue including many different realities and methods: peer support, peer education, peer projects, self-organised groups, user-led groups, community-based groups, drug user councils, drug user focus groups, etc.

To understand the situation, two levels can be identified:

- the organisations (empowerment) and services (involvement) level;
- the drug policies level (participation).

More info in the [background document *Drug user participation*](#) (page 4)

Drug user organisations (DUO)

Why drug users create self-organised groups?

This occurs at a local level rather than at the national level, with the aim of protecting themselves against discriminatory practices, carried out by policies, institutions, society and services. These groups arise in a manner totally external to services. Most users in these groups are not clients of therapeutic programmes.

More info in [Empowerment and self-organisation of drug users](#), Foundation Regenboog AMOC – Correlation Network, 2008 (see p. 48)



History of drug user organisations

You can read the main steps in the history of the drug user movement in *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008 (Chapter 4. p. 57)

You can also read an early history at the following publication soon available: Neil Hunt, Eliot Albert, Virginia Montañés, 'User involvement and user organising' in Rhodes, T. (ed.), 2009, *Harm Reduction: Evidence, Impacts and Challenges*, European Monitoring Centre for Drugs and Drug Addiction, Scientific Monograph Series No 10, Office for Official Publications of the European Communities, Luxembourg. Available soon. Chapter *Early history*.

About the DUO from the party scene, you can read *Safer Nightlife in Europe*, Thierry Charlois, Council of Europe COOP (2009) 4 (See chapter *Peer education and drug information*)

Example of drug user organisations across Europe

Auto-Support des Usagers de Drogues, France – <http://www.asud.org/>

Danish Drug Users' Union - <http://www.brugerforeningen.dk/>

Swedish Drug Users' Union - <http://www.svenskabrukarforeningen.se/>

Croatian Drug User Union - <http://www.uho.hr/>

Krakow association of substitution patients, Poland - <http://wyzwolenie.weebly.com/>

Bolton User Group Service, UK - <http://www.serviceusers.org/>

M.o.r.p.h, UK - <http://www.morph-uk.org/>

The Alliance, UK - <http://www.m-alliance.org.uk/index.html>

Drug Users RU, Russia - <http://www.drugusers.ru/>

Federación estatal de Asociaciones de Personas afectadas por las drogas y el VIH , Spain - <http://www.faudas.org/>

Landelijk Steunpunt Druggebruikers, The Netherland - <http://www.lsd.nl/>

Community-based organisations

A part from the strictly drug user organisations (DUO), community-based organisations are also places for drug user empowerment. Two different situations are observed regarding community-based organisations:

- The organisations in which drug users and professionals are equal partners. This is the case of the **MDHG**, the Medical-social service for heroin users, initiated in 1977 in Amsterdam and gathering drug users, parents of drug users, social workers and other interested people;
- The organisations in which people are from the same community. This is the case of the organisations issued from the party scenes in which members identify themselves first as sharing the same musical and cultural movement before becoming drug users.



Example of safer nightlife peer projects across Europe

- Technoplus (Paris)** – <http://www.technoplus.org>
- Keep Smiling (Lyon)** - <http://www.keep-smiling.com>
- Le Tipi (Marseille)** - <http://www.letipi.org>
- Prev'En Teuf (Louvier, FR)** - <http://www.preventeuf.org>
- Spiritek (Lille)** - <http://spiritek.free.fr>
- Energy Control (Barcelona)** - <http://www.energycontrol.org>
- Modus Fiesta (Brussels)** - <http://www.modusvivendi-be.org/modusfiesta>
- Raid Blue (French-speaking Switzerland)** - <http://www.raidblue.ch>
- Crew 2000 (Edinburgh)** - <http://www.crew2000.co.uk>
- Drogart (Ljubljana)** - <http://www.drogart.org>
- Drug scouts (Leipzig)** - <http://www.drugscouts.de>
- Eve & Rave (Berlin, Zurich)** - <http://www.eve-rave.net>
- Eclipse (Berlin)** - <http://www.eclipse-online.de>
- Party project (Breme)** - <http://www.party-project.de>
- Unity (Amsterdam)** - <http://www.unitydrugs.nl>
- Blue Point (Hungary)** – <http://www.kekpont.hu>
- CheckIt! (Vienna)** - <http://w3.checkyourdrugs.net/checkyoursite/index.html>
- Check In (Oporto)** - <http://www.apdes.net/> (see Unit 1)

Priorities and activities

According to a research conducted in 2007 by INPUD and the *Correlation Network*, the main priorities and activities of the drug user organisations are:

- advocacy and health/drug policy making;
- raising public awareness about the main problems in the drug user community;
- peer support for drug users and people living with HIV/AIDS;
- HIV education and prevention;
- producing e- and printed magazines and newsletters as well as other types of informational materials;
- organizing, conducting, moderating training sessions, workshops, seminars, peer meetings;
- educational and peer support work in the party scene;
- running accommodation projects;
- drop-in centres with various services;

More info in *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008 (Chapter 7. p. 117)

Strengths and weaknesses

From the point of view of a city, the main strengths of DUO or community-based organisations are their high level of empowerment and their legitimacy to represent efficiently drug users in a local and integrated partnership. In terms of empowerment, some of the DUO members have become professionals and so are available and look as credible in relation to the other partners.



Drug services and drug user involvement

Deciding to work with the resources a client has to offer and not just the “pathology” that has brought them to the drug services, is a choice that hardly needs mentioning and that today concerns a consistent minority of professionals¹.

How is the drug user involvement initiated?

The drug user involvement can start from different experiences such as «mixed groups» or spontaneous client groups.

More info in *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008 (Chapter 3.3. p. 47)

How to involve drug users?

Focus groups

A focus group is a form of qualitative research, in which a group of drug users are asked about their practices, their needs, their opinions, etc.

More info in *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008 (Chapter 5. p. 66)

Drug user Council

A user council is a democratic forum where users and staff and/or management within a treatment institution can work together to discuss and make decisions on various factors concerning treatment. More info in *Nr 49 Drug Users and Spaces for Legitimate Action*, Eds. Jørgen Anker, Vibeke Asmussen, Petra Kouvonon & Dolf Tops, Nordic Centre for Alcohol and Drug Research (see. chapter *On Whose Terms* p. 4)

Peer intervention

The peer approach is a broad definition that includes all interactive education strategies through peer-led groups.

More info at <http://www.emcdda.europa.eu/html.cfm/index10872EN.html>

¹ *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008



Cities supporting drug user empowerment and involvement

The involvement of drug users is critical in reaching the hidden population of users because they already have access to that world. More info in *Drug use, front line services and local policies - Guidelines for elected officials at the local level*, Anne Coppel, European Forum for Urban Safety, 2008 (see chapter 3.4. page 26)

Some experiences of cities initiating and supporting the development of drug user organisations (DUO) have been identified. Generally it aims at:

- getting representatives of drug users into local partnerships led by the cities (i.e. in the Dutch cities);
- Improving access and quality of the services;
- Developing prevention in recreational settings (i.e. Paris or Barcelona).

This support can be done either directly by providing funding, premises, training, etc. or indirectly through umbrella organisations. More info in *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008 (Chapter 3.4. p. 51)

Cities also initiate and support drug user involvement within the local services. This can be done by providing funding, organising training and practice sharing between drug services.

Read the Scottish Drug Forum experience of the developing a Drug user involvement model among several drug services in *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008 (Chapter 6. p. 95)



The participation of drug users in partnership-based local drug policies

Why cities improve drug user participation?

Integrated local drug policies bring institutions and organisations involved in reducing local drug problems together at one table to discuss the drug related problems in communities and their possible solutions. *Any authority that is making decisions or shaping services which affect drug users' lives can introduce policies that promote or require the meaningful involvement of drug users at all relevant points i.e. from the very beginning of planning, through to monitoring and evaluation².*

How to manage the drug user participation?

Different means of drug user participation have been identified among European cities:

- by inviting a local drug user organization (DUO) into the partnership;
- by inviting a national DUO or a local DUO from another city as experts. It is also possible to invite experts from a European drug user network (see chapter p. 22);
- by consulting or including in the partnership services involving drug users. Drug services are concerned but also other social and health services.

More info about the management of drug user participation in *Drug use, front line services and local policies - Guidelines for elected officials at the local level*, Anne Coppel, European Forum for Urban Safety, 2008 (see chapter 3.4. page 26)

² Neil Hunt, Eliot Albert, Virginia Montañés, 'User involvement and user organising' in Rhodes, T. (ed.), 2009, *Harm Reduction: Evidence, Impacts and Challenges*, European Monitoring Centre for Drugs and Drug Addiction, Scientific Monograph Series No 10, Office for Official Publications of the European Communities, Luxembourg.



European networks related to drug users' participation

International drug user networks are linked to the international HIV/AIDS and harm reduction networks. They are also linked to the anti-prohibitionist movement.

The International Network of People Using Drugs (INPUD)

INPUD was created in 2006 at the time of an [International Harm Reduction Conference](#) and is supported by the International Harm Reduction Association ([IHRA](#)). This is a network of individuals and organisations.

The INPUD activities are:

- ⊙ International advocacy for drug users' rights; Influence on regulation;
- ⊙ Promotion of harm reduction services and treatments adapted to the drug users' needs.

INPUD works with UN bodies such as [UNAIDS](#) and [UNODC](#) as well as the [EU Civil Society Forum on Drugs](#) (in this case through harm reduction networks) and the [International Drug Policy Consortium](#).

Basics Network “for dance culture and drug awareness”

Founded in 1998, the [Basics Network](#) gathers peer projects issued from party scenes among 12 European countries. Since 2005, the Basics Network has been leading a working group on safer nightlife in the framework of the [Democracy, Cities & Drugs](#) projects (DC&D).

Correlation, a “European Network for social Inclusion & Health”

The [Correlation network](#) develops projects funded by the [European Public Health Programme](#) with the aim of improving the access to services for the marginalized and excluded people. In the framework of the Correlation II project (2009-2012), an expert group called “peers support” aims to improve Peer Education (HIV & HCV).

The International Harm Reduction Association

[IHRA](#) is the leading organisation in promoting evidence based harm reduction policies and practices on a global basis for all psychoactive substances. It seeks to involve drug users in its meetings and processes and has provided opportunities for drug users to network internationally.

The European Coalition for Just and Effective Drug Policies (ENCOD)

[ENCOD](#) is a platform founded in 1993 by European citizens affected and/or concerned by the current international war on drugs. ENCOD members unite representatives of drug consumers, their relatives, health workers, experts, entrepreneurs and activists from the whole of Europe.



Drug users' participation and policies at the EU level

The EU Drug Policy

The [EU Drug Strategy 2005-2012](#) and the [EU Drug Action Plan 2009-2012](#) invites the member states to improve access to the services, to develop alliance between citizens and institutions but there is no reference to drug user empowerment and involvement.

However, the [Council Recommendation of 18 June 2003 on the prevention and reduction of health-related harm associated with drug dependence](#) invites member states to “*encourage, when appropriate, the involvement of, and promote training for, peers and volunteers in outreach work, including measures to reduce drug-related deaths, first aid and early involvement of the emergency services*”.

There is no drug user organisation among the members of the [EU Civil Society Forum on Drugs](#) but drug users are represented through the [ENCOD](#), the [Correlation Network](#) and the member organisations from the harm reduction field: The [IHRA](#), the [Eurasian Harm Reduction Association](#) and the [French](#) and [Romanian](#) harm reduction associations.

The EU Programmes

The [Work Plan 2009](#) of the [EU Public Health Programme](#) gives priority to projects *developing, implementing and evaluating drug demand reduction activities* but there is no focus on drug user involvement or empowerment.

However, this programme has supported some projects in this field, as for example:

- ⊙ 1996: *The European Peer Support Project: Encouragement, development and support of peer support aiming at harm reduction in IVDU communities. Dutch National Institute for Alcohol and Drugs.*
- ⊙ 2001-2002: *European strategy by the peer education associations within the Techno movement for harm reduction in consumption of synthetic drugs linked with the Techno/House scene (BASICS network)*
- ⊙ 2005-2008: *Promoting health and prevent disease through addressing health determinants across all policies and activities (Correlation Network)*
- ⊙ 2006-2009: *PEER - education-project for young drivers to prevent alcohol and drugs in connection with road use - Drive Clean!*

There is no reference to drug user involvement and empowerment in the [Drug Prevention and Information Programme](#) but in 2009 an application was submitted by the IHRA in which INPUD intends to create a European drug user network.



Conclusions

The *World Health Organization (WHO)* has more than once affirmed the importance for achieving changes – in particular regarding a series of questions where health issues are grounded in social problems – by working simultaneously on three aspects:

- *lifestyles of individuals or groups;*
- *the environmental context that induces this;*
- *and the current health and social system.*

The work of peer support, activation and self-help between users, meet at the crossroads of the three areas for change identified as strategic by the WHO:

- *There is the “community” that learns to protect itself, to produce behaviour change and self-propose a lifestyle that is safer and compatible with social integration.*
- *There is the “initiative group” that tries to have impact through a different social representation of the problems surrounding drug use in terms of the environmental context.*
- *Finally, there is the “peer-operator” who has influence regarding better access and relevance to needs from the specific socio-health services, modifying work methods and organization³.*

European cities have demonstrated that they can play an important role to support these changes:

- by helping drug user organisations;
- by promoting drug user involvement in the services;
- by including drug users within the local and integrated drug policies.

Finally, the European cities get the opportunities to improve their responses in this field by sharing practices with and using expertise from existing related European networks.

³ *Empowerment and self-organisation of drug users*, Foundation Regenboog AMOC – Correlation Network, 2008