



Empowerment and Self - Organisations of Drug Users

Experiences and lessons learnt

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Colophon

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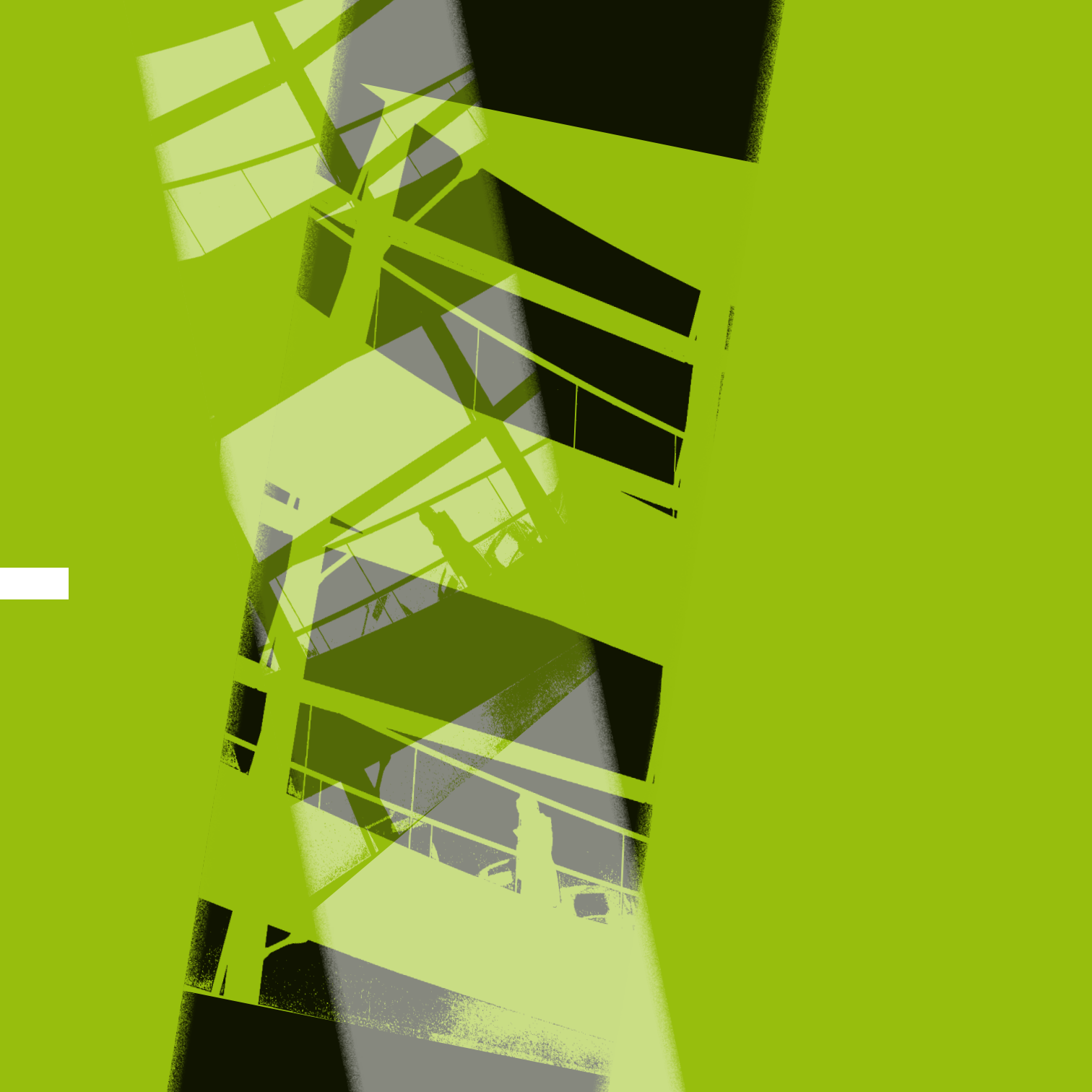
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1.

Executive summary

This reader has been compiled in the framework of Correlation - European Network Social Inclusion & Health. Correlation is based at the Foundation De Regenboog AMOC in Amsterdam and is financed – among others – by the European Commission. In its 2005-2007 working plan, Correlation implemented various expert groups, relevant to the issue of health and social inclusion. Those working groups exchanged knowledge, experiences and views; the working group members gathered and shared information and working methods that were expected to be valuable for colleagues all over Europe working in this field. This reader focuses in particular on issues around **empowerment**, in particular in the area of intravenous drug use (IDU). For the entire work plan and the other Correlation working groups, please see www.correlation-net.org.

The first section of the reader by Jørgen Anker et al. gives a comprehensive overview over drug user self-organisation, with a special focus on the Nordic European countries. The authors look into the history of the drug user movement, relating it to the similarities

and differences with broader social movements, in particular as far as changing policies is concerned. They also analyse, why different countries respond in different ways to the phenomenon of drug use, and in which way different policies have an impact on the formation of drug user self-help organisations. The relationship between (the ideology) of welfare states and empowerment/participation and questions around governmental – non-governmental collaboration are highlighted as well. According to the authors, the patterns of drug use – and how these are perceived in society – influence the extent and form of drug user self-organisation. In the area of (national) drug policies, the availability of services, such as methadone treatment, can be considered supportive for the participation and empowerment of drug users. Finally, the authors explore ideological and moral aspects that are reflected in terminologies regarding and attitudes towards drug users and that have an impact on opportunities for empowerment. They conclude that “... institutional contexts, national drug policies, patterns of drug use and dominant ideological and moral perceptions of drug use all contribute to the existence and survival of user organisations.”

The second section of the reader – an article of Leopoldo Grosso from Gruppo Abele in Italy – provides some models of good practice of empowerment in the area of IDU. The author looks into the opportunities that are created if and when drug users get involved, for instance in the area of peer support, and become an ‘active minority’. A positive impact can be achieved regarding personal change (from better knowledge to adjustment of attitudes and behaviour), regarding normalisation of drug use (by challenging stereotypes) and, finally, regarding the modification of services (by expressing and formulating clients’ needs from the angle of their own experiences).

The author identifies various forms of user organisations: a. Users self-made groups that are often created spontaneously and characterised by a high level of independency from services, developing pioneer work, mostly at the local level; b. Spontaneous client groups, which are related to some form of organisation, e.g. therapeutic programmes, but which develop their own agenda on certain issues to improve their situation; c. “Greenhouse” groups that are closely linked to drug services and where drug users, professionals and volunteers are involved jointly and on equal terms. Umbrella organisations – both nationally and internationally – can play an important role to support user organisations, and as far as service providers are concerned, the author pleads for genuine partnership between the actors involved. Finally, a summary of today’s priorities for successful empowerment strategies is presented in the article.

In the third section of the reader, Theo van Dam, an IDU activist from the Netherlands, summarises the main steps in the history of the drug user movement. Starting with the first services in the Netherlands in the 1970s, which were crucial for changes in the picturing of and attitudes towards drug users, he describes the development of comparable initiatives in other European countries. The focus on social acceptance and de-criminalisation was an important aspect of the drug user movement, as was the emergence of the AIDS crisis and its impact on IDUs.

The author looks into the situation in countries, where the history of self-organisation is more recent, such as in some Southern or Eastern European countries. The International Drug User Day has emerged as an important forum for bringing together a variety of groups and experts – from IDUs to social workers and police forces. Finally, the author pleads for a strong international drug user movement, which will be in charge of developing and implementing its own agenda.

The fourth section of the reader pays attention to the method of focus groups and its potential in the area of empowerment. After a brief review of the rationale of focus groups, this section contains reports from focus group sessions that were organised in various European countries in the framework of the Correlation network. In five countries – France, Sweden, the Netherlands, Italy and Norway – drug services hosted focus groups, in order to discuss empowerment issues and investigate attitudes towards drug users' rights with regards to dignity and respect, availability of information, and treatment, as well as the regulation/normalisation of drug use. Focus groups were attended by both service providers and service users.

A brief overview provides information about the procedures of organising the focus group sessions in the different countries. Conclusions are made about the separate focus groups and about the focus group methodology in general. Finally, some suggestions for further reading are included in this section for those who are interested in implementing focus groups.

The fifth section of the reader is a contribution from the Scottish Drugs Forum (SDF). The authors describe their experiences with and some concrete examples of user involvement. They stress the value of user involvement for getting information about the needs and behaviors of drug users, for the improvement of services and for changing public attitudes

regarding drug users. With the involvement of peer research, the SDF conducted a survey in the area of Hepatitis C prevention, contributed to a multi-agency inspection and obtained insight in barriers to training and employment for drug users. The article pays special attention to the recruitment of peer workers and describes the various activities that peer workers carry out.

Finally, in the sixth section of the reader, Stijn Goossens from the Belgian NGO *INPUD* summarises the results of an online research about drug user activism. The research looked into the respondents' main priorities, activities and services with the aim to create a database on existing services, to map their areas of work and to investigate opportunities for international cooperation. Based on the responses, the author concludes that activist organisations operate in a broad variety of fields, notably in the areas of advocacy/policy development and health promotion/harm reduction. Further, he suggests that drug user organisations are valuable partners not only for service providers, but also for civil society in general.



2.

Drug Users and Spaces for Legitimate Action¹

Jørgen Anker, Vibeke Asmussen, Petra Kouvonon, Dolf Tops

We are people from around the world who use drugs. We are people who have been marginalized and discriminated against; we have been killed, harmed unnecessarily, put in jail, depicted as evil, and stereotyped as dangerous and disposable. Now it is time to raise our voices as citizens, establish our rights and reclaim the right to be our own spokespersons striving for self-representation and self-empowerment. (Statement by The International Activists who use drugs 30 April 2006, Vancouver, Canada)

In our society it is very rare that people who use opiates, cocaine and amphetamine or any combination of these and other substances are invited to speak up and play an active role in the formulation of policies and practices in the drug field. On the contrary, drug users are often treated as second-rate citizens; not as subjects with rights, a voice and an identity, but rather as passive recipients or objects of help or measures of control, punishment and discipline.

¹ This article is an edited version of the introduction for the publication "Drug Users and Spaces for Legitimate Action", 2006, Nordic Centre for Alcohol and Drug Research, Finland

Drug users obviously do not speak with one voice. In fact, they are a very diverse group of people who are defined by one shared practice: their use of substances, which are currently defined as illegal and dangerous. Apart from being involved in a practice that is illegal, drug users vary in terms of age, sex, class, ethnic origin, place of residence, source of income, etc. Obviously, there are also characteristics that users share in common – the most basic of these being that drug users by definition are regarded as criminals because they use illegal substances. But many drug users also share the common fate of a rather miserable life on the margins of society. On the other hand there are also many users who do not live in misery, but who have permanent housing and a steady job.

The group of people concerned are described using a number of different terms: drug addicts, drug abusers, problem drug users, users of hard drugs, recreational drug users, active drug users, people who use illegal drugs, etc. These terms also carry with them different kinds of moral judgements, ranging from the derogative drug addict or junkie at one extreme of the continuum to 'people who use illegal drugs', at the other. The latter is the term that is currently preferred by activists in the field.

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 have been 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. Representing active drug users, the aim of these organisations is to raise issues where the situation of drug users is considered unacceptable in relation to treatment systems, control policies or the criminal justice system, for example. In this sense the organisations serve as interest organisations and a mouthpiece for active drug users.

It is a guiding assumption that user organisations and the patterns of participation they provide for have to be understood and studied in close relation to the social, cultural and political context in which they emerge.

2.1. Drug User Organisations: A Social Movement in Formation?

Some of the terms used to describe associations and organisations in this area include user organisations, client organisations, self-help organisations, patient groups, interest organisations, voluntary organisations, and social movement organisations. Indeed this field is characterised by great diversity. At the same time, though, the wide range of terms also indicates that a number of different analytical approaches are possible. We suggest that many of the organisations described here indeed have a certain family resemblance (Wittgenstein 1953) with phenomena that often are referred to as social movements (calling attention to groups, questions, values and rights of minorities that are often ignored or repressed by society). At the same time, however, the concept of social movement may be misleading if it is used in its traditional sense, i.e. as broad collective action that challenges existing relations of power – which is how the concept has been used in the empirical analysis of peace movements, labour unions, women's rights movements, or civil rights movements.

The organisations described here are often much more introvert, defensive and vulnerable than the powerful collective actors that are traditionally described as social movements. Nonetheless they may still be important to the participants themselves, to policy makers, and to the general development of drug policies and drug users' living conditions in the future. Indeed the associations discussed and described here, seen individually as single cases in their respective national political contexts, appear weak, fragmented and marginalised. However the picture is very different if we look at them not as separate and isolated national phenomena, but rather as part of a broader transnational current. The idea of movement becomes more relevant when the minor associations are considered as part of a more widespread trend that seeks to address, question and even challenge the conditions and policies that define and structure drug users' lives. In this way, some of the associations may be seen as being related to and stimulated by the emergence of an international harm reduction movement that challenges the hegemony of the discourse of a drug-free society (Bluthenthal 1998; Wieloch 2002; Tammi 2005).

One argument for this unified view on drug user organisations is that they tend to copy 'repertoires of contention' (Tilly 2002), applying similar forms of action to gain attention to their problems. For instance, drug user organisations in the Netherlands, Denmark, Norway and Sweden have copied the idea of awarding a prize to someone who has made a particular effort to help drug users in the field (Tops 2006; Anker 2006) The different

organisations also tend to support one another, and the Danish Drug Users' Union has directly supported the formation of drug user associations of similar ideological persuasion in both Norway and Sweden. Furthermore, there have been serious attempts to form and strengthen international networks and cooperation between associations of active drug users. Thus, at the annual International Conference on Drug Related Harms in Vancouver on April 30 – May 4, 2006, representatives of user organisations from all over the world gathered in a special session to agree on a common statement and to discuss ways of stepping up their collaboration.

Finally, some of the organisations are members of international networks and organisations that are committed to promoting harm reduction measures or the downgrading of control policies. While we must not overestimate the extent and weight of this cooperation, and indeed activists themselves tend to look upon their organisations primarily as national or local efforts, it is interesting that the phenomenon definitely is in evidence in many countries around the world, and that in many others it is only just beginning to unfold. All social movements develop through certain phases: they usually start as minor, more or less invisible units or networks, and gradually gather momentum. This was also true in the case of the movements mentioned above (Calhoun 1993). Our argument is not that these groups and associations are social movements proper; we acknowledge and emphasise that individual organisations should not be misinterpreted as social movements (Eyerman & Jamison 1991).

We find that each organisation may be analysed through the lens of social movement theory, and to underline this, we suggest that drug users' associations can be seen as 'social movement organisations' (Zald & McCarthy 1987). Social movement organisations are singular organisations that form part of a broader social movement. The purpose of applying this term is to signal that the associations concerned are basically 'just' normal interest organisations when studied individually. At the same time, though, they appear to form part of something bigger, and they address a specific conflict in society. They strive to gain recognition for the rights of a particular group of people and to gain influence over and to change current drug policies. In other words, even though they each apply rather pragmatic and non-confrontational strategies (with the exception of the Dutch organisation), their broader and collective aim is to change existing power relations and structures – and in this sense they may be seen as social movements in formation. We therefore use the concept of social movement organisations to describe these associations that are aimed

at changing local or national drug policies and that are – or claim to be – either organised by or work for their constituency.

2.2. Understanding User Organisations and User Participation

User participation and user associations are rather different in nature and deal with the issue of participation and interest representation in many different ways.. When examining these differences we gain very useful and important insights into the various dominant perceptions of user participation and user association in different national contexts. Even though the organisations share many similarities in common, the articles clearly reveal how sharply the ideas of drug user organisation differ in Sweden and Norway from those in Denmark and the Netherlands, and that in Finland drug user organisation is still very much in its infancy.

But how should these differences be interpreted? Is it possible to explain why user participation and association assume so very different forms in countries that in cultural, social and political terms are so closely connected? The following sections aim to provide a provisional outline of some of the features that appear to influence the landscape, opportunities and constraints of drug user organisations and participation. This, we hope, will help to pave the way to new and more focused comparative studies of user organisation and participation in which the relationship to national and international drug policies can be explored in more depth.

Theories of social movements are generally concerned to understand and explain why movements emerge and how they are organised, how they interact with other actors in their respective field and why some movements succeed while others fail. One line of social movement theory points at the importance of the resources of social movement organisations (Zald & McCarthy 1987), other theories emphasise the significance of political opportunities and political processes (Tarrow 1994; McAdam, McCarthy & Zald 1996), others still emphasise the processes of forming collective identities and the discursive struggles in which movements are engaged (Melucci 1996; Johnston & Noakes 2005). These different theoretical leanings each contain important analytical clues as to how the differences between drug users organisations in the countries included here are

understood. We do not propose to offer a full-blown theoretical argument that gives full credit to the different theoretical stances.

Instead, on a very eclectic and provisional basis, we present the dimensions that appear to be important in the case of drug user organisations. In other words, drawing on the thinking of social movement theory, we are aware of the importance of resources, opportunities, openings and constraints and we seek to take both institutional and discursive elements into consideration. The field in which the organisations and opportunities for participation are located, is absolutely crucial to the type of organisation and the kind of action that is possible. Moreover, it influences the type of collective unity and self-understanding that is created among drug users. In the same way as the organisation of labour structures the self-understanding, the action repertoire, and the fate of the labour movement, the trends of drug use, the organisation of services for drug users, and spaces of interaction among drug users are extremely important to drug user organisations and to drug users' participation. Following from this, Rucht (1996) applies the concept of context structure to the analysis of social movements. Context structure includes ecological elements, i.e. conditions external to a given movement.

The most crucial contextual dimensions are the cultural, social and political. Seeking to translate these dimensions into more specific empirical categories, we suggest that the three main aspects that should be taken into consideration when examining and explaining drug users' struggles for legitimacy are the dominant ideological and moral perceptions of drug use, the institutional contexts and patterns of drug use. We elaborate on these dimensions below.

2.3. Institutional Patterns: Inclusive Welfare States – Excluding Practices

Drug user organisation and drug user participation in the Nordic welfare state is characterised by a number of odd constellations and contradictions. On the one hand, a number of institutional and cultural practices provide opportunities for drug users. On the other hand, specific institutional practices and some overarching ideological and moral schemes tend to limit or remove the legitimacy of drug user organisation and participation.

Moreover, the situation varies in the different countries, as will be discussed in more detail further on. First, a few comments on the nature of the welfare system. From an international perspective it is important to emphasise that the Nordic welfare states as well as the Netherlands both provide a minimum level of social security to all their citizens. Even so, users of illegal substances often live a miserable life in poor conditions. However the existence of a public social safety net means that drug users, at least in principle, are guaranteed the satisfaction of their most basic human needs.

An illustrative example of the welfare system's role as a source of income is that many activists in the Danish Drug Users' Union receive early retirement benefits rather than social benefits. As their primary material needs are met, this provides, at least in theory, an opportunity for them to engage in organisational activities, such as in user organisations. The existence of a social security system in other words ensures that the energies of drug users may be channelled into activities that are not entirely a matter of physical survival. A number of specific restrictions are occasionally applied to the group of drug users, however. In Sweden, for example, there are requirements of remaining drug free for a certain period of time in order to qualify for different kinds of assistance (e.g. housing benefits).

Differences of this kind between the countries are related to the moral and ideological regimes, which dominate drug policies. Moreover, they may also either facilitate or hamper drug users' organisation and participation. The Nordic welfare state system leans heavily on Social Democratic ideologies. However, welfare states today are exposed to mounting pressures as a result of the challenges of globalisation, new demographic patterns, and growing neo-liberal ideologies. These trends are also felt in the field of drug user organisation and participation, where practices of social work as well as client categories are gradually changing. Stenius (2006), who has studied the citizenship and rights of substance users in Finland and Sweden, asks how two countries with extensive treatment systems for alcohol and drug problems both continue to have a group of substance users that is socially marginalised, in terms of weak social networks, poor housing and exclusion from the workforce? She concludes that both countries have changed into a society that no longer is able to provide work for all its citizens. Instead, a minimum normative goal is to produce independent consumers of goods and services, whose incomes also may derive from the welfare system. In practice, however, several aspects, such as legislation and the role assumed by the state, impacts the extent to which basic human needs are met.

One important aspect that needs to be addressed when discussing drug users' spaces for legitimate action is the shift in social political concepts from 'client' to 'consumer' (or 'user', as is the English translation of the Danish 'bruger', the Swedish 'brukar', and Norwegian 'bruker', Finnish 'asiakas'). Welfare policies in general and social policies in particular have been influenced since the 1990s by neo-liberal currents, new public management schemes and ideas of empowerment, which also lie behind the new understanding of citizens as 'users' (in the sense of consumers) of welfare institutions such as treatment systems, social security, hospitals, etc. (Asmussen 2003; Asmussen & Jöhncke 2004; Bjerge 2005). In short, this social policy discourse is based on ideas of user 'empowerment' and active 'participation'. In this understanding, citizens are offered a greater degree of freedom, but also expected to assume greater responsibility for managing their own life. The state, in this model, is responsible for providing efficient and targeted services for users, and user participation is one of the means for improving the effectiveness and efficiency of services. In other words the Nordic social policy context – somehow through the back door – advocates ideas and a rhetorical frame that enable drug users legitimately to promote their wishes and to claim their right to substitution treatment, for example. The social policy context has so to speak invited drug users into an exchange on the question of how to deal with drugs in society. In Denmark, the Ministry of Social Affairs has consistently provided economic support for organisations for drug users and homeless people since the mid- 1990s. Nonetheless there are still critical voices which suggest that user participation can also be seen as a particular form of control.

The Nordic welfare states and the Netherlands have long traditions of involving organised interests in the drafting of legislation and major reforms. Corporatism was gradually established in the 20th century, enabling labour market organisations to gain significant influence in the development of the welfare state. Voluntary organisations have also traditionally held a relatively strong position and degree of legitimacy in the Nordic countries, where they serve as claims makers and service providers in specific areas of the social welfare system, especially in the alcohol and treatment system (Stenius 1999). Compared to the Netherlands, however, voluntary organisations here play a minor role in the central fields of the social welfare system. In the Netherlands, with its strong liberal tradition, drug treatment facilities are almost entirely provided by NGOs.

In the Nordic countries the main responsibility for the provision of medical treatment rests with the public authorities at central government, county or municipal level. Nonetheless

NGOs and private foundations are still important suppliers of other forms of treatment. Even though these organisations are not officially part of the state apparatus, they work closely with the public system and depend heavily on public funding. As far as drug user organisations are concerned, this is something of a dilemma because these organisations are dependent on the authorities, which at once constitute a target for the organisations' actions. This implies a difficult balancing act and the organisations risk becoming co-opted by and adapted to the political structures to such a degree that they eventually lose their room for manoeuvre (Laanemets 2006).

However, even though the tradition of corporatism has been said to clearly favour a particular kind of interests (Hernes 1987), it also gives rise to a particular administrative and democratic practice in which organised interests are given a legitimate right to have a say in public inquiries. Johnson (2006) argues that drug user organisations have in fact had only very limited influence on Swedish drug policy, a trend that has continued (or worsened) with the further reinforcement of control policies. In his opinion, the emergence of the Swedish Users' Union is not an outcome of increased openness or better opportunities for participation, but rather of neglect and limited opportunities for interest representation.

2.4. National Patterns of Drug Use

Another feature that influences drug users' opportunities for organisation and participation apart from the dominant ideological and moral perceptions of drug use and the institutional contexts, is the pattern of drug use. Specific practices and traditions of drug use – which are obviously linked to the nature of drug policies – provide the basic condition for users to identify shared interests related to drug use and representation in relation to the authorities and the surrounding society. Different trends and histories with respect to drug use and perceptions of drug use are crucial to understanding the emergence of user organisations and the specific demands placed on the services provided for drug users. The lack of organisations for active drug users may for instance in the case of Finland be explained by the absence of a 'tradition' of heroin use. It seems that the presence of particular treatment facilities can often support and promote the establishment of drug user organisations. The following outlines some of the recent trends in drug use and drug policy in Denmark, Finland, Norway, Sweden, and the Netherlands.

Together with the rest of Europe, the Nordic countries saw increased levels of drug use in the 1990s (EMCDDA 2005, 11–12). In all countries the fastest growing category seems to be represented by poly drug use, but some substance specific comments can nonetheless be made. In Denmark heroin is reported to be the primary drug for about 60 per cent of those seeking treatment (National report to the EMCDDA, Denmark 2004). Injecting heroin use has been going on in Denmark for several decades, and even though this is still the most prevalent form of use, smoking heroin has become increasingly common among those entering treatment. In Norway, too, drug users who seek treatment are primarily intravenous heroin users (National Report to the EMCDDA, Norway 2005), and again injecting heroin use has been going on for decades. In Finland and Sweden there is a long tradition of intravenous amphetamine use.

Until the 1990s opioid use was virtually non-existent in Finland. Recent estimates of problem drug use around the turn of the century put the proportion of amphetamine users at around 70–75 per cent (Partanen et al. 2001). Among those seeking treatment for injecting opioid use in 2004, 27 per cent sought treatment for buprenorphine use, and only 3 per cent for heroin use (Clients in Substance Abuse Treatment/Stakes, 2004). In Sweden large numbers of users who seek treatment are on amphetamines, but the figure for those using heroin is rising and is now at almost the same level as amphetamine use (National Report to the EMCDDA, Sweden 2003–2004). In the Netherlands, heroin has been regarded as the most problematic drug ever since its introduction on the black market in 1972, although since 1990 it has been accompanied by cocaine. In 2003, the number of heroin clients registered in ambulatory treatment showed a tendency to decrease, while the number of cocaine clients was on the increase. The proportion of amphetamine clients remained steady (VWS 2005).

There are organisations for active drug users, mainly heroin users, in the Netherlands, Denmark, Norway and Sweden. Finland has organisations that are run by relatives of drug users, but none run by active users themselves. In the past year or so, however, small groups of users have been forming. Against the background of the different drug trends and traditions in the Nordic countries it is hardly surprising that Finland did not have any such organisations until 2006.

As Tammi (2006) explains, it takes time for the necessary critical mass to form, and since it was not until the late 1990s that hard drug use really began to expand in Finland this is still a novel phenomenon. Furthermore, the mean age of drug users in Finland is lower

than in the other countries concerned. Young people with a relatively short ‘drug user career’ can therefore hardly be expected to have gained sufficient experience and political awareness of the drug field to perceive a need for collective action. Yet if we want to gain a more in-depth understanding of what facilitates or obstructs the emergence of drug user organisations, we cannot simply explore trends of drug use in isolation from the ideological and moral perceptions of drug use, which are largely reflected in national drug policies. Moreover, it appears that drug user organisations often tend to emerge in the wake of developments in the treatment system. The services and intentions of the treatment system tie in closely with the ideological and moral principles that lie behind national drug policies. In the next section, we first provide a short overview of the most salient features of national drug policies, and then return to the question of how the treatment system is connected to drug user organisations and participation.

2.5. National Drug Policies, Harm Reduction and Substitution Treatment

The Nordic countries are often said to represent a particular type of welfare state model (Esping-Andersen 1990). However, as far as drug and control policies as well as drug users’ opportunities for legitimate action and participation are concerned, there are certainly many differences between these countries (Hakkarainen, Laursen & Tigerstedt 1996; Christie & Bruun 1985). Drug policies consist of different domains (control, treatment and prevention) that often contradict one another, mainly since they are often based on different – and often contradictory – drug policy ideologies. Basically, a restrictive control policy is typically associated with ideas of abstinence and a drug-free society in the realms of treatment and prevention. A liberal control policy, on the other hand, fits more easily with ideas of harm reduction.

Norway and Sweden have traditionally had the most restrictive drug policies in the Nordic countries, pursuing ideas of a ‘drug-free society’. Harm reducing initiatives, then, have been virtually non-existent, at least until recently. Denmark, on the other hand, has until today had the most liberal drug policy, both with respect to its control policy and the existence of harm reducing initiatives alongside drug-free treatment. Finland differs from the rest of the field in the sense that up to the 1990s, it had only minor drug problems.

Officially, the goal was to prevent drug use and minimise the supply of drugs. The country's drug policy was mainly control-oriented. Minimal attention was given to the treatment of drug abuse (Hakkarainen & Tigerstedt 2005).

The Netherlands has no mechanisms in place to try and eliminate drug use, and the official policy for almost 20 years has been one of harm reduction. Instead, the main focus has been on the (wholesale) trade of hard drugs and cannabis (Tops 2001). In the 1990s all the Nordic countries (and indeed northern Europe more generally) saw changes in patterns of drug use as well as an increased public awareness of the serious consequences of problematic drug use. This prompted new responses to drug use and new directions in drug policy. Still, the main strategies vary according to the ideological climates and the political compromises reached in the respective countries.

Today, drug policies seem to be moving towards an increased focus on substitution treatment or 'medicalisation' even in those countries that traditionally have had a restrictive drug policy (Skretting 2006). At the same time, however, there are no signs in the Nordic countries of their intending to downgrade the control against drug users. In Finland, for instance, the policy has moved forward on a dual track of both increased control and increased harm reducing measures (Hakkarainen & Tigerstedt 2005). In the past 3–4 years Danish drug laws have also become more restrictive (Asmussen & Jepsen 2007). At the same time there is a strong tradition of methadone maintenance treatment. Recently a three-year methadone trial with extended psychosocial support was initiated as an alternative to a heroin trial. An important part of this trial was to integrate user participation in treatment facilities in order to empower drug users and encourage them to take part in their own treatment.

Asmussen (2006) discussed the different forms of user participation implemented in the trial and addresses the question as to how far these initiatives provide opportunities for drug user participation in their interaction with the treatment system. Norway has continued to pursue a restrictive drug policy and it is now moving towards a more lenient criminal policy. The increasing number of drug-related deaths in the 1990s meant that the country began to lean more towards a harm reducing drug policy. Substitution treatment is today an integral part of the treatment offered to drug users in Norway. Even Sweden, which has taken the most restrictive stance on medically-assisted treatment, introduced substitution treatment with buprenorphine in 1999.

The first initiatives to establish drug user organisations or organisations that speak up for active drug users often takes place within or in close connection with substitution treatment facilities. The organisations raise critical questions with respect to the treatment provided, for example the availability of substitution treatment in general, the control of supplementary use of illegal drugs, as well as other forms of control measures practised by the treatment institutions. In Norway the first user organisation MIG-96 started up in connection with the country's first methadone trial, with the aim of improving the quality and availability of methadone treatment in general (Brandsberg Willersrud & Olsen 2006). In Denmark, the Danish Drug Users' Union (DDUU) was established in 1993 following the closure of a popular activity centre for methadone users (Anker 2006). In Finland, the Association for Support of People with Opiate Addiction (ORT) campaigned between 1997 and 2003 to increase the availability of treatment for opiate addicts and generally to improve the quality of treatment.

The first user-driven organisation, Support for Substitution Treatment Association (KT), consisting of four clients of a substitution treatment clinic in Southern Helsinki, was established in 2004 (Tammi 2006). The Swedish Drug Users' Union was set up in 2002, and one of its main criticisms has been against the strict formula for substitution treatment in Sweden (Palm 2006). The first organisation for drug users in the Netherlands was established in Amsterdam in 1975. In its first year the organisation advocated an alternative 'user-friendly' treatment approach. Soon, however, it shifted its attention to campaigning for a change in the national drug policy on hard drugs, which was seen as the main cause for the problems encountered by drug users (Tops 2006).

Apparently, there is some kind of connection between the establishment of substitution treatment programmes and the emergence of drug user organisations; but how can this connection be explained? We suggest that the introduction of harm reduction initiatives in general, and substitution treatment programmes in particular, open up opportunities for organisation and user participation among drug users. First, in a situation where the aim of a drug-free society dominates and rules out any other pragmatic options, there is very little tolerance for and acceptance of alternative voices. In a context of control, repression and zero tolerance, drug users will have only very limited room to manoeuvre as long as they continue using drugs. This situation seems to have prevailed in Sweden for many years, and the only legitimate and visible mouthpiece for drug users have been organisations of former drug users or associations of relatives. There must be a certain acceptance of harm

reduction initiatives in order for drug user organisations to emerge.

In both Denmark and Finland, relatives of drug users and medical doctors have been important advocates for harm reduction initiatives and substitution treatment programmes. They have sought to document the need for substitution treatment, they have highlighted the right of drug users to receive treatment, and they have occasionally sought to change practices themselves, for example by providing methadone to drug users through acts of civil disobedience. These groups are important allies to drug user organisations, and they often appear to be important because of their ability to mobilise and channel resources (economic, skills, strategic considerations, influence, etc.) to groups of drug users, thus enabling the subsequent formation of organisations. Moreover, once established, substitution treatment programmes create a closer and more formalised relationship of interaction between 'the system' (authorities) and drug users.

A number of other user organisations that have emerged in relation to the social welfare system, are based on categories that from the outset were defined and invented by the system. These categories (e.g. psychiatric patients, the disabled, the elderly), after being subjected to the development of specific policies and services, have then slowly come to form the basis for acts of resistance and the formation of collective identities (Williams 1999). In other words, these categories – and the subsequent collective actors – are to a great extent created and structured by the system. Gubrium and Holstein (2001) have called the identities institutional selves. This, we contend, is also the case with drug user organisations. Most drug user organisations are directed towards different levels of authorities in the drug policy field, they define themselves and their actions in relation to the authorities, and it is also from the system that they seek recognition and legitimacy as collective actors. This process is enabled by the creation of substitution treatment programmes (Anker 2007).

Substitution treatment programmes create a shared space and a shared point of reference where drug users are expected to conform to the previously defined rules and requirements. Whereas life as a drug user, without any formal relationship to the system, does not necessarily bring drug users together, the rules, physical space and interaction with health and social workers involved in a substitution treatment programme become a shared experience and an opportunity to interact as a group with particular characteristics. In this way drug users feel they are confronting the same opponent, and thus also have an identifiable target for their claims.

Finally, substitution treatment programmes draw the drug issue closer to the medical discipline, converting as they do the drug use into a matter of illness rather than just a moral issue. In other words, substitution treatment programmes also help to afford the drug user the status (and rights) of a patient who is entitled to claim his or her rights, proper treatment, and recognition and respect as a human being. Drug users may still object to this perception of drug use as an illness, but our point is that the hegemony of moral judgements loose strength when drug users become more closely connected to the health system, as patients rather than as social outcasts.

2.6. Struggling for Legitimacy in a Climate of Ideological and Moral Condemnation

People addicted to drugs are a small minority, and the majority of people in society do not share their experiences. However the 'drug issue' has been regarded as a very serious social problem for many decades now, and in that respect it has been of great interest to society. For drug user organisations, the challenge is to frame the problems of their constituencies in such a way that they resonate with cultural patterns in the population and are easy to recognize. The way that drugs and drug problems are conceptualised in national drug policies depends closely on the choice of language in describing these problems.

An example is the Danish government's use of language in the recent publication *The Fight against Drugs - action plan against drug abuse* (2003). The use of 'fight' here resembles the American drug rhetoric of 'war on drugs'. The choice of 'drug abuse', then, implies a particular moral attitude towards drug use, including a sense of 'irresponsibility', 'weak personality', 'lack of self-discipline', 'lack of motivation', etc. Decades of liberal Danish drug policy have now given way to a more repressive policy – and at the same time to rhetoric traditionally used in connection with repressive drug policies.

Drug use in general is constructed and perceived as something negative and dangerous, not only to the individual concerned but also to society at large, and it seems extremely difficult to shrug off the negative image of drug user that follows from this understanding (Christie & Bruun 1985; Gossop 2000/1982, Reinerman & Levine 1997). Drugs have

become a powerful metaphor with (extremely) negative connotations. Drug addiction, drug abuse and even drug use are blamed for the worsening of – or even seen as synonymous with – different traits such as criminality, instability, untrustworthiness, violence, mendacity, a weak personality, bad temper, irresponsibility, etc. Such is the power of the metaphor that drug users are identified by society as people with particular traits, regardless of whether or not this is the case.

It is important to underline that drugs and drug use may have devastating, even fatal consequences. People get into serious problems by using drugs, and some drug users can in certain situations be identified with the traits described above. However it is important to recognize that the general perception of drug use is so pervaded by moral and ideological judgements that other perceptions of drug use have great difficulties gaining legitimacy. These negative and moralising attitudes may also hinder drug user participation. In an environment of control and moral condemnation, drug users will often hesitate to openly admit they are drug users. They therefore often lack spaces of legitimacy where they could take their first steps of organisation.

One of the aims of organisations for active drug users is to try and change the existing, denigrating perceptions. Stigmatisation and marginalisation are among the key issues addressed by these organisations. One of the different strategies applied by drug user organisations to fight stigmatisation and marginalisation is to use concepts that avoid negative connotations. Therefore, rather than talking about ‘drug abusers’, ‘drug addicts’ or ‘junkies’ (Denmark & Norway: ‘narkoman’, Sweden: ‘knarkare’, Finland: ‘narkkari’), which all carry the negative associations described above, most drug user organisations prefer the more neutral term ‘drug user’. Their rationale is that a change in language in the long run will bring about a change in meaning and hence a change in perceptions of drugs as well as drug use.

Besides strategies to overcome stigmatisation, another probably more immediate effort to alter the negative perceptions of drug users is by demonstrating their ability to run or participate in running an organisation, to take part in meetings, keep agreements, etc. A related question is whether drug user organisations should be organisations by or for drug users. If run solely by active drug users, they will be exposed to vulnerabilities due to the usually unstable lifestyle of drug users and the repression of drug policies. This is basically a matter of the constituency of drug user organisations and whether these consist of drug users who are still using illegal drugs or of former drug users.

2.7. Concluding comments

Different solutions are applied in order to overcome problems related to drug user organisations' constituency and strategies. The way that organisations are run seems to be in a constant state of flux and their strategies to be constantly re-negotiated. The issue of interest organisations' recognition and legitimacy is crucial, and an enormous amount of energy is invested in pursuing that legitimacy. On some occasions, drug users even compete with former drug users, with different groups all claiming to speak on behalf of all drug users.

In the process of gaining recognition, new organisations are founded at the same time as others are closed down,. The survival and success of drug user organisations is never a matter only of suitable strategies, but merely an indication of how the messages articulated are heard and interpreted in a certain place and at a certain time. Therefore, as discussed above, the impact of the institutional contexts, national drug policies, patterns of drug use and dominant ideological and moral perceptions of drug use all contribute to the existence and survival of user organisations. The emergence of user organisations in the Nordic countries during the past decade also show that these are no isolated events, but part of a broader movement and network.

Networks and what Melucci (1996) has called the invisible phases of social movements are crucial to the development and understanding of social movements. They provide the necessary foundation for meaning work, and they are basically a prerequisite for the mobilisation of resources and for the creation of shared understandings of aims and strategies. So perhaps the fragmented initiatives of association and user participation – the efforts of the more or less invisible networks – that we are witnessing today, may prove to be an initial phase of a broader organisation and self-awareness among marginalised groups of the welfare society?

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3.

Empowerment – Models of good practice: Heroin use and peer support What lessons have been learnt?

Leopoldo Grosso, Gruppo Abele

Twenty years of harm reduction practices in Europe have already passed since the mid-1980's, a consequence of the connection between HIV infection and the intravenous use of heroin.

What lessons have been learnt, in particular with respect to the empowerment of users, considered one of the most important and also one of the most delicate and controversial tools of harm reduction? More specifically, in what terms has the active role of the user managed to play the part of essential resource for

1. a) the assumption of self-protective behaviours of use
2. b) advocacy for their rights
3. c) the direct management or co-management of certain services for drug users?

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 organization.

The mechanism activated by peer support is that of research-intervention. The actions produced in interaction with the surrounding environment determine the acquisition of new knowledge. This is translated into new work practices that in turn re-interact with the social context and on services.

3.1. The role of the active minority

The first lesson learnt concerns the crucial role interpreted by the active minority in terms of change. The data identified through social research, that quantifies 2.6% of the general population as the number of people willing to involve themselves objectively for a more general purpose, is also valid for peer support amongst injecting heroin users.

At first glance, this percentage appears very low and could be discouraging and depressing. However, seen through the eyes of a social epidemiologist, it is not to be ignored. According to figures provided annually by EMCCDA the problematic use of heroin involves less than 1% of the population in Europe, which means a total of a few million people, spread out across the States of the Union today.

If it is with these numeric dimensions that the phenomenon of problematic drug use is depicted, then it is hugely amplified at a symbolic level. Drug addiction is linked to questions of public safety and plays the role of scapegoat in the exploitation of fear during political debates.

In a population of a few million consumers in Europe, even allowing for some excess in the 2.6% calculation due to the specific difficulties connected to the problems of heroin use that can cause further preclusions from participation, it still signifies thousands of consumers that can be activated as protagonists for social change regarding this phenomenon. These can act as users, as ex-users, as clients who use health services or those who don't, as activists, volunteers, or peer-operators. Their personal involvement and their contribution represent a social capital that is either unrecognised or totally underestimated but which however is worth counting on

The effort spent in these years in harm reduction programmes and strategies - first in some northern European countries and then in others in the south and now the east - has demonstrated that involving users, even problematic users, is a realistic objective. The process of activation comes about in many varied and diverse ways, due to the cultural specificities of each national cultural reality. This in turn is influenced by important variables that can be placed along a continuum that goes from the types of legislation to the significance of social stigmatisation in each country, to the types of use and the lifestyles of the consumers. It also includes the personal history and background of each user.

However, what best unites the experiences of empowerment in peer support between problematic heroin users is the trajectory of the life experienced: from the phenomenon and the marginalized practices of a stigmatised group to becoming resources for the local community; from unsatisfied and quarrelling clients to integral partners in a social and cultural movement.

3.2 The multiform nature of the results of peer support work

The results achieved from peer support work have gone beyond the effects expected, leading to surprises compared to initial expectations. Above all, this is because they have reversed, like the many rivulets of a waterfall, with respect to differentiated needs, deviating with different effects on various levels: personal, social, health, cultural, political.

The level of acquired knowledge is widespread with respect to risks and harm associated with certain drug practices, and the determination put into action by the active minority of users, have had strong effects both in terms of the social representation of problems of dependency and with the organization of services.

It may be useful to recall the different areas where results have been achieved:

a) Personal change

Change can occur in terms of a more prudent mode of consumption, the self-limitation of episodes of abuse, the avoidance of risks of infection, but also a major attention to the legality of one's own behaviour, an improvement in relationships with health and social services, an increase in the motivations for change and initial and partial changes in lifestyle. Some of all of these, or a little of each one, translates into greater stabilization of user behaviours and lifestyle habits of people, that render them or re-render them compatible with heroin use. This includes intravenous use with existential choices and a project in itself not overwhelmed solely by the importance of the drug.

The real value of peer support, at a personal level, consists in amplifying the possibilities of individual choices, increasing the number of possible options, with which to measure oneself, making use of new social networks which s/he has become part of, and further opportunities, of which use can be made. For some, peer support is the stimulus - via knowledge, imitation and identification under pressure from peers - for the assumption of more attentive drug behaviours; for others it is an opportunity to meet other people, make contacts, develop relationships, have different experiences from those strictly and habitually determined by the world of drug use. Still others see peer support as an occasion for personal commitment, the acquisition of a different sense of identity, an almost militant practice or a semi-professional one such as peer-operator. For each of these, peer support, while stated personally, nevertheless signifies an experience of empowerment.

b) The social normalization of drug use

Normalization means treating the phenomenon drug use as any other socio-sanitary problem that society takes care of. It is precisely the opposite of the logic of continual emergency and a strategy that uses criminal law as the primary resource.

The stabilization of drug use and the maintained or re-established compatibility with a social, emotional and working life - an objective where the different harm reduction interventions and treatments converge - testifies to the fact that it is possible to live with even the hardest of psycho-active drugs, heroin, and at times with the most destructive method of use, intravenous. Not always and not everyone, but the fact that a consistent number of problematic users manage to not let drug use interfere in their social integration, is something that the social representation of the phenomena can not ignore.

Social representation and social normalization are close relatives: if the perception of the phenomenon is stereotypical and if a simplified image of the problem prevails in public opinion - one that uses rigid and dichotomous interpretive categories that adopt binaries such as on/off, dependency/abstinence - drug use becomes identified totally with "hell" and abstinence with "salvation". Black and white become the only two colours possible to describe the facts. The wide range of grey is ignored, which in reality constitutes the larger part of the phenomena that can be articulated between use, harmful use, abuse, problematic use, dependency and pathological dependency. 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.

To represent the “normality” of drug use and to let emerge the prevalence between users of responsible behaviours for themselves and with respect to others, requires the effort of social visibility. To modify a useful stereotype, one whereby the dynamics of scapegoat converge, utilized socially in the worst sense of the word, requires the user to choose public visibility and maintain his/her reasons and to testify to what he/she is and the life he/she leads. The drug addict who is high, behaving delinquently and socially in a highly dangerous way, is today a reduced component of the entire problem, often even the result of the way the question is dealt with. He/she is a small part but one that will most probably represent the whole issue.

The gap between the expansion of stabilized drug behaviours in reality and their reduced social representation constitutes perhaps the greatest obstacle to normalization.

The politics of normalization by institutions, or their duration over time are difficult to put into practice if they do not occur in parallel with a change in the perception of the problem by the general public. Much has been done over the past years and has been followed on in terms of normalization and integration. However, still little has been done with respect to communication and the efficacious description of scientific evidence and the results achieved. These can offer a different interpretation of the phenomenon, indispensable for the start and the consolidation of a policy of de-stigmatisation.

c) The modification of services

The drug users movement has 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. As was expressed in a Correlation seminar, at least in the dedicated and specific services, the objective to be treated with dignity and respect on par with other clients has been achieved. The right to receive information, first aid medication and treatment has also been attained, at least in those countries that have been European community members for a longer period of time. Many specific questions are still to be “perfected”, remaining in closed envelopes.

Nevertheless the network of outreach interventions has expanded, both for harm reduction interventions and for selective preventions. The threshold for access to health and social services has been lowered and treatment options have been both extended and strengthened. Above all, a dialogue has been triggered between users-clients and service providers, which has facilitated not only the need to consider different points of view but in the best of situations, to bring together reciprocal knowledge and competencies, capitalized in new initiatives or “adjustments” in service operations. On occasions it has even been possible to jointly plan and manage innovative interventions.

In certain exceptional situations official representation of users has occurred within institutional bodies more frequently, working in a consultative capacity with respect to service project planning or, alternatively, predisposed to undertake programme evaluation. In other situations that concern in general research, research-interventions or experimentation, users are involved, either individually or in virtue of the associations they represent, with ethics committees, where they function as a guarantee and to ensure that rights are respected.

3.3. The methods and the difficulties involved in starting initiative users groups

Innovative groups of users are rarely “wildflowers” that grow spontaneously. Today they are more often “greenhouse flowers” that start up with the help and willingness of certain service operators.

The type of beginning of a group, the method with which it begins, is very relevant to its future development, to what it will become, to its actual identity. The imprinting of the origins conditions the evolution of the group, at least for all of the initial period, connotating its characteristics and above all highlighting the fragility of the group.

The experiences over the years enable the identification of at least three modalities, three prototypes for the start of a group:

a) Users self-made groups

Often their origins arise from a spontaneous reaction to sometimes dramatic events and therefore of great symbolic value that, in terms of their selective significance, are experienced as the straw that broke the camel's back. This in turn reveals a condition of daily subordination towards a chain of overwhelming institutional and social events that is no longer tolerable. Born from this very intense emotional impact - which gives rise to spontaneous meetings in response to the open "wound" - they are organized as self-defence groups. This occurs rather at a local 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. At times, users approach drug services but they soon stop frequenting them. Some remain in contact for methadone maintenance or for some social benefit payment. Mostly these groups express the conflicting relationship with services, which are perceived as institutional offspring and which are treated with suspicion and distrust, as they are generally incapable of safeguarding user's rights. These antagonistic aspects structure the group and feed the sense of belonging of the participants. The complete autonomy of the group is also its expression of strength, one it self-provides, often with good organizational abilities, pride in its independence and entrepreneurship concerning its own needs.

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 exchange.

Apart from a few national situations, and with some exceptions, this type of user group represents a reality more from the 80's and the early 90's rather than today. These groups were characteristic of the pioneering phase, fated as they were by difficult conditions, at the beginning of the politics of harm reduction and within a repressive and stigmatising context.

b) 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 on the problematic aspect of who had made a request for help, but on valuing the resources, the knowledge and the competencies present. From this came a request for involvement and the search for a role where motivations and aspects of oneself could be expressed, which had until that moment often been silenced or had had no opportunity to emerge.

Even for the spontaneous users groups the conflict, in this case focalised on the care/cure system, can constitute an evolutionary step of the process. It can almost be considered physiological for the consolidating function it has on the identity of the group

Roger Coleman, a client of psychiatric services in England, describes eloquently his “voyage”, first within the evolution of the mental illness that afflicted him, and then within the psychiatric services. He recounts how, after the obligatory treatment he underwent in the first repressive phase of the therapy, he was then able to access a less cruel treatment method. This method was much more caring and respectful of the person and he was able to have the useful experience of participating in self-help groups. Developing that experience as a psychotic patient who “heard voices”, Coleman became an activist for self-help groups for people who hear voices, then a trainer of patients and professionals. He attempted to help other people with the same condition to control their symptoms better and to prevent the escalation of a psychotic crisis that could subsequently occur. Coleman is an example, as he himself relates, of how the methods used by professionals and the organization of services can favour the start of spontaneous initiative groups of clients.

c) “Greenhouse” groups or mixed groups

These occur where the service providers do not only play the role of midwife for the initiative group but are also the incubators. In these situations the users groups do not come about spontaneously nor as a consequence of good clinical practices, but necessitate a rather long period of working side by side, and it is not a foregone conclusion that they will evolve finally into the formation of an autonomous group. These groups arise from a proposal by drug services, and as such denote a high level of “ontological” vulnerability. They are a fragile matter, to be handled with care. In reality they are conceived by operators, not as groups artificially predisposed to the initiatives of the services, 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. The methods and the reasons for the start of such groups can also be very different.

Nevertheless what constitutes the common denominator of these experiences is that the initiative is exogenous. It comes from the services, and necessitates a phase of working with the invited members of the group, which is not yet autonomous and does not yet express a spontaneous capacity for initiatives. Furthermore, the participation and the “control” of the group are sustained by the presence of professional operators. The professionals do not have the paradoxical burden of “conducting” the group towards independence because such an event can be nothing but spontaneous. Rather the effort is in constructing a mixed working group of users and operators. 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 setting

The weakness inherent in the origins of these types of groups consists in the hetero-conception rather than the self-conception of the group. Nevertheless, the opening of such an innovative building yard constitutes a true laboratory, where the gamble on fertile creativity, produced from a reciprocal contamination of knowledge, can be won. What is required is sufficient conviction to be instilled in the objective to develop a willingness to “stay” with the new relationship, and to maintain a constant curiosity and openness with respect to the research.

The constitution of mixed working groups where user-clients, operators and volunteers participate, appears today to be the most realistic path to follow.

3.4. The importance of umbrella organizations

For each of these groups, umbrella organizations play an indispensable part, including the self-made groups. The umbrella organizations, both public and private or volunteer, 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, both of which users have need for, not only at the beginning, for continuity and development of their initiative.

The “refuge” that the umbrella organisations provide is above all, even if not only, material and concrete help, which is indispensable for the start and for the consolidation and reinforcement of planned actions. This means the possibility of using spaces for activities, to have communication and information resources available, to be able to undertake “consultations as necessary” with respect to a wide range of problems to resolve; to know who to go to for eventual assistance for those individuals temporarily in difficulty.

The “cover” provided by the umbrella organizations also concerns the work of mediation with respect to institutions and public opinion. This consists both in the social and cultural legitimisation and in the recognition and the valuing of the experiences carried out by peer support. These aspects are not easily understood and shared, above all when they are at the limits or “extreme”, and challenge the stereotypes and the prevailing prejudices locally where these interventions occur.

The European network *Correlation* is a good example of an umbrella organization. It strives, through a network of relationships between the north, southwest and east of Europe, to identify the tools that sustain peer support, aiming at a double objective with respect to the empowerment of consumers:

- a) to re-launch initiative groups as protagonists in each single country;
- b) to try to construct a network capable of giving voice, visibility and international representation to the consumer movement active in defending their rights.

3.5. The role of the service providers

Professional operators, but also volunteers, play a key role - more today than in the past - in stimulating, working together and strengthening the protagonist role and the initiatives of users. 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 professionals. Furthermore, the difference is in what is intended by valuing the resources of the client: not resources that can be mobilized in direct connection to treatment, finalized solely in terms of the treatment and therefore completely subordinate to compliance with the therapeutic programme, but resources vice-versa available in settings where personal involvement frees the individual from the role of client. He/she acts as a citizen, as a militant for a good cause, as a person who in doing so, acquires dignity and a sense of self-esteem.

What is necessary for the operator, in order to work with peer support, is to be able to at least momentarily abandon or put aside his/her clinical perspective on the issues and therefore leave the therapeutic role behind from the moment he/she gets ready to collaborate with consumer initiative groups. This is the only way that an equilibrium within the relationship can be reconstituted, by leaving behind the asymmetry of the actual power inherent in the operator-user relationship.

This operation constitutes a preliminary act and it is through this act - that is required by the professional - that a totally new and diverse adventure is embarked upon in the relationship with the consumer. The relationship, finally freed at least formally of its roles, obeys a statute of parity. Together, each with their own competence, they form a new group that defines an objective to work together on. The user is no longer the work objective of the therapist. Now they are two subjects, equal and allied in undertaking a third task.

For many operators this “side-step” wrongfoots them with respect to the usual frameworks and upsets the hierarchies of roles. This is seen as a loss, and not a small one at that, nor one to be renounced. The loss is above all that of power, and touches those aspects

of security and certainty of image and professional roles, all of which have profound and authoritative connotations when they are closely connected to the more personal aspects of one's identity.

Loss of power means adventuring into a work field where one's professional specialisation is of no help and is actually out of bounds. When you have to keep the rudder straight in open seas and when insecurity prevails over assuredness, your true nature is directly called upon.

Only a choice made clearly and calmly protects the operator from subsequent betrayal. The "betrayal" is manifested in a thousand ways, if unease is displayed with respect to the choice made: in the work ally the user only is seen and therefore the asymmetrical nature of the relationship is perpetuated; in dividing up the tasks the dirty jobs are delegated; the operator is less willing to step aside to favour the user as protagonist; energies are expended in the competition for the leadership of the group.

What is required is to recognize in the user the existence of a knowledge totally his/hers; to have the intellectual curiosity for all that is unexplored, even that which appears to be the most obvious; to know how to talk to people outside of their roles; to share the battle against the stigmatisation and discrimination of users. There is a premise, a prerequisite in this battle for the development of a good partnership between professionals and operators. If the partnership is real (and not a camouflaged reprint of the therapeutic alliance), anything and everything can happen: divergence of opinion, conflict, escalation of same, methods of resolving confrontation, even separation and splitting off, if this is considered necessary or inevitable. After the experience of partnership, nothing will be as it was before.

Empowerment that has been experienced leaves a mark; it constitutes a point of no return, above and beyond the different shapes that the commitment can assume after this. The user knows and feels that if he/she wants, he/she can play a different role and be the protagonist in his/her own social context and with respect to his/her relationship with services. He or she is no longer the client that asks for help, no longer the stigmatised drug addict, but an active subject with acknowledged resources that he/she can useful contribute to a reciprocal relationship.

3.6. Today's tasks

Empowerment strategies for users in Europe are widespread and consolidated, and the international situation appears “patchy”. A few work priorities are proposed for the future:

- The first objective consists of spreading the experiences of empowerment to those countries that today have had less exposure. This needs to occur in such a way that the new eastern countries can incorporate these experiences, adapting specific strategies to the characteristics of their own diverse contexts. The capitalization of the acknowledgement and the visibility of the user as an active subject, who takes part in policy and service provision debate, have only been achieved in part. What is required is the organization of a national assembly of users that at a consultative level is listened to first hand, without mediation. This is not an easy objective to be reached but neither is it unrealistic.
- Also necessary is a direct European representation of users, not mediated by operator associations. It would be important if a presence was identified within the one foreseen for civil society in the “green paper” that contemplates a consultative discussion at European level, at least for the more accredited international networks. It is crucial that the voices of users are not mediated by networks of operator stakeholders but that they can participate by direct representation.
- Considering the variety of national legislation regarding the use of psychoactive substances and the specificity of each single country, it is important to define a charter of minimum rights for users, of non-discrimination, of access to health and social services and their provision, all of which can be promoted by users themselves.
- To sustain the diffusion of empowerment strategies, it is essential to exploit good practices in order to make use of experiences already put to the test and to avoid repeating errors or taking unsuccessful directions. It should be possible to circulate simple and immediately applicable information. New drugs and new methods of use require continual research and continual up dating of the most efficient practices.
- 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.

- 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 protagonist.
- 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.



4.

Users unite

A brief overview about the drug user movement

Theo van Dam

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

(Joergen Kjaer)

4.1. Introduction

Users of illegal drugs traditionally and mostly do not have a strong and heard voice in the matter concerned 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 decide about drug users without taking their voices seriously into account. For many years, users of illegal drugs have 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 as every other citizen.

This brief overview describes the history of drug user organisations in particular countries in Europe, with a special focus on the Netherlands, and the development around European drug user movements.

4.2. History of the Dutch drug user movements

Nico Adriaans was the founder and chairman of the first advocacy/activist user group, Rotterdam Junkie Union (RJB) in the Netherlands in 1977. In this capacity, the Rotterdam Junkie Union played an indispensable role in changing the face and character of Dutch drug policy.

“...the Dutch drug user movement was able to push the discourse of the slowly developing local and national drug policies away from “compulsory treatment” and “Verelendings-philosophies” towards “acceptance,” “pragmatism” and “normalization.”” (Jean-Paul Grund in the Ibogaine dossier²). Acceptance of drug use and human rights of drug users were the main goals for the Junkie Union.

In 1977, the MDHG, Medical-social service for Heroin users, was initiated in Amsterdam.

A mix of drug users, parents of drug users, social workers and other interested people decided to initiate the MDHG, because they couldn't agree with the social and political answers on the epidemic of heroin users. They were convinced that nobody keeps an eye

² The full text can be found on <http://ibogaine.org/adriaans.html>

on heroin users but themselves. The main goal of the MDHG was to fight for the interest of drug users, with as topics:

- Social acceptance of drugs and drug users;
- Decriminalisation of the use of drugs; get drugs out of the law;
- De-psychiatric and de-medication of the drug user.

In 1980, there were fifteen local Junkie Unions all over the Netherlands with the same goals, influencing the drug policy. In those days, the Junkie Unions organized themselves as a federation: Federation Netherlands Junkie Unions (FNJB).

The experimental Aids-prevention-project 'No-Risk' started in 1989 with practical prevention interventions for injecting drug users. No Risk, and his users, were the initiators for safe-use and safe-sex training. However, while No-Risk started as an Aids-prevention-project for IV-users, this project changed over time more and more to an interest group of drug users.

In 1992, LSD, the Dutch National Interest Group of Drug Users started as an Aids-prevention-project as well, but had to change this policy after 6 months into an interest group of drug users. LSD was funded by the Dutch Ministry of Health for activities in the Netherlands. One of the main tasks was to create a kind of translation from street voices into policy and the other way around. LSD should bridge the gap between policy and practice. Health promotion for drug users was another main task of the LSD foundation.

In some other countries in Europe drug users started to organise themselves as well:

In Germany, drug users organized themselves in JES, founded in 1992. JES is a national self-help network of and for people who take (or did take) drugs. Keywords are solidarity and acceptance. In France, ASUD was founded in 1992 as well, and it has grown up to a national user organization. At the same time, the Danish Drug User Union in Denmark was organized. The Danish Drug User Union had their key activities in influencing policy makers.

At the end of the 1990's, users started to organize themselves in several other European countries. Some of them were supported by the experience of the "older" groups. In Spain, the user organizations were connected and supported by ASUD France. The Swedish Drug User Union is still cooperating intensely with the Danish Drug User Union.

User organizations in Croatia and Slovenia have been supported by the Dutch National Interest Group of Drug Users for many years.

4.3. International developments

On World Aids Day 1990, Werner Hermann of the Deutsche AIDS Hilfe, arranged a meeting of European professionals and user self help groups - including RJB - in Berlin. Out of this meeting, the European Interest Group of Drug Users (EIGDU) was born. The main aim of this network was to wake up policy-makers, to lobby and encourage them to accelerate the establishment of harm reduction programmes, in particular needle exchange programmes. This was done by many press conferences and later by the book entitled: The Situation for Drug Users in Europe³. EIGDU could start their activities, because the Deutsche Aids-Hilfe was willing to provide financial support.

EIGDU also wrote and widely distributed a declaration of 10 action points. EIGDU received professional support from Franz Trautmann of the Dutch Trimbos Institute. During the Verona meeting in 1992, 40 participants from 13 countries came together. The topic at that EIGDU annual meeting was to complete the black-book and to present it to the EIGDU participants. The black-book was a memorandum of the actual situation of drug users in Europe.

In 1994, EIGDU had to stop their activities, due to insufficient funding. However, the idea to organize and contact each other was born. Since the closure of EIGDU, user groups have proliferated all over the world, and in Europe in particular. However, even though user unions from Central Eastern Europe participated in EIGDU, they did not get stronger after EIGDU had to stop its activities. During the period that EIGDU existed, there had been no progress made in organizing drug users from southern Europe.

In 1996, LSD received some funding from the Open Society Institute, in order to support and initiate interest groups of drug users in Central and Eastern Europe. User organizations in Slovenia, Croatia, and the former Russian states received structural support from LSD,

³ European Interest Group Drug User (1993) Die Situation der drogenbenutzenden. Bevölkerung in Europa. Memorandum Berlin, Deutsche AIDS-Hilfe, 159 p

not only at the start, but also during their practical work.

Small grass roots user organizations in Spain, Italy, Serbia, Macedonia, Slovakia and the Czech Republic were also formed during this period, which were able to consult LSD for practical support with backup from other user organizations in Denmark, France and Germany.

User organizations in Germany, Denmark, France and The Netherlands (countries where at that time, local drug user organizations were in touch through national networks of user organizations) were discussing how to initiate again an international user organisation.

Drug users support each other in the fields of disease prevention, overdose prevention, accessing stabilising and life-saving drugs, i.e. substitution treatment information (methadone & Subutex), about living well; with nutritional tips as well as safer use and safer sex reminders, and by creating a new social justice movement.

The differences in goals and the differences between the national situations and laws made the national groups to decide in 1999 not to initiate a European drug user network again. The main goals should be to influence decisions makers, and drug users should feel the effect of this influence.

As an alternative for the international network, LSD decided to organize an International Drug User Day. Drug users and their organizations could meet and inspire each other. The organization of this IDUD was practical and simple; IDUD should be a congress for drug users; they should learn from each other about safer use, safer sex, about lobbying and how to influence policy makers. Presentations should be made by users from all over Europe. Even non-users could participate in IDUD. In addition to drug users, many social workers from low threshold projects enjoyed participation in the IDUD. Beside that, a lot of policemen were interested in the IDUD happening. For policemen this event was very special moment to get in positive contact with drug users for the very first time.

The IDUD was organized eight times (1995-2003). Every time, it was organized in the Netherlands as an invitational conference. The political situation in the Netherlands (at that time) made it possible to have this event. In 2003, the Danish Drug User Union organized, in cooperation with LSD, IDUD in Denmark. The IDUD always ended the conference with a big party with a band playing up to dance. During the conference and of course during the party, people were permitted to take their favourite drug and show their habits openly. We

invited some dealers to service the users gathered at IDUD with a good quality and price relation. For those users who would like to inject, IDUD organized an injection room with a medical doctor, and for those who would like to smoke, it was allowed to do that and take their drugs in the plenary room. In this plenary room, nurses were available. During all the conferences, we never had any accidents or fatal OD's.

As an extra activity we handed out the so-called Dr. Alderwright Award to honour the most user-friendly initiative of the year. Users from 24 different countries attended the IDUD. For some of them it was a shock to see how open and peaceful this event was possible to be.

Policemen were walking around talking to users, nurses, dealers and social workers. Drugs were seen as a fact and needed to be accepted as a fact – just like drug users.

The IHRA - **International Harm Reduction Association Conferences** - has grown over the last 17 years in popularity and worked as a possible annual gathering point for user activists from most countries. The IHRA has been very supportive, granting scholarships to many user activists, especially from the economically less developed countries. The IHRA conferences have therefore been a very important stage for user advocates and user activists to raise their voices and spread their opinions both publicly and internationally.

4.4. Conclusions

The need to meet each other as drug users from all over the world is still there. We realize that we need a strong and practical drug user movement to create justified drug laws, based on facts instead of emotions.

Since the early beginning of user unions in Europe, there is the need to have a powerful international democratically drug user movement. This international drug user movement needs to have clear goals and should be able to bridge the gap for users all over the world. This international drug user movement needs to have a broad overview about national differences in drug laws and drug scenes. The new international drug user movement needs to create an open discussion about the tasks to be done.

For this:

USERS UNITE!



5.

Addressing empowerment through the process of empowerment — a discussion

Coordinator: Lorenzo Camoletto, Gruppo Abele

Focus Group reports

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5.1. Introduction: Rationale and methods of focus groups

“A focus group is a form of qualitative research, in which a group of people are asked about their attitude towards a product, service, concept, advertisement, idea, or packaging. Questions are asked in an interactive group setting where participants are free to talk with other group members.” (Wikipedia – 20 November 2007 – http://en.wikipedia.org/wiki/Focus_group#In_social_sciences)

In the area of social sciences, “...focus groups allow interviewers to study people in a more natural setting than a one-to-one interview. In combination with participant observation, they can be used for gaining access to various cultural and social groups, selecting sites to study, sampling of such sites, and raising unexpected issues for exploration. Focus groups have a high apparent validity - since the idea is easy to understand, the results are believable. Also, they are low in cost, one can get results relatively quickly, and they can increase the sample size of a report by talking with several people at once.” (Marshall and Rossman, *Designing Qualitative Research*, 3rd Ed. London: Sage Publications, 1999, p. 115)

a) Methods

In the following part, the main characteristics and methods of focus groups are summarised in a concise way. For more detailed information, please see the suggestions for further readings in the section *Literature* below.

- Focus groups are focused on a specific, pre-defined issue
- Focus groups are particularly relevant to find out about peoples attitudes, believes and opinions
- The focus group participants share common characteristics
- Focus groups are generally designed for 8 to 12 participants
- A moderator guides the discussion
 - A catalogue of possible questions supports the moderator in his task

- The prepared questions need to be used in a flexible way to give space to the needs of the participants
- An observer takes notes during the meeting
 - The notes do not only reflect the spoken word but also non-verbal messages and the atmosphere at the meeting
- The information generated by a focus group needs to be analysed properly and can be used for the development of policies and interventions

Preparations

Before starting a focus group, the following questions should be settled:

- What specific information do we want to get from the focus group?
- How do we identify and select the participants?
- Who will conduct the focus group and how?
- What are the contents of the pre-defined question list?
- How will the information be analysed and reported back?

Selection of participants

For the selection of participants, some considerations should be made:

- Firstly, define the group, from which you expect to get the needed information
- From this group, you can select people at your convenience
- Make sure you have a good representation of people you want to include
 - Consider age, gender, ethnic background etc.
- Invite more people than needed – consider that people may not show up

Preparation of questions

Take care of the following aspects when developing the question line:

- Make sure that all can understand the questions
 - Consider language skills and intellectual level
 - Do not combine several issues in one question
- Avoid questions that may embarrass people or make them feel guilty
- Avoid too many `Why` questions; they may sound interrogative
- If questions are translated, check whether they are really understood

Collection of the information

There are various forms of collecting data from focus groups:

- Written notes – this is probably the easiest way to organise, but information can get lost, in particular when the discussion gets more lively
- Tape recording – this may be the most appropriate means of collecting information, as it is not too complicated to organise, and still prevents to a great extent the loss of information
- Video recording – provides even more information than tape recording, as it also reflects non-verbal expression; but it may be intimidating for participants.

No matter, which way of collecting information is chosen, it needs to be communicated clearly to the participants.

Analysis of the results

The analysis of the information should be done in various steps:

- Firstly, you should look at the data – notes, tape recording or video-recording – as a whole

- Next, you can read, listen, watch it again, taking into account specific indicators (e.g. how often a certain message/word/question occurs during the group session)
- You may use certain codes for those messages/words/questions to make the analysis easier

Rounding off

To finish the process of the focus group, you may wish to discuss the results and analysis with colleagues, in order to establish, whether the results provide the information that you were looking for in the first place.

b) Advantages and disadvantages of focus groups

It needs to be noted that focus groups are an important tool, but that they also have their limitations.

Advantages

- Focus groups produce a lot of information
- They can be organised more easily and at less cost than separate interviews with different respondents
- They are suitable for communities with limited literacy skills
- They can provide information about attitudes and opinions that might not be revealed in a survey questionnaire
- Focus groups can be fun!

Disadvantages

- 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 method

c) Literature

There is a wide range of publications and websites available that provide information about the methodology and potential of focus groups. A concise overview of some fundamental information about focus groups has been compiled by the Iowa State University (<http://www.extension.iastate.edu/publications/pm1969b.pdf>). The authors look particularly into the purpose and procedures of focus groups and compare them with other forms of (social) research. They address the way of communicating during and reporting after focus group sessions. In their summary they stress that focus groups "produce high quality data if they are employed for the right purposes, using the right procedures."

A more comprehensive and detailed publication has been developed by the Tropical Health Program University of Queensland Medical School: A Manual for the Use of Focal Groups. This document is based on materials of the WHO and UNDP and is available online (<http://www.unu.edu/Unupress/food2/UIN03E/uin03e00.htm#Contents>). Information is given about all steps of the implementation of focus groups – from the design of the study to the selection of participants and the analysis of the results. Special attention is paid to training of health professionals, in order to prepare them for properly conducting focus group sessions.

Another very comprehensive document is the book *Focus Groups: A Practical Guide for Applied Research* (RA Krueger, MA Casey, 2000). The authors guide the interested reader along all important aspects of focus groups, such as planning, developing the questioning

route, participants, moderating skills, analysis of the results and reporting. Parts of the book are accessible online.

5.2. The process of the Correlation focus groups

As members of the Correlation expert group on Empowerment⁴, we asked ourselves how it can be possible to investigate the meaning of empowerment and generate applicable outcomes, within our budget and time constrictions. We needed to find a simple, flexible method that is both useful for us and can also include clients and service providers in the process, and which, in doing so, can change each other's point of view and deliver results in terms of self-efficacy and self-esteem.

The choice of a “focus group” technique appeared to be suitable, as it can be relatively simply applied at a low-threshold centre (for example, involving participants within the group who are at the centre at a given time). The purpose was to gather a group of experts who, in accordance with our aim of empowerment, meant that drug users had to be involved and considered as experts too. This was a first step for us and meant that we all met people who were involved because of their personal knowledge of addictive substances and addiction-related lifestyles — a knowledge, at least of the same value as that coming from university studies.

A focus group can be defined as a “carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment,” (Krueger and Casey, 2000, p. 5). The focus group was designed originally as a marketing research tool and has been adapted for research in many fields, such as medicine and social sciences.

Focus groups are quite simple to organise and can achieve a win-win situation: in this context, they can address empowerment while at the same time empowering the participants involved.

During the Correlation meetings in Amsterdam and Krakow⁵, we decided to establish

4 Members of the group: see above

5 Egmond September 2005, Krakow March 2006

a number of focus groups in several countries where associations, drug centres and organisations exist that are members of the Empowerment Group.

The aim to discuss empowerment issues while promoting empowerment at the same time led us to choose (at the Amsterdam meeting) the focus group methodology and involve — as experts — both clients and professionals of low-threshold services, who would discuss the following:

- The right to be treated with respect and dignity.
- The right to receive information, medication and treatment.
- Regulation/normalisation of drug use.

Afterwards, in order to make empowerment the very core of the focus group, the following question was added:

- “Do you think clients can be actively involved in the work of service providers/centres? How?”

The focus groups’ target was to make comparisons between different European situations, but the “shadow-target” was to verify the participants’ perceptions, possible oppositions, and the availability of services, possibly leading to the founding of smaller work groups of clients and social workers, who would be able to work together. As for the methodology, flexibility was the guiding principle. Therefore, every group made adjustments according to its own situation. In order to disseminate and compare the focus groups’ outcomes, the tools that were chosen comprise of a short written report and a number of comparative overviews.

We established twelve focus groups:

- Four in France, in a drop-in service
- Two in Italy, in two drop-in services
- One in Norway, in a public resource centre for drug users
- Three in the Netherlands, one in a centre for low-threshold services, one in a drug-user room and one was carried out informally

- One in Sweden, in the offices of a drug-users' union
- One in Switzerland, in the offices of a parents' association.

The aims:

Firstly, for the Correlation conference in Sofia (September 2007), we wanted to create a document with outcomes detailing the experience of focus groups as well as some basic “guidelines” and answers to the following questions:

- Was it easy to work at the same level (clients and social workers)?
- What about feelings and feedback?
- What about a means to “pass the ball” to clients?

The second (and more important) purpose was to improve the involvement of clients in the decision-making process of social services.

However, this is only the first step and we want to establish how we feel about working together.

In this overview we summarise our focus group experiences in low-threshold centres, service providers and/users' groups, before addressing outcomes and feedback. The conclusions will be presented at the Correlation conference in Sofia.

5.3. Focus groups overviews

5.3.1. France

Who?

Hosts:

Espoir Goutte d'Or, Paris.

The initiative was taken by a service provider of a low threshold drop-in centre and the choice was made to invite only drug users attending the service. One or two professionals acted as facilitators and tried to influence the content of the discussion as little as possible, in order to collect data only reflecting the users' point of view.

Participants:

The first three meetings were facilitated by one or two people. The users attending the meeting were mainly marginalized crack users (only men). *The last meeting* was facilitated by one professional and attended by highly marginalized opiate users.

Despite the effort to invite the same people to the focus groups, every group was attended by different users. This is a problem often encountered in a low threshold setting: people attending our programmes are very marginalized, thus they are not always able to participate repeatedly, even though they might want to.

Why?

Again, it is about lowering the threshold so that people, who want to participate, can. It is very important to explain the purpose of the meetings. People are more willing to participate if they know that the results are going to be used (we wanted to present the results during a conference which would be attended by politicians).

How?

First meeting:

The users of the drop-in have a meeting every week; this particular week, the president of the users' committee was absent, so this focus group replaced their usual meeting.

The meeting took place without specifically inviting users. Information flyers were made one week before the meeting. Fifteen minutes before the meeting, one of the facilitators invited everybody present to join the meeting, explaining what the purpose of the meeting was. The meeting was held in a quiet corner of the drop-in. First, the users gave their own definition of every term (respect, dignity), and then we discussed the issue knowing we were all talking about the same thing.

Second and third meeting:

These meetings took place during opening hours of the syringe exchange programme in an open space downstairs. This means that, though separated from the usual activities, users could hear and see what was going on at the syringe exchange programme, but the other clients could not hear what was said during the meeting. In order to invite clients to the meeting flyers were made one week before.

Also, several users (those who attended the meeting at the drop-in before and other people who we thought might be interested in participating) were invited personally (after an explanation of the purpose of the meeting and an oral invitation).

Several evenings before the meeting, and also during the hour preceding the meeting, one of the facilitators invited everybody that came in to join the meeting, explaining what the purpose of the meeting was.

Last meeting

Due to low levels of participation in the previous group meetings (4, 3 and 4 people), we decided to invite people to participate in the focus group in a small restaurant where we would all eat. Seven people were invited and two people showed up.

Outcomes and remarks

The idea to have the meeting in a restaurant was good, but difficult to realise in such a setting. When the meeting takes place in a drop-in, it is no problem if someone does not show up because there are always other users who can join in. When a meeting takes place outside the organisation, “no-shows” can’t be replaced. To increase participation, next time, it might be better to bear the following in mind:

- Let everybody know in advance when a meeting will take place, on what subject and for what reason.
- Invite several users personally (because you think their input will be particularly valuable, because you think they will be able to take along friends to participate etc.)
- The meeting can be held in the drop-in. A special atmosphere can be created (food, drinks etc.) to make the users really feel welcome and respected.

5.3.2. Sweden

Who?

Hosts:

The Swedish users' union (SBF) office, where we have facilities to arrange conferences, seminars or other activities for our members and others in connection with drug use.

One of the main issues of the Swedish users' union is to incorporate real "user involvement" into Swedish drug policy.

Participants:

We have 12 participants so far. Five users, five professionals, one scientist from SORAD University of Stockholm, one municipal politician and one observer/moderator from SBF (the Swedish users union). Gender: Eight men, four women.

The professionals represented are: the Swedish social service, Swedish Justice Department, the association of drug counsellors and other service providers, such as representatives from the various substitution clinics in Stockholm. The users included: three from the Swedish users union (participating in the methadone programme), one "active" user and the chairman from the Swedish homeless association.

Why?

To create a more “balanced” division of power between clients and professionals.

The client participants of the focus group all felt free to express their opinions and feelings. They all had a feeling of mutual respect and understanding and the conversation was good, without irony or negativity. The clients believed that the focus-group form provides a good forum for discussions concerning these matters and they all look forward to our next meeting.

The professional participants all felt respected and comfortable with the discussions. The group gave a good response to the questions and opinions discussed. They all felt that the focus group could be a forum for a greater understanding and increased user involvement.

The discussions were a good way of visualising both the users’ and the professionals’ experiences and opinions.

How?

One employee from the Swedish users union (SBF) was given the task of preparing the focus group. We invited as many representatives of social/health service providers connected to drug use in Sweden as possible. And we invited users of both legal and illegal drugs. Until now we have had 12 participants. An overall introduction and presentation of the themes and Correlation’s work was sent to all the participants in advance. We decided to hold at least one meeting each month and the duration of the meetings is 2.5 hours including a break.

Outcomes and remarks

We raised the following four issues and received a broad range of feedback, which is described below.

1. The right to be treated with dignity and respect:

We discovered that there were not only prejudices between users and service providers/ social services, but also between the different organisations involved in our field. For example: a social worker has a hard time understanding and working with the doctors from a specific clinic. We all agreed that there is a problem with the respect for users in Sweden and all participants agreed that it is very important for both users and professionals that we achieve a better mutual understanding concerning the reality and daily life of both users and professionals. The group also found it very important to eliminate the stereotype image of "the user" and to try to reduce stigmatisation of and prejudice against the users nationwide.

In Sweden we have a large problem with the attitudes towards users. Because in theory, Swedish drug policy combines zero-tolerance towards both use and abuse of drugs with active police work and active social work. But in practice, Swedish drug policy means criminalizing both personal possession and intake of drugs. The authorities are thereby demonising both the drug and the drug addict. Swedish police for example, regularly enforce compulsory urine tests to detect personal drug use. We discussed the fact that many of the Swedish social workers and other service providers or government representatives have a strong moralistic attitude towards drug use. Condemnation and even contempt are common attitudes towards drug addicts. This is not a subjective statement, these are facts that are true for Swedish drug policies at all levels of the drug-user scale. Therefore, the right to be treated with dignity and respect is a very serious matter that we are working hard to improve.

2. The right to receive information, medication and treatment:

The right to receive medication and treatment has improved greatly in the past few years because the government took away the restrictions for accessing substitution programmes. But we still have a lot of work to do because in Sweden patients are regularly refused medication, when they are suspected of being under influence of drugs. This is just one example.

Another case worth mentioning that reflects the attitude towards users in Sweden, and in particular outside the urban environment, is a case from a small town, where a young man

had quit heroin and started using subutex by himself. When he and his father went to the social service to apply for substitution treatment, the social worker refused him anything other than a drug-free treatment, using the argument that *“He should not be rewarded for his use of heroin.”*

3. Regulation/normalisation:

The focus group agreed that we have to work towards a common goal — to get service providers and users to aim for the same objectives and to reduce stigmatisation and the political polarisation with respect to drug use and rehabilitation.

We will hold focus group meetings monthly and the number of participants will probably grow, since many different institutions have shown interest in the focus group. All the participants agreed that it is very important that we have a strong user involvement in the Swedish substitution programmes.

The work of the Swedish users union has been very important for the Swedish users. As an example: we now have a voice in the Swedish drug debate and we try to convince politicians and other people concerned to look also from the users’ point of view.

We are constantly working to establish several local user unions as a means to promote a collective users’ view. Another important task is to establish so called “quality councils” (a meeting structure on a regular basis, between users and the head of the clinic) at every team nationwide. This would be a good model for assuring real user involvement on a higher level at each clinic.

4. Do you think clients can be actively involved in the work of the provider centres? If yes, how?

To highlight the various situations and the everyday life of a user for other people.

To arrange meetings, seminars and conferences with/for social and health services, sharing and visualising the users’ experiences and problems.

The Swedish users’ union wants to standardise the focus group model and we will invite our local divisions in Malmö and Örebro to participate in the focus group in order to extend the perspective from Stockholm to a nationwide perspective.

5.3.3.The Netherlands 1:

Who?

Hosts:

AMOC in Amsterdam — service provider for European drug users, homeless people and boys working in prostitution. AMOC offers them daily basic facilities, a place to use in a safe hygienic environment. We also offer them daily counselling with social workers.

.Participants:

We worked with eight participants of which

- three drugs users:

- talian man (35 years old) living in Amsterdam for nine years
- Italian woman (39 years old) living in Amsterdam for seven years
- Spanish man (28 years old) living in Amsterdam for two years
- one homeless person: German man (36 years old) living in Amsterdam for two months
- one German man (34 years old) working in prostitution, living in Amsterdam for 12 years
- one woman (27 years old) working in a drop-in
- one man (44 years old) working in male prostitution project

How?

The focus group was organised by two Correlation team members (working at AMOC) plus one drop-in worker and one worker from a male prostitution project. It lasted for two hours, in which five clients and two workers were invited to answer to three questions (we didn't have the time to ask all the four questions).

Outcomes and remarks

All the members of the focus group agreed that it is difficult to be respected if you live in the streets. Some of them sell newspapers in the street, and they have to fight daily against mistrust of the society, trying to be well-dressed and clean just to earn a few euros.

The society asks respect from them, but is not ready to give it back.

When they arrive in Amsterdam, they think Amsterdam is a city of freedom and easy life, but soon they discover that this is not true. Amsterdam is free if you are a tourist. The lack of tolerance in the general society can be felt in the streets of Amsterdam and through the strict laws concerning immigrants and foreigners in the Netherlands. A reason for the negative attitude could be the large number of immigrants that arrived over the last twenty years and the response of the population and politicians to this.

Everybody has the right to receive information and it is possible to receive this if you are willing to invest energy into finding it. Organisations like AMOC have the responsibility to help clients with information. Unfortunately the social workers do not always have the time to find all information that every single client needs. Therefore, clients also have to be involved in developing peer support.

The improved involvement of clients is possible and necessary on a practical level, more so than on a decision-making level. The focus group thinks that the clients who come to AMOC on a daily basis should definitely be more involved on a practical level than the clients who only drop-in once in a while. This is nonetheless problematic, since the flow of regular clients changes on a monthly basis, when clients stop coming to the organisation.

Despite this, it would be possible to arrange regular meetings with clients and staff, to develop and organise common activities.

The members of the focus group proposed that clients could be involved in the daily activities in one or more of the following ways:

- Meetings every three weeks with the clients at the drop-in, to exchange information and plan tasks;
- regular evaluation of the involvement of clients and its results;
- a newspaper with more space for clients' ideas and wishes;
- sharing their experience and knowledge at regular client-staff meetings.

The focus group emphasised that clients need to feel more as part of the organisation, instead of just being involved in taking care of small jobs for money.

5.3.4. The Netherlands 2:

Who?

Hosts:

LSD bv. (Drug user activist company)

We were able to organise four focus group sessions. The four sessions were held in four different locations in four different cities. One of the locations was a drop-in centre for homeless drug users. The second location was a consumption room for registered problematic criminal drug users. The other two sessions took place during the national meeting of Dutch drug user unions.

Participants:

The users who participated were all known as base cocaine and brown heroin users.

Why?

Many drug users would like to be heard. There is still a big misunderstanding between users, workers and decision-makers. A lot of users are sure that they could participate in low-threshold programmes. They don't understand that this is possible for them, and to many of them this feels like a kind of distrust. They were happy that they could talk about the following topics:

- To have the right to be treated with respect and dignity.
- To receive information, medication and (the right professional) treatment.
- Regulation and normalisation (and decriminalisation).

Several times we got the comment that they hope that something will change because of these focus groups.

How?

The focus group in the drop-in centre started spontaneously. Users were talking about things, which had to be changed in the services offered. They were glad that they could talk and discuss about the topics mentioned.

The focus group in the consumption room was a special one where users were invited to join, however, other users participated as well. Users were sitting around the tables, smoking cocaine and heroin and still concentrating on the issues. This group was especially keen in their wish to receive the right professional treatment.

The focus groups that took place during the Dutch national meeting of drug user unions were just a part of the meeting and they were asked to think about the topics. These drug users are all involved in the local users union. They strongly believe that while they are allowed to talk about all topics, there is still distrust and misunderstanding between the organisations and users and their unions. They said that they get sick about talking about regulation and normalisation. They believe that the first big step that has to be made is decriminalisation. From their point of view the time to change things for the better is right now. They believe that the political situation in Europe has to change first.

For the second meeting of the Dutch national users union all participants talked with their local friends. This focus group did not have any special outcomes.

Outcomes and remarks

All participants of the focus groups fully agree with the topics mentioned above. In the Netherlands, drug users have some experience with interviews. When this is done by participants of (other) user unions, they can talk openly and freely about their needs and wishes. They still hope that the participation in the focus group will lead to some practical recommendations for decision-makers.

5.3.5. Italy

Who?

Hosts:

Gruppo Abele, Turin.

Two drop-in services located in the city of Turin were chosen. They are different in both management and users, and can be considered as examples regarding empowerment issues.

Participants:

The focus groups were attended respectively by:

- Two professionals and five clients (three men – two of which were strangers – and two women) in the Gruppo Abele drop-in.
- Two professionals (one of them a peer operator) and six clients (one of them with experience as a peer operator in another low-threshold centre).

The first drop-in service is located on the outskirts of Turin and is managed directly by Gruppo Abele. In the beginning, the working team was formed by peer operators and professionals who did not have the same contract: their tasks and responsibilities were equal, but the wages were different. During the focus group meeting, the working team was formed by professionals only.

The second drop-in service is located inside a hospital for infectious diseases. Most of the users are drug addicts and heroin is their primary substance of use. From the beginning, the working team has been composed by professionals and “experienced” operators who benefited from a common training and make the intervention planning together. This service belongs to the Local Health Service, and all the staff members are consultants and have the same contracts and wages.

Why?

As previously stated, focus groups are quite straightforward to organise and achieve two things at the same time: they address empowerment while empowering participants.

The purpose is to establish a group of experts. This is the first step for us, but also means that we are also one step closer to stimulating empowerment.

Having clients and professionals involved as experts with a different, but equally valued knowledge and experience base can help to change the mutual feeling between social workers and clients.

How?

Firstly, we carried out the process using two operators of “University of the street” (Gruppo Abele’s training centre). They were involved in:

- Contacting the drop-ins.
- Meeting professionals and clients.
- Deciding the dates.
- Moderating the focus and elaborating on the outcomes.

In both services we briefly explained that we need a group of 6 to 8 people (clients and operators) who agree to answer some questions putting together their knowledge. We asked some volunteers and also left a “memo” note on the notice boards. In the first drop-in we decided to invite the focus group in the morning, when users are present. In the afternoon, the drop-in service is attended mostly by illegal immigrants, usually homeless, who are not always drug users. During the meeting the volunteers who were not present were replaced by others present at the time. We described the Correlation project to the group and defined the goals of the focus group. We used a tape-recorder, and two moderators joined in.

Outcomes and remarks

The following two problems were expressed:

- The difficulty of having a person in charge of the service who is still involved in drug use.
- The difficulties peer operators have with making clients comply with the regulations.

Some clients spoke critically of the operators' actions ("They do not make regulations be obeyed, do not pay enough attention to those who need to talk, to relieve their feelings...", etc.). They also spoke critically of the working team pattern: the relationship between drug users and operators was considered to be modelled on "vertical" criteria that often seemed manipulative.

In this first setting, we experienced some reluctance by clients regarding a mixed management. The difficulty of making active users aware of their responsibilities in order to guarantee the service and its rules has been particularly stressed.

In the second setting there were no problems in the mixed management of the service and the focus group could discuss issues more connected to the difficulty of involving new kinds of drug users and the possibility to promote self-regulation and empowerment processes.

In both services we had a broad range of other experiences in the focus group, with different goals, and feedback from participants about their involvement was always positive.

5.3.6. Norway

Who?

Host:

Resource centre in Oslo.

The resource centre is an activity and competence centre for the local community in Oslo. The main principles are contribution from the users, and a positive approach, which in reality translates as "faith and focus" on each individual, and their resources in a group. The centre is primarily for people with some kind of problem, for instance with different types of drugs. The people and the centre work with one main target: to build a bridge to the rest of the society.

Participants:

The groups existed of about ten users (mostly men), and three workers that had a more passive role; for instance they took notes about the mood and the atmosphere at the meetings. The group consisted of the three workers that participated at the two meetings,

and two users (not the same at the last meetings)

Why?

The reasons are in line with the general goals already outlined in this report.

How?

The different focus groups that were organised were a part of a larger arrangement that was made after agreements at the Correlation conference in Krakow spring 2006. These agreements were made as a part of the cooperation with the Correlation expert group on Empowerment.

The following three issues were discussed:

1. The right to be treated with respect and dignity.
2. The right to receive information and medical treatment.
3. How can the clients be actively involved in the centres?

The responsibility of the focus groups was given to a student (political science), and a user who worked at the centre in Oslo. They had worked together before, had a good knowledge of the different groups, and the users trusted them. They had many meetings where they discussed how to approach this. Their starting point was to use some literature for inspiration. They chose Charles Baudelaire's *Intoxicate yourself*. As a part of the preparations, we had several meetings at our centre, talking about the focus groups and motivating people to join. We held two meetings, with three weeks in-between. We decorated the interior to create a special atmosphere. At the two meetings, the student and the staff member introduced the themes and contributed ideas from their own lives.

The discussions were taped and after the two meetings, a group of people gathered together to analyse the main issues of the discussions.

Outcomes and remarks

We ended the project when we reported our findings in the house meeting, where we also evaluated the project.

Conclusions

The methods to be applied in the focus groups were discussed and finally chosen at the Empowerment Group meeting during the Correlation Conference in Krakow (Poland), in March 2006.

The Empowerment Group represents various parties who work and are associated with drug use and drug policy in general, and with rehabilitation more specifically. The participants included drug users, relatives of drug users and professionals, including social workers and others from related areas. The group therefore represents and expresses various aspects associated with the previously mentioned topics.

The preparation of the focus group meetings and the way they were actually carried out can as a whole be characterised as follows:

- The preparation and the actual meetings were seen as each focus group's independent responsibility.
- The manner in which the focus group meetings were carried out was, to a small degree, affected by the differences between the participants. There is little difference between the meetings organised by drug users organisations, the clients, and those organised by social workers/professionals.
- Every meeting represents user-involvement in the way users were actively involved in the preparations and the meetings themselves.
- The meetings were positively received by the clients as well as the social workers.
- While the meetings were seen as especially useful for individual development, the usefulness of these meetings in regard to influencing the drug policies nationally and internationally was questioned.

Outcomes and remarks

In general, the results from the different focus group meetings overlap and are quite similar, despite the very different starting points. The reason for this may be the selected questions/topics. To some extent, these topics represent larger questions concerning drug use, drug policy and the general situation of drug users. The questions can also be seen as quite general in the issues they address and the way they are formulated. One may also get the impression that the outcome/results of these meetings were as expected, and that the results are relevant not just for drug users, but also for people from minority groups and people in a marginalized situation in general. The challenge is to consider these results very carefully. The results give us a picture of a challenging life situation, which is common and similar in many countries.

General responses to the topics discussed can be summarised as follows:

1. The right to be treated with respect and dignity

- It is very challenging to be a drug user and sustain one's self respect.
- It is difficult to be a drug user and be met with respect from one's surroundings.
- It is difficult to be the parent(s)/relative of a drug user, it hurts them when users are met with a lack of respect.
- It is often difficult for a drug user to meet former users/clients in their role as social workers.
- Treating drug users with respect is rare in the current social system.
- Rules are often considered and experienced as a sign of lack of respect.
- It is important to work with values to prevent stigmatisation.

2. The right to receive information, medication and treatment

- Too little information, especially concerning the side effects of medication used in rehabilitation.
- The social workers have a special duty to provide information.
- The information has to be concrete and individually specified and directed.

3. Do you think clients can be actively involved in the work of provider centres? How?

- Client involvement is both possible and necessary.
- Involvement needs to include the decision-making level.
- Routine and continuity are important to counteract changes in a user group.
- Criticism concerning lack of competence and work experience must be taken seriously.

5.4. General feedback for the use of the “focus group” methodology

The focus group methodology is useful at different levels. It can be applied formally (or structured) as well as informally. The organisation of focus groups is easy for both users and service providers (or DU unions). This way of working gives a two-way responsibility. The service provider has to do something with the outcome. It may not only end in statistics or in a report filed away in a desk and forgotten about. It is the most common reason for the service users saying: “We don’t want to be researched anymore.”

For service users it means an active involvement at least during the focus group. The formal and informal character of the focus group (or its organisation) is not strictly separated.

One of the remarks from the service providers as well as from the drug users is that both need training. The social workers need to really get in touch with the drug users – not only from a theoretical perspective, but also especially in a practical way. This kind of education should be given by drug users or their unions. The drug users, in turn, could use more skills regarding how to organise or moderate meetings and sharpen their active listening skills.

Even if only small changes can be achieved, progress would still be made because the relationship between the drug users and service providers becomes (more) dynamic. They get to know each other better. Also, the discussion at the drug centres is important. If your situation at local level improves, you can put some energy in policy making; perhaps even policy changes are achieved more easily. This was felt to be especially important.

It is also very important to make full use of the competence levels available. This will certainly lead to a better situation for everyone. Those who are actively involved should receive proper appreciation for their work (also in financial terms).

A question we heard several times was: “Who is really benefiting from empowerment?” For some service providers it is just a (legal) obligation to have a client board. If it exists on paper, they are legally off the hook. Do service providers have to push their service users to empower themselves? We all agreed that the client should have the freedom of choice. On the other hand, the service providers should actively offer the possibility and facilitate empowerment/client involvement. There is no excuse for them to sit and wait to be asked by the client.

We have now eleven examples of focus groups about empowerment. They were all evaluated as useful and the outcomes were beneficial for illuminated all actors involved. We hope this can inspire other organisations and service users, and we would like to thank everyone involved for their cooperation.

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CAPPUCINO
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TIMPS

6.

Developing a model of user involvement and social research in Scotland

By David Liddell and Biba Brand, Scottish Drugs Forum

6.1. Introduction

Scottish Drugs Forum (SDF) is the national non-government drugs policy and information agency working in partnership with others to co-ordinate effective responses to drug use in Scotland.

SDF aims to support and represent, at local and national levels, a wide range of interests while promoting collaborative, evidence-based responses to drug use.

Scotland has one of the highest levels of problem drug use in Europe. Just over 50,000 people have a problem with opiate and/or benzodiazepines; there is also an emerging

cocaine problem and an alarming crossover between drug and alcohol problems. Most drug-related harms, such as dependency, infections, crime and deaths occur in our most socially deprived areas. The latest drug-related deaths are the highest ever recorded - 421 people in 2006. Over 50,000 people infected with the Hepatitis C virus (80% through injecting) and it has been estimated that 1000-2000 new infections may occur among injectors each year.⁶

Many drug users also face a range of criminal justice, social and economic problems. With over 35,000 people entering prison each year, the average daily population has reached a record level of 7183, and nearly half of all new prisoners having a drug problem. Moreover, about seven out of ten people attending drug services in Scotland are unemployed - many long-term - with a similar figure claiming to use their welfare benefit payments to fund their drug use.

6.2. Background

Since the early 1990s, SDF has worked to involve those receiving services for their drug problem so that service users can influence how services are planned and organised.

Over a number of years, we struggled to create an effective role for SDF in supporting user involvement until 2003, when we developed a model of User Involvement which focused on social/peer research. Providing appropriate resources are made available, this is proving to be a very sustainable model, and one which we have delivered in the main urban centres and beyond.

This paper aims to describe the model, providing detailed information on how potentially others might replicate our model.

The host organisation is a crucially important aspect of whether or not such a project

6 Hutchinson, S.J., Roy, K.M., Wadd, S., Bird, S.M., Taylor, A. Anderson, E., Shaw, L., Codere, G. & Goldberg, D.J. (2006) Hepatitis C Virus Infection in Scotland: Epidemiological Review and Public Health Challenges, Scottish Medical Journal, Vol. 51 Issue 2

can be successful. Our opinion is that it should be an organisation sufficiently at arms' length from frontline services provision so that there is a clear distinction between the peer researchers as volunteers and their role of receivers of a service.

As far back as 1991, SDF held a conference on User Involvement and in the mid 1990s received short-term funding for a project in Dundee and one in Edinburgh to set up User Involvement groups. Through this work we developed a policy paper, which set out the value of this area of work as follows:

- 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 users.

However the work of the user groups in Dundee and Edinburgh at that time lacked focus and direction.

Funding was withdrawn and this coincided with a more hostile climate, where zero tolerance for drug users - and users - became a key focus of government. Consequently, there was little support at a government level from hearing the views of service users.

SDF took the opportunity arising from this hiatus to reflect on the situation and develop a new model of user involvement. In 1998 we applied to a charitable trust in order to set up a West of Scotland User Involvement Project, which primarily focused on Glasgow, which has many areas experiencing significant economic deprivation and social exclusion.

This funding coincided with limited Scottish political devolution from England, with

the impending creation of a Scottish Parliament for the first time in 300 years and the establishment of a devolved Scottish government administration. The policy environment became more liberal and open and there was a key focus on social inclusion.

At this point we came up with a model that focused extensively on peer/social research and this is the model described here. From the beginnings in Glasgow, we developed further projects across Scotland including Fife, Highland, Lanarkshire and a revitalised project in Edinburgh.

6.3. The SDF model

The key overall aim of the SDF User Involvement model is to aid an improvement in the quality of specialist drug services. User Involvement volunteers are clear on why they have been recruited and what the purpose of the project is. Too often user groups are created and supported because 'user involvement' is perceived as a good thing to do – or be seen to be doing – and their work has no clear objective or direction.

Stable service users who have an interest in helping improve service quality are recruited through treatment and care services. They are then trained in survey/interview techniques. Subject areas of research, dictated by group members' interests and by current policy priorities, are then agreed.

The work involves undertaking peer surveys, presenting findings to relevant authorities and then seeking service changes.

Focus groups are also held to gain more in-depth feedback from service users, often following individual interviews. These sessions are generally taped and typed up later by administrative staff.

6.4. Benefits of the model

There are a range of benefits of this model:

- After a short time of conducting surveys, the group develops a representative overview, rather than individual perspective, of issues facing problem drug users.
- The peer research model means that evidence is produced, which can be used to argue for service changes.
- There is more frankness during surveys, since both the interviewers and the individuals being interviewed have been or are 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.
- This move-on element also means that the group membership is constantly changing; therefore people don't become stuck with a 'user representative label'.
- The group remains 'fresh' – members are either still receiving a service from treatment agencies or have recently received a service.

6.5. Weaknesses of the model

While we clearly have a strong belief in the model we have been using, no model is perfect and clearly there are areas of weakness or potential weakness.

■ Recruitment to User Involvement groups are dependent on drugs agencies

We have found that 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 reputation as service providers. This can mean some will not identify any clients for user involvement. Alternatively they may, perhaps deliberately, refer individuals who are not suitable.

Therefore, significant energy has to be devoted to recruiting new individuals in order to overcome these obstacles.

■ Continuing support for members

On becoming members – and perhaps through the course of their membership - **many users still have significant personal issues which require support** (although we would hope that this support comes primarily through the treatment agency of which they are a client).

This level of support is required to:

- maintain the group
- support individuals with relatively complex lives and health issues
- build the confidence of group members, particularly prior to them delivering presentations on their work at conferences and planning groups.

■ Service providers' response to UI findings

There is no certainty that planners and/or providers will respond positively to the survey findings. Indeed, there have been cases where our funding has been threatened because the findings proved uncomfortable reading.

6.6. Examples of user involvement surveys undertaken

a) Glasgow Hepatitis C Virus peer research survey 2007

Scotland has an estimated HCV infected population of 50,000 (2006), around 80-90% of which are current or former IDUs, with 38,000 are thought to be chronically infected. Forty-one percent of these are in the Glasgow area and there are approximately 800 new infections locally each year (*Health Protection Scotland*).

In summer 2007, SDF Glasgow Involvement Group (GIG) were asked by the local health board serving the Greater Glasgow & Clyde area to conduct a peer research survey of drug users with HCV on the issue of HCV and injecting practices.

Peer researchers developed the questionnaire, practiced delivering it and prepared to conduct interviews. Members of GIG contacted peers across Glasgow to let users know that the survey was being done over two weeks in July at SDF offices in Glasgow. An incentive was used to encourage survey participants of £10 supermarket vouchers for each person.

A total of 79 suitable people came forward. Each participant was interviewed in a private room at SDF by a peer researcher from the GIG, with each interview taking approximately 45 minutes.

SDF staff developed a statistical database to take the information collected and peer researchers filled in the datasheets, which were in turn analysed by health board staff.

The survey established:

- There were 59 male, 20 female interviewees; mean age 36 years (20-53yr).
- After being diagnosed with HCV, 83% were not referred for support, advice and/or treatment
- Reasons for no onward referral: respondent did not know (10%), in prison (25%), current IDU/alcohol use (20%), professional lacked knowledge (15%), no symptoms (22.5%), other (22.5%)
- 80% had never received any treatment for Hep C
- 62% had not disclosed HCV status to immediate family

The main barriers to accessing treatment were:

- respondents thought the treatment would not work
- there was concern about side effects of treatment medication
- individuals were still using drugs/alcohol
- some individuals were in prison when diagnosed.

The main reasons for missed appointments for HCV treatment were:

- attending appointments were not main priority for individuals at that time
- long distances to get to hospitals and transport difficulties
- concern about what hospital treatment would involve
- long waiting times for appointments.

These findings will be in a final report available in February 2008 from Joan Currie (SDF Glasgow User Involvement Development Officer) or Justin Schofield (NHS Greater Glasgow & Clyde (area health board), Blood Borne Virus Co-ordinator).

b) Multi-agency inspection: Substance Misuse Services in Grampian 2007

This was the Scottish Social Work Inspection Agency's (SWIA) first thematic inspection of substance misuse services in Scotland.

It took a multi-disciplinary partnership approach and included a service user consultation element for the first time in SWIA work,.

The area under review was in the Grampian area of the North of Scotland.

In addition to SWIA and SDF, the partners were Alcohol Focus Scotland's User Involvement groups, the Care Commission, Grampian Drug and Alcohol Action Teams and the National Health Service Quality Improvement Scotland (NHS QIS).

Peer research section of this inspection was conducted over two weeks, with 157 drug and alcohol service users surveyed. Carers were also part of this inspection, although there were very few since it was difficult to identify them.

Findings from the service users and carers highlighted:

- Long waiting times for substitute prescribing
- Service users' comments about the good quality of services
- Issues of concern about low access to dental services and lack of citric acid in needle exchange services
- Attitudes from professionals from HCV treatment services were perceived as unhelpful
- All service users felt they had achieved some positive change as a result of their engagement with services
- Carers felt stigmatised in their community because they had approached drug and alcohol services for help
- Evidence of service users' views being sought in order to plan and develop strategies
- Perceptions that service user groups had been set up to influence service delivery

The full report - *Multi-agency Inspection of Substance Misuse Services in Grampian Report 2007.pdf (442kb)* – can be downloaded from www.swia.gov.uk

6.7. Barriers to training and employment survey

A total of 115 drug users trying to get back into employment and training were surveyed in 2001. These drug users were conducted in drug agencies across Glasgow.

Barriers to training and employment include:

- Criminal record (65%)
- Stigma of being a drug user (64%)
- Access to substitute prescription whilst working (50%)
- Council tax debt (43%)
- Lack of confidence (42%)
- Earnings drop (33%)
- Lack of experience (33%)
- Time unemployed (33%)
- Poor work record (33%)
- Illness (32%)
- State welfare benefits (22%)
- Child care issues (17%)
- Never had a job (6%)

Debt was a significant issue, with 57% being in debt of some kind, however only 8% of those in debt had been offered debt counselling.

The average debt to local government for Council Tax was £2000 per person. This is simply due to failure to complete local Council Tax forms on time - possibly because of literacy problems, chaotic lives and frequent changes of accommodation.

More than half, 54%, did not possess a bank account.

83% (91 individuals) had done casual work whilst claiming state welfare benefits. This was mainly manual labour and retail work, with 40% earning £100 - £200 per week on top of state welfare benefits.

Least popular jobs were in call centres and marketing (where there were many jobs available), and most popular jobs were in manual labour and college education.

When asked about how participants were treated by government welfare agency staff, SDF was told:

- 5% of individuals had either been made to feel embarrassed or felt they were subjected to “bad attitudes” from the staff
- 20% found the level of service with these agencies to be satisfactory, 54% unsatisfactory and 24% were OK about the level of service (2% missing).

Some quotes from individuals about treatment received from Welfare Agency staff were:

“(I am) not a good writer and was made to feel embarrassed”.

“I am slow at taking in information, they had to repeat”.

For more information on this survey please contact David Liddell, Director of SDF, email enquiries@sdf.org.uk

6.8. How to deliver the model

a) Recruitment

Preparation

Once there is financial support to provide a User Involvement project (see Appendix 1 for more on finance), partnership work with local services and planning structures should be developed to:

- find opportunities for peer research work, evaluations and reviews
- gain referrals of suitable volunteer peer researchers.

This would be carried out by the User Involvement Development Officer (UIDO). This worker will also develop protocols and policies for User Involvement work, where these do not already exist.

Selection

The key motivation for a potential recruit should be for them to wish to influence the creation, development and delivery of services.

Following a self-referral or agency referral, an assessment would be done with the potential volunteer. This assessment could be conducted over the telephone or face-to-face, ideally involving service users themselves and professionals who support User Involvement.

An initial assessment should be developed to establish the user's drug stability. This will help ensure volunteers are ready to represent the organisation and conduct surveys in external agencies with more vulnerable interviewees.

Safety of both UI group member and service users who take part in the surveys is paramount. SDF conducts criminal record checks as part of a duty of care both to volunteers and those being surveyed. Issues to be considered here are continued drug use, violence and recent arrests.

Group profile

Ideally a group should be formed with 6-10 stable drug users who are either drug free or stable for approximately a month or more on their prescribed medication.

It is important to ensure a balanced group with mixed gender and mixed approaches to abstinence and substitute prescribing.

At times the group can become dominated by any one group which can be destructive to the cohesion of the whole group and certainly be off-putting to quieter/minority members.

Group training

This should involve learning about User Involvement work, roles and responsibilities, as well as basic research skills and basic computing skills(see Appendix 3 for more information on User Involvement training required for volunteers).

Group meeting should be held weekly and each member should take part in individual approximately every two months with their UIDO. It is important that volunteers are making progress with their own goals towards influencing services and individual personal development.

Through regular updates on local developments and policies around drug issues and trends volunteers are aware of, new surveys can also be devised.

For example, SDF is currently conducting a national survey on aftercare. This began through volunteers expressing concerns about this issue and a majority of volunteers voting for this to become a survey.

Over time – and if budgets permit - training can be offered to ensure volunteers are gaining sufficient skills to fulfil their own personal goals in terms of education, training and employment.

However, while we feel that employability is an important offshoot of User Involvement work, it is not the key aim.

Influencing service development and delivery has to be kept at the forefront.

In each of the six areas of Scotland where SDF has User Involvement groups, there is a commitment to produce one or more large surveys each year. One large survey of around 70 interviews, with no other additional work, can take between three and four months - with very intensive work at the time of interviewing service users. A new group would take longer to complete these tasks.

b) Group Activity

Identifying the views of service users

Peer-led interviews and focus group work with other service users is the area of work for which User Involvement groups are best known.

The interview and focus group work has informed some national and local policy making as well as service provision in some areas of Scotland.

The basis for the UI groups undertaking the survey work, including commissioned work, is the “Peer Research” model.

“Peer Research”

This is a research technique most commonly used when trying to interview difficult-to-reach groups or where the information being provided could be sensitive or relating to illicit issues. The model works on the basis that peer involvement in planning and conducting interview will:

- help engage and encourage the interview to talk freely. Drug users don't always engage with people whom they feel do not understand what the user experience has been. Peer research increases the potential for more accurate responses as the interviewee will know that the interviewer is most likely to have had a similar personal experience and is understanding of their situation

- Identify key themes and questions which can be framed using language and in a manner most likely to be understood, and responded to, by interviewees ie 'street' language.

Once a survey theme is decided, the aims, objectives, a relevant questionnaire and finally, a database to analyse information from surveys, have to be created.

All of these should involve the volunteers in:

- group discussions which clarify the aims and objectives
- testing the questionnaire to prevent duplications, omissions and to ensure the questionnaire is extremely clear.

“Closed” (yes or no) questions are useful for comparison, producing quantified results. However, it is good to have some qualitative questions to open up discussion and to gain clearer views from service users on an issue.

Volunteers can be involved in inputting data over a succession of days, though it often requires a trained worker to analyse data accurately.

Representing views of service users/group

Planning Forums

A core objective of User Involvement is that groups will present their identified views to decision-making bodies.

There must be a commitment from other participants at the presentations that the User Involvement group attendance is as valid as attendance by anyone else.

It is essential to make clear to group members that they are attending as representatives of a service user group and not attending as individual “service users”.

They bring to the meeting the views of the group as well as the views of the wider service user community identified from the group's survey.

The group members can speak from their own experience and give their own opinions where they see fit but their **primary responsibility** will be:

- to represent the group and the group's work
- to report back to the main user group any decisions or any work in which the group may be asked to, or wish to, participate.

Specific training will be offered to those wishing to undertake presentations and group members are not forced to be involved in this particular area of activity should they not wish to.

Participation at Conferences

Participation at conferences can be a very enjoyable and worthwhile experience for group members on many different levels. They can gain increased knowledge and awareness on various issues, in networking and from the opportunity to represent the views of the group and service users.

Representation can take two distinct roles, as:

- a) conference attendee

As with other attendees, the primary objective from attending a conference is to learn both from the event speakers and from the other attendees.

It is normal now for most conferences to have a participatory element to the conference (i.e workshops, feedback sessions). This places an expectation on attendees to participate by providing their opinions/experiences on the chosen topics.

It is important that group members are aware of this, are happy to contribute and have something to say from which others can learn.

Some preparatory work can be very beneficial.

b) conference facilitator

The nature of conference facilitator is more defined and is to present or assist the presenting of a talk on a specific subject.

Facilitators can lead their work in a range of ways, from highly pro-active (ie asking all the questions) to guiding participants to shape the agenda and responses. Irrespective of the method, this requires considerable preparation on the part of the User group member as those attending are expecting to learn and benefit from the group member's input.

Meetings

The UI groups should meet once a week. In the initial stages of the Group's life, the agenda will be set by the UIDO who chairs the meeting.

However, any group member present can raise issues of concern or interest and make any appropriate input into the meeting. Once the group has been established and training provided on how to run a group, the expectation is that the group meetings will take a more proactive role in running the group meetings.

Group meetings are an important part of group membership

because they are the forum for:

- discussing the group's activities
- debating the issues that the group could be involved in

- exchanging knowledge and information
- seeking help and support from the group and the UIDO
- getting to know each other better
- training

Disciplinary issues

If volunteers return to illicit drug use or become unstable in their drug use, they are asked to take some time out from the user involvement work, and not to conduct peer interviews in drug services.

This means they can return to the group with a two-to-three month period, once they are stable again.

If appropriate, the person's original drug worker can offer support during this period and the SDF UI development officer would keep in contact with the volunteer during this period.

Appendix 1

Finance for an SDF user involvement project

- Travel - for volunteers and staff
- Vouchers - for survey work
- Training - for volunteers and staff
- Salaries - for one fulltime User Involvement Development officer (UIDO)
- Management - of overall project and UIDO
- Administration - frequent petty cash handling, occasional data inputting, typing up taped focus groups

Start up costs

- 2 computers (1 for UIDO and 1 for communal use of the UI group)
- SPSS software
- Stationery
- General office equipment
- A total of £55,000-65,000 per annum is the average annual cost for an SDF model of a UI project in an urban area.

Appendix 2

Role & Responsibilities of UI Development Officer (UIDO)

The volunteers are the project's core and the UIDO is the lynchpin that keeps the project together. The UIDO's primary responsibilities are:

- to develop and maintain the group
- to provide the link to local and national agencies, including funding agencies
- to provide and/or organise training and support for group members to undertake their UI activities
- to administer and manage the UI activities, including the project's funds
- to provide and/or organise training and support for group members to progress into education, training or employment opportunities
- at times to represent the views of the UI group at planning meetings
- to provide regular reports on the above to line managers and/or funding bodies.

Appendix 3

Training for volunteers

During the first three months the new group member should receive Introductory Training (2 days) covering all the following:

- User Involvement
- Concept
- Aims & Objectives
- Introduction to UI Activities
- Roles/Responsibilities of the Volunteer and the Development Officer
- Scottish Drugs Forum
- Aims & Objectives
- Sections
- Membership
- Decision Making/Planning Process in the area
- Team working/building

This training should be completed during the first three months. New group members will also shadow more experienced group members undertaking user involvement activities, for example, survey work or presentations. New survey work will involve an informal element of re-training where particular issues with questionnaires can be addressed.



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7.

Drug user activism – an overview

Stijn Goossens (INPUD)

7.1. The research – purpose, methods, international response

In 2007, the International Network of People Who Use Drugs (INPUD vzw) in cooperation with the European Correlation Network conducted a six-month on-line research on the profile of drug users' (DU) activism and self-organisation. The research gathered information about the type of the drug users' organizations (DUO) world-wide, the level of involvement of DU community in the work of the DU activists' (DUA) organizations, about the geographical coverage, as well as about the regions, in which the DUO are most active, and others. The main aims, the main area of work of the DUO, the types of funding they receive (governmental, municipal, private, local, international, etc.), their partners, targeted allies and opponents, their main expertise, and other related questions were the topics of the research.

The main aims of the research were:

- to create a detailed database of the DUO world-wide
- to map the areas they work in, their main needs and interests
- to identify possibilities for international cooperation and support

On the longer term, the analysed results of the research will be used by INPUD vzw and the Correlation Network as a base to develop a medium- and long-term strategy for involving the DUO that have participated in the study, as well as their partners and colleagues world-wide (that were included later on in the data-base) in the international DU activism and in closer cooperation at international level with other community-based organizations, professionals and service-providers working with all marginalized communities.

The research started in May 2007 by publishing a questionnaire, which included questions on all topics mentioned above, as well as control questions on some main topics (e.g. level of involvement of different peer groups, areas of main activities, main expertise, others) on the INPUD web site (<http://www.inpud.org/>). 38 INPUD members and supporters from 21 countries worldwide responded to the request and filled-in the on-line questionnaire. The full information about the DUO, included in the research, their legal status, activities are collected in a database.

7.2. Summary of Results

Detailed information about the results of the questionnaire can be found in annex 1. By the end of October 2007, the results from the first six months of the research were evaluated. In order to be able to include as many DUO as possible in the database, the on-lined questionnaire is still opened, the database is constantly updated, and the results are re-evaluated.

7.2.1. Regional coverage

The results from the first six months of the research are based on the analysis of the answers of 38 DUO from 21 countries worldwide. Geographically they are spread as follows:

- from Europe

countries: number of countries from the region: 14;

percentage of the overall number of the countries: 66.67%

DUO: number of DUO from the region: 19;

percentage of the overall number of the DUO: 51.35%

- from the European Union

countries: number of countries from the region: 12;

percentage of the overall number of the countries: 57.14%

DUO: number of DUO from the region: 17;

percentage of the overall number of the DUO: 44.74%

- from Asia

countries: number of countries from the region: 3;

percentage of the overall number of the countries: 14.29%

DUO: number of DUO from the region: 10;

percentage of the overall number of the DUO: 26.32%

- from Oceania

countries: number of countries from the region: 1;

percentage of the overall number of the countries: 4.76%

DUO: number of DUO from the region: 1;

percentage of the overall number of the DUO: 2.63%

- from North America

countries: number of countries from the region: 2;

percentage of the overall number of the countries: 9.52%

DUO: number of DUO from the region: 6;

percentage of the overall number of the DUO: 15.79%

- from South America

countries: number of countries and the DUO from the region: 0

- from Africa

countries: number of countries from the region: 1;

percentage of the overall number of the countries: 4.76%

DUO: number of DUO from the region: 1;

percentage of the overall number of the DUO: 2.63%

- DUO working at international level

DUO: number of DUO from the region: 1;

percentage of the overall number of the DUO: 2.63%

7.2.2. Main priorities

6 DUO (i.e. 15.79% of all DUO that have filled in the questionnaire) have not provided information on the topic. Judging by the main expertise the DUO from the research have appointed for their organizations, by the areas they work mainly in, as well as by the their partners and targeted allies, the main priorities DUO have are listed below in descending order:

- advocacy
- harm Reduction
- peer support and education in DU community in general - e.g. for IDUs, for people on substitution treatment, for ravers and people from the party scene
- peer support for PLWHA
- media production
- trainings and workshops, peer meetings
- accommodation and service providing programmes

- detoxification, treatment, rehabilitation centres
- community empowerment and mobilizing
- education and drug and blood born disease (BBD) prevention in youth community
- public Health system
- networking at International level

7.2.3. Main activities

According to the information provided by the organisations that took part in the research, the main activities in descending order are listed below. 4 DUO have not provided information about their main activities. Part of the side-activities, included in the answers of the DUO, have no statistic significance and are not included in the list below. The complete information on this topic is available in Table 2. The main activities can be summarised as follows:

1. advocacy and health/drug policy making
2. peer support for PLWHA
3. peer support for DUs
4. HIV and other BBD education and prevention
5. issue/publish e- and printed magazines and newsletters
6. producing other types of informational materials
7. organizing, conducting, moderating trainings, workshops, seminars, peer meetings
8. educational and peer support work in the party scene
9. running accommodation projects
10. drop-in centres with various services
11. rising public awareness about the main problems in the DU community

7.2.4. Services, provided by the DUO

8 DUO (e.g. 21% of all DUO that have answered to the questionnaire) have not provided information on the topic. The services the rest of the DUO from the research provide are listed below in descending order:

1. awareness and information
2. peer support for all communities above
3. outreach and prevention / information
4. newsletters and magazines
5. information, educational and promotion materials
6. drop-in with various services (e.g. basic needs, different classes, tel., Internet, etc.)
7. needle exchange
8. drug and BBD education and prevention
9. trainings, seminars, and workshops in the area
10. detoxification and treatment centres
11. support and information for party organizers
12. syringe patrolling
13. face to face consultations
14. medical referrals
15. legal help and advice
16. drug checking
17. psychological support related to drugs consumption
18. relax zone, chill-out
19. accurate information through regularly updated Internet sites
20. telephone hot-lines and help-lines

7.3. Analysis of the results

The strongest impression by the results of the research is made by the obvious increase and upraise of drug user organisations worldwide, the broad range of areas DUO work in, and the variety of services they provide. DUO from Europe and particularly those from EU-member states are obviously most prevalent. Another obvious result is that most of the DUO have appointed advocacy and health/drug policy making as their main priority and main area of activity, which is also proved by the answer of 16 DUO (42.11%) that identify policy makers as one of their main targets / involved parties in their work, and 17 of the DUO (44.74%) state that they partly target / involve politicians in their work. This is also related to the answers of 25 DUO from the research (67.57%) that they received governmental funding for their work at municipal, regional and/or national level. Only 1 of the DUO answered that they received governmental funding for activities at international level. The fact that the local municipalities / governments are willing to finance the work of DUO at local, regional, and national level, but still do not see the need to finance their work at international level, can show the need for better coordination, networking, cooperation, exchange of ideas and experience between local DUO at international level, which should result in improving their work at local level, introducing best practices that exist world-wide in their local communities, thus giving decision-makers in their countries evidence-based proof that cooperation at international level is vitally important for the activism in marginalized, community-based organizations. This is also supported by the fact that 52.63% of the DUO that have taken part in the research, received private grants for activities at international level.

The second main activity and priority, appointed by the DUO in the research is harm reduction. The connection between drug users self-organisation and the current global policies on drugs is more than obvious. In the years when global prohibition and its logic results – restrictions, stigma, HIV and Hep C epidemics, etc. have reached a peak in causing damage and harms to society at large and especially to the DU community, DU organize themselves to advocate for more effective and more cost efficient health approaches to the problem of drugs use. At the same time, peer-support and raising public awareness about the most acute problems in the DU community have also a high priority amongst activities of DUO worldwide.

Still, the main benefit from this research is that it shows that the profile of DUO world-wide (and the profile of the DUA that run the DUO) completely differs from the general image of drug users that has been imposed on society for decades. The research showed that DUO are capable of running a variety of services and have proved themselves to decision makers in their countries as reliable and capable partners and as an indispensable part of civil society. The next logical and inevitable step would be to develop and expand newly founded DUO unions and networks at international level, and proving decision-makers from all international institutions involved, that DUO should be considered not only as competent and equal partners, but also as indispensable experts in the drug-policy making process.

Annex 1

Total number of organisations		38		
Period of the Online Research	6 months			
Criteria	Results in numbers	Results in percentages	Number of answers "Not Available"	Percentage of answers "Not Available"
Regions:				
from Europe			0	0,00%
countries	14	66,67%		
organizations	19	51,35%		
from EU				
countries	12	57,14%		
organizations	17	44,74%		
from Asia				
countries	3	14,29%		
organizations	10	26,32%		
from Oceania				
countries	1	4,76%		
organizations	1	2,63%		
from North America				
countries	2	9,52%		
organizations	6	15,79%		
from South America				
countries	0	0,00%		
organizations	0	0,00%		
from Africa				
countries	1	4,76%		
organizations	1	2,63%		
International	1	2,63%		
Total				
countries	21			
organizations	38			

Years of existence				
Less than 1	7	18,42%	7	18,42%
Up to 5 (including less than 1)	14	36,84%		
More than 5	17	44,74%		
Legally registered	37	97,37%	0	0,00%
Statues	29	76,32%	6	15,79%
Registered membership	27	71,05%	1	2,63%
Number of members				
Up to 50	14	37,84%	5	13,16%
More than 50	9	24,32%		
Non-members organizations	10	27,03%		
Maximum nr. of members	650 members			
Funding				
with private funding	21	54,05%	1	2,63%
with governmental funding	25	67,57%		
with both	9	23,68%		
Governmental funding for activities at: (level)				
City	12	31,58%	4	10,53%
Regional	11	28,95%		
National	10	26,32%		
International	1	2,63%		

Type of organisations							
an Interest (Advocacy) Organisation							
	not at all	8	21,05%	o	0,00%		
	partly	11	28,95%				
	very much	19	50,00%				
a Patient Organisation							
	not at all	11	28,95%				
	partly	14	36,84%				
	very much	13	34,21%				
a Drug User Organisation							
	not at all	1	2,63%				
	partly	7	18,42%				
	very much	30	78,95%				
a Peer driven Harm Reduction Organisation							
	not at all	2	5,26%				
	partly	14	36,84%				
	very much	22	57,89%				
A Specified Peer Organisation							
	not at all	3	7,89%				
	partly	12	31,58%				
	very much	23	60,53%				

Types of the groups for specified peer organisations <i>(in order of involvement, 8 organisations haven't provided information)</i>				
DU in general				
Injecting Drug Users				
DU on maintaining treatments				
Peer support for DU educators				
Peer support for IDUs educators				
Sex Workers				
Ravers and party stimulant users				
Homeless				
PLWHA				
DUs, affected by blood born infections				
Street scene in general				
Gay and transgender groups				
Women living with HIV/AIDS				
Women DU s				
Users' relatives				
Women's peer support groups				
cannabis consumers				

Levels, the organisation work at				
City	4	10,53%	0	0,00%
Regional	4	10,53%		
National	3	7,89%		
International	5	13,16%		
City, Regional	5	13,16%		
City, Regional, National	2	5,26%		
City, Regional, National, International	12	31,58%		
City, National	0	0,00%		
City, International	0	0,00%		
National, International	3	7,89%		
Main activities:				
<i>(in order of involvement, 8 organisations haven't provided information)</i>				
advocacy and /health&drug/policy making				
peer support for PLWHA				
peer support for Dus				
HIV and other BBDs education and prevention				
drug prevention				
e- and printed magazines and newsletters				
producing informational materials				
trainings, workshops, seminars, peer meetings				
education and peer support in the party scene				
accomodation projects				
drop-in with various services				
public awareness				
prevention and education campaigns for adolescents				
safer sex and safer drug use education				
detox, treatment, rehabilitation				
help and hot lines				
basic health care services				
making research and guidelines				
overdose management program				
legal counseling				

Groups/People Involved/Targeted by the work of the Organisation				
People who use drugs				
not at all	0	0,00%		
partly	1	2,63%	0	0,00%
very much	37	97,37%		
Policy makers				
not at all	5	13,16%		
partly	17	44,74%	0	0,00%
very much	16	42,11%		
Scientists				
not at all	14	36,84%		
partly	22	57,89%	0	0,00%
very much	2	5,26%		
Medical professionals				
not at all	6	15,79%		
partly	21	55,26%	0	0,00%
very much	11	28,95%		
Non-medical professionals in drug use related fields				
not at all	6	15,79%		
partly	25	65,79%	0	0,00%
very much	7	18,42%		
The public				
not at all	2	5,26%		
partly	21	55,26%	0	0,00%
very much	15	39,47%		
Media				
not at all	9	23,68%		
partly	20	52,63%	0	0,00%
very much	9	23,68%		
Specified Peer Groups				
not at all	2	5,26%		
partly	14	36,84%	0	0,00%
very much	22	57,89%		

Types of the peer groups involved in the work of the organisations: 2 organisations do not involve specific peer groups and 8 organisations haven't provided information.				
The specific peer groups in decreasing order :				
IDUs and DU community				
DU at maintaining treatment				
PLWHA Hep C. infected, and other BBDs infected people				
sex workers				
imprisoned and with prison background				
peer educators				
Women DU and IDU				
Homeless users				
cannabis consumers				
youngsters at risk of drug use, BBDs infections				
affected population				

Main expertise:				
6 organisations haven't provided information. The specific peer groups in decreasing order :				
Advocacy				
Harm Reduction				
Peer support and education in DU community in general - e.g. for IDUs, for people on substitution treatment, for ravers and people from the party scene				
Peer support for PLWHA				
Media production				
Trainings and workshops, peer meetings				
Accommodation and service providing programs				
Detox, treatment, rehabilitation centers				
Community empowerment and mobilizing				
Education and drug and BBDs prevention in youth community				
Public Health system				
Networking at International level				
Service Providing				
Yes	37	97,37%		
No	1	2,63%		

Types of provided services				
8 organisations haven't provided information. Services in order of involvement:				
Awareness and information				
Peer support for all communities above				
Outreach and prevention / information				
Newsletters and magazines				
Information, educational and promotion materials				
Drop-in with various services (e.g basic needs, different classes, tel., Internet, etc.)				
Needle exchange				
Drug and BBDs education and prevention				
Trainings, seminars, and workshops in the area				
Detox and treatment centers				
Support and information for party organizers				
Syringe patrolling				
Face to face consultations				
Medical referrals				
Legal help and Advices				
Drug checking, Psychological crisis related to drugs consumption support - Relax zone, Chill Out				
Accurate information through regularly updated Internet sites				
Help and hot telephone lines				



8.

Authors

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Jørgen has for many years and in many different contexts been studying social movements, empowerment and user organisations. For the last few years he has been dedicated to a research project which explores the emergence of user organisations by homeless people, drug users, and social assistance recipients. His most recent publications includes an article on the emergence of an interest organisation of homeless people (in Critical Social Policy) and a comparison of opportunities for autonomous organisation by drug users in Denmark and Sweden (in Journal of Social Sciences).

Vibeke Asmussen Frank

Senior Lecturer, Centre for Alcohol and Drug Research,
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Vibeke has done qualitative drug research focusing in particular on drug user perspectives, user participation, and the psycho-social aspects of methadone maintenance treatment. She is co-editor of a reader on drug user perspectives. Recently she has included the different changes and effects of cannabis policy in Denmark into her focus of research.

Petra Kouvonen

Helsinki

Petra has been employed at the Nordic Center for Alcohol and Drug Research since 1999 and has been engaged with epidemiology and qualitative analyses of drug use and interventions. Nowadays she is working at her phd. The theme is societal handling and care of children placed outside their homes. The interest lies in the ideological shifts in policy and practice.

Dolf Tops

Lunds University

Dolf has had a great interest in drugs and drug use since the sixties. After a career as a social worker he now works at the School for Social Work, Lunds University and does research in Drug Policies. He also is member of the Board of the Swedish Users Organisation.

Lorenzo Camoletto

Social worker, Gruppo Abele, Turin

Lorenzo is a social worker and a trainer of Gruppo Abele foundation since 1994. From 2002 till now, he is working at 'University of the Street', which is the training agency of Gruppo Abele. Issues are: empowerment, low threshold and harm reduction services, linked to users, migrants, and homeless people. He is a member of the regional network of low threshold workers and was involved in several European projects: Ac-Company, Living with the Daily Dose, Equal Palms, Achille's hills.

Leopoldo Grosso

Psychologist and psychoterapeut, vice-chairman of Gruppo Abele, Turin, Italy.

Leopoldo is in charge of the Social Affairs Ministry Work Group on Low Threshold Interventions, member of the National Drug Addiction Commission of the Ministry of Social Affairs. has worked for the Rivoli Sert, a service provider of national health service as psychologist from 1979 to 1989 than for Gruppo Abele, in which he is vice-chairman and 'università della strada' director (the training agency of Gruppo Abele).He has conducted several courses on social diseases issues to professionals all over Italy.

He has published several articles on addiction, prevention and prostitution issues.

Theo van Dam

Advisor, Netherlands

As an (ex-) user Theo is involved in drug user organizations since the 1980ies in the Netherlands. He was the initiator of several trainings for users and workers; e.g.; safe use and safe sex training, and the training how to become a social dealer, training respect and dignity. He initiated LSD foundation. Nowadays he is working as a trainer for Harm Reduction Workers and students of Schools of Social Work about Harm Reduction Plus strategies. He is still working from the perspective of drug users.

Stijn Goossens,

Director, International Network of People Who Use Drugs, Antwerp

Stijn was involved in the foundation of several user and advocacy groups in Belgium and currently is director of the international user foundation INPUD. He is advisor for the International Harm Reduction Association and the International Harm Reduction Conference.

David Liddell

Director Scottish Drug Forum, Glasgow

David has worked in the area of drug policy and practice since the early eighties. He has been an active proponent of evidence based harm reduction policies He has been a member of the Scottish Advisory Committee on Drug Misuse since its inception in 1995. He is joint Secretary to the Scottish Parliament's Cross Party Drug and Alcohol Misuse Group. He is active in ERIT, a European Association of umbrella organisations working in the drug field in Europe. He was recently appointed to the UK Advisory Council on the Misuse of Drugs.

Biba Brand

West of Scotland Regional Manager, Scottish Drugs Forum, Glasgow

Biba has 14 years involvement in the drugs and care field. Her current role focuses on Alcohol and Drug Action Teams (ADATs), strategic planning groups in the West of Scotland. Other duties include managing User Involvement projects and a moving into work project. She was also active in the development of local ADAT employability subgroups in the West of Scotland. Recent policy work has resulted in the setting up of a successful overdose prevention pilot - the Glasgow Take-Home-Naloxone (THN) project for drug users and carers. The THN is an inaugural pilot in Scotland and the largest in the UK. Prior to joining SDF, Biba worked within residential/outreach drug services for women in Glasgow. Before entering the care field Biba trained as a teacher, in a wide range of settings, including residential schools in India.

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In its 2005-2007 working plan, Correlation implemented various expert groups, relevant to the issue of health and social inclusion. Those working groups exchanged knowledge, experiences and views; the working group members gathered and shared information and working methods that were expected to be valuable for colleagues all over Europe working in this field.

This reader focuses in particular on issues around empowerment, in particular in the area of intravenous drug use (IDU). For the entire work plan and the other Correlation working groups, please see www.correlation-net.org.



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