

Junkies in the House of the Lord

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Introduction

During the last decade, a growing social justice movement has been evolving, which challenges the illegalisation of some drugs and posits that the "war on drugs" is causing more harm than the drugs themselves. (Drug Policy Alliance - DPA, Open Letter to Kofi Annan 1998) This 'war' also referred to by leading AIDS/drugs activist - J.Mordaunt (1957-1995) - as a 'war on drug users'- includes the denial of clean needles to injection drug users (IDUs), an AIDS prevention policy, which has been proven to work by researchers all over the world (Stimson G et al,1989).

In America, half a million non-violent 'offenders' are incarcerated on drug related charges – part of "the impact of the war on drugs" (M. Mauer, 2003) This 'war' continues unabated in countries with ultra-prohibitionist policies: April 2004 saw the first internationally coordinated campaign within this movement against the extra-judicial killings of small user-dealers in Thailand. Even Amnesty International contributed to this – something long awaited by reformers and hence viewed as some kind of a turning point. Previous to this, most Human Rights organisations had rarely collaborated with campaigners on drugs issues, hence the potential significance this may have for furtherance of international drug policy reform issues.

This policy also includes the enforced herbicidal eradication of coca in Latin America and opium plantations elsewhere, which has been shown to destroy part of the natural ecology, and previously gave employment to thousands of peasant farmers then left unemployed (Blickman & Bluestone 1998). The U.N. Office of Drugs and Crime (UNODC) has made efforts to provide 'alternative crops' to farmers but the fact remains that their successes are minimal; no sooner has one crop been eradicated when another blooms a few acres away. (Molinski, 2004). While this continues, millions are incarcerated for such minor 'crimes' as cannabis-use and street warfare increases between rival dealing gangs fighting over unregulated drug-trading arrangements.

Several names for this movement are used interchangeably: in the U.S. it is often called the Harm Reduction¹ Movement, where basic access to drug treatment, particularly clean needles is continually denied. At a drug policy conference in 1999, an ex-IDU harm reduction advocate challenged the acting head of the U.S. Office of National Control Policy about zero federal funding of Needle Exchange Programs (NEPs) in the U.S. His reply was that G.Soros (who has funded NEPs) "*just wants to come into our country and ruin our communities by legalising drugs.*" In fact, an article by E.Nadelmann, DPA's director, said that neither he nor Soros were convinced that legalisation was the optimum policy. However, in Europe, where Harm Reduction has been integrated into several countries' drug strategies, full-time campaigners are more likely to speak of legally regulating the drug trade. Though the name(s) of the movement may seem irrelevant to many, it would be useful to clarify which label refers to what. Suffice it to say that in general (globally) the drug policy reform movement mushroomed out of the harm reduction movement though the latter tends not to include 'recreational' drug activists.

User groups (or *Unions*) are active components of this movement. These groups comprise people who are, in general, understood to physiologically require drugs daily in order to function. An encouraging fact unearthed in the research is that drug-users have organised to lobby for their health and human rights in at least 30 countries, including Brazil (2003) and Nepal (the Lifesaving and Life-giving Society of Kathmandu.) In countries as far apart as Australia, Holland, Canada and Argentina, drugs-users (with and without professional assistance) are well organised.

Many of the groups include ex-users, who continue to experience discrimination in employment and health-care (post-addiction). It is implicit within the movement, that unless users damage a person or their property, they should not be arrested and/or punished for consuming drugs.

Several issues make this subject matter interesting including the inside/outside position of drug users. In one sense, users are victims of profound 'labelling' (Becker 1963) and yet from

¹ "*Harm reduction is a social policy which prioritises the aim of decreasing the negative effects of drug use,*" (Newcombe, R 1991), which has previously lived uneasily with the aim of persuading users to abstain. However, as a consequence of AIDS, there was an urgent need to prioritise stopping HIV from spreading. In the U.S. licit clean needle distribution (a strategic component of harm reduction) was seen as condoning drug use/addiction...

the outside they stand and challenge what goes on 'inside' and thus dare to challenge prevailing attitudes and policies towards drug users. In doing so, they highlight ways in which alternative approaches may benefit themselves and the community as a whole. In efforts to appreciate this partial integration, i.e. the responsibility of running a bona fide charity, users tend to work diligently. Given this and their potential opportunity to affect change, I strongly identify with K.Fox (1991), when she says, "*What I did begin to question is the morality of the enterprise if our work is not at least intended to inform some policy decisions...*" Certainly the importance of ongoing daily peer support should not be understated, but how, if at all, can drug users, improve social policies that affect themselves and their surrounding communities?

Aims:

This dissertation explores the extent to which such drug user groups may influence drug policy and practise, with a focus on a few countries, which have funded these projects.

Another question concerns the role of the church in user's lives, particularly as one Dutch church has been accommodating a consumer room (safe place for daily users to ingest their drugs without police intervention) for many years, facilities that merit particular attention due to their specific functions. In summary then, it seeks to show whether these groups have had any impact on drug policies locally or nationally, and thus in the wider drug policy reform debate, and if so, what these impacts have been.

A key aim of the research was to clarify - by documenting the work of some groups - where member's energies are best used, and so focusing their attention there. (Regardless of policy, many allies believe these groups have a therapeutic value in creating the opportunities for users to help themselves, but increasing nos. of user group activists also seek to change drug policy itself.) Moreover there is so little written on this subject, many activists believed it was past time to change this. M.Taylor (2000) concurs with this also, saying there is very little written on user empowerment particularly in the voluntary sector, (though she is speaking more generally) not just about illegal drug users.

What is a User Group?

Drugs users, illegal or prescribed, have developed many models of self-organisation but their great diversity in size and function can make definition difficult. A group could consist of as few as three people focusing on local improvement of their drug treatment services (REFORM in London) to larger Non Governmental Organisations (NGOs), with sufficient funding to pay employees, e.g. the Drug Users Advocacy Group in Amsterdam, (MDHG), who also lobby on a national level. Albeit that some User activists are salaried, it should be clear that the majority in this research, and in general, are volunteers. The reasons for this range from a lack of skills, confidence or consistent good health to the State undervaluing their inputs as politically unacceptable or lacking in therapeutic substance. Drug users are often led to believe that they 'owe' something to society, thus establishing the notion that they do not deserve salaries, not to mention the fact that known drug users experience overt and covert employment discrimination, (less likely to be an issue in the drugs field.)

In their article "Defining the Drug User," (1998) Balaran and White differentiate between 'recreational users' and users who appear to have lost the choice to recreationally use. They challenge ex-users who desire union membership to consider whether they are 'strong' enough to be around active drug users without lapsing, and to take responsibility for the lapse should it happen. M. Southwell, founder of the National Drug Users Development Agency (U.K./NDUDA) also offers a definition: "Drug users, who may/may not have used treatment services, but have worked within the established user groups, and related activism."

I will define User Groups as, "*A group of ex/current criminalised drug users who try to improve the quality of their lives and of their wider communities by campaigning for local and/or national drug policies, which typically work towards reducing the death, disease and (where possible) crime, related to illicit drug use.*"

In the course of this research, it became clear² that many 'drug addicts' in this movement reject terminology that in any way pathologises, judges or belittles them, e.g. *misuser* and 'addict.' They refer to themselves as drug-users, or 'people who use illegal drugs.' For them, it is their criminalisation, which causes most of their health and social problems, i.e. forced into criminal markets to buy poor-quality highly priced substances (Becker; pp35) creating their problems.

Some commentators believe the word drug-user is inadequate too, as it does not differentiate between people who use drugs recreationally and those who use in order to prevent withdrawal sickness. Indeed, many related documents on the subject speak of those who "cannot or will not stop." Hence we see the jury is still out on this issue. A recent study by Keanes and Strang (2004) actually found that 'patient' was the word many found most acceptable.

Drug user organisations have been part of Harm Reduction implementation (Friedman, SR 1996) in many ways including teaching one and other about safer injecting (or other) drug-using practises, lobbying health-care authorities to establish adequate BBD-prevention programmes, BBD-prevention itself and media work about how non-criminalising drug policies can enhance lives (not just those of drug users.) They also, of course, keep themselves and others up to date about addiction treatments(s). Their own newsletters, e.g. *Mainline* in Holland and the *Users' Voice* and *Black Poppy* in the U.K. have facilitated many of these functions.

Another specific example of a harm reduction measure is the Safer Injection Rooms, whose essential role is to provide a safe and hygienic environment for 'hard-to-reach' daily injectors to ingest their drug, with medical supervision if and when necessary. Safer Injection Rooms can reduce the nos. of overdose deaths and bring more users into drug treatment.

² Since the end of the 1990s the 'DPFU' list consisting of experienced long-term User Activists from Australia, Holland, Germany, U.K. Denmark, France, Canada and America, has facilitated relevant discussion. Following a 'mistake' in the *Users' Voice*, where the word 'addict' is used, several members of this list conducted a heated semantic-debate (for at least a fortnight) about the words used to describe daily users, much of which is felt to be demeaning and hostile towards drug users. As I had made the 'mistake' I suggested that we used literal words, e.g. daily heroin user; this was accepted as politically inoffensive amongst others, e.g. *illegalised users*

Self-help organisations in the drugs field generally refer to those that are about assisting one another to come off drugs and remain abstinent, e.g. Narcotics Anonymous. These are different from self-organised groups of active drug-users engaged in treatment advocacy or harm reduction interventions, which are the models researched here.

In Holland, as far back as the late 1970's, IDUs started informal needle provision in response to a rapidly spreading Hepatitis B epidemic, which had already killed six injectors. More recently, as the expanding choir about the dangers of the 'war on drugs' has grown, such User-groups have begun to contribute, at least in debate and written word to the growing chorus of politicians, (Mo Mowlam) academics (Drucker.E, Wisotsky, Nadelmann, Levine, HG) clinicians (A.Wodak) and others, who question Global drug prohibition, and list its failures:

- The spread of life-threatening blood borne infections amongst injectors
- Increasing numbers of incarcerations of non-violent drugs-users.
- Increased nos. of drug users.
- The decrease in price of drugs in parallel with the increase in purity.
- The ongoing corruption of 'legitimate' institutions discovered-to-be benefiting from the trade.
- The huge waste of citizen's tax money that goes towards upholding this system.

Research

Methodology

I interviewed 30 drug users from Holland, England and Denmark, and I chose these countries because: 1) I had been repeatedly invited to visit one of the user groups, so I felt eager to take this offer up. 2) It was suggested that I choose a few European groups and detail their work closely. In this instance, some respondents were eager to participate, as they enjoyed sharing their life and work to a known (long-term) user activist

This research was carried out within a mixture of ethnography and qualitative methods. Face-to-face interviews were used as, having been part of user groups myself, I am well aware of their priorities – *survival*. Questionnaires-on-line come near the bottom of their list of ‘things to do.’ I might also be described as participant observer too, cooperating in activities of the group.

The process was not without complications. Some of the interviews were held within the context of ‘club night’ at the MDHG, which constitutes up to 70 people socialising, many of whom are smoking heroin and/or cocaine. Though this doesn’t necessarily affect the ability of respondents, it did intrude upon the flow of interviews, as others constantly sought drug-using paraphernalia, or drugs, from each other. On occasion, users would answer the question about their personal histories far more deeply than others, but for the most part, we managed to focus on the prepared questionnaire. In Copenhagen, I was kindly accommodated overnight(s) by one respondent, whom I would often awake to find injecting heroin intravenously: this was worrying, as she appeared almost unconscious. I simply made sure she wasn’t and carried on.

It was vital to interview leading members in all three countries, who are responsible for representing their group at local, national or international fora, as they were the campaign-workers of (at least) two of the groups and thus knew of drug policy alterations as a result of such activity.

Of the three organisations, MDHG has the longest history – 30 years. However, other groups included equally skilled advocates. It is important to note that in this investigation, many respondents specifically chose to be named (rejecting anonymity) In fact, they deemed this

essential, viewing it as furtherance of the aims of their groups, i.e. to take the shame out of addiction and drugs-use generally.

I asked each drug user activist the following questions:

- How long they had worked at their respective User Group.
- Whether they had represented any other similar organisations? How they had represented any/all of them.
- How long they had been promoting harm reduction and what their understanding of it was?
- How long they had used illegal drugs; a little of their personal history, to give an indication of the social, health and/or legal status of each user.

MAIN QUESTION:

Please cite examples of your input and/or impact either

a) As an organisational representative, **or** as an individual, as it might affect local, national or international drug policy.

b) Have you had any involvement with the drug policy reform movement?

Most of the respondents were white males between 30 and 52 yrs old. The women were also white, apart from one Surinamese non-using worker at MDHG, of the same age group. All apart from one of the respondents were currently in treatment, and/or smoking heroin daily and had worked at their respective Unions for times spanning between a few weeks and 7 yrs, with an average of 2 years.

Findings

Holland ‘Kicks Off’ With Junkybonds

Holland has the longest officially recognised history of drug user groups, called Junkybonds. MDHG in Amsterdam, which now calls itself a users' advocacy group (as opposed to Junkybond, as it once did) is comprised of a mixture ex/current drug users, with a paid workforce of four. It was established in 1977, and at least until 1992, received funds from the Amsterdam City Council.

Their life-saving BBD-prevention work was first reported in 1984, when they started to exchange clean syringes for used ones. The State-led drug agencies saw this intervention as promoting injection drug use (IDU), and didn't officially include it in service provision for another five years. In their book "Drugs and AIDS in the Netherlands," they describe their *raison d'être*, "...Based on the acceptance of drug users, and, thus, also the acceptance of drug-use." A direct impact that the MDHG had at this time, was to stop the implementation of the 'city centre banning order.' This would have banned users from entering the city centre for 14 days if they were deemed to be repeatedly creating a public disturbance, defined as congregating collectively in small groups and just talking. (This was – is - especially so if they had received up to five previous eight-hour bans.) The MDHG considered this measure contrary to principles of the legal order and so challenged the Chief Administrative Judge of the NL, and won the case.

Rotterdam

Nico Adriaans founded Rotterdam's Junkiebond, the first Dutch group in the mid-1980's. At the height of the Dutch heroin epidemic, Adriaans is noted as having “an indispensable role in changing the face and character of Dutch drug policy”³ (Dr. JP Grund, 1995). The Rotterdam Junkiebond worked towards establishing drug policies away from compulsory treatment towards pragmatism and normalisation.

³ This mention of Adriaans (R.I.P) comes from the Ibogaine Dossier website. Ibogaine is a scheduled (not illegal to possess – U.K. – but one is not allowed to administer it without authorisation) drug known to successfully treat chemical dependencies. Adriaans is mentioned on this site, as he was one of the first opiate users to publicly speak about his successful withdrawal from heroin with Ibogaine.

Reverend Hans Visser, director of the Pauluskerk (St Pauls Church) near Rotterdam central station, lamenting the lack of innovators like Adriaans these days in Holland, refers to him as an *"intelligent and creative rebel"* and inspirant regarding the establishment of consumer rooms in his church. Reverend Visser's account of his impulse to set up these rooms came when he was arriving to work one day and found an IDU using water from a puddle in the ground to set up his next injection. Hans Visser told him to come into the Church and get some clean water.

At the Pauluskerk, they are described as 'Toleration Zones' where illicit drug injectors are permitted to ingest their substances without interference. There is constant supervision and strict rules of hygiene. The KSA say that they allow this illicit use to relieve nuisance to society but it is also to be able to intervene medically when necessary.

Perhaps the most well read report on 'Drug Consumption Rooms' published by the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), is wary of stating that all the key objectives of these rooms have been achieved. These include establishing contact with 'hard to reach users,' providing a safe and hygienic environment to (particularly) inject, reduce overdoses (ODs) and other drug-related deaths (including through the transmission of BBDs,) promoting access to other health and social care services as well as "reducing public nuisance" in the locality as the KSA put it. Though they are cautious, they do state, "According to available research, the evidence suggests that the benefits of consumption rooms can outweigh the risks." They also advise that such facilities are established through the consensus and active cooperation of key actors, especially health workers, the police and local communities, and that it is acknowledged that these facilities are necessary to address needs 'that other responses have failed to meet.'

An adjunct that led to the success of the Pauluskerk facility was the acceptance of four 'social (or house) dealers' within the church. Here's a situation where (albeit under strict rules) – *No violence, No threats of violence and good quality drugs*, they carry out their work without interference. Social norms develop to encourage a particular kind of drug-using culture; particularly of safety and more respect for one and other. These other 'norms' are then rapidly embedded within the group, (J.Young, 1967). Hence a calmer atmosphere (devoid of fear of law intervention) ensues than on the street where anything can happen.

However, these 'House Dealers' were ejected from the Church Sept 2003, by order of the City Council, Fedde, an MDHG-worker indicated, so a year after I began my research I returned to Rotterdam in an attempt to establish what precipitated this harsh move, which goes contrary to the usual Dutch accommodation of deviance. Accumulated rumours over time that the Public prosecutors Office heard about, concerning using and dealing at Pauluskerk mostly from law enforcement meant they had to be 'seen to be doing something' so an investigation was mounted. The Press Officer at the Director of Public Prosecution's office stated that

"We told Hans Visser that we couldn't accept dealing or using in your church. The criminal investigation unearthed there were dealers and we gained evidence against them and they have been imprisoned."

There had also been complaints from neighbouring householders, who had become fed up of "tip-toeing through groups of whores and junkies in the street..."

The significance of good quality drugs (see above) becomes clear when we recall the infections, and in extreme cases, deaths of longstanding drug injectors who had injected into muscle and developed moderate to severe inflammation at the site of injection, followed, in several cases, by multi-system failure and death. (Eurosurveillance Weekly, 2000) One hundred and eight U.K. cases were diagnosed; 43 deaths. Microbiological investigations led to the identification of Clostridium Novyi, which is a spore forming anaerobic bacterium commonly occurring in soil. It is known that illegal drugs are hidden anywhere (in this case in the earth) according to one media report, which alleged that the heroin was deliberately mixed with the soil by a rival dealing gang, who wanted to settle an 'economic dispute.' (Guardian 2002)

Set my people free?

On the question of whether drug-users would use a church-based service, there were mixed feelings from drugs-users. One UK-based harm reduction specialist and ex-user said,

"I am very, very suspicious of the role of the church in all walks of life. For me, it is inextricably linked to abstentionism, moral and social engineering, intolerance and

prejudice. It sees drug users as a soft target for its evangelising and that any pretence of support for drug users is in fact a smuggling device for soul saving."

While churches may deem that they have an essential role in the 'saving of souls,' they have also been instrumental in providing basic amenities - food, befriending and referral to welfare services – particularly of the homeless, a significant no. of who are constantly using drugs (including alcohol.) It may also be the case that users have sought refuge from religious institutions, and that they have tried to substitute one emotional dependency - drugs with another - God, as one of many tools to arrest their compulsion to use, but if one church in Rotterdam can express such acceptance towards compulsive drug users, perhaps we should be asking why religious institutions generally reject them.

In parallel to this, the drugs-users at Rotterdam's Pauluskerk were not delighted with their situations but were very grateful for a safe place to use with no risk of arrest. Another fundamental matter in this situation is that the client group are immediately under the wing of a social work organisation - the KSA, who can refer them for housing, treatment and rehabilitation, as well as accommodate them overnight when they have nowhere to sleep.

Amsterdam

An Amsterdam advocate for drug users, on the mental health board of the Municipal Health Service (GGGD), reported that in his latter illicit-using days, he locked himself in the wardrobe as he was

"Convinced that the police were living under my bed! I had been using a lot of freebase cocaine day and night for weeks on end, barely sleeping or eating. By the time, I arrived at the heroin clinic I weighed [all 6ft of him] six stone and was virtually insane."

Maintained well on 500mgs/day of heroin, (which he is obliged to collect in the morning and evening,) he is now in a 'special position' as advisor on this board not only for daily users, but also others who suffer with mental health problems. He is being trained on the job and says the GGGD are obligated to listen to user's voices – (at least most services now have a patient's council.) He receives some hostility from other users who claim he is being 'treated

like a child' – patronised. Based on data from users in other countries, the suggestion here is that ultimately he cannot advocate anything politically radical, as he is beholden to the drug-service (within the addiction specialist's bureaucracy) he is a patient of.

Some ex/current drug users are employed by the MDHG as part of their re-training and re-integration program, the equivalent of Job Start in the U.K. The Melkert-Baan program is a government program enabling the long-term unemployed back into the job market. Peter v.d Gragt depicts a case of how clients have and do use the User groups as a rehab of sort. From his first step in 1994, as client and rapidly volunteer; he is now employee and daily working as a campaigner, writer and activist. We discussed policy impact in relation to a lobbying event at The Hague, where a gathering of Dutch user groups lobbied MPs about legislation and police brutality, but his overall sense was that *"we talk but they don't listen."* He believes MPs are not listening as they have already decided their policies. He deems it necessary to separate the survival issues implicit in harm reduction work, from those of legislative change and thereby the politicization of users.

The MDHG has been promoting and implementing harm reduction since 1977 and can celebrate being a significant part of the establishment of Needle-exchange in Amsterdam, the establishment of low threshold methadone programs, the setting up of low threshold drop-in centres for users in Amsterdam, e.g. User Rooms, generally the requirement for a users voice to be heard when making policy, Mainline Magazine and organisation and finally the founding of LSD, as an (inter)nationally operating organisation.

The coordinator of MDHG is Job. J. Arnold, who comes to the post without 'addiction' war-stories, but with a passionate interest in legislative change. He says, "I feel confused when I have to explain our policy to foreigners!" He means that possession for personal use is 'tolerated' though heroin, cocaine and cannabis even are illegal on the statute books. He gives the MDHG great PR, partly as he deliberately dresses smartly destroying the stereotype of 'dirty unmanageable dope-fiends.'

Arnold played a critical role in rescuing MDHG from being closed down, assisted with the implementation of Buprenorphine maintenance in Amsterdam, helped set up a client council at the Municipal Health Service (GGGD), re-opened the women-only evening and increased media attention for the users perspective and drug policy in general. As a result of the

additional services and publicity users have received, has there been any particular attitudinal change about users amongst the general population then? "Yes" he demurs, "from criminals to poor sick bastards!"

Daan v.d Grouwe runs LSD, which is a user-group development project. Grouwe has worked in drug services, but has been an advocate much longer and firmly believes that a better understanding has evolved between service delivery personnel and drug users, particularly inasmuch as they appear to take users more seriously. He adds that another critical point is that the users know there is an organisation that works on their behalf and this can encourage more to get involved.

Fedde, who works at MDHG says his own perception is that the MDHG does have local and national impact and confirms the commentary of many about drug users initiating NEPs in several locations, as *"they knew well that providing sterile injection paraphernalia would reduce the spread of BBDs"*, i.e. before researchers proved it; (Hartgers et al 1989 to mention one of many such studies). As research evaluates things ad hoc, there is a sense then of drug users in this situation being the innovators (distributing clean injecting paraphernalia) before the State was enlisted. As a consequence of MDHG's longstanding and impressive history, service-providers feel obligated to ask them for input. A final oblique comment he made was that the client group of MDHG don't necessarily know that some of the staff also use.

Two MDHG members (one woman and one man, X and Y from hereon in) were interviewed together for logistical reasons, which threw up debate about gender roles also. She had financed her drug habit and raised three kids (after the death of her husband,) working as a 'prostitute.' She notes that

"The crimes women commit are often different from male users."

An inference that women users had it easier generally and were less involved at MDHG made Y interject,

"We all take advocacy seriously as this is our lives. We men could also argue that it is easier for women as they can go home to their kids and we are the ones out on the street scoring and committing the more risky crimes"

However, in all three organisations researched the work of women was as peer counsellors and cleaners, as opposed to any technical work or having overriding decision-making roles. What this could be attributed to, aside from the general institutionalised inequality was not easy to decipher, though the shame of using-leading-to-prostitution for some women is felt deeply and seems to be one factor that disempowers women from being more visible in User groups. (One user activist described how her husband hated her talking about past sex-work generally, but when training AIDS helpline counsellors together, he coerced her into educating the trainees about it, so that they understood how 'strung-out' women are pressured into having unprotected penetrative sex with demanding male clients thereby risking contracting or transmitting STDs.)

A voucher system, reminiscent to Y of the way Jews were treated in the holocaust, has been instituted for the homeless; it involves spending a lot of time travelling from one bureaucracy to the next to access basic amenities. He then explains;

"Of course, if we harm others, law enforcement has a role, but not for simply using drugs. We must defend our freedom to use and to live."

For him, capitalism needs criminalised users as scapegoats to blame for many of society's ills as this is a process by which it is possible to sustain the gross unequal power relations in society. Y completes this discussion concluding

"Society is against us Junkies. They will do anything with their 'war' to stop us."

Finally, a long-term member of the MDHG, who had been witness to the early days of the AIDS health crisis, proudly suggests that Holland's drug policies had been a guiding light for other countries. He described how he first came to the MDHG to meet others in the same position, but soon he became a volunteer and board member. He confirmed all the successes that Arnold lists, and adds,

"We cannot just do drug law reform. We must also try to make the situation as humane as possible for those who suffer from addiction. Not all users are psychiatric patients though there is some overlap."

He organised one of the first AIDS meetings of IDUs to the Health Department but says now the health authorities are reluctant to give Hepatitis C treatment to active injectors; they argue that this patient group cannot comply with strict treatment protocols proven to be untrue by a study from Holland, presented at an international hepatitis C conference. He also spoke of the dangers of heroes amongst activists, given the level of debilitating health symptoms but also wavering drug-use; his concern was that members look up to leading MDHG workers, but when they 'fall down' it can be hugely disappointing. There was also reference to the increased supervision of drug taking –

"The State argues they do this in order to prevent 'street leakage.' What if we want to go to the beach for the day?"

'Alex' insists that once people are stabilised, this is just not necessary. He concludes that the quality of user's lives would be significantly better if they were not forced to lie, as they "must" under prohibition.

Danish Interviews

I spent almost a week in Copenhagen as a participant observer within the family-style set up of the Brugerforeningen (BF): twice a day, all the members gather around to eat together, with the chair of the Union always sitting at the head of the table, reminiscent of father's place in many family households. Everybody called themselves an activist whatever their job or responsibility was/is. Thus at least nominally, everybody was equal.

Their most prevalent attitude around drugs use was that it is a vital necessity in order to function, a mixed blessing and burden and something that they must work very hard to encourage 'normal' society to understand is nothing to do with morality, intelligence or personal value system.

One HIV+ ex-user expressed dissent about BF saying that they didn't really make a very "radical noise." As I interviewed the BF president, J.Kjaer, later in the week, I asked him if he thought this comment was fair. He responded that the union walks a very fine line between representing the health and human rights of its 500 strong membership, and focusing strongly on positive imaging of drugs users in Danish society (e.g. an clearing the streets of used

'works.')

That ultimately, since some of their funding comes from government, they are uncomfortably tied to some level of compliance with prohibition-based drug policies, and though this is not a perfect situation, they are doing the best they can to influence politicians and other professionals about its detrimental affects on their lives. He in fact, had been called by an MP asking for advice about Safer Injection Rooms (SIRs), as she had read his comments and required further information. So, while the political impacts appear limited, and they are often anecdotal, they are not insignificant.

BF provides two-hour drugs education sessions to police-cadets, which are actually a mandated part of the police's training programs. (This is a significant achievement for BF.) These are fundamentally opportunities for drug users to describe their lives. This has served to make subtle but profound changes in thinking (and hence behaviour) of police towards users, and should not be understated. Moreover, the HIV+ ex-user added that BF's drugs education for young people was excellent. I heard several accounts of this youth education, much of which was information-oriented; what is a drug, their names, how they affect the body and so on. It was notable that many of these teachers were hardly advocating drugs use. One of them was adamant – *"I just don't want anybody else to have to go through what I did, "meaning, jails, other institutions, huge health losses and repeated bankruptcy.*

One BF member, who had very high employment expectations put upon him by his Father and became a qualified physicist, said he could not get employment now because I've been in jail. Consequently, he became involved with User Involvement work at the BF. As drug activist for the Union, activities that have made his work meaningful include drugs education, which encouraged a 26 yr old man to stop using. When asked about his place in the reform movement, he answered:

"We ought to be more involved but we are talked down to by people who are our carers, and they constantly speak on our behalves. They think because they have read two textbooks they know. They are smart enough to stay in the [drug] closet and are seen as experts and specialists, but what are they doing about the denial of our human rights? We cry out but nobody answers."

A leading activist and heroin user described himself as a reluctant methadone drinker! As he was wasting away from 'snowballing,' he was eager to try another substitute medication,

Buprenorphine. This member worked non-stop until the weekend when he collapsed for 48 hrs. His contribution to the Union is as website manager, and training other members of the Union in IT skills. When asked about how long he advocated or encouraged Harm Reduction measures amongst IDUs, he responded,

"Long before I got involved with the Union, I was doing what we, at the Union call peer education [encouraging fellow injectors to implement harm reduction strategies into their daily drug use], with my using friends and acquaintances."

He also said that BF had been engaged with networking Christiana employees with the wider international drug policy reform movement. (Christiana is a small area of Copenhagen which was inhabited by 'alternative society people') and where cannabis was sold without police intervention. Recently, this 'open scene' has been closed down, allegedly for a no. of reasons, not least of which is the interest of real estate to take over the area, and there is regular police presence to enforce the new regime.

It is evident that several people only visit in order to eat, and they do not engage with the step-by-step activity approach, which is a regular component of BF. When new people arrive asking to get involved, they are slowly given increasing amounts of responsibility, and this includes ex-users. Hence, the overall picture of the BF is of a day program run by drug users for drug users, which includes a gym, a small and user room and a dining room where people sit as a family to eat.

A former Narcotics Anonymous member (community-based abstinence-oriented self-help group program), who had once provided a 'coming off drugs testimony' to rehab residents, had returned to heroin use. He was adamant that if the State is not willing to fund enough rehabilitation places to detox people, they should be providing free medically prescribed heroin. Officially, he had not politically advocated on behalf of or represented the Union, but privately he had spoken with a few politicians (responsible for distributing drug treatment and rehab monies) and to the Mayors office though he "seriously doubted" that his efforts had had any impact. He expressed profound concern that twenty times more funding was being funneled into law enforcement of the government's drug budget, than drug prevention, education and care. He was clear that users do have a role in speaking out for reform as

"Most officials are ignorant. They speak about aiming towards a Utopian world of no drugs use, but the fact is there are addicts, and they should face the facts and not simply be trying to be rid of us."

User Groups and their allies in the U.K.

These groups have had as long a history as Holland, though not as well funded or long lasting. In the late '70s, patients of Dr. Daly set up the Drug Dependency Improvement Group (DDIG) within their own clinic 'to promote their interests and serve their needs.' DDIG's first group lasted four hours and was observed by a Guardian journalist, Andrew Veitch. (Dr. Daly, a prescribing doctor, struck off for 'over-prescribing' lost her case against the General Medical Council (GMC); currently users in England are discussing ways to support Doctors of the Stapleford Clinic, currently being accused of similar 'misconduct.')

In 1988, a group of former Phoenix House (London) rehabilitation residents, most of whom were living with HIV established the first HIV/drugs support self-help organisation with a £10k grant from the National AIDS Trust (NAT) – Mainliners. Since its first incarnation, Mainliners has grown and now employs non-users too, and thus does not call itself a User group, though some of its' frontline staff are ex/current IDUs. It has since accommodated Hep C support groups, and in 2003 launched a report, which addresses discrimination against HCV+ workers. Many living with Hep C have a strong desire to increase the lobbying by and on behalf of people with Hep C in the political arena, highlighting the disparity of services, treatment and support for those affected; hence they formed the Hep C Assembly. The Hepatitis C Assembly had its secretariat there.

AIDS posed a challenge to the drug treatment orthodoxy inasmuch as clean injection paraphernalia were not made freely available until this point, but by 1988, even government stipulated that AIDS presented a greater health threat to injectors and the wider community, and therefore must have its' prevention prioritised. Other treatment practices that re-surfaced, or increased included methadone and heroin maintenance, though the latter has always been within the jurisdiction of doctors with Home Office Licences to prescribe though they rarely do, for fear of addicting users indefinitely. Doctors are also afraid of being labelled as 'liberal prescribers' and perhaps within an atmosphere of ongoing persecution of prescribers, this is

not surprising. These two interventions were (are) major corner-stones of Harm Reduction as well as condom and needle outreach to injectors on the streets as a proactive effort to reduce the spread of HIV amongst injectors and/or those who sold sex for money for drugs.

Merseyside became famous for its prescribing of heroin and cocaine cigarettes as another tool in successfully reducing crime and AIDS in the region. Liverpool researcher and writer, Peter McDermott, involved at this time in the region remarks,

"I was fortunate insofar as I was in the right place at the right time working at an agency staffed by users and ex-users, with very sympathetic commissioners and an extremely talented and charismatic leader."

These days, McDermott is on the management team of the National Treatment Agency's (NTA) Opening Doors program, which is concerned with improving access to treatment, and writing guidance papers for the NTA encouraging commissioners to think about the role of service-users in the process of commissioning. A service user taking on such a lead role was inconceivable three years ago, he believes.

Something is changing...

In the late 1990's, government was still winning elections based on how 'tough on crime' they could be. Thus, drug-users re-surfaced as one of the country's major pariahs. In parallel to this, the new set of clinical prescribing guidelines encouraged doctors to take patients off benzodiazepines, minimise methadone doses and stipulated that any doctor working with users should be re-trained regardless of years of previous experience treating 'addiction.' In addition to this, the increased use of crack-cocaine (Brain et al, 2001) had become a problem for service providers, who had no substitute medication to prescribe, (though a few doctors recommend a short-course of anti-depressants and tranquilisers.) Meanwhile, Drug Testing and Treatment Orders, (DTTOs) were piloted, in an attempt to reduce drug-related crime, which mean regular visits to probation officers (and others) who would regularly urine-test clients to ensure they had not used heroin or cocaine; this can go on for a period of up to three years. If their urine tests positive for drugs, their Orders can be adjusted to restrict them further, or are imprisoned for the original crime. DTTO's are less costly than incarceration of users.

As a result of these changes, other drug user group models evolved. These groups focused on supporting peers whose primary concerns were ensuring they received appropriate levels of drugs of choice or need. A few were also concerned with protecting prescribing practices of private doctors, some of whom were thought to be prescribing more 'maintenance' (rather than reducing) scripts of methadone and/or other drugs than they ought. This latter function was not officially written into User group's constitutions but rather was an inevitable part of their protecting their own right to use medically prescribed legal drugs. One such group, Addicts are People Too! (ADAPT) carried out a piece of research into the practise of their own clinic, which highlighted the nos. of users, who were being prescribed oral medication when they had been injecting for years and so led to their lapsing on street drugs and many who were being rushed through three month methadone detox's. This piece of work was carried out at one of the services that followed the enforced tightening up of prescribing guidelines, as an exit poll. A particularly frightening fact was that at least three discharged but reported on clinic records as 'cured' were in fact dead.

Arguably the leading User group in the U.K. and inspired by the National Alliance of Methadone Advocates in the U.S. is the Methadone Alliance (M.A.) , now referred to simply as 'the Alliance.' Funding requirements and organisational requirements deem that the board should be comprised of over 50% users/ex-users including drinkers. Its' functions include:

- Responding to clients calls about being discharged from treatment suddenly for using illegal drugs i.e. 'using on top.' (Challenged by advocates, managers explain that commissioners expect them to successfully detox a certain no. of users in a particular timescale, so if they have patients who are not serious about 'coming off' they feel obliged to eject them, in order to make places available to patients who are.) Closer inspection shows that some users get two or three chances in fact. (In many clinics, patients are then required to wait at least three months before they can return.)
- Advocating for less supervised consumption of prescriptions. Clinic rules stipulate the patient must arrive early each morning to drink their methadone on site. Patients with jobs, work training, parental or educational commitments must simply fit into the clinic's schedule, and if the script is heroin, this will be at least twice a day.
- Lobby for reduced invasive (often-observed) urine testing; clinicians will argue that this is essential to prevent the patient concealing any clandestine drug use. Advocates

argue that it is usually obvious if a patient uses on top of their prescription and that if the relationship between clinic and patient is therapeutic, clients will inform their key-workers about lapses anyway.

- Representing drug users on government committees e.g. the Home Affairs Select Committee (H.A.S.C) led a series of hearings to examine whether U.K. drug policy was working (2001/2). This key user-representative role was executed by one of the Alliance, though many other groups sent in written submissions including the National Drug Users Development Agency (NDUDA) and the John Mordaunt Trust (JMT) as well as a no. of groups who advocate for the legalisation of cannabis.
- Instrumental in educating GPs about the health and psycho-social needs of drug users; too many await specialist drug-treatment when they could just as easily get substitution medication(s) from their own GPs. The Substance Misuse Management GP Project (SMMGPP), who are physicians experienced at working with users and thus able to inform their colleagues, has driven this work. At least one of the SMMGPP is on the board of the M.A. bridging the gap between users and doctors, as well as promoting treatment within a harm reduction framework.
- The Alliance. has designed advocacy trainings that it regularly provides to both users and co-workers in the field, as does the NDUDA.

The paid advocate has carried out a research project in Wales that showed that most GPs are unwilling to treat drug users for *any* condition. Some members of the Alliance ideologically oppose punitive prohibition, but again are not in an independent-enough funding position to express this in any concrete way.

All over the country, Drug Action Teams (DATs) are responsible for the development of drug services regionally, and are made up of managers of health, social, law enforcement services, including managers of Primary Care Teams (PCTs,) who according to Bournemouth Alcohol & Drugs Substance Users Forum (BADSUF,) are often seen as best-placed to negotiate funding. DATs liaise closely with Joint Commissioning Groups, responsible for the allocation of resources, and are governed by the regional managers of the NTA, and are responsible for writing templates for the organisation of local drug service provision. Below them structurally are Drug Reference Groups (DRGs) who more likely to comprise local drug

service managers who are in a position to inform the DAT about vital missing services in an area. User group members advocating within this infrastructure can do so (for the most part) at DRG level.

Each DAT receives £23k to promote User Involvement in their area, but one advocate is concerned that this money will simply be used to run focus groups, which are unlikely to be user-driven. However, he also admits that there are simply not enough trained and experienced users to run groups nationally, which could lead to the most knowledgeable advocates carrying out specific work that the NTA ultimately controls. Ultimately not all advocates are agreed about drug policy or treatment provision issues, thus he claims that, "*It would be easy for the NTA to divide and rule,*" by re-asserting government's policies whatever the user advocates demand.

An ongoing concern about User-involvement is the lack of work-experience or training of oftentimes-enthusiastic newcomers to advocacy. However, the NTA does not provide monies for training, though it provides a modest level of training to them itself. The NTA also employ two drug-users, who work as consultants representing the interests of users within its ranks, e.g. Peter. McDermott manages the NTA's Experts by Experience Program and writing guidance papers aimed at changing 'how commissioners think about the role of users in that process.'

Another leading U.K. advocate said; "*Users ultimately have very little power in affecting policy particularly.*" He considers that user's and carer's ideas are effectively stolen from gatherings NTA pays for, thrown into the NTA 'policy-dictated-by-government-pot' and translated into whatever version of U.I. the NTA wants. This mirrors the uncomfortable belief of the NDUDA founder, Mat Southwell, who says the government call it U.I. to minimize its' strategic or political effectiveness.

I also interviewed two members of the NTA staff, who have been a) responsible for ensuring monies were available to develop U.I, and b) part of a region, committed to it. The former indicated that the DATs are responsible for establishing 'structures where those groups meaningfully have a voice in decision-making.' Every DAT is supposed to be reporting to the NTA about what procedures they are using to involve users, so there is some pressure on

them to do so. Simultaneously he states (2003) that an NDUDA worker was commissioned to write a document which was "supposed to cover all aspects of U.I." which he did. An NTA worker was then supposed to work on improving it, but to date an overarching document mandating them to include users has not surfaced" (2003).

Nevertheless, BADSUF have managed to 1) prevent a Primary Care Trust (PCT) reducing its funding, 2) stop authorities barring drug users into treatment for failing to give particular detailed information about themselves to third parties, e.g. social services could be stopped from providing personal details to potential employers - (use of the Data Protection Act registrar) and 3) stop male workers from overseeing observed urine-tests to women.

Discussion

In a Standing Conference on Drug Abuse (SCODA, now renamed Drugscope) consultation document (1998) it is suggested that gains which can be made through User Involvement include being able to set up more cost-effective quality drug services and increasing the accountability of commissioners and policy-makers. However, this doesn't marry well with the following comment from NDUDA's M.Southwell, who believes that the term itself is a way to minimalise their policy impact – *"After all, involvement could mean anything."* Certainly a number of respondents felt that their input was frequently tokenised (though, U.I. is generally considered progressive.)

One initiative, instigated by ex-user J.Veale (1996), was Lewisham Council's Citizen's Jury, which sought to redress the democratic deficit within the borough, giving the local people a voice in local drug policies. Following intense training of the 'people' and expert witnesses brought in to give evidence on specific drug treatment and policy issues, most of the people began to see the inadequacies of punitive policies particularly those targeted at 'dependent' drugs users, and this was another concrete example of U.I that positively impacted on local drug policies.

In an attempt to understand how a few allied drug-workers and policy-makers might see U.I, I also asked them a few questions about issues discussed herein. The U.K. ex-assistant anti-drug coordinator, M. Trace was keen to see the heroin protocols piloted around the country, though he was less clear about user rooms but thought these would become an automatic adjunct to the prescribing of heroin. In Denmark, a Green Party MP was broadly in favour of establishing user room, whereas a social democrat MP said that the current position of her party was that they feared it would attract further dealing and/or violence to the area.

It should be noted that at least two of the countries investigated here are renowned for having (or having had) more progressive drug policies without which these groups are generally far less likely to emerge, i.e. the pragmatism of the "British System" (MacGregor & Smith 1998), which prescribed heroin as a maintenance medication till the late 1960's and Holland with its policy of 'tolerance' since the 1970s, ('Coffee-shops' where cannabis is openly sold to over 18s.) Denmark may not be renowned for liberal drug policy, but its Welfarist social

care systems are set up in such a way as to allow for the advocacy tier of their health system to be run by its recipients.

There were notable differences between the Danish and Dutch using-arrangements; small private locked rooms in Copenhagen v open societies 'club- night' in Amsterdam. Legal issues make this necessary; the Danes are simply not legally permitted to have a similar arrangement as the Dutch. As mentioned above, Denmark has no official user rooms as yet.

As previously mentioned other issues provoked drug users to set up groups (Hepatitis B in Amsterdam, the persecution of prescribing doctors in U.K). However, it should be acknowledge that without AIDS decimating IDUs as it was and *still* is, the financial support for such groups would not have increased at the rate it has. AIDS also increased the urgency for drug users to self-organise, and some responded accordingly, but the obstacles to developing drug user advocacy projects in countries with monolithically prohibitionist policies have been immense, though it was, within those very countries that some of the most radical activism occurred e.g. illegal needle exchange in the U.S.

"In 1985, when ex/current users fought the AIDS crisis together," says the methadone Alliance's general secretary, Bill Nelles *"Being 'out' and employed would not have been countenanced, whereas in 2004, active drug users are outreach workers, maintenance-advocates and all manner of harm reduction trainers in several different countries around the world."*

This 'outness' is a key human right that these groups have fought for, and a recent BBC News bulletin, (March 2004) showed a patient prescribed heroin speaking publicly about his life as a highly skilled employee of an IT firm. Hence, though drug users cannot claim all the credit for society's attitudinal change, or celebrate significant decriminalisation of their use, they can, at least, see that they are viewed with somewhat less hostility than they were twenty years ago.

Blood Borne Disease Prevention

A key focus of user group participation has been the prevention of BBDs, beginning with the AIDS crisis. *"Here" says S.Friedman "they have taken the lead in many countries ...in distributing risk reduction supplies."* In some countries, drugs users and their allies defied the law (still do), found physicians and other pragmatists in medical institutions that were willing to assist, and accrued clean injection paraphernalia to distribute amongst street users. Often these law-breaking acts were in collaboration with the direct action group - AIDS Coalition to Unleash Power (ACT.UP) who became famous for their defiant efforts, (initially in the U.S.) in the face of government inertia and hostility.

In the late 1980's various test cases were brought before the courts. One test case that relates to this involved J. Parker and C.Annacabe, arrested for illegal distribution of needles. When the foreman came to announce the courts verdict, he said *"not only are they not guilty, but they are outstanding citizens carrying out life-saving work for our communities, and I have decided to join them!"*

In Western Europe, where NEPs rarely had to be fought for, it is notable that here didn't seem to be a close relationship between the HIV organisation - a house for users and ex/users - and Brugerforeningen (BF). A no. of reasons could account for this including: ex-users might experience loss of user-identity as well as fear of relapse. There were also no other self-disclosed HIV+ people at BF. It was difficult to say exactly why, but in both Holland and the U.K. the relationships between these overlapping care services appeared closer.

Finally, though this small group of ex/current drug users would not claim to represent a (non-existent-homogenous) Class A drug using community, most of them are in favour of overarching law reforms, which would end (or certainly undermine greatly) their criminalisation. Hence, some have begun contributing to the wider reform movement. In the recent past, this has played out most overtly in relation to cannabis legislation. In Copenhagen, when the 'open scene' in Christiania was threatened with closure, members of BF were divided as to whether they would sign the petition that fought to keep Christiania open. BF members challenged the 'anti hard drug user' strategy, which Christiania activists

had used, e.g. wall-papering the area with posters saying ‘hard drugs out!’ Others chose to view this more globally – that is to accept that while possibly stigmatising their peer-group further, they should understand it was strategic (expressing their anti-‘hard’ drug sentiments) rather than ideological (against the prohibition of hard drugs and their users.)

Moreover, where cannabis is concerned, heroin (and cocaine) users have a commonality with cannabis users and/or campaigners, inasmuch as some heroin users have used cannabis to stay off Class A drugs, and/or medicinally. Where the U.K. government has confused some of the public by ‘effectively’ (but not actually) decriminalising cannabis, activists have defied the law and established small medical marijuana cafes, (though most of them have been penalised for this.)

Currently both police officers and less controversial figures are collectively engaging with forwarding these issues. Indeed, one former officer is currently selling fresh psilocybin⁴ mushrooms in one of Europe’s largest markets.

Various user advocates (within the ‘user movement’ or not) believe that users ‘outing’ themselves before they had access to society’s social or economic power structures was not helpful in garnering the social and political support needed. However, it was also deemed essential that some should publicly disclose illegal drug use in order to dispel the mythologies and stereotypes.

⁴ Psilocybin is a psychedelic mushroom. Psychedelic comes from two Greek words meaning “soul-revealing.”

Conclusion

This overly short piece about user groups seems to have mixed summations. While generally user activists often express little hope in positively effecting drug policy as a means to reducing drug related harm or being treated with a basic semblance of respect by 'society at large' still other's optimism persist regardless. Perhaps the following example goes some way to explaining why users generally believe that their voices remain unheard.

In Germany 'drug-help' evolved directly from the affected communities - the RELEASE movement and patient collectives of the 1970's - but are now largely run by professionalized helping bureaucracies. Within this 'takeover' is a sense then that we had an impact on the development of drug services at least but

"Unless there is someone working in the system while being a daily opiate user semi-secretly we are not taken seriously, and therefore not part of hearings they hold prior to bringing up any new law initiative."

Most user groups are in fact coalitions of drug users and non user allies, where the majority of the members and the board are active drugs users. This has been proven to be pragmatic given long-term and/or chronic illness of significant numbers of the membership.

Unresolved questions that require further investigation might be what the role of drug users in treatment could be within the wider drug policy reform movement. While most accept that their role is largely to simply authenticate the words of more recognised commentators, still others deem this inadequate. However, whatever debates ensue on these matters there are a few irrefutable facts: 1) Drug users have been at the forefront of AIDS prevention initiatives in various countries during the last two decades. 2) Funders are generally more willing to resource user groups in order to improve health and social care outcomes in drug users lives and 3) There is a growing global social justice movement challenging the 'war on drugs' and drug users are becoming a critical part of it.

References

- R.Balaran & C.White, (1998), Defining the drug user, paper **in** Harm Reduction Communication Newsletter of the Harm Reduction Coalition, U.S.A
- Becker, H (1963) The Outsiders; Studies in the Sociology of Deviance. The Free Press
- Brain et al, (2001) 'Untreatable? Hidden Crack Cocaine & Poly Drug Users' **in** U.K. Drugs Unlimited; new research and policy lessons on illicit drug use. Eds. Parker, H; Aldridge J and Egginton, R. Palgrave
- Blickman T & Bluestone, K (June 1998). Lessons To Learn. The World Today pp 4-6.
- Anne Daly, (1990) 'A Doctor's Story'- pubs Macmillan, London.
- Drug Policy Alliance; Open Letter to Kofi Annan, printed in the New York Times on the occasion of the UN General Assembly Special Session on Drugs (UNGASS) June 1998. www.drugpolicy.org
- Eurosurveillance Weekly 2000; 4:000601. Serious unexplained illness among injecting drug users in Scotland: update
- Fox, K (1991) The Politics of Prevention: Ethnographers Combat AIDS Among Drug Users **in** Ethnography Unbound: Power and Resistance in the Modern Metropolis. Eds. Buroway et al. University of California Press
- Friedman, SR (1996) "Theoretical Bases for Understanding Drug Users' organisations" in The International Journal of Drug Policy 7: pp212-219
- Hartgers, C, Bunning, EC, van Santen, GW, Verster, AD, and Coutinho, RA. The impact of the needle and syringe-exchange programme in Amsterdam on Injecting Behaviour **in** AIDS. 1989; 3:571-576.
- Hedrich, D; (EMCDDA 2004) European Report on Drug Consumption Rooms – Executive Summary accessed at http://www.emcdda.eu.int/multimedia/project_reports/responses/cconsumption_rooms_report.pdf
- Home Affairs Select Committee (2001-2), The Governments Drug Policy: is it working? HMSO
- JP Grund, in The Ibogaine Dossier (1996) Accessed at <http://www.ibogaine.org/>
- Ed Jurith of the Office of National drug Control Policy (U.S.A); Personal Communication.
- Keaney F, Strang J et al, (2004) Does Anyone Care about Names? How Attendees at Substance Misuse Services Like to Be Addressed by Health Professionals, in European Addiction Research (2004) 10; 2:75-79

MacGregor, S and Smith L. The English Drug Treatment System: Experimentation or Pragmatism? Klingeman, H et al (1998) Drug Treatment Systems in an International Perspective. Sage Publications

Mauer, M (2001) The Causes and Consequences of Prison Growth in the United States in Punishment and Society: the International Journal on Penology. Vol. 3, Issue 1. Sage

Dan Molinski (Aug 6, 2004) Philadelphia Inquirer "US Official Calls For Persistence In Drug War."

MDHG, (1990) Drugs and AIDS in "The Netherlands: the Interests of Drug Users" Renee Mol, Delco Otter & Angelique van der Meer

John Mordaunt (R.I.P) – Berlin World AIDS Conference Plenary, (1993)

Nadelmann, Ethan, (2001) "Ending the War on Drugs." in Lapis Magazine.

Bill Nelles, (1990) Models of Self-Help for Drug users with HIV/AIDS, in AIDS & Drug Misuse, Eds. G. Stimson and J. Strang

R.Newcombe (1991) The Reduction of drug-related harm; a conceptual framework for theory, practice and research, in The Reduction of drug-related Harm. Eds. O'Hare et al.

Mat Southwell (U.K. 2000) DPFU International User Activist e-mail list, (Personal communication)

Stimson G et al: Syringe Exchange Programmes for Injecting Drug Users, AIDS 5: pp253–260, 1989.

Marilyn Taylor, (2000) The Future of User Involvement in the Voluntary Sector: a contribution to the debate in Meeting the Challenge of Change: Voluntary Action into the 21st Century (Report of the Commission on the future of the Voluntary Sector)

J.Young, (1971) The Drug Takers, Paladin

Background Reading

Cannell, T (2004) The Struggle to Implement Needle exchange in Three Cities, accessed at <http://www.yaleph.com/story1.html>

Davenport-Hines, R (2001) The Pursuit of Oblivion. Weildenfeld and Nicholson

Friedman SR, Neaigus, A & B.Jose, (1998) AIDS Research and Social Theory; selected enigmas and contributions from a long-duration program of applied research, in Research in Social Policy, Vol. 6, 137-158; JAI Press Inc.

Report by Opinion Leader Research on the citizens jury commissioned by the London Borough of Lewisham (1996) People Take Drugs: What can we do to reduce the harm to the community and to individuals?

Taylor, A (1993.) Women Drug Users – An Ethnography of a Female Injecting Community Clarendon Press

Dissertation Glossary

AIDS – Acquired Immune Deficiency Syndrome

BADSUF – Bournemouth Alcohol and Drug Substance Users Forum

BBDs – Blood Borne Diseases.

Black Poppy – a U.K.– based User magazine

BF – Brugerforeningen; Danish Drug Users Union in Copenhagen.

DPA – Drug policy Alliance; NGO, leading the movement for drug policy reform in America, now nine years old. (Merger of the Lindesmith Centre and the Drug Policy Foundation in 2000 gave birth to the DPA.)

EMCDDA – European Monitoring Centre on Drugs and Drug Addiction, based in Lisbon, Portugal.

GGGD - Gemeentelijke Geneeskundige en Gezondheidsdienst; Amsterdam Municipal Health Care Agency

Hep C or HCV – Hepatitis C, one of the many strains of viral hepatitis that injectors have suffered epidemics of, transmissible through blood products and far more virulent and strong a virus than HIV.

HIV – Human Immune-deficiency Virus; retrovirus that started killing injectors in the late 1970's.

John Mordaunt Trust – London-based User advocacy project set up (1996) to honour the memory of one of Europe's leading drugs/AIDS human rights activists.

IDU – Injection Drug User

LSD – similar project to MDHG in Holland, also assisting local groups to get set up and helping to develop them.

MDHG - Belangenvereniging voor Druggebruikers – Drug Users Advocacy Group. Amsterdam, Holland.

M.A. – the Methadone Alliance, (now often referred to as *the Alliance*); U.K. user group, much of whose work is ensuring drug users receive adequate supplies of their drug(s) of addiction from prescribing physicians.

Monkey – North of England User magazine

NDUDA – National Drug Users Development Agency – an umbrella organisation of U.K. - based user groups.

NEPs – Needle Exchange Programs, also known in the U.K. as **SEPs**, Syringe Exchange Programmes.

ONDCP – Office of National Drug Control Policy (U.S.)

UNODC – United Nations Office on Drugs and Crime

REFORM – small unregistered user group in London, U.K.

SIR – Safer Injecting Room, also known as Drug Consumer Rooms, Consumer Rooms or Toleration Zones

U.I. – User Involvement

The Users Voice – magazine (and now website) of the John Mordaunt Trust

'Works' – Injection paraphernalia