

GROUPS FOR HIV POSITIVE DRUG USERS

Some drug users at risk of or with HIV/AIDS have been doubly let down: first by drug services; second, by the gay self-help groups they turned to when the services failed to respond. Now groups are being formed by and in some cases specifically for drug users. Bill Nelles sets the scene, then we hear about three of these groups — Mainliners, Positively Women, and the group at the Terrence Higgins Trust.

Bill Nelles

BY THE TIME you read this about 1200 days will have passed since the first UK AIDS and drugs conference. Given the magnitude of the threat, those of us involved in organising the event hoped that within weeks emergency programmes would be launched encouraging users into treatment, educating them about the hazards of sharing needles, and giving them clean ones.

But by the end of the day it was clear how divided and cautious most of the workers had been. The goals that had seemed to be the most logical starting point to those from AIDS organisations were not, it seemed, the goals of most of the drug agencies, some of whose members shared little common ground in their views on managing drug dependence.

The debate about those goals continues. But, in the main, those tactics first proposed over three years ago became the official policy recommendations of the government's most influential drug working parties. Most voluntary agencies have anticipated the changes, and have good policies and plans — but little money to fund them, and a lot of bureaucracy to tackle if they want some. In the statutory sector, these policies are still nowhere near being implemented. Even if agreement could be reached on what to do, the £1 million funding for establishing HIV and drug programmes this year works out to just £20-50,000 per district. Largely due to their HIV-related workload, existing projects too need more staff, impossible on existing budgets.

The author is consultant trainer to West Berkshire HA on AIDS and drug misuse issues. For three years he was Drug Education Officer at the Terrence Higgins Trust, where he helped start the trust's drug users' support group. Bill Nelles also compiled and edited this feature.

Many health districts maintain only a drug counselling service with no formal medical links. These are finding it particularly difficult to cope with their HIV workload. They have district-wide responsibilities but without access to beds cannot provide inpatient withdrawal, are unable to arrange for prescribing, neither can they provide outpatient therapy with substitute drugs.

Despite two major official reports in 1986 and 1988 recommending flexible prescribing and a change of approach in relating to clients and their needs, at times it seems impossible to overcome the inertia in the statutory treatment system. Most areas are 'discussing' the recommendations — not acting on them.

AIDS groups step in

Failure of the system to help them at the time of their greatest need alienated many HIV positive clients and led some to reject treatment. Many approached AIDS groups for help, relegating drug clinics to a minimal role, usually merely as the source of a prescription. Some have found these 'gay-founded' AIDS groups very helpful; others have had unhappy experiences.

In some AIDS organisations there has been pressure to offer drug users programmes based on a notion of equality, rejecting traditional client/worker relationships and allowing the client sometimes to be a person in need of help, sometimes a person giving help. At times this has worked well, especially with recovering/ex-drug users — but at other times clients and workers have been hurt and become confused.

Gay men have sometimes related to drug users either as a stereotyped group of criminals and psychological misfits, to be politely shunted off to special facilities or, more fraternally, as another persecuted minority. Both points of view can be equally misguided.

It was hard for gay men in these groups to appreciate how messed up someone taking drugs can get. Used to taking a stand against the portrayal of homosexuality as an illness or a deviation, they imported gay liberation politics from an arena where it was appropriate to one — addiction — where it was often inappropriate and sometimes destructive. In their turn the drug users wanted to work as they saw the gay men working, but many were not yet and perhaps never would be at the point where they could stop seeking and start giving help.

Telling someone who feels compelled to inject themselves with powerful substances that it's their right to do so, and that their lifestyle is as valid as anyone else's, does not help them overcome what any objective observer would see as a problem. The effect is rather to reinforce the most negative aspects of a drug dependent lifestyle.

Groups where this attitude predominated nearly veered away from a support and therapy role to adopting a 'user's rights' stance where the client's definition of what they needed was accepted without challenge. Challenge would have invited accusations of being prejudiced and patronising, not only from the clients but sometimes also from one's colleagues. In some circumstances this meant that the vulnerability of someone still dependent on drugs and their potential to get into deep water went unnoticed.

People still dependent on drugs and struggling to cope with being diagnosed HIV positive need neither to be rejected as 'not one of us', nor saddled with the added burden of being an activist help-giver and told their lifestyle is OK. But, whatever their mistakes, these early AIDS groups held the bridge for a long time while drug treatment agencies were learning the realities of AIDS. For that, many clients are and were grateful. AIDS groups are now learning about drugs work, but still need to find out how to bring it into the mainstream of their activities.

GIVEN THIS HISTORY, it is not surprising that HIV positive drug users have recently moved to set up their own groups to provide support in an atmosphere unique to drug users, and with a structure offering the chance for total participation. Some of these have got bogged down in 'right to use' arguments, but some, usually those with drug worker involvement, have avoided these traps. The largest of these groups, Mainliners, is following the road pioneered by ADAPT in New York, forming a coalition of professionals and 'clients' to decide on appropriate services and to deliver them to drug users as a group.

Most of all, these groups represent a new phase in the battle against AIDS — a time when drug users with HIV start to look after their own. Gay men started doing it five years ago. It's been a long time coming for the drug users, but I feel a new time may have begun. □

Turn over for reports from three HIV support groups

On these two pages we focus on three HIV self help and/or support groups involving drug users. All have been running some time and have worked through many of the problems of self definition and self organisation. The THT group is part of a larger AIDS organisation, but the other two are not, marking the beginning of AIDS organisations reflecting the interests of the 'cinderella' risk groups: women and drug users.

For the THT and, to a lesser extent, for Positively Women, key issues such as who served who with what service were dominant for the first months. In the THT group there were early arguments over whether they needed a facilitator, and over reconciling the position of those on methadone prescriptions with those who were drug free.

Basic to THT's *raison d'être* is the protection and empowerment of people with AIDS and HIV. This puts a tremendous burden on the organisation, which consists of people with HIV

and AIDS and those committed to their care. They do not always agree and this was the case at the birth of the Drug Users Support Group. Charged emotions must be expected where young people are dying and feel forsaken and alone. However, these were at times destructive and frightening for people coming to the group for help.

To its credit (though some may shudder) the THT group set out to break down barriers between users and ex-users, and to give members a major say in both the practices of the group and its ethos. Most of the original fights have been resolved, and the group seems to have reached a stable point at which the Drug Education Group (the professionals at the THT, from whom the facilitators have been drawn), the Trust's drug counsellor, and the participants all feel involved. Time will tell whether this model of 'unity in adversity' will work.

Though its first members were ex-drug users, Positively Women sought from the start to avoid being a support group solely for drug users. They felt

their shared identity as women was the cement with which they wished to bind the group. They have never engaged a professional facilitator, relying on their own ability to support each other and to run the group. They hope to continue to broaden their base among women, while always supporting those hurt by drugs.

Mainliners is the most recent of the three groups and unique in that the whole organisation is given over to AIDS and drug users, past or present. Established in large part by ex-residents of Phoenix House, it now operates out of the premises of a London drugs advice agency. The group is facilitated by a one-time senior staff member of Phoenix House and is well placed to offer more dynamic therapeutic group work to its members. Mainliners' founders have been very careful to bring many diverse views together onto its governing committee. It is to be hoped that this will prove to be to their advantage. □

Bill Nelles

Positively Women supports women who are HIV positive or who have ARC or AIDS, however they became infected, though the first members of the group were drug users.

The support group started meeting a year and a half ago. Then, although most women who knew they were HIV positive were or had been drug users, existing women's AIDS support groups excluded drug users. Most drug services were, and still are, male-oriented, and AIDS organisations ran groups consisting mainly of gay men. As a woman and an ex-drug user with HIV, I felt doubly isolated. Contacting other HIV positive people was invaluable, but to carry on living with the virus I and other women in my position needed support which fulfilled our needs as women. This just did not exist — hence Positively Women.

I started Positively Women by sending a poster everywhere I could think of where women with HIV might go. At first it was mostly other drug users who responded, but now most of my new contacts are with

Mainliners was started off earlier this year by a group of HIV antibody positive ex-drug users who were fed up with the lack of specialist services for drug users around HIV and AIDS. In the beginning myself and Stuart Menzies, founder members, decided that a support group run by a qualified facilitator was the best idea. But, as we spoke to different drug agencies, needle exchanges, STD clinics and to drug users themselves, it became apparent that what was needed was a new organisation offering practical help as well as emotional support.

From that moment we decided that a different approach was needed, so we registered Mainliners as a charity to enable us to secure the necessary funding. We started a support group of ex-users because it was quite easy to do this with little financial

POSITIVELY WOMEN

Sheila Gilchrist — the group's founder — describes Positively Women.

women who became infected through sexual activity. About 30 women participate in the group with an average 10-15 attending each fortnightly meeting.

Having had my fill of being counselled by professionals, I decided not to involve professionals at all. My need was simply to talk to other women in my situation from all walks of life. Although in theory I facilitate the group, in practice we all know that I need support as much as anyone else in the group. Partly to help shed the 'drug users group' label, we now meet at the Soho Women's Hospital rather than on drug agency premises. The first half hour

of each meeting is open to other organisations to come and tell us about their work, but the next two hours is attended only by women with HIV.

Positively Women has also developed beyond its London-based support group to provide a mutual advice/information/counselling network for over 100 women throughout Britain. I also give the added service of one-to-one counselling to women who, apart from the issue of living with HIV, have additional problems which at first they find difficult to discuss in the group. The work goes on without any funding beyond small donations from individuals.

The women that contact me now are still disillusioned with what the AIDS groups offer. Mixed-sex groups are available but these fail to take into account the fact that there is a lot more pressure on women with HIV and even more prejudice against female than male drug users. □

Positively Women can be contacted on 01-671 4469 or 01-734 1794.

MAINLINERS

Ian Palliser, one of the founding members, tells the story of Mainliners, currently the largest of the AIDS/drugs self-help groups.

support. The group has proved a success, with most of the major drug rehabs in London allowing residents to attend.

We intend firstly to support ex-drug users, and secondly to work with people who are HIV positive and still using drugs, though we realise these two groups have somewhat different needs. We hope that by early next year the Mainliners centre will be

open. The initial service will include a drop-in centre staffed by volunteers and paid staff. An assistance vehicle will provide essential transport for clients to and from hospitals, etc. We also intend to provide many social events as well as a crisis intervention service.

Mainliners has received a lot of support and, probably more importantly, some money to further its aims. The National AIDS Trust provided £30,000 to the group for set up costs, but this will soon be gone — so whether Mainliners continues and grows is as much a question of money as of the dedication of the people involved. □

Mainliners can be contacted at The Enterprise Centre, 444 Brixton Road, London SW9, phone 01-274 4000 or 0836 726775.

THE THT DRUG USERS SUPPORT GROUP

A support group for HIV positive drug users and ex-users has been running at the Terrence Higgins Trust since October 1987. The aim was to support drug users who had been diagnosed HIV positive (including those who had gone on to develop ARC or AIDS) and who had made a decision to try and live in a more responsible way. Although there have been attempts to make the group take the role of an HIV positive drug users' rights group, and to provide practical (eg, financial) assistance to its members, these soon proved beyond the resources available. The primary aim has become clearly established as that of providing a safe space in which to ventilate feelings.

At first four facilitators attended the group on a rota, but the lack of continuity did not promote a secure atmosphere. As a result one of the four (Susan Hogarth) began taking the group on a regular basis. At this time a business meeting was held to outline some criteria for group membership. These were:

- ▶ Those attending the group should have been diagnosed HIV positive.
- ▶ Everyone wishing to attend should either be stabilised on medication or drug free, but not still using street drugs or injecting.
- ▶ Anyone turning up in a drug-induced state may be asked to leave — at the group's discretion.
- ▶ Everything said within the group and the identity of its members should be absolutely confidential.
- ▶ Changes to the structure or purpose of the group should be put to a vote before implementation.
- ▶ The facilitator should emphasise the confidentiality of the group at each meeting.

These guidelines were never formally implemented but were generally adhered to. As with all guidelines, exceptions have had to be made. It is important to have clear criteria and some understood guidelines, but at the same time, the facilitator must use common sense and judgment. We are aiming to support the drug users, not to alienate them.

The members are equally divided into ex-users who are abstinent, people who no longer use regularly but still occasionally use potentially addictive substances, and those on a methadone prescription. It was anticipated that mixing these groups might have caused difficulties due to their different aims and needs, but this has not always proved so, with the ex-users being a positive influence on the others in terms of generating motivation to come off drugs, as well as being generally supportive.

The members are at different stages of HIV infection, ranging from asymptomatic to ARC and AIDS. Current health problems are therefore a regular group concern, with the asymptomatic ones being supportive to the less well, but at times experiencing guilt at still being well, and fear of having to go through similar experi-

Susy Hogarth, Massimo Riccio and Geraldine Mulleady, three members of the Terrence Higgins Trust Drug Education Group, describe the workings of the THT Drug Users Support Group, one of the first such groups in Britain.

ences. For this reason, some asymptomatic members have, at times, been reluctant to continue attendance.

Attendance fluctuates as weekly attendance is not required. Overall membership is about 30 and 8-10 members attend each group. About two-thirds are men and one-third women, with the women attending less often than the men, perhaps due to the fact that the women are mostly asymptomatic at present.

Group dynamics

Primarily drug addicts have had a code of behaviour that has not embraced the morality of any society. There is usually a premise of choice in what they have been doing. Addicts will defend their right to use, to destroy themselves and to survive without help from society. Although there is often cooperation with authority, there is no acceptance of authority. Along with this seems to go the attitude that anything that may happen to them (overdoses, prison, etc) is an accepted risk.

With the recognition that they are infected for life, the belief system of HIV positive drug users has been shattered. Addicts have a real problem not only with the fact that they cannot change the reality of HIV, but also with having to accept being trapped and needing help from a society they have done without. Being HIV positive is a burden they can't carry on their own.

The changes in lifestyle and behaviours that having the virus requires are enormous and very unpalatable. Drug addicts who attend the support group have made a decision to come together to support each other in their efforts to make these changes and to take responsibility for not putting anyone else at risk. Often they feel there is not nearly enough recognition of how hard it is for them to change their behaviour.

Another belief that the addicts had was that their addiction was temporary — that one day they would cease these behaviours and go on to meet the right partner, have children and put their addiction behind them. The reality that they can never have that dream fulfilled has been a major grief issue in the group.

Poverty is another major issue and provokes envy of the gay HIV positive man — the assumption being (often correctly) that many gay men have led a productive life so have homes, cars, bank balances and jobs. Even though the addict must accept that it has been their behaviour which has left them without these things, they have to face the fact that they may never be well enough to be able to change the situation.

Most group members have problems with housing, food and clothing, and are very frustrated by the system, and then very frightened when they are ill and need these basics. Members with more experience of dealing with these issues are very informative and now are offering to meet (outside the group) to help others get through these problems. Members are also now noting which health workers and clinics are the most supportive and passing that information on in the group. This came about after much ventilation of anger at disrespectful treatment in both outpatient and inpatient settings.

Present sexual behaviour is another ongoing issue. It is absolutely clear that, as heterosexual men and women, the members are not considering alternatives to penetrative sex and are resistant to the gay message of alternative sexual activities. Nevertheless, there is an enormous amount of fear around the risk of infecting a partner, and we regularly hear about the risk factors of the condom (breakages, etc).

Health problems currently affecting particular members are dealt with on a weekly basis. Several are quite ill and their attendance is dependent on their health. There has been a poor level of acceptance of the physical limitations of being ill, connected with the addicts' lack of maturity and ability to take responsibility for maintaining their health before knowing they were HIV positive. There is a great deal of anger and frustration at the inability to be independent and also at not feeling like doing things.

Towards self help

Since the beginning of the HIV epidemic, gay men have been actively organising and running their own self help groups, which have played an important role in health promotion and in offering support and advice. At first drug users may require more input from professionals to establish and maintain their own self help network, as in New York City during the early development of ADAPT. The extra input may prove crucial in helping drug users develop their own coping strategies to reduce risk behaviours and stem the spread of HIV infection. These groups may pave the way for the development of a self help network, facilitated by the fact that group members will have a greater knowledge of, and easier access to, current drug users in the community. □

The section of this article headed "Group dynamics" has been adapted from Susy Hogarth's contribution to the THT booklet Support Groups for Drug Users with HIV, ARC and AIDS, available from THT at £0.75 inc. p&p. Susy Hogarth was the group's regular facilitator from October 1987 to February 1988. The group now meets at a more accessible location near Victoria station, and can be contacted through David Bickerton at the THT, phone 01-831 0330.