

*“ An AIDS trainer described drug users as ‘mad, bad and dangerous’ ”*

# FALLING through the MUDDLE

## Mainliners Ltd

*Can HIV or drug agencies meet the needs of those at the sharp end of both problems – HIV positive drug users?*

IN RECENT YEARS drugs service organisations have been under financial, social and political pressure to tackle the problems associated with HIV; likewise

AIDS organisations have been pressured to tackle drugs and drug users. Already struggling to meet their original aims, many have been put under further strain. Despite their efforts there remains a lack of care, support, understanding and good quality information for people affected both by HIV and by drugs – including those working in the field. People doubly affected by a serious disease and by drug use often need individualised intensive support with an emphasis on good health, good living conditions and minimising the health risks of continued drug use. Achieving this kind of transformation is no easy task, particularly for those with few financial or social resources.

But there is little clear recognition of the needs of drug users with HIV and in many agencies the service offered them is largely tokenistic. Some drug agencies have focused exclusively on harm minimisation – a needle exchange and primary health care – which does not constitute a comprehensive service.

Drug rehabs have also not adapted sufficiently to the needs of HIV positive residents; the few changes have been cosmetic, such as ‘reducing the level of stress’. Some are so fixated on ‘total abstinence’ for their clients that they fail to provide even basic information about safer drug use.

Much of the information available from AIDS organisations is simply no use to drug users, especially if their lives have become very chaotic: tips on healthier living, alternative treatments, nutritious diets and so on are useless to somebody who hasn’t got enough money to buy food to stem the nausea from AZT.

The fact is that at the moment, drug users with HIV aren’t getting a good deal. In theory they ‘plug in’ to either drugs or HIV services; in practice many (perhaps by choice) do not. This leads to isolation, inadequate medical care, lack of financial resources, poor diet, and increases the problems associated with their drug dependency or their HIV-related illnesses – an unknown number are “fixing themselves to death”, in the words of one inner-city outreach worker.

It may be idealistic and naive to assume that it’s possible, or even desirable, for one service to suit all comers – as some AIDS organisations are now attempting to

do. People affected by drugs, by HIV, or by both, have different needs which must be tackled independently.

Some services, notably the Healthy

Options Team in Tower Hamlets, the Health Improvement Team in Bloomsbury, and Mainliners, were set up specifically to deal with the needs of drug users with HIV, who feel removed from the traditional role of both drugs and AIDS services.

Drug users with HIV have to face disproportionate prejudice and discrimination, even from within so-called ‘caring agencies’ – a trainer on a counselling course run by a prestigious AIDS agency recently described drug users collectively as the “mad, the bad and the dangerous”.

To challenge this prejudice, services need to enable those with drug-related HIV to become active participants in the planning and provision of services. This goes beyond having a selected user ‘on the committee’, to developing an entirely new structure for the transformation of the client role from passive to active and its integration into all aspects of service planning.

The stigma attached to illegal drug use has to be exposed as judgmental, moralising, and damaging to those at the receiving end. There is an urgent need for training for GPs, hospital staff, workers in HIV/AIDS agencies, social workers, home care teams, and other services in contact with drug users.

One of the major flaws in services generally is the tendency to focus on HIV or on drugs to the exclusion of all else: the individual is seen only as HIV positive, or as a drug user: their needs as an individual, which may be completely unrelated, get lost. Users and ex-users need places to go where they feel welcome and accepted, and where they can get involved in creative, productive activities which can provide a sense of purpose and self-worth.

Mainliners hopes to play a key part in developing and improving services for drug users at risk of HIV. Mainliners is fundamentally committed to the principle of self-help. Through a process of consultation we aim to provide a range of services to enable people to empower themselves –

setting up the structures for HIV positive drug users and ex-users to start taking control of their lives, making demands about the kinds of services they want, and realising that they are entitled to a certain quality of life just like everybody else. ■

*Mainliners is a national charity for people affected by HIV and drugs/ alcohol. Contact on 071-274 4000 ext. 443 or 315.*