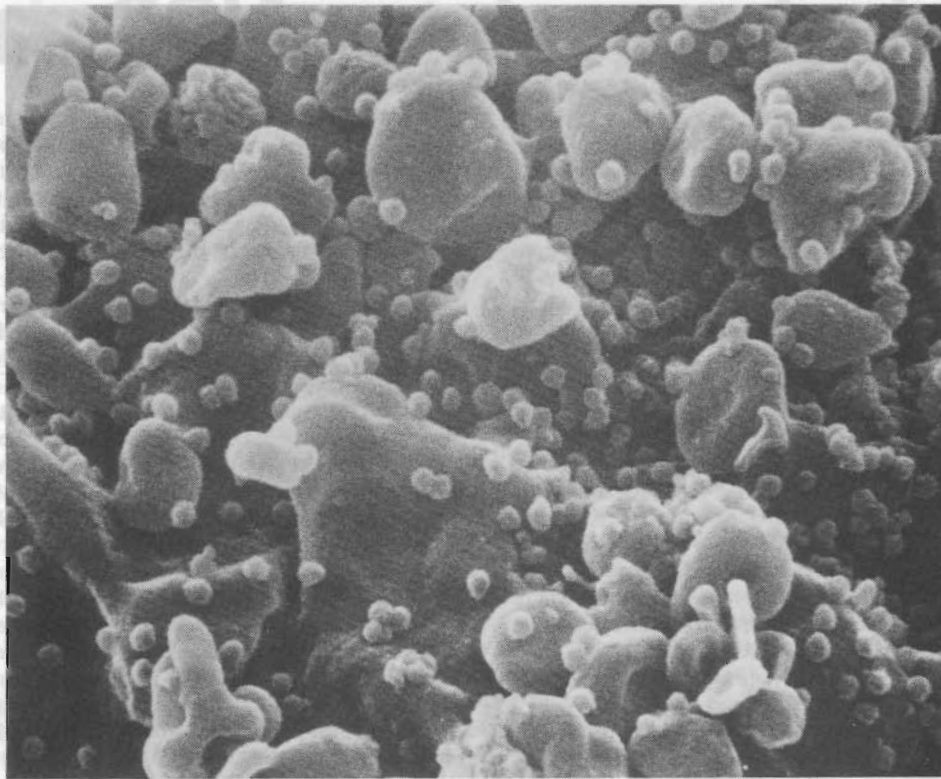


The physical reality that's creating a social revolution in drug treatment. At x40000 magnification, myriads of small spherical HIV particles can be seen budding from an infected T-lymphocyte immune cell.



National Biological Standards Board

COPING WITH AIDS

A summary of a report from the Advisory Council on the Misuse of Drugs

IN ITS FIRST report on AIDS and drug misuse the Advisory Council dealt with preventing HIV spread. *AIDS and Drug Misuse Part 2* is about what to do when prevention has failed and services are faced with HIV infected drug users.

At least in theory the first report broke the mould of drug services in Britain by promoting the prevention of a physical disease (AIDS) to top priority, overriding traditional preoccupations with overcoming drug problems and achieving abstinence. Inevitably *AIDS and Drug Misuse Part 2* is a less revolutionary document. But it is also more workmanlike, giving detailed and practical guidance to the range of services likely to be dealing with the expected (in some places, existing) wave of HIV infected drug misusers.

It first points out that drug misusers are the fastest-growing group of people with AIDS in Britain, with as many as 1000 cases expected in England and Wales by the end of 1992 and around 500 new cases in Scotland between 1989 and 1991. Nowhere is excused — all parts of the country must, they say, prepare to cope with increased numbers of ill drug misusers.

The impact of having to deal with HIV

Mike Ashton is the editor of Druglink. AIDS and Drug Misuse Part 2 by the Advisory Council on the Misuse of Drugs (HMSO, 1989) is available from ISDD at £6.70 inc. p&p. Pre-paid orders only, cheques payable to ISDD.

***AIDS and Drug Misuse Part 2* completes the Advisory Council's review of how HIV is transforming the response to drug misuse in Britain. It is essential reading for anyone who is or might be working with HIV infected drug users. It gives an urgent prod to the planners and funders of those services. Some of the main points are summarised here, the full report is available from ISDD.**

Mike Ashton

affected drug users will be felt by services in the AIDS field and by services in the drugs field. These and other services must attract HIV positive misusers early to prevent further HIV spread and to help retard the progress of the disease. They must also be prepared to deal with infected misusers who continue to use drugs and even continue to inject.

Testing and confidentiality

An extended discussion of the pros and cons for drug misusers of being tested for HIV concludes that increased understanding of HIV disease and the availability of treatments may be shifting the balance of advantage towards testing. In any event the council stresses that:

- the person concerned should make the decision; no one else should make it for or require it from him or her;
- no one should make a decision without appropriate information, advice and counselling from someone with the necessary counselling skills and up-to-date knowledge of HIV;
- the decision whether or not to have an HIV antibody test will be determined by individual circumstances.

Confidentiality over HIV status has become a major issue for drug agencies. Complications arise as agencies find themselves increasingly working with medical and welfare services needed to respond to the needs of ill people, but which may have different ideas of what confidentiality means and of its importance.

The council stipulate that the rule that an infected person's serostatus should not be revealed without their informed consent should only be broken in one situation. That's when a specific named contact is at risk of catching the disease and could protect themselves if they knew the client was infected.

Services helping infected drug users are often starting from a lower base than with other infected groups. Under-use of medical and welfare services, social and financial deprivation, poor health, insecure accommodation and estrangement from friends and families, all can put drug misusers at a disadvantage.

Clearly, HIV positive people need regular medical attention. With drug misusers the need could be all the greater as lifestyle, drug use, self-

neglect and other infections transmitted through injecting take their toll on physical health. A regular six-monthly check up by a doctor experienced in HIV is recommended.

Misusers should be counselled against activities which could accelerate progression to AIDS. Those listed are injecting, especially using unsterile equipment and contaminated drugs, exposure to sexually transmitted disease, and re-exposure to HIV by whatever route.

Advice, support and counselling should all be available to infected people, but the council give a blunt reminder that these cannot compensate for cold, hunger and discomfort. For infected drug users adequate housing is both a medical need and, if it takes them out of their drug using environment, an aid to stopping drug use, which could itself benefit health. Local authorities and housing associations should prepare to meet this need, but the council is forced to recognise that in some areas the problems are at present "insurmountable".

'The service offered by specialist drug services is radically altered by the advent of HIV disease'

Heart-rending dilemmas can arise for infected women. Those who planned to have children may be depressed to find this possibility cut off. Others may react with an intensified need for children but will have to face the 25-40 per cent chance that their child will be born infected, with all the practical problems and guilt this can bring. To give these women the support and advice they need, it is even more urgent that services "consciously" seek to attract women and remove barriers (such as child-care problems, fears over children being removed, etc) to their attendance.

HIV infection increases the need to gain access to primary health care through a GP. But many misusers are not in contact with a GP and many GPs are unwilling to take on drug users. The Advisory Council saw the problem as being urgent enough to require the establishment of a working party to look into increasing the involvement of GPs, including offering them money to take on drug misuse treatment.

The role of specialist services

The council's earlier report argued for a re-ordering of priorities away from 'curing' dependence towards preventing HIV spread. Nearly a year later their second AIDS report notes that "a number of [drug] services appear to have made inadequate changes ... some staff ... have deeply entrenched attitudes on management of drug misuse by withdrawal".

As infected drug users become ill, more will approach drug services as a 'friendly' access point for obtaining information and help. Many of these will have no intention of stopping drug use. Rigidity of attitude making abstinence the only goal will, says the council, greatly restrict the help drug services can offer these people.

Making HIV infection a reason for giving priority to treating that individual's drug problem implicitly decreases the priority given to people not known to be HIV positive. In prevention terms this is a mistake, says the council. Priority should be given to clients at high risk of transmitting or contracting HIV, regardless of their known HIV status.

As an "absolute minimum" specialist drug

services should provide advice and information on HIV disease including the transmission of the virus and general health care once infected. Services unable to go beyond this should arrange for other agencies to provide more intensive support for HIV infected clients.

The council is firm that residential drug services should not exclude people known to be HIV infected nor require testing. For the purposes of infection control policies, all residents should be assumed HIV positive. An implication drawn is that stress and ill-health, which may aggravate HIV disease, should be minimised regardless of the resident's known HIV status. No-holds-barred encounter groups and confrontational therapies in some therapeutic communities are among the targets of the council's remarks on stress.

Most existing residential rehabilitation units for drug users are not equipped to meet the requirements of a nursing home for people who are seriously ill or dying. Hence the council's call for at least two specialist houses for drug users or ex-users to go to when they become ill, one drug-free, the other for residents receiving prescribed drugs.

The council's line that prescribing substitute drugs to drug dependent people should not be restricted to those seropositive follows from their insistence that all those at risk must be presumed infected, and from their stress on the need to prevent new cases of infection. Such prescribing should, they repeat, always be aimed at encouraging change to more healthy or less risky behaviour.

If prescribing drugs other than oral methadone (such as injectables or stimulants) could achieve

Planning failures

What AIDS and Drug Misuse Part 2 has to say about planning for the HIV epidemic to come makes depressing reading. Most of Britain is in the fortunate position of AIDS not yet being endemic, but the Advisory Council found little evidence that this interlude is being used to plan for the epidemic to come. They stress that advance planning and adequate funding are needed if services are not to be caught unprepared.

Planners are warned that complacency and denial now will result later in panic measures when the need becomes impossible to ignore. But baseline information on how big the problem is or is likely to become is lacking in most areas, and frequently local AIDS and drugs committees work in isolation from each other.

Among the council's recommendations on planning are the appointment of someone in the health authority and in social services to ensure that the health and community care needs of HIV infected people are met. Continuity of care is stressed and the report suggests a particular worker take on the role of case manager for each client. They would be responsible for seeing that the client's needs are met at each stage of the disease. For drug misusers the case manager might be a member of a community drug team.

these ends, then, says the council, it might be justified. But, other than in exceptional circumstances, they doubt if such prescribing would have net benefits.

To cope with the new demands of dealing with large numbers of ill and infectious people, additional earmarked and continuing resources are needed for drug services. Government responded to this call from the council even before their report was published (see last issue of *Druglink*) but the report gives no clue about how much money they were looking for.

Staff in hospitals and HIV counselling clinics will need training in working with drug misusers and to develop two-way referral routes with drug services. In this respect the council sees a clear educational role for specialist drug services, who in turn will need training in HIV and related nursing and medical issues. Close liaison in training and referral and sessional swapping of staff is envisaged.

Avoiding imprisonment

The report makes a bid to marry up the criminal justice and treatment systems in the interests of public health, swimming with the tide of the 1988 Home Office green paper, *Punishment, Custody and the Community*. The council say HIV makes it more important than ever that police refer drug misusers they contact to local drug services and that the courts use treatment alternatives to imprisonment.

In making these proposals the council is aware that many drug agencies will not want to take on clients forced into treatment by the courts. Non-residential services in particular are unused to this role. They will have to get used to it, is the council's message. Extra resources will be needed for which, says the council, the Home Office is the obvious source.

'Working with people with HIV disease requires a high level of commitment in the face of great intensity, stress and sadness'

All else failing, drug misusers infected with HIV, whether known to be or not, will end up in prison or become infected there by sharing scarce injecting equipment. Several pages in the report are devoted to a detailed criticism of the isolation of known HIV positive prisoners under viral infectivity restrictions. The denial of work and recreation opportunities this entails is argued to be counterproductive in health terms and unnecessary for the prevention of HIV spreading to other prisoners.

Here as elsewhere the most telling point is that separate treatment of known HIV infected people ignores the probability that many more will be infected, unknown even to themselves. Singling out people known to be HIV positive may give the dangerously reassuring impression that everyone else is free from the virus.

In its last chapter the council's report outlines a formidable array of training needs—formidable not just in terms of updating knowledge in a fast-moving field, but also in terms of equipping workers with the attitudes and emotional resources needed to help people infected with an incurable and usually fatal disease. Workers' attitudes, knowledge, skills and support structures all need to be systematically developed if inappropriate responses and premature burn-out are to be avoided. ■