CHAPTER 4 HIV INFECTION AND AIDS: SOCIAL ISSUES

The social consequences of AIDS. Prejudice and blame. Prejudice against lesbians and gay men. Racism and AIDS. Injecting drug use, HIV and AIDS. Prostitution. Calls for compulsory testing.

THE SOCIAL CONSEQUENCES OF AIDS

All diseases have social and economic consequences which go beyond the medical sphere. People who experience arthritis or cancer soon discover that their diagnosis influences their lifestyle, and the lifestyles of those who are close to them. What is more, the perceptions of other people often alter in the face of disease, and so influence the interactions experienced by people who are defined as being 'sick'.

We might logically expect that people with HIV infection and AIDS would experience similar social consequences as those with other potentially life threatening illness such as heart disease or diabetes. HIV is not contagious and people living with AIDS can be fit and well depending on their current medical condition. However, HIV infection and AIDS are clearly associated with social consequences which are far more extreme than those associated with most other diseases.

It has often been said that the advent of HIV and AIDS has brought about two epidemics: the disease itself, and an epidemic of fear, prejudice and misinformation. This has affected not only those with HIV infection and AIDS, but also their partners, families and friends. Prejudices against particular minority groups have become further entrenched as a result of the AIDS epidemic, which has led to scapegoating of groups such as gay men, Black people and drug users. Prejudice against minority groups, and the desire of some influential individuals and institutions to advance a particular moral agenda, has lead to demands for compulsory testing and periodic calls for the quarantining, segregation and incarceration of those testing HIV antibody positive. Strategies for challenging the epidemic, such as the delivery of accurate health education, distribution of condoms and provision of clean needles, have met with resistance and protest from those who wish to promote one way of living based on their own particular moral opinions.

It is crucial that we examine the social issues which have arisen out of the AIDS epidemic, and make a distinction between the health education objectives which seek to halt the transmission of HIV, and the particular 'moral' objectives which have framed and shaped responses to people infected with, and affected by HIV and AIDS.

Young people have not been immune to such pressures. Even before public awareness of HIV infection and AIDS, many young people were believed to be unknowledgeable, irresponsible and inordinate risk-takers. Some adults even subscribe to the view that young people should not be taught about sex, for fear it may encourage them to 'experiment'. Such views have led to young people being denied the opportunity to make informed decisions about their lives. Although some young people seem to thrive on risk, this is no more true of them as a group than it is of adults. It is important for those working with young people to take the views, feelings and experiences they express seriously, and not to relegate them to the status of a 'phase' or 'stage'.

PREJUDICE AND BLAME

Much debate around HIV and AIDS has centred on a division between the 'innocent' and the 'guilty'. The 'innocent', who are considered deserving of support and sympathy, have been characterised as babies born with HIV infection, people with haemophilia and others infected through blood transfusions. It has been widely suggested that other groups of people with HIV infection and AIDS have somehow brought about their own 'downfall' through their irresponsible and immoral behaviour. Not surprisingly, given the prejudices which exist in our society, gay men, drug users, and prostitutes are, by implication, to be held responsible for their HIV infection. People with HIV infection and AIDS are often divided into those to be 'blamed' and those to be sympathised with. It is also suggested that people who have acquired HIV through their own 'wilful' behaviour should be held responsible not only for their own infection, but also for the infection of the 'innocent victims' of HIV and AIDS.

Although these ideas are clearly illogical, not to mention vicious and cruel, they are important in that they have influenced demands for the testing of people supposed to be 'at risk', and the isolation of people who are considered to be a threat to 'mainstream' society.

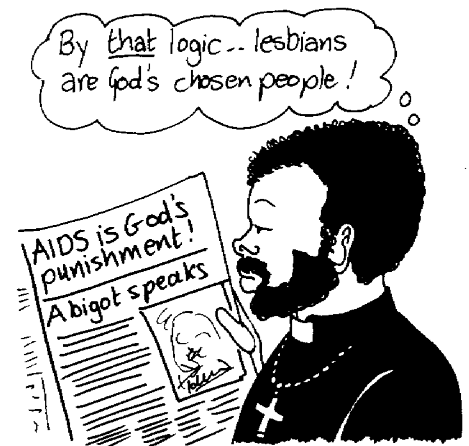
Because HIV infection and AIDS has been so closely linked with minorities such as gay men, Black people, injecting drug users and prostitutes in the media and the popular consciousness, many people believe that those who have not been identified in this way are 'safe'. The 'sanctity' of the monogamous, heterosexual relationship is thereby preserved, and the 'real threat' is perceived as originating with those who might act as a 'bridge' into the predominately white heterosexual world.

This is not the only viewpoint though. Almost anyone can somehow manage to blame AIDS on what they perceive to be an outside group. Some lesbians see bisexual women who have sex with both men and women as the route by which AIDS can 'get into' the lesbian community, while some young gay men tend to think of HIV infection as a concern only for older gay men. The belief that it is 'other people' who are likely to be infected, and not 'people like us' arises from the desire to distance ourselves from HIV and AIDS. But what often results is further victim-blaming and prejudice, and at worse even physical attacks on minority groups. In terms of health education these beliefs have tragic consequences. For we may believe that it is only other people who are vulnerable to HIV infection, and become less likely to seek to protect ourselves and our loved ones.

When working with young people we need to be aware of the ways in which prejudice towards others, and the fear and anger arising out of this, influences attitudes towards HIV and AIDS. It is important to find ways to raise awareness about the illogicality of calls for compulsory testing for example, and the prejudicial assumptions upon which such demands are based.

PREJUDICE AGAINST LESBIANS AND GAY MEN

Because HIV infection and AIDS first affected gay men in the West, the overwhelming response of many people has been to link the epidemic solely with gay men. The enduring myth throughout the epidemic, has been that gay men are somehow the 'cause' of the spread of HIV infection and are therefore to 'blame'. As a result, prejudice against gay men, and by extension all same-sex relationships has increased. In actuality, as mentioned in Chapter 2, lesbian sexual activity is in fact very safe - a fact which has failed to confound those who see AIDS as a divine punishment for engaging in same-sex relationships.



Prejudice against gay men has also informed government responses to the epidemic. It is now clear that early in the epidemic a more rapid response from the U.S. government might have significantly halted the spread of HIV infection in the developed world. However, because U.S. health agencies mistakenly believed that the syndrome only affected gay men, the epidemic was not taken seriously. By allowing prejudice to override a public health issue, the chance to limit the epidemic in its early stages was missed, and thousands of people died, and will still die, quite unnecessarily.

Aside of the specific concerns which have arisen as a result of AIDS, heterosexism is an important issue for all work with young people. Young lesbians and gay men are growing up in a society where they are faced with widespread prejudice and discrimination. Section 28 of the Local Government Act 1988 (see Chapter 1) has seemingly condoned heterosexist attitudes, and the advent of AIDS has brought about a new wave of prejudice. Heterosexual adults working with young people need to examine carefully their own beliefs, and need to recognise that it is not only name-calling which constitutes anti-gay prejudice, but also the common assumption that our colleagues and the young people we work with are heterosexual.

As already discussed, the belief that AIDS is a 'gay problem' serves as a barrier to effective health education. If heterosexual young people believe that AIDS does not affect them, that HIV infection is a punishment for certain kinds of behaviour, and that it doesn't matter if gay men die, health education will not be effective.

Furthermore, it is important to challenge anti-gay attitudes so that people with HIV disease and those close to them do not have to endure prejudice in addition to illness.

RACISM AND AIDS

There has been a great deal of media coverage on the prevalence of AIDS in parts of Asia, South America and most particularly, sub-Saharan Africa. Much of this reporting has served to reinforce and reproduce existing racist stereotypes especially those about Black people.[1]

There is much controversy as to where and how AIDS 'originated', but the suggestion, which is contested by many, that HIV came first from the African continent has allowed some people in Western countries to 'blame' African people for AIDS.

There are two implications for working with young people. First, as already discussed, people often seek an opportunity to distance themselves from AIDS, and racist attitudes which label AIDS as an 'African problem' or a 'Black problem' may allow some young people to 'switch off' to AIDS, and so negate effective health education. Secondly, many young Black people are finding that abuse such as 'AIDS carrier' is being added to the daily racist abuse they endure. Young people who experience this kind of racism may feel stigmatised, blamed and become isolated.

Challenging racism is an important part of all work with young people, and young Black people should not have to endure racist abuse, whether or not it includes reference to HIV infection and AIDS (see Appendix E for additional resources).

INJECTING DRUG USE, HIV AND AIDS

The common stereotype of an injecting drug user is that of a selfish, irresponsible and dirty 'junkie' who has no control over his or her life and will steal and lie in order to fulfil the desperate need for a 'fix'. Media representations and government anti-heroin campaigns serve to reinforce this stereotype. In fact, drug use is found in a wide cross-section of society. In working with young people, a judgmental attitude to injecting drug use is very unhelpful and often counter-productive. Also, prejudicial attitudes are actually hypocritical since drugs are widely used in our daily lives. By the way drug use is portrayed, it would seem as if only a few people used them. Yet most of us use drugs. Coffee, nicotine and alcohol are a routine part of many people's daily lives. These are not only legal, their use is actively promoted - companies make profits and the government secures vast sums of money in taxes.

It is important to recognise that using drugs does not mean you are an 'addict'. And their use, even if injecting, will not in itself put you at risk of HIV infection. However, if injecting, sharing a contaminated needle does. For many drug users, the everyday risks involved are more closely linked to the illegality and socially unacceptable nature of their behaviour than to the dangers inherent in the drugs themselves, or to HIV infection. Alcohol is obviously a dangerous drug, yet because its use is legal and socially acceptable, the production and sale of alcoholic drinks is strictly monitored. So we are unlikely to be poisoned by a glass of what purports to be whisky but is in fact spirit contaminated by weedkiller or household cleaning fluid. The consumer of illegal drugs has no such protection, and his or her family is unlikely to sue the supplier if she or he dies as a result of injecting spiked heroin (heroin mixed with other potentially lethal substances). In the context of illegal drug use, HIV infection is just one of a number of risks that need to be assessed.

Many long-term, older injecting drug users have taken responsibility for protecting themselves and others from HIV infection. Younger injecting drug users are also beginning to pay attention to advice about protecting themselves against HIV through using needle exchange schemes. There are some areas of Britain, notably in the Strathclyde and Lothian regions of

Scotland, where due to past needle-sharing practices, injecting drug use has been the commonest transmission route for HIV. It is important to be aware that, amongst injecting drug users, it is not only those sharing needles who are at risk, but also their sexual partners, whether in gay or heterosexual relationships. It is possible to be punctilious about using clean needles while being casual about practising safer sex, and it is important when working with young drug injectors to remember that their need for information about safer sex is as great as their need to know about risk reduction in relation to drug use.

There are now a number of resources to support work on drug use (see Appendix H), and even if there are no known drug injectors in the group, you should use some of the exercises on drug use in this pack. This is partly because drugs are offered to young people in the most unlikely of circumstances, and so all young people need to be informed about the risks of HIV transmission associated with injecting. It is also because prejudice against 'junkies' is simply another mechanism for placing the threat of AIDS as far away as possible, and as such, needs to be challenged by anyone supporting young people around the issues of HIV and AIDS.

PROSTITUTION

Despite a marked tendency among some people to 'blame' prostitutes for AIDS, there is very little evidence that prostitutes 'spread' HIV, although it is probably true to say that their work puts them at greater than average risk of encountering someone with HIV. Sex workers are traditionally well-informed about good sex-related health care, and have ensured that information about safer sex is distributed, and that condom use or safer sex is widely practised. Some injecting drug users sell sex in order to buy drugs, and this obviously increases the potential risk.

As is the case with the stigmatisation of all the groups who are popularly perceived as being at 'high risk' of becoming infected with HIV, these groups are also perceived as placing the 'rest' of the population at risk. Whenever prostitution is mentioned in the context of AIDS, it is prostitutes who are blamed for spreading the virus, rather than those who use them.

CALLS FOR COMPULSORY TESTING

A common response to the spread of HIV is to call for compulsory testing or screening of whole groups of people. In the light of everything discussed thus far, it is not surprising that the groups who are generally singled out for compulsory testing are drug injectors, immigrants, prostitutes and gay men, reflecting popular ideas which have grown up about the 'sources' of HIV. The 'solution' to the epidemic usually offered is to force all the members of the group concerned to 'take the AIDS test' and then to lock up all those who test positive. Three issues are raised by suggestions such as these: the effectiveness of testing as a means of halting the epidemic, the feelings that lie behind calls for compulsory testing, and the social implications of being tested.

Testing as a means of halting the AIDS epidemic

Advocates of testing believe that the test will identify people who are capable of transmitting HIV and will enable the 'spread' of HIV infection to be contained through segregating or incarcerating those people. This argument has several flaws.

First, there is no such thing as an 'AIDS test'. The tests in common use, test for HIV infection, not AIDS. The HIV antibody test detects the antibodies which are produced in response to HIV infection. This test has certain shortcomings which are important to understand. First, as discussed in Chapter 3, the virus can exist in the body for a period of between a few weeks and three months (or even longer) before antibodies are detected. This means that it is perfectly possible for someone to have the virus and yet have a negative test result. People taking the test are often advised, if the result is negative, to return for a re-test in three months time by which time it is likely that antibodies will have developed if they are infected. During that three months, care must be taken not to engage in any activities which might lead to infection, as if the virus is contracted, it will still not necessarily appear on the re-test. Given an accuracy of 99% (probably impossible to achieve in any medical test), there would still be large numbers of people with either false negative or false positive results. Because of this, testing can have only a very limited role in disease control.

The Reasons Behind Calls for Compulsory Testing

It is important to recognise too that demands for mass testing often have little to do with desires to contain the virus. They may instead result from both an uninformed fear of HIV and a desire to punish those groups believed to be 'responsible' for AIDS. Young people, forced to think about issues such as safer sex, and deluged with demands that they limit their sexual behaviour, sometimes feel quite cheated. There is a common suspicion that adults, who grew up in a period when HIV infection was not a recognised concern, have had a chance to 'experiment' in ways which are being denied to young people today, because of fears of AIDS. Some young people feel quite resentful, and there is a tendency to want to take revenge on those groups seen as in some way 'responsible' for AIDS. The suggestion that all gay men should be tested, quarantined, tattooed or whatever, can be an expression of this resentment, and needs to be challenged as such.

The Implications of Taking a Test

The decision whether or not to take a test is both personal and complex, and will depend on individual circumstances. However, this is rarely recognised or acknowledged by those who appear to believe it is an easy solution to some of the problems posed by HIV and AIDS.

First, as we have seen, a negative test result does not guarantee that a person is uninfected. Second, anyone contemplating testing needs to ask themselves how they would cope with the consequences of a positive result. A positive result is obviously very distressing, and apart from feelings of shock, fear and depression, can also result in major changes in relationships with parents, friends, lovers, partners and children, as well as possible difficulties with employment, accommodation and insurance. It can also, of course, mean a chance to seek appropriate medical advice and can enable steps to be taken to remain healthy for as long as possible.

SUMMARY

HIV infection and AIDS has linked into a complex web of pre-existing fears, prejudices and beliefs. This has serious implications for people living with HIV and AIDS, who already have to struggle to come to terms with their diagnosis, and who in addition may have to cope with prejudice, misconceptions and inadequate resources. It also has important consequences for educating young people about HIV and AIDS, and demands an approach which seeks to disentangle prejudices from helpful information. On the positive side, techniques which challenge some of our unexamined beliefs and behaviours offer us the opportunity to work for a more open and equal society.

REFERENCES

1. **Jenny Kitzinger and David Miller (1992) 'African AIDS' and Audience Beliefs. In Peter Aggleton, Peter Davies and Graham Hart (eds.) AIDS: Rights, Risk and Reason, Falmer Press, London.**