AIDS

Can We Care Enough?

report of the conference for

World AIDS Day 1988

organised by the

NATIONAL AIDS TRUST

in association with the

King's Fund Centre

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Introduction

AIDS: Issues for social policy

Virginia Beardshaw, King's Fund Institute.

On December 1st 1988 the National Aids Trust and the King Edward VII's Hospital Fund for London organised a conference for World AIDS Day. With the title "AIDS: Can we care enough?" it was designed to focus attention on the challenges that Acquired Immunodeficiency Syndrome (AIDS) and human immunodeficiency virus (HIV) infection pose for UK health and social services and the voluntary sector. This conference proceedings report is an edited compilation of papers given at the conference.

In December 1988, Britain was six years into the AIDS epidemic. In those six years, its extent and implications had gradually become clearer. In particular, it had become apparent that AIDS is a public health problem which poses old challenges about health promotion, preventive medicine and health care delivery in a stark new form. Medical science has not all but conquered infectious disease. Instead, the relative absence of life-threatening epidemics since polio in the 1950s appears now to be atypical.

By the time that the conference took place, AIDS was already the most important single cause of death for men under 35 in the United States. There, the "first wave" of people with AIDS, which was largely composed of young homosexual men, has begun to give way to a new and more heterogenous phase. Increasingly, the AIDS epidemic in the US is becoming linked to social deprivation, as the virus is spread from people who inject drugs into their families and wider social networks. There are already signs that a similar pattern is developing in Scotland, where drug injection has always been the main mechanism for HIV spread. The problems and dilemmas that this poses for AIDS/HIV health promotion and care in Scotland are considerable, and it appears now that there is a very real danger that AIDS and HIV-infection will become knitted into the pattern of deprivation in Scotland's disadvantaged neighborhoods.

The shape of the UK epidemic

The Cox committee - which was asked to inform the Chief Medical Officers of England and Wales on predictions about the incidence and prevalence of AIDS and HIV infection - reported on the day before the conference took place. Its report estimated that between 10,000 and 30,000 cases of AIDS are likely to be diagnosed by the end of 1992, and that by the end of 1992 between 7,500 and 17,000 people will have died of it. The committee concluded that the pace of the epidemic in England and Wales is slowing, probably because of changes in the behaviour of homosexual men during the mid-1980s. Nevertheless, the committee estimated that by the end of 1987 between 20,000 and 50,000 people in England and Wales were infected with HIV, the virus which can lead to AIDS. There is no broad agreement on the proportion of people with HIV who will go on to develop AIDS, but as the epidemic develops it is expected to increase.

The Cox committee's estimates necessarily have very wide ranges. This is because the extent to which AIDS/HIV can be controlled will largely be determined by behaviour change, which no one can yet predict. There are no equivalent estimates for AIDS/HIV prevalence in Scotland, but by the mid-1980s it was already apparent that there was a very high incidence of HIV infection - more than 50 per cent - among intravenous drug users in Lothian Region. Another study in Scotland suggested that 1 per cent of men aged between 15 and 45 are HIV-positive.

Costing care

Caring for people with AIDS is expensive. In his presentation to the conference, Professor Adler gave estimates of the cost of hospital care. His figures are preliminary, but they put the cumulative care costs for people with AIDS at between £75 and £770 million by 1992. This does not include the costs of care outside NHS acute settings, or of new treatments.

Zidovudine - the first drug therapy for AIDS - costs over £400 a month for a full-dose treatment. Using the Cox committee's estimates, Professor Adler found that drug costs in 1998-2003 would range from £72 to £178 million for AIDS patients. If zidovudine is found to be effective in altering the progression to AIDS in people who are HIV-positive, additional treatment costs could range from £468 million to £1.4 billion in 1992. Other drugs are certain to be developed. In addition, the costs of caring for people with AIDS in the community is unknown, and information on this is urgently needed.

New disease: old problems

The AIDS epidemic is new, but the problems it poses for health and welfare agencies relate to two enduring issues for British social policy. Both had long histories well before AIDS surfaced in the early 1980s. The first is the difficulty of creating effective disease prevention strategies for the general population and specific "at risk" groups. The second is the problem of coordinating appropriate and effective help for people with long term needs.

Preventing HIV spread

Medicine offers no defence against AIDS: safe behaviour is the only protection. Stimulating sustained behaviour change by conveying information about safe and unsafe practices in a way that convinces the general public as well as those groups most at risk is a tall order. AIDS tests present-day expertise in health promotion to the limit. It also points up important limitations in existing knowledge about influencing behaviour. To compound the problem, controlling AIDS involves changing behaviours - sexual practices, illicit drug injection - about which little is known. Many of them are by nature resistant to outside influence, particularly when that influence is construed as coming from statutory health, welfare or law enforcement agencies.

In addition, AIDS - with its potent blend of "unclean" body fluids, sexual practices considered taboo by many sections of the population, forbidden drugs, unpredictable opportunistic infections, dementia and untimely death - has considerable power to alarm. Fear breeds a host of defensive reactions, both collective and individual, and this too can make health promotion more difficult.

In theory, health promotion and disease prevention has been a national priority since the health service was founded in 1948. *Prevention and health: Everybody's business*, a national strategy document published in the mid-seventies, was intended to place health promotion higher on national and local policy agendas. In practice, the demands of formal health care services have always comes first. As a result, Britain's record on heart disease and lung cancer - both twentieth century epidemics where control involves health promotion activity to stimulate behaviour change in individuals, organisations and groups - is not an encouraging precedent for AIDS.

Dr Spencer Hagard's presentation to the conference emphasises that controlling the AIDS epidemic will involve changes in sexual behaviour across the whole population, and an end to particularly risky practices by homosexuals and intravenous drug users. Currently, we are ill-equipped to achieve this. Basic information about sexual behaviour is lacking, and there are few tried and tested methods of bringing change in it about. Groups for whom the AIDS message is highly pertinent - for example, young people - have proved resistent to equivalent messages in the past. In addition, although homosexual men appear to have made substantial reductions in risk-taking, no one can claim to know how to begin to bring about similar change in people who inject drugs. NHS drugs services have atrophied over the past decade, and reach only a fraction of people who inject. Dr Strang's speech makes it clear that new approaches are badly needed, particularly in Scotland. Overall, the taboos associated with gay sex, multiple sexual partners and drug injection compound the problem of communicating effective health promotion messages on AIDS.

The epidemic has also revealed substantial inadequacies in the structures we have created to promote health and prevent disease. In particular, the mesh between national mass-media campaigning and practical advice and counselling services at local level has been poor. Health and local authority health education units in many parts of the country are badly placed and ill-equipped to fill the demand for information and practical advice generated by national advertising campaigns designed to raise awareness about AIDS. Many of them lack the skills and contacts needed to develop health promotion programmes at local level.

As a result, AIDS organisations in the voluntary sector have been stretched to their limits, and it is likely that needs have gone unmet. In many areas of the country, AIDS/HIV prevention policies designed to coordinate the full range of voluntary and statutory activities taking place at health and local authority level are only now being planned. Nationally, the main thrust of health promotion activity remains concentrated on mass-media campaigning, and effective linkages between the two levels have yet to be forged in any comprehensive fashion. Inevitably, in the absence of strategic guidelines, much local health promotion activity has been reactive and ad hoc. Many local health promotion and education units remain unclear about whom they should target and whether their basic aim should be to raise general awareness or to influence behaviour. Unsurprisingly, in this context, few local initiatives are evaluated, with the result that little is being learnt about what works well.

Coordinating care

Currently, our de facto AIDS strategy amounts to awareness raising and caring for people with AIDS. Here too, the epidemic is highlighting a range of problems concerned with coordinating care between and within statutory services and other agencies. As Professor Walker's address makes clear, these same problems of coordination have plagued the thirty-year effort to move from institutions to "care in the community" for people with mental illness and mental handicap. They stem from the stuctural dislocation between health authorities, primary health care and local authorities - a situation that breeds inefficient services on the ground. The practical problems this can create were raised in discussion at the conference when a participant described a Scottish woman with AIDS who had been visited by by twenty or more professionals from a wide variety of agencies, but still lacked the practical help she needed.

Sir Donald Acheson's speech emphasises that the majority of people with AIDS wish to live in their own homes, and that that care could and should be delivered to them there whenever possible. Voluntary organisations concerned with caring for people with AIDS have made the same points repeatedly, and most health and local authorities are in broad agreement with it.

The main elements of what is required for good home health care and support are well known from innovations in other community care fields, and from the community-based care available from many hospices and NHS terminal care teams. Linking home care and nursing support services with appropriate housing is, as Peter Larkin stressed at the conference, essential. So is building on, or adapting, existing care structures - like home help services - wherever possible. "Policy learning" across care-groups is important, if services for people with AIDS are to make good use of what has been achieved elsewhere. In addition, it is clear that being effective at coping with the unpredictable consequences of AIDS means that services must be flexible, and respond readily to the needs of the individual in the way in which Jonathan Grimshaw described to the conference. Experience with other groups of people who have fluctuating needs for care suggests that in practice the statutory sector will find this very difficult to achieve with existing services and approaches.

Making sure that good practice is generalised will be particularly important in the next phase of the epidemic, where is is already clear that it will be crucial to reach disadvantaged groups, like people who inject drugs, if services are to have any chance of success. This is not an area where statutory services are particularly skilled or knowledgable, and the expertise of voluntary organisations will be critical to what can be achieved.

The stigma and discrimination associated with AIDS complicates service delivery. People with AIDS can lose their jobs, their homes, and the support of families and friends, with the result that they need additional help from voluntary and statutory agencies. Terry Munyard's presentation to the conference discusses the ramifications of AIDS-related discrimination; Peter Larkin's address makes the implications of this for housing clear. Victimisation of individuals with AIDS means that agencies must operate effective anti-discrimination and confidentiality procedures, and train their staff in appropriate methods of safe contact and care.

Knowing what to do is one thing; achieving it on a large scale is another matter. Problems of aligning goals, funding and practical arrangements between health, social security, social services and housing departments have stymied the development of widespread community care for other groups. In all too many places, people with AIDS fall into the "community care trap" which people with mental illness, mental handicap and older people have experienced, and which was described at the conference. If humane and cost-effective ways of caring for people with AIDS are to be developed - as they must be - the waste created by the absence of coordinated services cannot continue. Currently, high-cost hospital care fills the gaps. If this continues unchecked, it could lead in time to uncomfortable questions about how much money we should spend on people who are dying.

More positively, one of the epidemic's possible effects is that improving care for people with AIDS might lead to wide-reaching improvements in links between hospital and community, and to better home care for older people and other priority groups. Older people with dementia provide a case in point. Taking an optimistic tack, it could be that good services for people with

AIDS-related dementia will in time provide useful models for better services for older people. Similarly, it is clear that NHS managers and professional staff could already learn lessons from the way that many GUM out-patient clinics are changing their services to be more "user-friendly" for people with AIDS and HIV. The fact that expert counselling is beginning to be built into services for people with AIDS, instead of being treated as an optional extra, could stimulate improvements in other services - for example cervical cytology - where good information for users is equally important. On the health promotion side, it is possible that the urgency of AIDS - and the attention and new resources devoted to it - will help us become much more adept at influencing behaviour in a way that is positive for health.

Above all, AIDS has demonstrated the importance of involving people in planning and monitoring their own care. This is true at individual case level, where professionals caring for people with AIDS have already learnt the value of offering people options about the type and style of care that they receive. It is also true for service planning, where people with AIDS and the organisations which represent them are becoming increasingly involved in developing new approaches to care. If this continues productively, it is possible that AIDS-related health and social care services may provide a practical demonstration of the viability of involving users and their representatives in service design.

Into the 1990s

As the Minister for Health, David Mellor, stated at the conference, the answer to the question "AIDS: Can we care enough?" is that we have got to. The message from World AIDS Day 1988 is that "caring enough" means doing two difficult things well.

The first is the kind of multi-faceted, far reaching health promotion that Spencer Hagard describes in his talk, where awareness-raising at national level is backed up by active health promotion locally which is aimed at changing behaviour. The second is achieving good quality health and social support services for people with AIDS which are based on individual need and preferences, and delivered wherever possible at home.

This introduction has already stated some of the reasons why it will not be easy to do either. However, the conference also made it plain that the voluntary sector is playing a major role in developing both health promotion and community care strategies for AIDS. "AIDS-specialist" voluntary organisations like the Terrence Higgins Trust, Frontliners, Body Positive, Scottish Aids Monitor, Landmark and London Lighthouse pioneered new forms of health promotion, counselling and care as the UK epidemic emerged. Their efforts, professionalism and expertise means that a further positive outcome from AIDS could be the forging of a new relationship between voluntary and statutory sectors, as health and local authorities learn to use the skills and flexibility of voluntary groups more effectively. Already, a number of these organisations and their local equivalents are members of AIDS planning teams, where they are having a direct influence on care and health promotion strategies.

The challenge for the next decade will be to generalise the progress that has already been made with statutory services in some parts of the country, and to involve the generalist voluntary organisations in the job of promoting health and caring for people with AIDS. Christine Reeves, Director of Services for the British Red Cross, indicated in her talk that the "generalist" organisations are beginning to respond to AIDS. The extent to which they are able to do so by collaborating with statutory health and social services will help determine whether we are able to "care enough" about AIDS in the 1990s.

So will improved collaboration and coordination by central government departments. Although AIDS is the only health issue to have its own cabinet committee to coordinate government policy, contradictions persist between major departments of State. Better coordination of services at local level means, in part, aligning policy and practice between the Departments of Health, Social Security and the Environment. For health promotion to be effective, the Departments of Health, Education and Science and the Home Office must work consistently, and together. Policy coherence of this kind is extremely difficult to achieve in practice, but it is essential if the challenge posed by AIDS is to be met. Professor Maynard's contribution to the conference highlights a number of anomalies in the level of AIDS funding NHS Regions in England and Health Boards in Scotland, and questions whether the twin requirements of equity and efficiency are well served by present arrangements. These seeming anomalies are symptomatic of the policy coordination issues that remain to be addressed by central government. A robust and reasoned response to these and other questions about strategy is required if a national policy framework which will permit statutory and voluntary sectors to "care enough' is to develop for the 1990s.

I. RESOURCES FOR THE 1990s

The Government Response

The Hon. David Mellor, QC, MP, Minister for Health.

World AIDS Day gives us all the chance - the Government, the voluntary and statutory sectors and the public - to focus our attention on AIDS. I am grateful to the National AIDS Trust for organising this useful conference.

But whilst I welcome World AIDS Day, I think it is equally important that people should not tomorrow relax their interest in AIDS. We must not lose the momentum which a day such as this can generate. Today gives us a chance to drive home the message. But the message must be heeded on every day of the year, not just one.

The theme of this conference is "Can we care enough?". But in a sense it is not a fair question if it admits of equally acceptable alternative answers. I believe there is only one answer to the question "Can we care enough?". It is that we must.

Since I became Minister of Health last July, I have made it my business to learn as much as possible about AIDS. I have visited St Stephen's Hospital, the London Lighthouse and the Terrence Higgins Trust, to name just a few. I have been greatly impressed and encouraged by the commitment and skills of the people whom I met. I feel strongly that only by knowing the facts about AIDS and HIV can we have proper and balanced discussions about the best way forward.

Taking Stock

But before discussing the future, can I just briefly take stock of the current position? As you well know, the picture remains very serious. AIDS continues to spread and the World Health Organisation now estimates that between 5 and 10 million people worldwide are already infected with HIV. Furthermore, some 125,000 cases of AIDS have been reported so far, although it is probable that many more cases have not been either recognised or reported. Under-reporting here is probably around 20 per cent - in the developing world it is bound to be much more.

And, very worringly, the predictions about the numbers infected with HIV who will go on to develop AIDS or AIDS-related conditions have sharply increased. As recently as two years ago experts suggested there was only a 30 per cent chance that people infected with HIV would go on to develop AIDS. Now, most believe that almost everyone who is infected will, over 10 to 15 years, go on to develop AIDS or AIDS-related conditions. In this country, our surveillance system indicates that at the end of November 1,926 people were reported as having AIDS, of whom 1,035 had died. And at the end of September some 9,300 people had been found to be HIV positive. As I shall mention in a moment, that figure is almost certainly too low.

Cox Report

Indeed, one of the difficulties which policy-makers, service providers and indeed the general public have faced in coming to terms with the AIDS epidemic has been the lack of a consistent view about the likely future spread of the disease. That is why my predecessor, Tony Newton, asked an expert group under the chairmanship of Sir David Cox, a leading statistician, to make predictions for the number of cases in the next few years. As many of you will have seen their report was published yesterday.

The report's key conclusions are highly germane to our discussion today. First, the report argues that between 10,000 and 30,000 cases of AIDS are likely to be diagnosed between 1987 and 1992, and it recommends a figure of 13,000 cases for planning purposes. Secondly, by the end of 1992 between 7,500 and 17,000 people are expected to have died from AIDS. Thirdly, it concludes that the rate of increase of new AIDS cases is slowing, probably due to changes in the behaviour of homosexual men several years ago. Finally, the report estimates that by the end of 1987 there were between 20,000 and 50,000 people infected with HIV, compared with the 9,3000 officially notified at the end of September.

As I said yesterday, I am extremely grateful to Sir David Cox and his colleagues. The Government accepts the figures in their report as a basis for future planning. Moreover, we will be updating those figures and publishing the results annually.

And the report indicates that the general heterosexual population would be very unwise indeed to sink into a sense of cosy complacency about AIDS. There are figures from overseas which strongly reinforce this view. For example, of the 408 reported cases of AIDS in Belgium at the end of September, over half - 51 per cent - were thought to be the result of heterosexual contact. In Italy, nearly two-thirds - 54 per cent - of the 2556 cases of AIDS reported at the end of September were drug misusers who claimed to be heterosexual.

What these figures show is that the spread of HIV infection into the heterosexual population, from whatever source, is still a real threat. And there is scant evidence so far that enough heterosexuals are changing their behaviour to protect themselves from AIDS. Yet protect themselves they must. This is true for the 'disco generation' who are engaged in a disco lifestyle. Teenagers have no reason to be complacent. After all, Sir David Cox's group was unable to predict the future numbers of those infected with HIV because these depend so crucially on unforeseeable changes in behaviour patterns. As Dr Anthony Pinching pointed out in an article in yesterday's *Independent*, "heterosexual intercourse is probably the commonest risk behaviour for HIV infection worldwide". He went on to decry those heterosexuals who persist in an ostrich-like attempt to ignore such facts.

There are some important general lessons from the Cox report. As it makes clear, we still face a serious problem in this country from AIDS. But of course I welcome the evidence that many homosexual men are heeding the warnings and changing their lifestyles to protect themselves against the disease.

This shows clearly that there is nothing inevitable about the spread of HIV infection - it all depends on how we respond to a common-sense message. As the gay community is showing, the rate of spread of this appalling infection can be reduced by changes in personal lifestyle.

But - and it is a big "but" - there's no excuse for dropping our guard. As the report itself says "it would be a gross error to regard even the lower predictions as grounds for complacency". I wholeheartedly endorse this sentiment. It's all too easy for people to slip back into old habits. In the first place, those in the gay community need to remain vigilant and not let themselves slip back into some of their previous risky practices. And they need to ensure that new entrants to their community do not do so either. In the absence of either a vaccine or a cure, this is not a battle which is likely to have a final or a decisive outcome, at least in the foreseeable future.

Those who inject drugs also obviously remain at high risk. That is why the Government has just launched a new campaign designed to reinforce the message about the dangers of misusing drugs, dangers which of course include contracting HIV infection.

Monitoring and Surveillance

Good predictions are vital for future planning. So are sound means of monitoring the spread of HIV infection. Last week the Government announced the action it was proposing to take on ways of improving further our monitoring and surveillance system. In doing so, we took fully into account the recommendations of an expert group chaired by Dr Joe Smith, the Director of the Public Health Laboratory Service.

As you will know, we are asking the Medical Research Council to draw up, within three months, proposals for a programme of surveillance studies. Those studies will be designed to give us better information about how the epidemic is developing both in the general population and in specific groups. They will include studies based on anonymous testing, that is, testing blood samples taken for other purposes but which cannot identify the donor. We envisage that several hundred thousand blood samples will be tested in this way for each year that the study continues.

There will also be complementary studies of particular groups based on voluntary and named testing. These might include further surveys of pregnant women in addition to the two now beginning in Scotland, as well as studies of other groups such as those who attend drug misuse services and sexually-transmitted disease clinics.

I know that some have expressed reservations about anonymous testing. These have centred on the impossibility of informing and advising those who prove HIV positive. But I should emphasise that the purpose of these anonymous tests - which will in any case be performed on only a tiny fraction of all the blood samples taken - it to obtain general prevalence data, rather than information about individuals. Anyone who wishes to have a named test can have one and any doctor who thinks a named test might be advisable for a patient can offer one. Anonymous surveillance testing will not affect this.

But I should say this also. I do not believe that the general public will be too worried about the ethics of what we are proposing. They would be much more concerned if we shied away from taking the necessary steps to gauge the extent of the problems we face and the effectiveness of our response. And I have to say they would be right.

I mentioned that Cox made no predictions about the rate of spread of HIV infection because they depend on behaviour patterns. In other words, if we fail to get the health education messages right and if we fail to encourage people to change their behaviour, we face the risk that much larger numbers of people will become infected in the future, with a consequential impact on the number of those who go on to develop AIDS. We must do everything we can to stop that happening.

I believe we can take some credit in this country for taking action at an early stage in the epidemic to slow down and prevent its spread. For its part the Government has run education campaigns for more than two years now and they have done a great deal to increase awareness of HIV and

AIDS. I am also very pleased with the extensive coverage which the media have been giving to this subject this week. This is very helpful in keeping up the level of awareness.

But we are now at a critical point. There is a grave danger of people becoming complacent. Many people who should know better still refuse to accept the implications which the HIV epidemic has for everyone who is sexually active or who is drawn in to drug misuse.

Apathy must not rule. Instead we must keep up the momentum. At the national level, we look to the Health Education Authority to develop a UK-wide public education campaign.

The first advertisement in this new campaign is being published in the national press today. The campaign has three aims; to influence behaviour, particularly among young sexually-active adults; to ecourage people to act responsibly; and to provide the information which people need to protect themselves.

As with previous campaigns, the material will be evaluated through independent research. Further campaigns targetting particular sections of the population's communities are planned for the New Year.

Local Initiatives

Advertising and media campaigns will be less effective in the long run if their messages are not continually reinforced in the local community. That is why we have asked every health authority in England to develop local community-based initiatives aimed at preventing the spread of AIDS infection among particular target groups, in particular, gay and bisexual men, drug misusers, prostitutes and their clients and those who attend clinics dealing with sexually transmitted diseases.

I am pleased to announce today that we will be making up to £14 million available in the next financial year for such schemes. And we are making some funds immediately available to enable staff to be recruited or redeployed at regional level to begin necessary planning now.

Service Development

Another important issue concerns the provision of services to those who do become infected. This year we provided the NHS in England with some £60 million of additional money towards the cost of HIV-related services. Next year we will be more than doubling that sum, to a total of almost £130 million. This enormous increase shows our determination to tackle this disease sensibly and effectively.

I shall be announcing shortly how that money will be allocated to each Regional Health Authority. In part, allocation will reflect the current distribution of cases between the various regions. And we expect the greater part of these new resources to go towards the cost of providing treatment services for people with HIV and AIDS.

I intend to allocate a significant proportion of the remainder pro rata to the population of each region. That money will be for services which all health authorities should be developing now.

Those services include those aimed at preventing the spread of HIV infection among drug misusers.

Unfortunately this is one area where some people do not want to admit there is a problem. My message to them is plain. If you do not get involved in preventive work with drug misusers now, you will end up being involved with drug misusers later - when they become seriously ill.

And, as I have said, the behaviour of drug misusers may hold one of the most important keys to the rate of spread of the infection throughout the general population. I am therefore looking forward to receiving early next year the second report of the Advisory Council on the Misuse of Drugs which will concentrate on AIDS and drug misuse. That report should provide valuable advice on how services for drug misusers should develop. No sensible suggestion will have a door slammed in its face. I look for good advice.

Secondly, health authorities need to strengthen the capacity of sexually-transmitted disease clinics to cope with the additional workload created by the HIV epidemic.

Thirdly, the NHS must do more to develop counselling services, particularly the counselling and emotional support of those who do indeed prove to be infected as well as those who go to develop AIDS.

And, finally, we expect all health authorities to identify training needs and to pump additional resources into staff training. They also need to take measures to improve their infection control procedures when necessary so as to prevent the spread of HIV and other blood-borne pathogens.

I mentioned our planning guidelines. These emphasise the importance of effective joint planning between health and local authorities and the voluntary sector. I announced last month that we shall be allocating £7 million in specific grant to those local authorities facing the greatest demands for AIDS related services. I want health and local authorities to use these new resources not only to provide services directly but also to provide grants to voluntary organisations which themselves can provide services. The voluntary sector has an important role to play here and that is why we have given London Lighthouse a grant of £170,000 this year towards its planning costs.

I am also pleased to announce today that, in addition to the new resources we are allocating to health and local authorities, we will be providing £500,000 in 1989/90 for the evaluation of new HIV-related service developments. We have already commissioned major studies into the needs of people with AIDS which should provide important consumer feedback on the quality of services currently available. With this new money we will be establishing a centrally co-ordinated programme of evaluation. Through it, we will be able to collect and disseminate information on what is being done throughout the country.

Conclusion

Since AIDS first hit the headlines just a few short years ago, public debate about this issue has been immense. But, perhaps as a result of the sexual connotations of the disease, misunderstandings and mythology were rife at first. So the Government took a firm and early lead in public in publicising how best to counter the threat posed by AIDS. The result was a major public education campaign. In the new climate many people took note, they changed their sexual behaviour. Others stopped misusing drugs or sharing needles.

But it would be quite wrong to think that we have done all that needs to be done. It is clear to me that so far as AIDS is concerned, we are a long way from the beginning of the end. Indeed, we have probably not even reached the end of the beginning. So we must continue to work together against the threat of AIDS. Two years ago our message was "Don't die of ignorance". Today our message must be "Now you know the facts, for your own sake, act upon them".

The Medical Challenge

Professor Michael Adler, University College and Middlesex School of Medicine.

When AIDS first occurred I felt it would go away and even now it often feels like a bad dream. Yet clearly it will neither go away nor is it a dream. The daily brutal clinical reality of the disease in our patients and the brutality (still too often seen) of society's response acts as a large waking pinch to any somnolent state. We should be under no illusions that the problem will just "go away". All of us will be concerned with AIDS for the rest of our professional lives. Of course, we should all hope for the magic bullet of a cure or vaccine and achieving this is an exciting scientific challenge. But this possibility should not lull us into a false sense of inertia or allow us to take our eye off the medical challenge of "here and now". The challenge of AIDS is colossal because patients develop an array of physical, psychological, social, occupational and legal problems. Surely none of us can remember a situation in our life times when one single virus and disease has made such an impact upon society and engaged virtually every professional and religious grouping, and government department?

My assessment of the medical challenge covers three areas: firstly that presented by the lack of knowledge of the size of the problem; secondly that surrounding the cost of medical care and the need for good community care; and finally the need for coordination of our efforts.

The Size of the Problem

The Committee chaired by Sir David Cox to look at the predictions of the potential size of the current and future size of HIV infection and AIDS reported yesterday. Table 1 summarises the main findings. They calculate that by the end of 1987 there were between 20,000 - 50,000 individuals infected with HIV. This is from 16 to 40 times more infected people than cases of AIDS. The report goes on to estimate 10,000 to 30,000 cases of AIDS by 1992 and by 1998 to 2003 a total of between 16,000 - 40,000. These figures have substantial ranges on them mainly as a result of the lack of accurate data on a number of important variables required for accurate projections, not least of which is an appreciation of the number of individuals in the population infected with HIV. I warmly welcome the Government's announcement last week on anonymous testing.

TABLE 1

POSSIBLE SIZE OF THE PROBLEM

CATEGORY	1987	1992	1998 - 2003
AIDS	1227	10,000-30,000[1]	16,000-40,000[1]
Seropositives	20,000-50,000[1]		

[1] Cox report

I have always been amazed that we face the most major public health problem for the United Kingdom this century and still don't know how many people are infected. All of us would be appalled if one of our generals was to go into battle without an idea of the size, strength and reserves of the opposing forces. Likewise, fighting and controlling an epidemic requires a sound appreciation of the extent of the problem within the community and how it is altering. The fact that no one can agree as to whether there are sixteen or a hundred times more infected individuals than those with AIDS and Cox and his colleagues have put wide ranges on their estimated figures illustrates how inadequately prepared we find ourselves to combat the epidemic. We must obtain the essential information of the level of infection in the general population if we are to develop and monitor an adequate control programme of education and provision of services. This can only be done effectively through a surveillance system based upon anonymous testing.

Medical Care

I would now like to turn to the second medical challenge and that is the one concerned with care. The long-time span from infection to the development of AIDS and death results in demands by patients on a broad array of services within the community and hospital.

Let us start with hospitals. There are two main elements that currently contribute towards care of patients in this sector of the health service; namely out-patient departments of genito urinary medicine (GUM) and in-patient ward management. The majority of infection and cases within the United Kingdom occur as a result of sexual transmission. Initially this was among gay men, but increasingly in the future it will be amongst heterosexuals. Departments of genito urinary medicine, venereology, STD, or whatever we wish to call it, can offer one-to-one health education, avoidance of infection and continuing clinical and psychological care for those infected and, as a result, often keep patients out of hospital. The workload in such departments, as measured by total number of cases, has shown a five-old increase in the 15-20 years prior to the HIV epidemic. I have always maintained that those of us working in the specialty of genito urinary medicine should be given the Queen's Award to Industry.

A group set up by the Department of Health has travelled around the country assessing the facilities for genito urinary medicine. I would be surprised if they were not appalled by what they are certain to find in terms of inadequate staff and facilities.

At least with GUM the infrastructure is there ready for modernisation. This cannot be said of the other pivotal service needed in the field of HIV, namely that for drug misusers. I realise that £ 3 million has recently been made available but this cannot start to deal with a service that hardly exists and as a total sum is less than the cost of caring for one infected drug misuser in each District Health Authority from diagnosis to death. One only has to read the Runciman report on AIDS and drug misuse to see what is required. Essentially the report is asking for changes in the service which will make it attractive to users and the development of community based services. No doubt these points will be expanded upon later in the day by John Strang. Control and prevention of HIV can only occur if sexual and drug behaviour is modified. That services for genito urinary medicine and drugs are made able to play an essential pivotal role is a medical challenge. I hope this challenge will be met; at the moment it is not.

Preventing new infection and modifying behaviour is cheaper than hospital care which is the inevitable outcome at one or many times for those infected. There are various assessments of the hospital lifetime costs of looking after patients with AIDS. Table 2 indicates these costs and the lifetime hospital costs and cumulative costs to the end of 1991 in the United States and 1992 in the United Kingdom. The estimate of cumulative medical costs by 1991 in the States range from $6.3 billion to $45.4 billion. Most of this variation is accounted for by the variation in the estimates of the lifetime number of in-patient days from 34-168 days. In the UK the lifetime costs are less variable. For the sake of working out the cumulative costs I have taken a range for

1992 of 10 - 30,000 cases of AIDS as suggested in the Cox Report. This gives a range of cumulative costs by 1992 for out and in-patient services of $134 million to $1.4 billion.

TABLE 2

MEDICAL CARE COSTS ASSOCIATED WITH AIDS (1986 dollars)

STUDY	COST PER DAY	LIFETIME COST	CUMULITIVE To end 1991 (USA) 1992 (UK)
USA (270,000 cases)			
Andrulis	683	23,000	6.3 bn
Berger	723	36,000	9.7 bn
Hardy	1003	168,000	45.4 bn
Kizer		77,000[1]	20.9 bn
Scitovsky	934	32,000	8.8 bn
Seage	775	55,000[1]	14.9 bn
UK (10,000-30,000 cases)			
Johnson		134,000[1]	134 - 402 m
Cunningham		46,800[1]	468 m-148 bn
Rees		36,300[1]	363 m - 1.0 bn

[1] Out-patient costs included

[Source USA Figures: Bloom and Carliner, *Science* 1988]

Most of the lifetime costs that I have shown were on studies prior to the use of zidovudine, previously known as AZT. It is an expensive drug. Full dose therapy namely 1200 mgs per day, costs £468 per patient per month or £5,616 per patient per year. Not all patients can be maintained on a full dose, and some have to discontinue temporarily or permanently or go onto a reduced dose. The current groups for whom therapy has been shown useful are those patients with AIDS Related Complex (ARC) - a term that is now obsolete - and AIDS and usually there are the same number of patients with ARC as those alive with AIDS. If we return to the 1992 projected figures of 10 - 30,000 cases of AIDS, half will be dead but there will be the same number with ARC so that 10-30,000 may require zidovudine. In calculating the cost I have assumed current cost and 20% of patients permanently discontinued, which is our experience at the Middlesex. I have not taken into account reduced dosage or temporary discontinuation since we do not have a sensitive enough feel of how long these situations will last in a patient's overall drug history. With these assumptions the costs for zidovudine range from £45 million for 8,000 patients per year to £135 million for 24,000 patients per year. If the Cox committee are correct and there could be between 16 - 40,000 cases by 1998-2003 the costs would range from £ 72 - £ 178 million.

Finally just to complicate this, let us not forget that current trials may show that treatment of asymptomatic HIV positive individuals will alter progression rates to AIDS and that this would become routine therapy. The only financial consultation is that a reduced dose of 1000mgs might be used at a cost per patient year of £ 4,680. It is difficult to know the ratio of HIV positive individuals to those with AIDS by 1992. I think it would be wrong to assume that it will be the same as in 1987, namely between 16 - 40, therefore I have taken a conservative estimate of ten times more people infected than cases of AIDS. Thus between 100,000 and 300,000 seropositives would require treatment. If we treated all without any discontinuation because of a lower dose in 1992 the additional costs would range from £ 468 million to £ 1.4 billion per annum.

TABLE 3

COSTS OF ZIDOVUDINE

	1992 (thousands)	1998 - 2003 (thousands)
AIDS (Total)	10 - 30	16 - 40
AIDS (alive)	5 - 15	8 - 20
ARC	5 - 15	8 - 20
Suitable for drug:		
(80% of total of AIDS alive and ARC)	8.0 - 24	12.8 - 32
Costs per year	45 - 135 million	72 - 178 million
Seropositives (total)	100 - 300	
Costs per year	468 million - 1.4 billion	

I accept only too readily that these are very crude calculations but they do indicate the considerable financial cost resulting from hospitalisation and therapy with only one drug. You will notice that all the costs that I have covered are mainly hospital and it is absolutely vital that we also obtain an accurate assessment of the community costs. The support provided outside hospitals will become increasingly important. The ability to be innovative and imaginative within the Health Service is rare. AIDS has provided some of us with the chance to develop models of both hospital and community care within our districts that could be picked up by others looking after similar patients. But also, these models and approaches that have been developed through HIV and AIDS show the way for managing other client groups since such a wide range of caring issues are raised by AIDS. The whole of human life is there. I am acutely aware that patients with non-AIDS conditions may feel that they also would like to latch into the services that we have built around our HIV and AIDS patients. This rightful desire by other client groups and their providers must not create envy and a backlash. Instead, we should learn the lessons of good total patient management from infection to death that AIDS has brought and use the models throughout the Health Service for patients with other conditions.

I have identified some of the medical challenges that concern me. I am concerned that we should have a much more sensitive appreciation of the size of the problem both numerically and financially. But let us be absolutely clear that throwing money at AIDS will not work on its own.

I have always been concerned at the fragmentation and disorganisation of our response to AIDS and for many years have called, and continue to call, for a national strategy for what is after all a national crisis. I am alarmed at the lack of response of some district health authorities. I am alarmed at the lack of response of many social services and social work departments. I am alarmed at the lack of a housing policy and wonder whether the department of environment have yet heard of AIDS. I am alarmed at the myriad of different forms of care that are being developed without evaluation and answerability; I am alarmed that we are doing so little about the terrifying epidemic in Scotland; and I am alarmed that six years into the British epidemic I still remain alarmed.

Coordination

In my evidence to the Social Services Committee looking at the problems associated with AIDS, I called for a nationally coordinated and funded strategy. This should include a network of regional hospital AIDS centres; designated and trained staff at district level; a national plan to upgrade departments of genito urinary medicine; and 3-5 year plans for local social services departments. Common to all these developments is the need for committed money now for at least 3-5 years into the future so that reasonable long term plans can be developed. The time of the short term finger-in-the-dyke approach is over. Damage limitation has been the hallmark of our response. We must move from this to a longer term national strategy.

However, this on its own will not be enough; someone somewhere has got to coordinate and be answerable for this strategy. We need more than the original Whitelaw and now Moore Committee. The Americans are examining what could be achieved by a permanent national commission. Such a commission would develop and supervise a national strategy. We are often critical in the UK of the American response to health issues. However, unlike us, they do not find themselves locked into set response to solving problems, nor are they bogged down in procedures. They are able to adopt innovative approaches to new problems. We could also be innovative. We have a Northern Ireland office. It would also be possible to create a Whitehall department or ministry for AIDS with its own budget that had the remit to cross all boundaries of health, social services, housing, discrimination etc. This would be an ideal solution and it is unlikely that this would be allowed to happen. But we must start to think in a strategic way and find a way of developing, coordinating and supervising a national strategy.

AIDS needs a strategy, but it also needs all of us to be concerned and involved. AIDS-specific groups such as the Terrence Higgins Trust and Body Positive have shown great commitment and courage and are always generous in giving of their expertise. But AIDS is no longer a battle for AIDS-specific groups alone: we are too tired and limited in our resources and vision. The Red Cross, the churches, the National Association of Citizens Advice Bureaux, to name a few, are all national organisations who now wish to be involved. Allowing and welcoming their involvement will turn AIDS into a problem and challenge for the whole of society. We must avoid the arrogance that goes with self righteousness, the arrogance that will not welcome groups and individuals to join the fight because in the past they were not there when wanted or are judged not to be sympathetic enough. We must act together and get our act together so that we can look back on our working lives with pride and say that we did as much as we could as well as we could.

The Economic and Social Challenge

Professor Alan Maynard and Keith Tolley, University of York[1]

The funding of the hospital and community health services (HCHS) element of the NHS to provide care for AIDS patients has been developed in an ad hoc manner and differently in England and Scotland. The first part of this paper explores this process.

The development of community care for AIDS patients, both from statutory services, voluntary agencies and careers, is also proceeding in an ad hoc manner. Existing community care services (for the elderly, the mentally ill and the mentally handicapped) are fragmented and compartmentalised. The new challenges created by the HIV epidemic are explored in section two.

Funding hospital care for AIDS patients

The Department of Health has made available a total of £151 million over the three financial years 1987/88, 1988/90 to the English health region for "AIDS related services".

In 1987-88 the DHSS allocated a total of £25.1 million to the regions, with the majority (£22.5 million) going to the three regions with the greatest number of AIDS patients (NW Thames, NE Thames and SE Thames).

In DHSS Circular HC (87) 37 (23rd December 1987), £54.3 million was allocated for 1988-89. This consisted of an additional £50 million and a total of £4.3 million on recurring 1987-88 expenditures in NW Thames, NE Thames and SE Thames. The funds were for services, to be provided by English regions and districts, to assist the prevention of the spread of the virus, the provision of diagnostic, treatment and support services, and the promotion of a better understanding of HIV infection.

A letter to Regional General Managers (25th February 1988) explained the basis for the distribution of the additional hospital and community health service allocations for 1988-89. They were made "approximately pro rata to the distribution of reported live AIDS cases...as at the end of November 1987", at which time 54 per cent of such cases were in NW Thames and 19 per cent were in NE Thames. Dividing the additional £50 million regional allocation for 1988-89 by the number of live AIDS cases in November 1987 (the Department's basis for the allocation) produces a distribution ranging from £70,000 per live AIDS case in the South West to £117,000 in the North West.

Dividing these English HCHS allocations for 1988-89 by the number of live AIDS cases in August 1988 produces a more uneven distribution of resources and must call into question the efficiency of this allocation procedure. This distribution is shown in the table and gives a range of £79,500 per lives AIDS case in NE Thames to £16,000 per live AIDS case in the South Western Regional Health Authority.

During 1988-89, an additional sum of £5.3 million (including £0.5 million to the Special Health Authorities) was provided to the English Regions for specific AIDS/HIV treatment, prevention, diagnosis and related projects. The breakdown of these allocations, in total, are set out in column two of the table.

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[1] *Professor Maynard delivered this paper at the december 1st conference*

TABLE 1

REGIONAL AIDS ALLOCATIONS 1988-89

	HCHS(1988-89) Additional allocation per live AIDS patient as at August 1988 (£'000s)	HCHS Additional funding provided for specific initiatives during 1988-9 (£000s)	HCHS (1989-90) for treatment per live AIDS patient as at October 1988 (£000s)	HCHS (1989-90) total allocation for HIV oreventaion and diagnosis initiatives (£million)
Northern	59.0	315.0	24.0	2.8
Yorkshire	52.5	319.0	43.5	3.3
Trent	58.0	454.0	28.0	4.3
East Anglia	75.0	187.0	17.5	1.9
NWThames	74.5	404.0	6.0	3.3
NEThames	79.5	383.0	10.51	3.5
SEThames	60.0	366.0	23.6	3.4
SWThames	53.0	263.0	32.5	2.8
Wessex	62.0	267.0	24.5	2.7
Oxford	72.5	289.0	24.0	2.4
South Western	16.0	279.0	68.0	3.0
West Midlands	42.0	553.0	41.0	4.8
Mersey	39.5	219.0	48.0	2.2
North Western	50.0	488.0	45.5	3.7

In Circular HC(88)66 (22nd December 1988), the Department of Health initially split the allocation of £52 million+ for 1989-90 into two parts; one for treatment (£8 million) and one (of £44 million) for non-treatment.

In addition, £2 million was allocated to the Special Health Authorities.

For purposes of distribution, the allocation of new money for treatment in 1989-90 (£8 million) was combined with the total of £59 million already allocated during 1988-89. This total consisted of the initial £54.3 million allocation for 1988-89 and an additional £4.8 milllion allocated during the year. This cumulative total was then divided between the regions on the basis of numbers of live AIDS patients as at October 1988. However, as only an additional £8 million has been made available in 1989-90, this ambiguous approach only serves to perpetuate the unequal allocation of additional HCHS funding, as is apparent from column three of the table.

The allocation of non-treatment funds for 1989-90 (column four of the table) was calculated using regions' population as a basis. This approach was an attempt by the Department to take greater account of the wider resource implications related to preventing the spread of HIV infection in those regions with, as yet, relatively few AIDS patients.

In a subsequent letter to Regional Managers (February 1989) the Department of Health has combined the treatment and non-treatment allocations. The regions have been advised that their total allocation can be spent freely in such areas as the treatment of AIDS patients, genitourinary services, HIV prevention measures, heat treatment and the improvement of infection control.

The Department of Health advocated in its 1988-89 allocation a simple basis for allocating these funds. However, simplicity and equity have to be reconciled and it is apparent that this may not be achieved in the 1988-89 allocation in which, for instance, the South West Region gets four times less per live AIDS patient than NE Thames. Obviously, NE Thames has the majority of patients, but if prevention and understanding as well as treatment (which were all grouped in the 1988-89 allocation) are to be funded effectively, those regions funded so parsimoniously may require more resources.

In 1989-90 the initial splitting of the AIDS allocation into treatment and non-treatment components makes for a more equitable distribution of the former remains.

During 1988-89 a further £3 million was made available for measures to prevent the spread of HIV infection amongst, and by, drug misusers (DH circular HC(88)53, September 1988). An allocation of £9 million has been made for drug misuse services in 1989-90 (DH circular HC(88)66, 22nd December 1988).

The allocation of AIDS funding to Scotland is complex. In March 1988 Scotland was allocated an additional £1.64 million as a contribution to the additional burden placed on its health services by AIDS. Lothian Region received £261,000 of this as a result of the SHARE (the Scottish equivalent of RAWP) formula being applied to the total (£1.64 million) Scottish allocation, plus a further £47,000 during 1988-89 for specific AIDS related projects.

However, the Lothian Health Board also bid for funding for a Special AIDS Unit at the City Hospital in Edinburgh. The Scottish Home and Health Department allocated #1.52 million in 1988-89 for this project: £1.07 million of revenue and £450,000 of capital expenditure. Of the revenue expenditure £500,000 will be spent on AZT and other drugs, £430,000 on staff and £120,000 on laboratory tests and related costs: a total of £1.05 million. In addition to a small current revenue underspend of £20,000 only £190,000 (out of £450,000) of the capital resources will be used in 1988-89.

The appropriatness of these allocations in England and Scotland can be questioned. The English allocation per live AIDS case, the formula favoured by the Department of Health for treatment costs, produces major inequalities in the allocation. The Scottish general allocation (£1.64 million in 1988-89) is parsimonious in isolation but complemented by the special AIDS unit funding. The allocation basis of this general funding is the usual budget formula (SHARE) rather than the live AIDS cases used in England. No doubt this is due to the practical abandonment of the (RAWP) budget formula in England and its replacement by ministerial fiat.

The development of community care

The future demand for institutional (HCHS) and social care is uncertain. Between 20,000 and 50,000 people are infected and it is estimated that 17,000 will die in the next 4 years (Cox Report, 1988). These "questimates" will create substantial burdens on the statutory and private community care services.

The nature and volume of demand for support and counselling will vary:

a) Between geographical areas: the problems faced by those in London may not be those faced by HIV or AIDS infected people in the provinces. Where the incidence and prevalence is low, support may be more inadequate and the problem of isolation and loneliness more acute.

b) Between services: service responses in the statutory services are geared to specific groups e.g. home helps for the elderly. Can these statutory local authority social service managers provide home helps for young males with HIV/AIDS when they may still be part time in the labour force? Cleanliness and hygiene for such clients will be at a high premium but such service demands are novel for LASS service providers. If the statutory services cannot respond, will voluntary agencies and carers meet these needs?

c) Over Time: demands may fluctuate over time and the range of needs may be very wide, in part due to discrimination and the prejudice and ignorance of the general public. Such attitudes will affect the flexibility of social care and housing service responses over time. "Care packages" will ideally be flexible, client-led and client centred. Services such as laundry collection, the provision of a spare bed, and fluctuating needs for incontinence will be needed with varying degrees of intensity at different times. Only if efficient care packages are provided will anxiety and stress be minimised, the immune system be protected and the length and quality of life enhanced as much as is possible.

The supply of social care

The existing system of community care is fragmented and compartmentalised with perverse incentives throughout its component parts. Community care, as was recognised in the 1988 Griffiths Report, is an ill-coordinated shambles with no routine cost system and little evaluation of the efficiency of competing social care packages, statutory and private:

i)The hospital and community health service (HCHS) system is cash limited and creates incentives for hospital managers to reduce length of stay and hospital provision, "dumping" patients and costs elsewhere in the health and social care system.

ii) The primary care service has open ended budgets and, no doubt, HCHS doctors and managers will seek to shift costs onto this budget (eg drug costs).

iii) Social care: what is it? Community care is an amalgam of public and private endeavours, e.g:

a) Public sector: community nursing services (part of HCHS and controlled by hospital doctors and managers); counselling and care in general practice; social secuirty benefits such as attendance allowance board and lodging allowances and others means tested benefits.

b) Private sector: voluntary groups such as Frontliners and the Terrence Higgins Trust; informal carers such as partners/families/friends/neighbours.

The efficient provision of care

Who will be the guardian of the clients' interests? All client groups find it difficult to negotiate the fragmented social care market. The Government seems unable to reform this market due to fundamental disagreements between the Prime Minister and the author of the Griffiths Report. It is likely that the NHS Review will further complicate this market place. However, this "redisorganisation" seems unlikely to assist the efficient provison of social care for HIV and AIDS clients let alone other customers.

Conclusions

i) The basis of resource allocations for AIDS related services needs to be reviewed. Is the basis of these allocations efficient and equitable?

ii) The demands of clients outside the hospital system are largely unkown and government funding in England is slowly taking shape (see circular LAC (89) 1 January 1989) in a conservative manner. The development of the organisation of these and voluntary services will have to triumph over the community care shambles that exists in many places at present: that is the economic and social challenge of AIDS in the 1990s.

The Human Challenge

Jonathan Grimshaw, Director, Landmark.

I am going to change the focus from abstract to the personal and individual. I was asked to talk about the human challenge and I really only know how to do that by relating it to personal experience, going, as it were, to the heart of the matter.

Last night I had, as I expected to have, a telephone call from someone I have met only once but who has rung me once a week for the past two years. This person wants, desperately, to live. He phones me for advice, and for re-assurance that all the things he is doing to protect his health - to try to stay alive - are the right things. Like me, he has HIV. Like me he watched the nine-o-clock news last night and heard that 90%, perhaps more, of people with HIV will develop AIDS within ten years. We discussed this and just before putting the phone down, he said, "Its a bit much isn't it, you try so hard to keep alive and then they keep telling you you're going to die" and I agreed that, "Yes, it is a bit much." I'm sure Doctor Sir Donald Acheson and Spencer Hagard, if they saw and treated patients with HIV, would follow good counselling procedure and advise those patients to do everything they could to protect their immune systems: avoid stress, eat a balanced diet, get plenty of rest, avoid other sexually transmitted diseases, change to a healthy lifestyle. I wonder what Sir Donald or Spencer would say to me if I was their patient and I said to them "What's the point of doing any of these things? Why should I change to a healthier lifestyle? What's the point, when I saw you on television last night as good as saying I'd have AIDS within 3 years and AIDS is fatal isn't it? You give me no hope because what you're really saying is nothing I do will make any difference."

My telephone friend's doctor has not told him that AIDS is virtually inevitable; that doctor is going to be in some difficulty when my friend attends for his next appointment.

The HEA invited me in recently to talk about a campaign they wanted to run to provide health education to people with HIV. There seems to be some paradox in the HEA about educating people with HIV how to be healthy when the HEA is educating those same people through its advertising campaign that the only difference between HIV and AIDS is time.

I wanted to begin my talk in this rather combative way not because I wanted to embarrass the CMO or HEA, although you may detect some exasperation with inconsistent information, but because I wanted to show you how when you have HIV, life and death uncertainty is so much a part of one's life as to become the topic of a routine telephone call.

The first challenge faced by everyone with HIV is how to live with uncertainty. If one is well, the uncertainty of when or where or whether the first symptom of AIDS will appear; if you are ill, the uncertainty of how long you've got, and how you will die. For two people with HIV living together its the uncertainty of not knowing who will become ill first and if you are lovers the fear that you may not be able to cope with your lover's illness and death, and the fear of being left to die already bereaved, alone, in pain and perhaps dementing. For a single mother with HIV, it's the uncertainty of not knowing when she will have to say goodbye to her child and who will care for it when she is gone. If the child too has HIV, that mother may have to watch her child die, and then prepare to die herself.

Everyone with HIV or AIDS faces the uncertainty of how people will react: will they be fearful, hostile, judgemental, blaming? According to monitoring of public attitudes during the last HEA campaign, there was a 45 per cent chance that if in June this year you told someone you had HIV, their reaction would be "you've only got yourself to blame". Many other people prefer not to take the risk and put up barriers between themselves and others - their parents perhaps - to conceal that they have HIV and to conceal what emotionally, spiritually and physically it is doing to them. Those barriers undermined relationships which may previously have been built on honesty and trust.

Isolation, whether it is self imposed, or imposed by others, is increased by the fear that your lover, if you have one, will leave you, or if you don't have a lover, no-one will want to make love to you again. Sexual intercourse is, for many people, the most important means of affirming and maintaining a loving relationship. If you have HIV it may seem as though you can offer so little sexually, safely, that no-one will want you and that you will become a very lonely person indeed. You may feel, as I did, that you have become a sexual cripple.

It's the uncertainty of not knowing how long you will be able to keep your job, not knowing how long you will be able to support yourself, keep your home, keep your place in the community, keep your self respect. And it is the uncertainty of not knowing whether, when you become dependent, those who you become dependent on will have the training, the confidence, the resources, the experience and the skills for you to feel safe in their hands.

Above all, perhaps it is the uncertainty that surrounds loss, whether real or anticipated: loss of an assured future, or at least the assumption of longevity which most of us need in order to set ourselves goals and give ourselves the hope of achieving them; the loss of health, friends, lovers, relationships, the loss of job, income, home and comfort, the loss of security, self respect and dignity. The loss of love and now it seems, almost inevitably, the loss of life with perhaps the loss of sanity along the way.

Astoundingly, perhaps, people with HIV cope with all of this, and of all the challenges posed by HIV. The personal, individual challenge of having this disease is the one that is met with most success, most courage and most dignity.

Perhaps this is because people with HIV live in such an uncertain environment that certainties have to be found within oneself. Everyone else has to live in that uncertain environment and to make an individual response to AIDS within it. Even the certainties that we do have are to many people not credible. For example, I was talking recently to a lecturer who had just given a talk about HIV to nurses. They all knew that you couldn't catch HIV by being in a swimming pool with a person who had AIDS. "Right", said the lecturer, "There are 50 people with AIDS in a swimming pool, how many of you will jump in?" Not one nurse raised their hand.

We are uncertain about public attitudes to HIV. Those lay beliefs about disease - that disease is spread like a miasma through the air (or water); that it is somehow in the environment, waiting to pounce; that it is a product of twentieth century life; or of moral and social non conformity; that it is distributed according to some metaphysical arrangement of justice; these beliefs are extremely deep rooted and affect public opinion of what should be done to control HIV. And ultimately public opinion constrains and determines the actions of the politicians who decide what measures and resources are appropriate. The problem is confounded by uncertainty about the incidence of the disease. That uncertainty generates a time wasting and exhausting factionalism where those responsible for ensuring that the allocation of resources are proportional to the size of the problem are caught between allegations that HIV is not the threat it is maintained to be on the one hand, and warnings that HIV is so serious a threat that it will make the health service unmanageable on the other. As an example of the damage this factionalism can do, I serve on a national committee formulating policies for statutory sector service providers and was told that the work of this committee is in danger of losing credibility because certain people believe it to be manipulated by the "gay lobby". We lack certainties and because of that we lack a consensus and without a consensus there is mistrust and conflict.

The individual challenge for those nurses is to overcome their irrational fears. The challenge for the doctor is to learn how to care instead of to cure. The challenge for the politician is to recognise that his or her political life will probably be shorter than the life of AIDS, and to resist the temptation to take short term "popular" measures which may preserve his or her political skin, but not ultimately the public health. This has already happened. The government, as one of the subscribers to the London Declaration on AIDS Prevention, promised in January this year to "forge through information and education and social leadership, a spirit of social tolerance".

Some indicators of public attitudes show that whilst sympathy for people with AIDS appears to be increasing, tolerance towards at least one social group most effected by HIV has decreased. The Government has enacted legislation which signifies that it colludes with this intolerance. I have not seen any indicators of attitudes to drug users, but it seems as though the language in which they are being described in the context of AIDS - "bridging groups"- is almost designed to ensure that they will be blamed and vilified as the incidence of HIV in the heterosexual community increases. We are all challenged to ensure that we do not allow the concepts we use to analyse the epidemiology of HIV - concepts such as "bridging groups" - to engender the threat of social violence against those already threatened by a brutal and violent disease.

I would like to end on what is, for me, an uplifting note. I believe myself to be extremely fortunate. I belong to a community which has faced collectively and individually the challenges posed by HIV. In that community people with HIV have not been ostracised; they have not had their autonomy threatened by calls from the uninfected majority for coercive measures to protect them. Members of that community have volunteered in their thousands to give practical and emotional support to those infected. Members of that community have changed their sexual behaviour, as the Minister has acknowledged, in a way that makes it unnecessary to discriminate even, and especially, in the act of making love between those who are infected and those who are not. That seems to me a remarkable social achievement. And because of that I, and many other people with HIV, have been able to achieve our own personal and private victories over this disease.

I think that it is our responsibility and our individual challenge to ensure that this opportunity is made available to everyone over the next few years - whatever the uncertainties.

II. SERVICES: THE HIV AGENDA

Health Promotion

Dr Spencer Hagard, Chief Executive, Health Education Authority.

The theme of World AIDS Day across the globe is: "A time for understanding". It requires all of us in the HIV and AIDS field to re-examine what we are doing and to explain and justify it or make changes for the better. Work in the field of health promotion, nationally and locally, in all agencies and in all sectors, is no exception. So, I have been asked to speak about the messages and who is responsible and who is accountable for AIDS health promotion.

The London Declaration on AIDS Prevention, at the end of the UK-hosted World Summit ten months ago, provides a good starting point for this task. The Declaration includes the statement: *"In the absence at present of a vaccine or cure for AIDS, the single most important component of national AIDS programmes is information and communication because HIV transmission can be prevented through informed and responsible behaviour".*

These requirements - information and communication - are fundamental to health promotion in the field of HIV and AIDS which the Health Education Authority is charged to lead and support.

We define AIDS health promotion as: *"the culture-specific process which seeks to influence positively the relevant health practices of individuals and groups so as to prevent the transmission of HIV infection"*, and in a way which meets fundamental humanitarian criteria. Our AIDS Charter published today vigorously restates these criteria.

At the individual level, this process is based on the hypothesis that people will adopt appropriate personal behaviour if they understand the threat and they know how to protect themselves and they believe that such behaviour will benefit them and they are empowered through acquiring appropriate skills and having access to necessary services to facilitate such behaviour, and they are given the support to maintain it over time. At the group level, the AIDS health promotion process is directed at influencing collective values and behavioural norms, in recognition of the profound influence that groups have on the real choices that their individual members are able to make.

Whether at individual or group level, AIDS health promotion requires:

- the latest scientific knowledge and understanding of HIV & AIDS;
- thorough understanding of the cultures and workings of our heterogeneous society - particularly the determinants of behaviour relevant to the promotion of HIV transmission;
- information, publication, and communication strategies; and mobilisation and coordination of multiple channels and multiple institutional responses.

Which brings us to the nature of the HIV and AIDs promotion messages themselves. They need to be:

- as accurate and clear as possible;

- honest and truthful about uncertainty and - in response to Jonathan Grimshaw - I would say simply that we have a duty to respect and communicate facts as they become known. For a person with HIV, ignorance is not empowering - quite the reverse;

- not offensive to reasonable-minded people;

- not alarmist or otherwise conducive to feelings of guilt, fear or despair;

- relevant and realistic;

- not victim-blaming, anti-sex, stigmatising or stereotyping;

- self-empowering in the sense that they help individuals to build confidence and self esteem; encourage them to respect and care for others; and develop understanding and skills to facilitate informed choice.

To meet all these requirements will clearly necessitate a variety of strategies, and the employment of mass media, community-based approaches, and one-to-one work. These should be supported by production and distribution of relevant health education materials; training people in the use of the materials; encouraging peer group learning; promoting informed debates in the media; and supporting the National AIDS Helpline.

Obviously the formidable challenge of AIDS health promotion requires the contribution of many different organisations and individuals at national and local level. This generates multiple responsibilities, which bring with them the need for very clear thinking about accountability for each and every responsibility. This is not unique to AIDS - the need for collaboration amongst different agencies is inherent in the commitment which the Government has made to the achievement of Health for All by the Year 2000.

Thus a clear understanding of what one's own agency might contribute is necessary. So is knowledge of what others might contribute; what responsibilities one agrees to fulfill; and how to take others' contributions into account in fulfilling these responsibilities efficiently and effectively and sensitively. All these understandings are a sine qua non of working together in partnerships, alliances and networks.

To this task the HEA is able to bring its long and growing experience of working in this way in other fields of health. We are specifically able to commit ourselves to contributing the following to the AIDS health promotion challenge, and to be held accountable for fulfilling these commitments. They are to provide:

- a sound basis in the theory and practice of health promotion;

- a defined contribution to monitoring and research into the health and health related beliefs and behaviours of our population;

- a defined contribution to the policy making process;

- the products, wherever relevant, of our long experience in developing, piloting, disseminating and evaluating curricula and materials in schools, colleges and youth settings; publications of many different kinds and work in the mass media and our growing experience, likewise, in workplaces, and primary care settings;

- our long experience in the professional development of health promotion workers;

- our growing experience in community development

- and the finest collection of health education material and resources in Europe - at the heart of our shortly-to-be-redeveloped information service.

As I said at the beginning, we accept the need to re-examine continually the contribution we can make and how it can be improved. We believe we can contribute greatly to improved understanding.

Housing

Peter Larkin, Frontliners .

One of the greatest threats to the good health of people with AIDS (PWAs) and HIV disease is stress, which, in itself, can provoke the onset of many life- threatening opportunistic infections. One of the greatest causes of stress to PWAs is homelessness or inadequate or unsuitable housing. By ensuring the ready provision of, and easy access to, good quality housing for PWAs we will enable them to concentrate their energies on fulfilling the promise of the maxim that "quality of life is more important than its quantity".

At present we are not in such a position. The people I know - such as the eighteen year old with AIDS who had to give up his home because of repeated attacks and beatings at the hands of local youths; or the man in his thirties who was evicted by an unscrupulous private landlord and had his belongings strewn onto the street outside; or the man in his fifties who was turned out of his family home by a wife and children who did not try to understand - have no hope of a speedy resolution to their housing problems. At best, they are being forced to live in inadequate bed and breakfast accommodation in some seedy, overcrowded and rundown hotel.

You might say to me, "Surely such people will be regarded as being vulnerable under the provisions of the Housing Act, and therefore, be considered to be in priority need, and, as a consequences, be easily rehoused by their local authority?". I would have to reply that, yes, most local authorities, who have a policy regarding AIDS and HIV Disease will accept people with AIDS or AIDS Related Complex as being vulnerable. However, most local authorities will not accept people who are HIV positive but asymptomatic as being vulnerable, and some are like a certain South London borough I know where the Deputy Director of Housing told me that they will not necessarily accept someone with full-blown AIDS, and homeless, as being vulnerable unless they were in the terminal stage.

However, even being accepted as vulnerable under the Housing Act does not mean that a PWA's problems are over. Assessment is only the first step to gaining housing, and further problems occur at the stage of allocation because of the overall shortage of housing. AIDS could not have come at a worse time. Homelessness is a desperate problem in this country and it has recently been exacerbated by Public Expenditure controls over council house building, right to buy legislation, and the new Housing Act. I do not propose to spend much time on the Housing Act but I will say simply this. Ministers do know that their legislation will not help but rather hinder the provision of special needs housing. I was, and I am sure that many of you were, distressed and appalled recently, to see Lord Caithness, interviewed by Jonathan Dimbleby on the BBC's On the Record programme, having his case demolished as he tried to defend the indefensible. If you privatise British Telecom the most you can lose is your telephone; if you privatise housing you can lose your home.

Where does this leave us? We have seen that one route to housing, or rehousing, is, possibly, providing a myriad of conditions are met, through local authority (LA) housing departments. However, as we have seen, these already face a housing problem with which they cannot cope. It is true that some, but by no means all, local authorities are willing to house or re-house PWAs; there is, often, the political will to do something. But all LAs need the one commodity which PWAs do not have in abundance - time. In London it is common for 6-12 months to elapse between an application for housing and an offer of suitable accommodation to a PWA. As a result people are dying much sooner than they need to.

Before we can consider how to provide housing services to PWAs we need to discover what it is that needs to be provided. The recent Griffiths report on community care degrades the role of housing to a provider of "bricks and mortar" only. I am afraid that special needs housing for PWAs means much more than this.

As I have said, AIDS has revealed the general inadequacy of all sectors of housing in meeting the needs of people with serious health problems. It has also highlighted the need to provide housing which is flexible to changing circumstances, with support and care services which allow people to stay in that housing for as long as they want to. It is of no advantage to house someone with AIDS in a property which will soon become inadequate to their changing needs.

I would like to expand on my perception of what the special needs of PWAs are. These are largely covered under 7 headings.

Access

Access comes first. Interviews with a PWA should be handled sensitively and in private. Confidentiality is of paramount importance, but we need to define exactly what the word "confidential" means. It does not mean "secret". Any organisation dealing with PWAs, whether statutory or voluntary, must, therefore, have a clear, written policy on confidentiality. Breaches of such a policy must in all cases be subjected to a disciplinary procedure. It is equally important that a PWA understands the policy of the body with which he or she is dealing. PWAs must know what is going to happen to information which they provide. During such interviews staff must listen to a PWA, to find out exactly what it is that the individual needs. When the interview is over, applications must be processed speedily; as I have said, PWAs may not have time to wait.

Design

The homes of PWAs should be of an adequate size. By no means all are single people, and all will, at some time or another, need carers to stay overnight. It is, therefore, apparent that studio-type accommodation is inappropriate and at least 2 bedrooms should be the minimum even for single people. Furthermore, all home should be designed to at least mobility and in some cases to wheelchair standards.

Environment

Thirdly, environmental factors need to be considered. All homes should be fitted with efficient central heating systems under the control of the tenant; shared heating systems, often found in LA properties, are inappropriate for someone with AIDS. Washing, heating, sanitary and other self-management facilities should be sensibly designed, as should waste disposal systems. Wherever possible accommodation should be offered either furnished or unfurnished. The installation of telephones and entry phones are vital.

Security

This brings me to the fourth area of special need, security. It is a sad, but nonetheless true, fact of life that PWAs are open to physical attack, abuse and harassment simply because they have been diagnosed with a terminal condition. It is, therefore, essential that their homes are physically secure. They should be equipped with good external lighting and internal security, such as the fitting of toughened windows with locks, within the terms of fire regulations. Where wardens do not exist, warden alarm systems should be in operation. Clear procedures for protection from the threat of violence should be designed well in advance of such a threat being made.

The fifth consideration is location. The home of PWAs should be near, and have easy access, to shops, transport, medical facilities and support services. Furthermore, people will want to be near friends, not just family, whilst others such as drug users, black people and those who have been harassed, may wish to move away from old haunts.

Tenure

Penultimately, tenure: all PWAs should have full security of tenure in their homes. Their rents should lie within benefit limits and be affordable so that those who wish to continue to work are able to do so.

Transfers

Finally, transfers: transfer requests must be considered sympathetically. There are many PWAs living in accommodation which is patently unsuitable given their changing needs. It is not uncommon to find PWAs living on the 15th floor of a tower block, or in accommodation which is damp and cold. This accommodation may have been provided in the first place because of their diagnosis. Local authorities and housing associations still have a lot to learn about AIDS.

Given the seven points I have referred to, it is equally important to understand that no one model provides the perfect answer to the housing needs of PWAs. There is a need for a wide variety of solutions. Some PWAs may need to live in shared accommodation, others in cluster types or supported accommodation. And others in totally independent homes. They will all need the availability of support in varying degrees.

Now that we have identified what is needed, how do we ensure its provision?

I am afraid that I do not have the answer to this final question. We can all see that the solution proposed will be expensive and we need a clear commitment for Government to be responsible for and responsive to the housing needs of PWAs.

The voluntary sector too have an important role to play. Indeed, of the projects which have, so far, actually housed PWAs, all have been initiated by the voluntary sector. Mistakes have been made but we can today celebrate the first birthday of the AIDS and Housing Project, a body which has for the past year, with myself and others, been pressing the urgency of the problem and encouraging all organisations, whether statutory or voluntary, to adopt a strategic plan and a coordinated approach to the special housing needs of PWAs.

Housing need not be a problem for PWAs. It will only become one if we allow it to.

Law and Advocacy

Terry Munyard, Barrister.

Jonathan Grimshaw has said far more eloquently than I could that the message that we are getting from government and from the lawmarkers is at the best a very confused one. It is a mixed message of approval and disapproval, of support and denial, and that is reflected in the law, as you would expect it to be. The law always follows behind social progress and change.

There are very many areas of the law that have an impact on HIV and AIDS and I am just going to touch on a small number: probably the areas that are most well known. As each week passes and new problems arise, people discover that they are up against the law in relation to health as far as HIV and AIDS is concerned.

There is the issue of testing, the question in law of consent for testing for HIV, screening, mass screening: there are legal as well as moral, ethical and medical questions here. Then there is the question of confidentiality of information, confidentiality about a person's medical records, and medical history. The law can in some circumstances give some protection; generally speaking the law gives very little protection.

I think that the law on confidentiality of information in Britain is probably the least developed in the western world and there is very little that an individual can do to prevent information about him or herself being given out. It was therefore very surprising and very welcome when the High Court refused to allow certain - I won't call them newspapers - but Sunday publications to name doctors who were ill with AIDS who were still practising in hospitals. That decision, very welcome though it is, is a significant exception to the general state of English law on confidentiality of information.

The area of employment law, which is an area that I particularly specialise in, is one in which we see the mixed message once again. The Department of Employment and the Health and Safety Executive put out a small booklet about eighteen months ago and sent it to all employers in the country on "AIDS and Employment". It was a very positive, constructive and helpful document; it set out the medical information and it also gave clear guidance that dismissing somebody simply on the grounds that they had HIV or AIDS rather than that they were not able to do their job, or were perceived to have HIV and AIDS would be unfair.

Shortly after that, two industrial tribunals decided that it was in fact fair to dismiss people who were perceived to have HIV. One of those cases was overturned. It was not overturned by the Employment Appeal Tribunal, there was an appeal lodged and then the employers agreed that they would have been found to have been unfair and so they settled the case. That was the instance of the cinema projectionist that many of you will know about.

But, again, we see the confusion in the law. The government is saying that the protection is here and yet the tribunals and the courts for the most part are not in fact giving people the protection they need.

Housing has been touched on again very eloquently by Peter Larkin a short while ago. There is a right to housing if you are in priority need - and what better example of someone in priority need than somebody with AIDS - and yet you have heard of the examples of the way in which that particular piece of legislation is not being operated to protect those who most need it. I think that the social fund operates particularly iniquitously against those with HIV and AIDS.

Officially we do not have any immigration control in relation to those who have HIV or AIDS or are again perceived to, but in practice immigration controls are being operated in relation to such people and people are being either barred from entering this country or held up at ports and airports. We also have legislation, the 1985 public health infectious diseases regulations, which actually provide for the compulsory testing of individuals and the compulsory removal to hospital and detention in hospital of individuals who have AIDS. The compulsory testing provisions incidentally do not apply only in relation to people who have actually been diagnosed as having AIDS but to people those who are thought to be likely to be carrying an organism, in other words HIV, which could result in the disease.

Then the area that also has received a great deal of publicity and is probably one of the most difficult to resolve in strictly legal terms is that of insurance contracts. We have heard only last month of a number of insurance companies deciding that they are going to discontinue life cover altogether, or discontinue life cover for certain categories of individuals. We all know who those are: they are for the most part people like me, unmarried men between the age of 25 and 45. Then there is the area of education that has also been mentioned this morning, whether or not an individual child can be barred from a school because it has HIV or even because its parents have HIV or AIDS.

There is also the whole area of access to facilities and services, and the question of whether or not local authorities are obliged to provide certain facilities and services to all within the community. Yet we have laws - and I am thinking particularly of section 28 of the Local Government Act 1988 - which actually stigmatise and give constitutional legitimacy to disapproval of lesbians and gay men and deny them the right to access to facilities and public services. The supreme irony perhaps of that piece of legislation lies not so much in the fact in the first part of section 28 where so-called promotion of homosexuality and teaching that homosexual relationships are as acceptable as a family relationship as any other sort are prohibited. It lies in the fact that a second part of the section recognises that of course the message contained in the first part completely negates the government's messages on HIV and AIDS and so there is a specific exclusion written into the statute to exclude anything to prevent the spread of disease and even that is perhaps not the most supreme irony. What I have in mind is that on the 13th May this year, at the 41st World Health Assembly in Geneva, which is the assembly of the World Health Organisation of which this country of course is a member, a charter or a statement was issued unanimously: "World Health Organisation against AIDS Discrimination", and I will read just the first paragraph.

> *"The World Health Assembly urges member states particularly in devising and carrying out national programmes for the prevention and control of HIV infection and AIDS, to foster a spirit of understanding and compassion for HIV infected people and people with AIDS through information, education and social support programmes, to protect the human rights and dignity of HIV infected people and people with AIDS and of members of population groups and to avoid discriminatory action against and stigmatisation of them in the provision of services, employment and travel.'*

And so it goes on.

Two weeks later, on the 24 May, Section 28 came into effect, the same government subscribing to apparently contradictory notions.

Now thus far almost all the legislation that has been passed around the world in relation to HIV and AIDS has concerned itself either with reporting mechanisms, statistical data gathering, or restrictive legislation, restricting the rights of the movement of people with HIV and AIDS, and there is is a wealth of such legislation. The World Health Organisation has produced a table of all the legislation from around the world.

There is a vast body of legislation already but very little of it is actually concerned with carrying out the message from the World Health Assembly and the London Declaration, from the Council of Europe and from the EEC, namely, that we should be avoiding discrimination and stigmatisation and therefore that laws should be giving specific protection to people with HIV and AIDS.

We now know enough about the modes of transmission of HIV and AIDS to recognise that the real dangers, or the principal dangers, lie not so much in people with the virus passing it on to others and legal dangers resulting from that, but the other way round: that it is people with the virus, or perceived to have it, who are most at risk and who most need the protection of the law. That is what I hope the message will be that will go out from this conference today. We should be looking to give a clear message, not a confused message, and a message in line with all the various high sounding international declarations that our government and many others who behave in the same way have been all too happy to sign and pay lip service to. We should be perhaps considering specific legislation to outlaw discrimination against people either with HIV and AIDS. Perhaps it would be a better approach to outlaw discrimination against anybody with any sort of handicap or impairment as a result of their state of health.

I raise finally one caveat about that. I suggest that we should perhaps be looking to lay down or enact general laws covering all categories of people who have certain diseases or illnesses rather than being HIV or AIDS specific because I think there is a danger in passing specific laws on this subject of further marginalising and stigmatising those who have the virus.

And so, as I say, at the moment the state of the law is very confused. There are a few glimmers of hope but while the government and the legislators continue to fail to give a clear message, then there is little that we can hope for from the courts and the tribunals and we have to look to those parliamentarians, whose responsibility it is to follow up those international declarations in our law.

Drug Services

Dr. John Strang, Bethlem Royal and Maudsley Hospitals Drug Dependence, Clinical Research and Treatment Unit.

I was insulted earlier this morning by Michael Adler about the fact that I represent services which are rudimentary or non-existent, and I can honestly say I have never been so delighted to be insulted in public.

It is important to recognise that fact because it poses problems quite beyond the issue of just funding. It actually means that even if funding is made available, there is a lack of clarity, a lack of direction about how those funds should then be used. I think that this confusion contributes to much of the unproductive debates that goes on about possible developments in drug services in this country.

Certainly, skills in advocacy do not really exist within people working in the drug field. They are not used to having the opportunity to extend their services, and I am delighted to be able to support the suggestions that have been made about a need for much clearer central direction on the way in which such services should be developed. It is quite insufficient if one is in the fortunate position of there being some funding to develop services just to cut it up into various bits of cake and sort of hand it out partly according to how many people there are and partly to who shouts most. I obviously still hope that if I shout a bit I will get a slightly bigger piece of cake, but clearly that is not the way in which expansion should be developed.

I need to stress at the beginning that I am speaking in a personal capacity. I am looking at the specific issues for drug users and drug services and I will not be dealing with issues about sexual behaviour amongst drug users. Before talking, I did want to put a marker on the issue of services in Scotland in order to say that they are a particularly fine example of the disasterous situation that can occur if there is no planning and if there is no funding. I think it is the planning that is perhaps more absent, although if the planning was then available the funding would become an issue. It is also an example of the point that other speakers have made about the whole response being very disappointingly reactive rather than proactive; it being very much a matter of damage limitation.

A final point I wanted to make before getting on to the main body of my talk was to do with the calls that have been made today for gathering basic information about clinical developments and the extent of the problem. This is a compound problem in the drug field because we do not even have any valuable basic data gathering about what is happening with drug problems themselves even for those people who are presenting the services. One of the very significant developments of the rudimentary service over the past decade or so has been the central funding of community based initiatives, many of which operate on the fringes of the NHS or outside it. We have virtually no system of collecting information about who they are seeing, and what people are taking. When the whole HIV issue began to emerge we did not have any information on whether the people presenting to drug services were injecting or not. Just that sort of basic information, at least knowing whether people were injecting, would have been fairly useful.

Just to illustrate the practical relevance of this, we have a very modest data collection system within our own clincial service and over the last year this has thrown up immensely useful bits of information which have practical relevance. Most of the people we see do not come through orthodox NHS referral channels. They are either self referrals or referrals from what is called social services or voluntary agencies. In practice this means two local street agencies. One per cent of them were from social service departments, the remainder were from the two street agencies. That has practical implications for how we provide the service and how other local agencies should provide their service.

Another example, I do not quite know what to make of this, but we do not seem to get young men into our services. We get a fair number of young women heroin users presenting to our service, but we get virtually no young men under the age of twenty. Either in Southwark and nice parts of South London like that they are not doing things like using heroin if they are men, or alternatively, for other reasons they are not presenting to the service.

Another practical example: we have discovered that half of the heroin users that we are seeing are not injecting their heroin, they are smoking it. They are people who have not injected at all. That forces us to consider with a much more critical gaze what are we going to do to develop of services that not only benefit the heroin users and the other drug users that we are seeing who are injecting, but also do not bring damage to those who are not injecting. Clearly the issue needs to go beyond just those who are currently injecting.

The final practical issue which I would emphasise with the modest developments that are taking place with drug services is that they will silt up. This is our first year of operation. In our first quarter, our first three months, we had a walk-in service where you could walk in, be seen, and you would be involved in some sort of treatment programme within a matter of a few days or certainly within a week. We were getting on average at least one new person to us per day from just the local district population. That carried on through until about four months when our system silted up. We were not processing people fast enough and we did not have the capacity to carry on in that way. For about three months we got away with it by goodwill. Local agencies still referred people to us because they thought we were decent folks, but in the last quarter people had had enough. They thought, "if there's a two month wait to get into a walk-in service there's no point even going along", and our referrals dropped to a very low level. The following quarter it was even worse than that.

I wanted to address some assumptions that are about at the moment which I think are examples of the naive thinking that needs to be countered. Various people will get up and argue that either prescribing drugs or giving needles and syringes or increasing control or any of these approaches are in themselves a sufficient response and that they are the answer. The nation, the medical profession, everybody is desperate to be told what is THE answer. It is important to realise that there is no such answer. In the Drug Advisory Council Report chaired by Ruth Runciman the fact that policies need to look at securing multiple small gains rather than "master strokes" is stressed. In allowing the belief that there is a master stroke, that there is a simple solution, we actually miss the opportunity for valuable interventions.

In my work with drug users, one of the very useful approaches that I regularly use is doing some sort of cost-benefit analysis with them of their personal situation, or a pay-off matrix. So if they are thinking of changing some aspect of their drug use, for example, if they are dependent and wanting to stop using or if they are wanting to stop injecting or any other change - what are the advantages or disadvantages to the various options available to them? It is often a surprise to them that I am working in this way because it involves acknowledging that there may be advantages to continuing as well as disadvantages and so on. I find this an extremely useful way of looking at actual developments that we might consider with drug services.

Traditionally we have high threshold treatment programmes in this country. There is a considerable level of precaution before I would start prescribing for the drug user because of my concerns about creating a problem where a problem did not exist: prescribing to people for whom it is inappropriate. There are disadvantages with this. Several - I think most drug services are moving quite strongly to low threshold treatment programmes. The community service I was talking about earlier is just such an example. I would commend that way of viewing it as a useful example of identifying there is no one answer is appropriate or inappropriate.

A similar approach with needle and syringe availability identifies advantages and disadvantages. It is certainly clear from my point of view that no availability seems to have virtually no advantages, whereas at least the needle exchanges give competing options.

I am sad to announce the fact that I think we have taken an enormous step backwards in our understanding of what drug use comprises. We are now going back to some old-fashioned view of drug addiction being some sort of demonic possession where individuals have no sense of personal choice or personal responsibility. I regard this as a tragic move back to an old fashioned view. It does seem to be partly responsible - or accounted for - by the whole HIV issue, which does bring out some pretty old fashioned views in lots of people.

It is the sort of question that is asked, you know, "Is someone a drug addict or are they not?" and I think one has got to grasp that in drug use we are talking about a range of behaviours. The way in which someone uses will vary immensely. There is experimental use, from nosiness or curiosity. There is recreational use when someone is clearly exercising personal choice and choosing to use a drug. The majority of people I see will be people who are using compulsively where the locus of control is clearly no longer firmly located within them.

In terms of our concern about drug use itself, it might be substance-specific or technique-specific. Is our concern to do with the drug itself or is it to do with the way in which people are using? Many of the approaches that we are talking about are not going to be equally applicable across the three types of drug use: experimental, recreational or compulsive. Recruitment into a treatment programme would be a strange option for the person who used a particular drug for the first time yesterday. Clearly it would be a strange option and yet one is needing to consider health issues to that person themselves and to others even with such isolated use.

I am particularly concerned that the debate over the last couple of years has talked about drug users being either motivated to change or not motivated to change; that there are people who want to give up and there are people who do not want to give up. It just is not human nature to be firmly located within one category. As somebody who eventually gave up cigarette smoking myself having wandered around for years somewhere between those two categories, I certainly do not think I ever existed in any of those categories firmly at any one time. Believing that people are firmly in one category or the other leads your discussion into areas that I think are not very helpful.

Once you recognise that perhaps the responsibility of services is taking people who are poorly motivated to do anything, and working with them to increase their resolve to change - increasing their sense of self-determination about their continued drug use - then it becomes appropriate to work with people who traditionally would have been called poorly motivated.

I wanted to bring in three concepts now which are talked about in the Advisory Council Report. I find it useful to consider services from the point of view of their ability to capture, to retain and then to promote throughput. I will just talk about capture, retention and throughput briefly. I think there is great value in developing the concept of loss-leaders like a drug company or somebody trying to sell me cornflakes is going to use. They will give out freebies as a way of drawing someone into their service, but the measure of the effectiveness of that service is not the uptake of those loss-leaders. Instead, it is the proportion of people who then go on to make the change that you have identified as the key change.

If we announce locally in South London that there are free lunches at the drug clinic, the measure of success will not be the number of free lunches we give out but our recruitment rates as a result of that exercise.

It is possible to see prescribing to drug users, and it is possible to see syringe and needle exchange schemes as quite good examples of loss-leaders, but it does mean that our measure of effectiveness is not just the actual operation of the service. Our services are currently pretty large mesh in fishing terms. We scoop up pretty big fish. You have got to have a fairly weighty drug problem to be identified and to feel the need to present to a service. We need to develop much sort of smaller mesh services so we actually scoop people up earlier in their drug using careers. Typically, people will have been injecting for about three years by the time they present to the service.

The American Presidential Commission talks about treatment on demand as a concept. It seems a splendid point from which to start trying to develop services both here and in the States.

There is a lot of interest at the moment in capturing people, lots of advertising campaigns recruiting people into drug services and far too little attention being paid to what on earth you do once you have actually captured whoever it is you are trying to capture. You have got to look at the actual stickiness of the service. Having had a contact with the service does somebody stay in contact with that service? Possibly prescribing might increase the stickiness of a service; you have certainly got to avoid things that reduce the stickiness of the service.

And finally on this issue: throughput. There is insufficient examination of what on earth I am going to do with my clinical practice. Everybody says, drug users are an important group and HIV is an important issue. They tell me that therefore I should work much longer term with them. Now if I work longer term with them I then take on less people into my service. Those sorts of practical considerations are not being dealt with adequately.

So, summing up, I think it is unacceptable for us to wait for spontaneous conversion into either believing in or acting on some message that we might give out. That is unacceptable in our work with drug users. We have got to be more pro active. This is unacceptable with our generic colleagues who may not be interested in working in this group. Something has got to be done that shakes them up a bit more. We need to consider capture, retention and throughput of services rather than just whether we can actually capture people initially.

We do have to establish backup facilities behind this capturing drive that is currently on at the moment which is going to involve properly staffed services. I have probably one of the few units in the country that has a reasonable level of staffing. A regional unit in one of the regions of this country has one doctor and three nurses to serve a region. That is not actually the country responding adequately to the biggest post-war threat.

We need to ensure a clear community orientation and emphasis of the service. The main feature is that there should be ease of access into the service and making sure that it is then palatable to potential clients or patients of that Service. My main point is that change needs to be driven, not just awaited.

III. THE COMMUNITY CARE TRAP

AIDS and community care

Sir Donald Acheson, Chief Medical Officer, Department of Health.

What I would like to attempt is a brief analysis of the issues concerning the care in the community of people with AIDS and AIDS-related illnesses and to highlight one or two questions for further discussions. Although it is a complex issue, the message is relatively simple. Most people with AIDS-related illnesses and AIDS want to get on with their normal lives as much as possible, and most of them want to live at home. Hospital, hospice and day care provide crucial support services - but whereever and whenever possible the necessary psychological and physical support should be provided in the setting of the home. Of course, sometimes, regrettably in an imperfect world, there is no home and we have to provide for that as well.

First, let us look at the current scale of the problem. At the moment, there are probably about 1000 people who have AIDS living in the UK, and perhaps three times as many with various AIDS-related conditions. Perhaps as much as 75 per cent of the total clinical burden falls on the four Thames Regional Health Authorities - and in particular on parts of the metropolitan area within these regions. It follows that in much of the rest of the country, except perhaps in the large conurbations, AIDS cases are still sufficiently uncommon to test the community services - not through clinical load - but in terms of unfamiliarity. This has all the attendant risks associated with lack of experience with irrational fears of infection leading regrettably occaisonally to stigmatisation of patients or clients even within the health and social services.

Within the UK the great majority of AIDS cases - 83 per cent - have so far been in homosexual and bisexual men; the other groups each providing very small numbers of cases. However there is evidence that the picture will slowly change with a gradual increase of the case load due to intravenous drug abuse and heterosexual spread. We know of almost 1000 women within the UK who are infected with HIV - and that must be a small proportion of the total - about half of whom are drug abusers mostly in Scotland and we can regrettably expect that most of them will eventually develop AIDS-related illness. AIDS in haemophiliacs is a considerable problem with an extra element of tragedy. Obviously these patients have their own special needs and I would like to pay tribute to the work of the Haemophilia Society. As you know, as a recognition of the exceptional position of haemophiliacs the government has provided an ex-gratia payment of £10 million to the MacFarlane Trust, to administer on their behalf.

From what I have already said it will be obvious that people with AIDS are not a single homogeneous group presenting identical needs. Whilst they will indeed have similar general needs for psychological, social and physical support, these needs will vary considerably from individual to individual, and will change in each individual's case as the disease progresses and as his or her circumstances change. Care and support plans need to be tailored to each patient just as they should be for all people who require health or social services, and we must be careful to avoid the use of standard "packages" of care regardless of the actual needs of the patient.

This emphasis on consumer choice need not make the planning and resourcing of service provision difficult however. The job of service planners and of the clinicians and other professionals providing services to people with HIV infection is to be aware of the diversity of needs and to seek to ensure that these can be catered for.

We should not underestimate the difficulties of developing a strong community-based element to services for people with HIV and AIDS. So far, the major demands for services have fallen on hospitals, but I believe that service planners and managers must work out with clinicians what more can be done to involve GPs, district nurses and health visitors to provide alternatives to hospital treatment, which may prove more suitable to the individual. And one can reckon that of a lifetime of eighteen months to two years for an AIDS patient about three months will be in an acute hospital.

In addition, I hope that those of you who provide professional services to people with HIV infection and AIDS, or who are responsible for planning services, will ask yourselves carefully how far you can involve the voluntary sector. There is no doubt that both in this country and abroad, voluntary agencies are in the forefront of developing new styles of service to help people with this problem. I see no reason why, for the future, the health service should not formalise working relationships with organisations such as the Terrence Higgins Trust and London Lighthouse so that the voluntary and statutory sectors work constructively together to help meet the needs of people with HIV infection. Similarly you must consider issues like the provision of space in health authority accommodation for voluntary bodies, as is being done at St Stephen's and in Oxford. I now turn to some of the services that people with HIV infection, AIDS or ARC require for their physical and psychological support.

The acute illnesses will probably be treated in hospital but during the periods of remission and during the final stages support will be required from a whole range of care providers. With improvements in treatment, it is more and more likely to take place in the community.

Let us consider the periods of remission when the patient's energy levels will be falling, when his work capacity will be lessened and his general mobility will be curtailed. This, accompanied by increasing depression and possible dementia gives us a picture of a generally young debilitated person in need of constant support from a variety of sources. How do we cope? I realise this picture can be compounded by other major problem areas, particularly when thinking of the needs of drug misusers and mothers with children, but the underlying philosophy of care remains the same.

Clearly, good liaison between hospital and the domiciliary support services is essential, and this is being approached in various ways. One example are the outreach teams that some London hospitals have developed. The development of day-care facilities is another important facet of community care. The Kobler Unit at St Stephen's Hospital is one of the first such units and provides a number of facilities including counselling, therapy, blood transfusions, and a lounge area for patients to meet and to discuss their care plan with care providers. The unit facilitates liaison between hospital staff and those from social services and voluntary groups.

Local authority social service departments have an important role to play. Many authorities have already produced a policy on AIDS to provide a framework within which their staff operate. Authorities who are providing help and support to substantial numbers of clients are already providing the following range of services. These include: home helps, meals on wheels, social work support both from hospital and community social work, occupational therapy, foster care, counselling, and day care.

Other local authority departments have a role. For example, people with AIDS who live in inadequate or inappropriate accommodation need to be rehoused. Consideration may have to be given to the provision of sheltered or hostel-type housing, where such people can be cared for and can care for each other. Some local authorities, in London, have already taken steps to provide this type of housing. Voluntary bodies can also provide important services in this area. I was impressed on a very recent visit to the United States by one project in New York which I believe sets an example which we might try to follow here. Homelessness is a significant problem in New York, and people with AIDS are affected by it. As a response to the problem, the City Health Department is paying for a voluntary agency - the AIDS Resource Centre - to provide a sort of hostel for 44 homeless people with AIDS. It is called Bailey House and operates from a converted hotel in Greenwich Village West. About half residents are gay men, and half have been infected through injecting drugs. 12 per cent of the residents are women. Bailey House does not provide nursing care like Lighthouse, although visiting nurses come in. But it does provide accommodation, single rooms with beds, companionship, and therapeutic support, a bar/dining room and so on. It tries to encourage those who use drugs to develop individual responsibility and to provide a structure for their lives. As far as possible residents who develop dementia stay at Bailey House. There are twice-weekly support meetings for staff - much needed given the stress of knowing that, on average, one resident dies every week. I hope we can learn something from this example in New York.

In discussing housing needs we have to recognise that varying needs exist. For example, drug misusers. This group, so important in considering the furture of the epidemic, are less likely than others to be in suitable, stable accommodation.

Finally, there may come a time when it is not possible to care for someone at home any longer and hospice care becomes appropriate. Some existing hospices have provided care and have been able, from their experience of caring for the dying, to give advice and training to people looking after those with AIDS. The two AIDS projects in London - the Lighthouse and the Mildmay - are now operational and are providing hospice and respite care among their other services. These and other voluntary bodies are a key element in the provision of hospices - and hospice-style care - and we look to continuing close co-ordination between statutory and voluntary bodies to ensure needs are met.

But I end where I began with the affirmation that to the maximum extent possible, we must ensure that people with AIDS and AIDS related illness are cared for throughout in their homes supported by their friends and families, backed up by services provided by the State and by the voluntary sector.

Community Care Policy and AIDS

Professor Alan Walker, Sheffield University.

I welcome the opportunity of speaking at this major conference. I should emphasise that I am not an expert on AIDS, but it is clear to me that most people with AIDS like most people with disabilities want to live in their own homes in a familiar environment in the community. And so I think we can use the history of policy research and policy analysis on community care to have a bearing on thinking about the way that community care might develop in relation to people with AIDS.

So what does community care consist of and what lessons from community care policy can be learnt by those seeking to develop services for people with AIDS? These are the questions I want to quickly address.

The starting point is to recognise that it is not the community that cares, it is primarily the family and within the family it is female kin. So AIDS has a double impact on women. Of course, they are likely to get it, but much less likely than men, so the primary impact on women is as carers of people with AIDS. And society, including the family, the medical profession, the social services, all make an assumption about the primary duty of women to provide care. Some social service departments still ration resources according to whether there is a female relative living nearby. The expectation of women is that they should provide care. Rarely are they asked whether they want to provide care; rarely are they asked what support services they want to help them.

Secondly, care itself is not as simple as it may seem. Care consists of hard labour. It is often backbreaking work: cleaning, shopping, lifting. Labour. But there is another side to care: love, duty, guilt, worry, particularly if you are caring for someone in your own family. What I am talking about is a realtionship of affection, and it is women again who bear both of those burdens. They bear the burden of labour and all the cost that that entails. That means giving up work or taking a part time job, that means the physical strain of looking after someone, and they bear the mental cost that care can entail.

So the first lesson from experience on policies on community care in the post-war period is not to idealise the concept of community care. The history of community care policy is characterised by a gap between political rhetoric on the one hand and what is actually delivered on the ground on the other. All politicians agree that community care is a good thing - who could be against community care? Like motherhood it is a wonderful concept and up to the end of the 1970s there was a high degree of consensus among politicians that services should be delivered in people's own homes, through domicilary care, home care and so on. But there have always been insufficient resources to truly deliver a community care strategy. In the past I have written about what I call a "care gap" between the needs of people on the one hand for care and on the other hand the availability of resources. That gap has existed over the whole of the post-war period. But from 1979 onwards, we have had a policy of severe resource constraint in public expenditure and a policy where a government turns its attention more and more to the community and less and less to local authority social services. In the 1981 White Paper on care for the elderly the government said that "care in the community must increasingly mean care by the community." That means that families, neighbours, friends, must increasingly step in to perform the roles that previously social services provided.

The danger is that if we assume that the family, and the so-called community, is not doing all that it can already, then we are going to over-idealise the prospects for community care and we are going to overburden the family and the community. This policy has come under heavy criticism from a range of authoritative sources. The House of Commons Social Services Select Committee is one. The Griffiths Report itself is critical of the lack of funding for community care. The Audit Commission two years ago said community care policy is in some disarray. As I have said already, it means that women in particular are overburdened by our expectations.

Secondly, related to that, it is mistaken to assume that local authority services can be cut back because they will be substituted for by informal care, by voluntary care, by friends, neighbours and so on. We know that the family performs functions that friends and neighbours are not prepared to perform, for example close personal care. We know that the private sector is keen to develop services, but in the more profitable residential and nursing home sector rather than the domiciliary sector.

In contrast to that assumption that we can remove local authority services and up will spring informal caring relationships, research shows over the last thirty years that local authority services can act in a very supportive way to sustain the caring activities of the informal sector. In particular, research on caring for elderly people who are suffering from dementia shows this. It struck me on thinking about this conference that the particular stress of caring for someone with AIDS must be not knowing how the illness will progress, not knowing how to deal with swings in mood from hope to despair and the experience of loved ones turning against you. This is an experience that we encounter in relatives looking after people suffering from senile dementia.

There is good evidence from previous community care research that good supportive services can prevent those stresses arising within the family. That is, if services act in partnership with the users, the carers and the cared for.

Thirdly, community care must be adequately resourced. As I said, there is already a care gap in most local authorities, and for various reasons, because of the increasing demands from older people for example, that care gap is likely to widen.

Now there has been a conscious policy over the last ten years of removing resources from local authorities through our block grant system, the rate support grant system. So the policy of cost efficiency has gone before the policy of care effectiveness: cost rather than quality has led the way. That has not been done openly. The rate support grant has been cut year on year in negotiations with local authorities, and here is just one example that demonstrates the importance of this to you. We know that last week there was an announcement that seven million pounds extra had been given to local authorities to develop services for people with AIDS. Local authorities are expected to top that up with thirty per cent making ten million. But in the current rate support grant settlement for local authorities, the settlement is eighty to a hundred and twenty million pounds below what was an agreed sum. So on the one hand we find that Department of Health Ministers are targeting resources where they are needed, giving money specifically for AIDS development. On the other we find that the Department of the Environment Ministers are actually cutting the base funding going to the personal social services in local authorities. So you have a difficult task on campaigning on AIDS to decide who it is you should be campaigning with. Because the larger sums are being taken out of local authority social service budgets by the Department of the Environment, not being given back by the Department of Health. So not surprisingly, many local authorities find it difficult to meet the competing priorities they are faced with and our services operate on a casualty basis in that when the caring relationship breaks down along comes the ambulance and steps in. So we find there are geographical variations between authorities.

Fourthly, it is important to see community care in broad terms and to co-ordinate the activities of a range of different services, not just the health and personal social services. For example, income and housing are absolutely crucial. We know that most people with AIDS experience financial hardship, so an adequate income is important for them to remain in the community. We know that housing is crucial for people to remain close to their family or to be close to hospital to provide a consistent environment, but there has been a complete failure on the part of policy makers to recognise the special housing needs of some of our local authorities, Kensington and Chelsea, Westminster and so on. Indeed, the latest Department of Health circular specifically excludes housing from consideration. Funding is for personal social services, not for housing.

So there is a lack of co-ordination at the highest level, yet those operating services on the ground are told constantly that they should co-ordinate their activities better. I think on this score there should be leadership from the front.

Fifthly, it is necessary to recognise the critical importance of local authorities in the provision of community care, and I realise that to say this swims against the tide of current policy. Local authorities, in partnership with the voluntary sector, are best placed to judge local need and to make local provision. Which brings me to the Griffiths Report which does assign to local authorities a central role in the management of caring services but not in the provision of caring services. There are a number of problems with the Griffiths model. It could lead to a two-tier service, one tier for the private sector, one tier for the public sector where the stigmatised users, such as people with AIDS, would be cared for.

I believe that the Griffiths model entails a lack of accountability to users, both those caring and those cared for. There are a number of difficult proposals in it, for example that there should be an auxilliary band of JTS school leavers brought into the caring field, which strikes me as an odd way on which to build a professional caring service. I believe that Griffiths could entail the continuance of a casualty-based service, not a preventive service that steps in before the caring relationship breaks down and provides sustenance to people in the informal sector.

However, the logic of a single managing authority I think is inescapable. We need a single managing authority if different services are going to be co-ordinated.

So, in conclusion, the track record on community care is not impressive. But that is not because the concept is a faulted one. We know that most people want to be cared for in a familiar environment. We know that in the field of AIDS there is an impressive range of services that have sprung up very recently from day care to home care to buddying to hospices. We know that when resources are provided, local authorities can operate in a supportive and preventive way. The two million pound grant given to inner London authorities provides plenty of examples of specific services that have been developed to meet a specific need. So that experience shows that community care is only a trap if it is underfunded and if politicians succeed in convincing us that community care exists rather than being something that we should aspire to.

Voluntary Organisations and Community Care

Ruth Sims, Mildmay Mission.

I manage a hospice for people with AIDS in the East End of London which currently has nine beds. It opened at the end of February this year, and so far we have had eighty referrals, including referrals for women, drug users, people with haemophilia, people infected following blood transfusion, heterosexual transmission and gay men. Our beds have been full for the last four months. We are opening a further twelve beds at the beginning of the year, and a day centre and a home care service. Lighthouse is offering a similar facility, but I believe that the majority of people with AIDS are still dying in acute hospital beds. For some of them, this is appropriate, it is the place where they have the confidence, it is the place where they want to be.

For some, hospice provision is the appropriate option and choice, because they may have frightening symptoms or they have no-one to look after them. But for many people with AIDS, wishing to be cared for or to die at home, I believe that community care is not an available option. Why? Because there are, as has already been mentioned, inadequate resources in terms of finance, manpower and staff training. Our experience at Mildmay leads us to believe that the mode of dying of people with AIDS may necessitate skilled nursing care twenty-four hours a day for seven to ten days or longer.

As a district nurse myself for many years, I know that if I had a patient dying of cancer for two days, I could hand my case load over to my colleagues and concentrate on that one person. But there is no way that I could have done this for a week or more. We are admitting some people to our unit because community staff and volunteers with the best will in the world are not able to supply that level of care.

Another point I would make is the lack of emotional support to the patient and significant others in the community, bearing mind that we are looking at mothers and fathers who are grieving for their sons and daughters. It is usually the other way round, and the support needs are great in that client group. And that lack of emotional support is there not only from carers but from society. We have a young boy in our unit at the moment and his parents say that he is in the Westminster Hospital and that he has leukaemia. They can not guarantee that their friends and families in the community would have any compassion at all if they told them the truth.

Many community staff are not trained to give intra-venous (IV) drugs, and this is a very important thing because they are given in palliative care to many people with AIDS. One drug in particular is given to prevent blindness and this surely is something that will mean great decrease in quality of life. This drug therefore needs to be given. I am on a management course at the King's Fund at the moment and there are twenty-one other people from different health authorities on it and nobody within my group can tell me that care for IV lines in the community is available in their area. I know it is available in some areas, but that is my experience at this time. Therefore I believe that care in the community in many instances is inadequate to meet the present need. The problem is not one that we need to plan for, it is here with us today.

I think our emphasis has to be on community care. It is the way forward and as I have said already many areas are addressing the issues. The reality of the situation is that in our unit at the moment there are three young men who could have gone home two months ago if the appropriate community care had been available. Sadly, it was not available and it is not available now.

Lighthouse and Mildmay, both voluntary sector initiatives, play an essential and significant part, but more beds are needed. We need suitably trained doctors and nurses and the provision for emotional support and bereavement follow-up in the community. This is sadly lacking but we need it so that community care can be available not just for people with AIDS but also for the many people who are disabled, have cancer or other serious illnesses who are being cared for or who are dying inappropriately in hospital beds.

Community Care in Scotland

Derek Ogg, Chairman, Scottish AIDS Monitor

I wanted to say something about some of the assumptions we make when we talk about care in the community. The first assumption we all make is that we all know and agree with each other about what those words actually mean, and I wonder if that is in fact one of the problems we have. We have differing definitions of "care" and "carer" and "community". To me a person may be employed as a carer but may not be caring in connection with the delivery of service to people with AIDS. Ask the London Ambulance Service about that.

Similarly you can have someone who has no professional qualifications at all, no social work qualifications, no letters after their name, no high powered job, no great eloquence, but who is very good at caring. And we talk about communities caring in the community. One of the great conceits and one of the great lies I have heard about in this whole AIDS debate is when people say that the gay community are so good at looking after their own people. "Hasn't the gay community done very well". And I even heard Jonathan Grimshaw, a man I admire and respect a great deal, talking about how well the gay community have done.

What Jonathan meant was how well the gay community in London had done. Let me take you up to Edinburgh. I have been a gay man all my life. Show me the gay community in Edinburgh. Show me it in Dundee, in Krief, in Krale, in Salcotes, in Aberdeen and Inverness. It is non-existent, it is not supportive. So let's not use those words as ways of dumping and putting responsibility elsewhere. Let's be careful about how we talk about that.

When we talk about community do we include the prison community in the community we are actually talking about or are we talking about the prison community as a community all of its own? These are issues that we have to agree when we talk about care in the community. And if we talk about carers. One of the first things I learned about AIDS is that a person with AIDS cares about AIDS and a person with AIDS is a carer. And we talk about all the people who have caring jobs - the government nurses and doctors and occupational therapists and home helps, and ambulance drivers and buddies and so on. We can forget that there is a person who has a hands on experience as a carer twenty-four hours a day in that team, and that person is the person with AIDS. In Scotland, with the particular problems we have with drug abuse, when we talk about care in the community, I often hear about the person with AIDS as being described as the problem. AIDS is the problem, not the person who has it. A person with AIDS is not even part of the problem. A person with AIDS is part of the solution to that problem and I think that is another agreement in principle that we all need to make when we talk about care in the community.

I think voluntary agencies by and large appreciate this almost instinctively because we did not drop onto this planet from some other planet to deal with this crisis. We actually grew up within a community very much affected by AIDS so we were hurt by it, it affected us, it scared us and it made us want to do things. I think that is why a lot of voluntary agencies appreciate these things without needing to be told. I think sometimes voluntary agencies, we in Scottish AIDS Monitor - and I talk about us as opposed to anyone else - need to remind ourselves of these things from time to time.

The statutory agencies do suffer from what I call the "well, well, well, well" syndrome which is being well intentioned, well off, well insulated and well. Now none of those things prevent a statutory agency from delivering services which can be accessed of choice by people with AIDS. None of those things prevent it, but they can collude together to cause problems in the way that that delivery system works. And I like to think of people as accessing services. We heard the expression "partnership" being used, but I would like to think of the person with AIDS as being the senior partner in that case in such a partnership. I do think statutory agencies have a tremendous job in bolstering voluntary agencies and in bolstering the community. That is the group of people around the person with AIDS, the particular person with AIDS, in the informal caring structures.

When we talk about needs we can design a system which does not work and there is a system in one particular part of this country which is called the supported accommodation team. The idea is that you provide accommodation for someone and it is supported: there is a social worker there that goes in and provides support and counselling. Now I think that if someone's need is accommodation it is unethical to give them supported accommodation. Because what you are saying is that "provision of a roof over your head and a nice, clean, dry, warm house which you don't have at the moment is contingent upon you buying in this other service I want to offer you, you've got to take it." That is unethical in my view, and I think what we should be saying is "if it is accommodation you want but you don't want this counselling arrangement that I've got set up here, here's your accommodation, the best way I can support you is by staying out of your way and making sure that you can choose other ways of doing it."

The old perspective of defining needs and saying that is what we are delivering - rather than looking at wants and negotiating with people about what we are delivering - has led to problems in the past. We still have a massive engine of destruction in drug abuse in Edinburgh because we do not have a strategy to deal with drug abuse in Edinburgh. What we do have is any number of people running around who are wanting to deliver services to drug users who have AIDS and HIV. Now that is a fireman fighting a fire at a petrol station before thinking about switching off the petrol pumps. That is part of the strategy. It is not drug users who have AIDS. There are problems of drug abuse affecting people and problems of drug abuse and AIDS affecting people, and I think those are perspectives that very much affect the practical systems that we end up delivering.

If I have a burst pipe in my house, you may say I need a plumber to fix it. I may want to fix it myself. But if I do get a plumber in, I tell the plumber what I want done and the plumber does not then go round my house and tell me all the other things in my house that need fixing or that he can do a job for.

If there is a problem, however, in the sewage out in the street, a major structural problem with the way in which my city is plumbed so that we are having these leaks all over the houses, yes, then statutory agencies, central government authorities have a major role to intervene there. But we are not talking about delivering care in my community to me and you delivering care. Let me choose it, let me negotiate with you about the extent of it and let's agree what we are talking about when we are talking about care and when you are talking about my community.

IV. THE ROLE OF THE VOLUNTARY SECTOR

The Role of AIDS-Specific Voluntary Organisations

Nick Partridge, Terrence Higgins Trust.

I wanted to start with a little bit of history. Although we have only been involved with AIDS since 1982, it seems a lot longer than that. In the beginning, there was the London Lesbian and Gay Switchboard. They organised the first conference on AIDS in 1983 and from that, and from their experience in organising a voluntary response, the Terrence Higgins Trust gained a number of volunteers, most particularly Tony Whitehead. That created the germs of what has grown to an organisation which currently employs 25 people and has about 600 volunteers.

In 1985 when I first joined the Trust we had two offices, in a rabbit warren of a building at Mount Pleasant. It felt very lonely at that point. We have always tried to liaise with and involve as many other voluntary and statutory agencies as we can and Mike Adler from the Middlesex hospital was one of our first directors.

What I want to give you is just a broad brush history of what has developed since then. It is a remarkable range of services extending from the Trust services, to a network of 85 helplines up and down the country, through to the remarkable monument of London Lighthouse and the Mildmay Mission - truly outstanding examples of what the voluntary sector can achieve.

I think the easiest way to show the scale of what we have got now is to look at the National AIDS Manual. At the reference section at the back of this are the areas and places that people can now get help and assistance from. This manual in itself is the product of the voluntary sector as well, and I urge you to use it.

I want to talk for a little time about the limits of voluntary sector organisations. I think it is very noticable that today there are no black and ethnic minority representatives here. And that is primarily because there are very few black and ethnic minority organisations capable of taking up the necessary role. The organisations that do exist - like BCAT, the Black Communities AIDS Team - are overstretched with demands to come and attend and share their experience. That is the first thing I want to point out, that we can not expect the voluntary sector to pick up the pieces. We cannot expect it to continue to give the level of service provision that it has managed to do by hook or by crook so far.

In the early days of the Trust, one of the criticisms was that we were trying to do too much. That was forced upon us because of the lack of response from the statutory services. Much of that has changed now and it means that we in the Trust have to look very carefully at what our proper role should be - what our role in housing should be, what our role in buddying should be. A very interesting point that was made earlier on was about the changing face of AIDS and HIV with the introduction of new prophylactic drugs. For example, aerosol pentamidine makes a superb difference to the quality of people's lives. If we can access that to people quickly enough they will live much longer. What does that mean in terms of the number of people we have to care for on a day-to-day basis, and knowing that that is going to be caring not for eighteen months, not for six months, but for two years, three years and five years? What is that going to mean in terms of the number of buddies that we have to involve and to train and then to look after over a very long period of time?

We started off at the Trust and opened up immediate links with other voluntary organisations, most particularly the Haemophilia Society, also the Alzheimers Disease Society when the role of HIV-dementia became clear, and now we are seeing the involvement of the Save the Children Fund and the Red Cross and a number of non-AIDS specific charities.

There seems to me to be a dual role. There will always be a role for the AIDS-specific charities, but we need to involve the expertise and the numbers of people that already give their time to non-AIDS specific charities as widely as we can. How that is going to be done is something which the National AIDS Trust has a very clear role in developing over the next five to ten years.

I want to think again about the limits that the voluntary sector can have and I am thinking particular of the AIDS-specific organisations. Last night while I was preparing what I wanted to say today it struck me that at the moment one director of the Terrence Higgins Trust is very ill. The director of Sussex AIDS Helpline, who is also Chair of NOVOAH and a member of the National AIDS Trust English Advisory Board, has just left hospital. Of the six original founders of Body Positive, only two are still alive. A couple of months ago one of the directors of Frontliners died only a few weeks after being elected as a director. One of the Trust's longest serving volunteers died last Friday; his funeral is tomorrow. Now while that gives us a very immediate and close connection with the changes in AIDS and HIV - the very reason why we created the organisation in the first place - it also puts tremendous strain on what are generally very small organisations.

Particularly outside London and the other major metropolitan areas, the demands on people to provide a regular service are sometimes not going to be able to be met and we should always remember that voluntary organisations are often very fragile. It says a great deal that the Trust has managed to survive this long. At times it didn't look like it was going to. It has been a very close run thing. It says a great deal that London Lighthouse can raise the money and change a derelict building into a superb monument for people with AIDS; a living and working monument.

My year started as - with Christopher Spence and others - we gathered a thousand people onto the streets of London at the beginning of the World Health Ministers' Conference. It was a remarkably dignified response to AIDS and HIV and one which any of you who were there will never forget. The sight of ten thousand people carrying candles walking down Piccadilly was quite remarkable.

In the middle of the year over a million people came to Covent Garden for Shop Assistance to raise funds for Frontliners and for Terrence Higgins Trust. At the end of the year we see the publication of the National AIDS Manual which brings together the work of so many organisations.

It is difficult for me to get any kind of balance between the real sense of loss of people through this year and yet also the real sense of achievement of what has been created: seeing Lighthouse open, seeing the Mildmay Mission open. So the message really I just want to leave you with is that there is a huge diversity of voluntary contribution to this epidemic. It needs to be nurtured, we need to be able to work out the difficulties we are going to have with community care. We need to have patience in our negotiations with statutory bodies and patience with the Health Education Authority.

And yet for us who know that there isn't that much time, patience is a very precious quality and so we are going to be very angry at times. I am not very good at displaying anger, I never have been, and I am not very good at arguing with people, but I can only say that that what Jonathan Grimshaw said this morning about the iniquity of taking away people's hope has to be re-emphasised and that the voluntary organisations and involvement in voluntary organisations has been one way that I have been able to channel my anger into something which is constructive and that is the other vital role the voluntary organisations will continue to play.

Voluntary Organisations in Scotland

Joy Roulston, Abelour Child Care Trust.

After the comments that were made earlier this morning about Scotland I did note down that I should say to you that I felt that I was coming to speak, albeit as an Englishwoman, from the land of the dark ages. I do know that there are maps in which Scotland is identified as "Here-Be-Dragons". Nevertheless there are some very important initiatives which have taken place in the voluntary sector in Scotland, and I believe those should be built on.

I would like to draw your attention to begin with to certain aspects of the National AIDS Trust trust deed, which was set out when the National AIDS Trust was started. It states that the Trust should "promote voluntary effort directed to the prevention of HIV infection, to seek to co-ordinate the voluntary effort, to identify needs and to encourage the development of new voluntary organisations and to reflect the views of the voluntary agencies in the field of statutory bodies and to government". I would like to think that this first conference on World AIDS Day 1988 is the first of many consultations and conferences which will make that Trust deed come alive.

It seems to me that the role of the state both at national and at local level has a major influence on the setting of objectives for voluntary organisations in whatever field. We have seen over recent years some voluntary organisations finding themselves in a complementary, even an ancillary, role in some areas of work. They have found themselves on the edges of the welfare state acting as a safety net. However, in certain areas, notably that of drug and alcohol misuse and HIV infection and AIDS, voluntary organisations have proved themselves to be in advance of statutory organisations in exhibiting a pioneering role. Therefore it follows that good relations and communications between the voluntary and statutory sector is vital, and that is an area I would wish to return to in a few moments.

Statutory services seem to respond rather more naturally to immediate crisis. Voluntary organisations have the capacity to provide within their activities preventive as well as crisis-focused work. Rather like a certain lager, voluntary organisations can reach the parts of our society which the statutory sector cannot reach. The provision of highly specialised skills and services will not often be possible for the statutory sector which has a wide range of responsibilities to provide for.

And this difference between the statutory and voluntary sector may be reflected in the standards of service which are provided by voluntary organisations in terms of their unique and innovative qualities or in the depth of their expertise.

Instead of plugging the gaps, we should be in there from the beginning making sure that we are part of strategic planning and policy. Voluntary organisations involved in the delivery of services to those infected by or affected by HIV have shown an enormous amount of commitment, expertise, compassion, and I would like to think from the point of view of some in Scotland, entrepreneurial skills. We have also pushed back the frontiers of imaginative working practices and have pointed the way for service provision in a way which the statutory sector seems unable to do.

For example, our own project - which is to open in early 1989 in an ordinary local authority housing estate in Edinburgh - is for women who have substance dependency problems and their children. The majority of them are illegal drug abusers and are at risk of being, or know themselves to be, HIV antibody positive. Their children are at risk too, or are themselves HIV positive.

It was virtually impossible at the beginning of the development of the project to get anyone outside the voluntary services to listen to the needs of women and children. They were seen to be a sector of the drug-using community which was very small and therefore really did not need services provided for them. Anyway, as one member of the Lothian Health Board, who is also an elder of the Kirk of Scotland, said to me in an official discussion: "well, should these women not be sterilised anyway, it would save us an awful lot of bother?".

You will not be surprised to know that I went out of some meetings extremely angry and Nick is right when he says that anger needs to be channelled constructively in order for it to be used positively. I think the anger that I felt about lack of funding and the anger that I felt about people's attitudes, particularly towards substance dependent women, has brought us to the state at which not only the National AIDS Trust but also organisations like Crusaid felt it within their power to be able to give us the money to get on with the job. That is what I mean about entrepreneurial skill: you do have to go out and sell yourself.

I am not the only one though. Derek Ogg from Scottish AIDS Monitor is also well versed in this field and he forebore to tell you this afternoon that it is his, and quite rightly his and Scottish AIDS Monitor's, pioneering work in prisons in Scotland that is going to make a difference in the future.

Voluntary agencies are able to be more flexible, and to effect change more quickly than statutory agencies. Strategies do not have to go through endless committees before decisions can be taken. And of course in the voluntary sector we are far more able to take risks, but risk-taking calls for enormous backup and support, particularly on the part of managers. Much of the work of the voluntary sector is done in the face of severe financial hardship. We can no longer accept pump-priming monies which will determine from year to year what particular policies should be put into practice. Through all of that we have managed to keep in post staff who are overworked, overstretched, yet totally committed, and who obviously deserve better.

Speaking as a member of the voluntary sector, I do not wish to be patronised, but to be seen as a partner in a race against time where every second counts. As we heard earlier today, it would seem that some people do not take that race as seriously as others do.

Now perhaps it is true that some small voluntary groups run mainly by volunteers do not understand the bureaucratic language of the committee structure, but that is no reason why their voices and their own personal experiences should not be heard. I did welcome Sir Donald Acheson's remarks about the relationship between the National Health Service and voluntary bodies, and I trust that we shall see an immediate response to that suggestion.

Co-operation is an over used word these days. Rather like the word love, I think it is in danger of being debased. True co-operation is based upon mutual respect and understanding of another's point of view. The statutory and the voluntary sectors need each other. We do need to work hand in hand, though the mechanisms for doing that will take time and endless patience on both sides.

No-one owns the problem of HIV and AIDS except the people directly infected. Helping agencies, either statutory or voluntary, should act as the enablers to respect and support those individuals. Now in Scotland we do actually have a laudable history of services began and rooted in the field of drug misuse in local community. Many initiatives were begun by men and women who were directly affected by drug-use in their own families. They provided the impetus for help within their own localities. They developed fresh ways of tackling problems, actually in the face of very few statutory services at all, and they plugged gaps and they took risks. With the advent of HIV infection, these services have had to change focus with, as I have said before, very little extra support, either in cash terms or in the extension of statutory provision to back up the work. I concur wholeheartedly with what Dr John Strang said this morning with regard to the fact that just by putting money into something does not mean that it is going to make it any better. We need a long term strategy. At the moment we feel rather as if we are sticking the sticking plaster over an ever-opening wound.

The voluntary organisations deserve the backup of statutory services, not to be taken over but to be complemented by such services. Might I suggest that statutory services have much to learn from the voluntary sector, particularly in the area of community development. For example, through employing people who live in the area in which they work and who have true street credibility. It is important to remember that members of the injecting drug-using community in particular are not used to using the welfare services; neither have they found themselves very popular with the health service. However, past problems cannot be allowed to stand in the way of providing those user-friendly services.

I have been disturbed to hear negative statements - such as the one: "I'm not showing the little bleeders how to do it properly", from a health care professional when we were discussing safer drug use. It did not seem appropriate for him to be engaged in harm-reduction or damage control - but someone has to find it appropriate, don't you think? Good working practices must be developed between agencies if communities are to respond adequately to the HIV/AIDS challenge and we look at the National AIDS Trust to enable us all to meet on common ground.

The Role of Non-AIDS Specific Voluntary Organisations

Christine Reeves,The Red Cross.

I was delighted to have the invitation to speak on two accounts, firstly because I would hope that a little bit of what the Red Cross is trying to do is worth speaking about and, secondly, of course I am delighted to be able to have the opportunity for a small platform for an organisation like the Red Cross.

However, I have been struck by a number of comments during the course of the day and the comments have themselves in a sense been pertinent to some of the points that I wanted to make. Some of the comments are about things like: "we don't have much of a problem in this area" or things like "ownership of AIDS and HIV is for those who are infected."

I would just like to challenge those statements because I think that ownership of HIV and AIDS is everyone's role and that we do not have to be infected in order to take a responsibility. The longer that I have been looking at the sort of role that an organisation like the Red Cross might perform, the more I have become aware of just how important AIDS is for those organisations that are non-AIDS specific and for those organisations who are not predominantly involved with gay individuals or with drug users or haemophiliacs even. They have a very special and important message to give.

Recently, when I was chairing our European Task Force on AIDS for the Red Cross I was very conscious of a statement that we put together which was saying: "AIDS is a Red Cross issue."

We are actually saying that AIDS is an issue for everyone. One of the very pertinent aspects of that has been the fact that by our very example of living in the community with people with HIV and AIDS, in working in the community with people with HIV and AIDS, in giving assistance to people with HIV and AIDS, by that very example we can do an enormous amount to actually support, to actually help understanding, to actually say, "it is OK".

An organisation like the Red Cross has an enormous network of volunteers. It has a branch, which normally means it has a building, in more or less every county in the country including Scotland and including Northern Ireland and Wales. It has an international movement too. I believe that that network should be a valuable resource in combating ignorance or in actually developing education on AIDS.

The issues or the areas of support may be very simple. They may be to do with simply offering the use of premises. But it does not begin and end there, because it is actually that offer of support, it is actually that offer of involvement, it is actually saying not just "there is a building here", or "there are volunteers here", but it is actually saying: "we are prepared to get involved, we are not wishing to discriminate or stigmatise", and that seems to me to be the important part of the involvement of volunteers, of voluntary organisations who are non-specific to HIV and AIDS.

There are many kinds of voluntary organisations - they fall into two particular categories. There are those dealing with money, and I think they have got a very important role to play and develop a range of expertise to undertake AIDS work. There are those who have what I call non-human resources which might be the development of helplines, advisory services and so on, and there are those organisations who, like the Red Cross, deal with volunteers. Perhaps that is their very specific and very special contribution, that they deal with people from every walk of life. Surprisingly enough, the Red Cross actually does deal with people from every walk of life, although perhaps its popular image is more of the lords and ladies of the land. However, coupled with these come individuals from all levels of society, all walks of life, interested in their fellow human beings because they wish to give their time in voluntary activity with other people. Many of them given an enormous amount of time.

In a sense they are working for the community and therefore in this case I would have said they are actually living with AIDS. In some way the Red Cross' first and primary role is to see its mission as informing and educating its own members. If we actually multiply that worldwide, we are talking about quite a large number of people, going into millions.

I see this as part of a trickle process. When you start to talk with people that are closest to you, the people who you are working with in a voluntary capacity in an organisation like the Red Cross, you actually begin to create an empathy and understanding, a concern, a compassion. Then you ask them to go out and talk to others and so it begins to jell from there. I found that it brought a benefit to me too recently, because I was advertising for several new members of staff and chose to mention the fact that we were looking to working in the field of AIDS in the advert. I was absolutely delighted that a number of people who made enquiries about the job did so because we mentioned the word AIDS. I thought then "the Red Cross must be moving into the 20th century".

The other intersting aspect of this is the issue of advocacy and independence - but particularly the issue of advocacy. I was wanting to touch on that by talking about the role that ordinary individuals can play by being prepared to talk about the issue, by being prepared to work with and amongst people with AIDS. We had a very interesting situation arise not very long ago which I was reminded of when one of the speakers this morning spoke about immigration controls. I think it is fair to say that AIDS specific organisations need to look at organisations like the Red Cross to see what kind of value they have, and vice-versa. It came as a bit of a surprise when we found that the Red Cross had a name and a reputation which we really ought to use and capitalise on more than perhaps we are doing, particularly in the field of AIDS.

We became more aware of this when there was a young man who was being held at the airport coming in from America and Marcus Stephan, who is our development officer working in the field of AIDS, had been informed that this young man was due to come into the country and had been asked for some assistance about forms and so on. On the day he arrived, he received a phone call from the lady that was meeting him and that was sponsoring the young man, to say he was being held at the airport and could Marcus in any way assist?

So he contacted the immigration authorities and spoke to someone at the end of the phone saying he understood that such and such a person was there, was this true and was it true that he was being held because he was known to have AIDS? The official said, "Where did you say you were from?" Marcus said, "The Red Cross." The official said, "Just a moment, I'll go and get someone." So the phone went dead and a moment or two later the voice at the other end said, "Who did you say you were?" and he said, "Marcus Stephan from the Red Cross." "Did you say the Red Cross?", "Yes, I said the Red Cross." And the reply came, "Oh, there's been a mistake. In fact, he is not really been held at all and he is about to be released immediately."

And perhaps there is a more important message in that than we might dare to think. It gives me quite an onerous sense of responsibility to think that that was in fact the way in which the name of an organisation like the Red Cross might be viewed, but I think we can not escape that fact and it seems to me that what we ought to do is capitalise on it and work together with other organisations in order to build some of the bridges using that kind of reputation.

We have talked a great deal about co-operation and I would like to say what I think about to use the word complementing. I think that voluntary organisations working together is about complementing each other's skills and each other's expertise as much as about a sense about co-operation.

About a year ago when we first started to think about whether the Red Cross had a particular role to play with regard to the AIDS issue, we invited together a group of people who were already very much involved in the field of AIDS, with the intention of saying, "Look, we are not the specialists, you are, you tell us what it is and where the gaps are, where the areas of activity are that would appear to need to be filled. We'll tell you a little bit about where our skills, where our resources lie and we'll see if there are then ways in which we can perhaps offer some kind of help and support." And I think that is a very important way forward.

I think that it is important to recognise in a sense what I see as the privileged information and knowledge held by people who are HIV infected or have AIDS or their respective organisations and that we must use it to devise and develop services which support those in need. I think that is extremely important.

The memory sticks very much in my mind of Richard Rector, who was the subject of the programme, "The Visit", some little while ago, who has since done a great deal of work for the Red Cross internationally. He was telling us that when he first told his mother that he had AIDS he said to his mother, "What are you expecting, Mother, somebody to come in a wheelchair, or very deformed and whatever?" And I am quite sure that there are an enormous number of people in the community that still have that image of people with AIDS and HIV and therefore again it is important that organisations such as ours work together with those organsations like Frontliners and Body Positive and so on, to try and create a much more positive message.

And I am sure it is relevant to say that AIDS will act as a spearhead to many other activities and objectives and, in a sense, methodologies for organisations. This is all too often true of situations where there is a crisis. Where there is a kind of disaster, it mobilises our thinking and our forces to achieve better outcomes.

I cannot leave this platform without just mentioning one area where we have put an enormous amount of money and investment of time. That is the development of an HIV/AIDS education programme for young people.

The Red Cross has a youth organisation of its own but our HIV/AIDS education programme is not only aimed at those young people; hopefully other voluntary youth organisations and schools will take this programme up. It is of a rather different kind, as far as we know, to anything else that is presently being developed. It involves a participative approach, and looking at the issue from the point of view of decision making, of peer group pressure, of responsibility and the stresses that are around for young people taking responsibility in today's environment. If we can help them to actually begin to address those issues for themselves, then in a sense we have gone a long way to helping them to address the kind of issues that are around AIDS, that are around sexuality, sexual behaviour and so on. So, hopefully, young people that participate in that programme will get a bigger spin-off than just having understood more about AIDS and HIV.

And, in conclusion, I can only say that I am reminded of a saying which for me has been a guiding principle for the work that we are trying to do and I hope will do in the future, which is, "give what you may to someone, it may be worth more than you dare to think."

V. AN AGENDA FOR THE 1990s

An Agenda for the 1990s

Margaret Jay and Carl Miller, National AIDS Trust.

December 1st was a day when the World Health Organisation focussed global attention on AIDS. For the National AIDS Trust, it was a time to look to the future, with the minds of the politicians, planners and decision makers at the conference concentrated on the major challenges of the next decade. "AIDS: Can We Care Enough?" was a question of commitment: from David Mellor's opening address, through contributions from academics, doctors and front-line workers throughout the day, the determination to act was apparent. For participants, the challenge was to develop that commitment in their own areas, learning quickly in a complex and fast-moving field.

Indeed, for the National AIDS Trust itself this conference has been a learning experience; a chance for a young organisation to hear from those whose knowledge and experience place them at the forefront of work to deal with this epidemic. There are many lessons to be learned, nowhere more so than in the political arena. That the conference addressed some key questions became apparent the following month in January 1989, in a House of Commons debate on AIDS, when many points raised in the first session, "Resources for the 1990s", were taken up by speakers. The co-ordinated national strategy for which Professor Adler called in his conference paper found general and enthusiastic support, with Charles Irving, one of those Members of Parliament who attended the conference, calling for the appointment of a Minister for AIDS.

Such a proposal is one to which the National AIDS Trust gives its support, but the challenge of a national strategy is, as the opening speakers made clear, a wide one. We require the best information in order to plan effectively, and immediately before the conference two announcements were made which begin to address that fundamental gap in our resources: the publication of the Cox report, with its predictions of the size of the epidemic into the next decade; and the government's agreement in principle to a programme of anonymised testing as described in Professor Adler's paper.

That data must not, however, be pursued for its own sake or simply for the purpose of statistical battles. Where there is inequality in the distribution of resources, we must act to remedy this. In the House of Commons debate Harriet Harman MP, Labour Party front bench spokesperson on health, quoted Professor Maynard's paper for just this reason, drawing attention to the disparity in resources provided, particularly in Scotland, asking "why should Lothian receive just one quarter of the amount received by one London region?"

Professor Maynard also drew attention to the absence of coherent data on the costs and resource implications of care in the community, an area of obvious and increasing interest to those of us in the AIDS field. That the NHS White Paper "Working for Patients" makes no mention of community care reinforces the impression that the government still perceives it as a peripheral issue, rather than a fundamental resourcing challenge. Such questions take us outside the strictly medical arena, for HIV infection demands complex and multi-disciplinary responses in social policy as much as in medicine. Often, this will require individuals, organisations, even entire sections of society developing new and effective ways in which to co-operate. These are not necessarily the most obvious, or most immediate answers: the National AIDS Trust is committed to promoting the imaginative and lateral thought which will produce new forms of joint working. The respect accorded to voluntary action on AIDS from statutory bodies has been hard won. The National AIDS Trust continues to be committed to the development of that trust and exchange at every level. We cannot afford to be frightened of co-ordination. It does not mean the loss of independence, nor of individuality, except in cases where idiosyncracies create nothing but a destructive muddle.

In bringing together the concerns of the voluntary sector around HIV, the National AIDS Trust sees a key role for those who may have experience in other fields, developing, for example, flexible care packages which can be usefully applied to AIDS. It is mistaken and wasteful to assume that the challenges posed by HIV are all new, when experience tells us otherwise. What is new, however, is the contribution that has been made to such planning by those best placed to judge: the consumers. People with HIV and AIDS have from the first stood alongside their carers, offering unique and valuable insights; voices which we may learn to hear from other groups, particularly people with disabilities. Indeed, if AIDS proves to have brought us any benefits, it will be in the lessons it teaches us which we can use elsewhere. In community care and health promotion - both vital but until now neglected areas of health policy - our discoveries through working on HIV may be the springboard to yet greater achievements.

As became clear in the conference, different sectors of activity require varied responses. The problems raised in providing adequate and supportive housing for people affected by AIDS, described by Peter Larkin, are very different from, for example, the issues addressed by Spencer Hagard in his paper on health promotion. The National AIDS Trust seeks, not to operate large programmes itself, but to work with flexibility in whatever way seems to advance the area of concern most effectively.

In September 1988, Trustees identified a number of areas as priorities for the the National AIDS Trust's work: advocacy and legal issues, children, drug use, housing, prisons, and prostitution. Although not excluding other work, this has provided a framework for our current development. Advocacy, drug use and housing, together with health promotion - to which the National AIDS Trust also attaches great importance - were addressed in the conference session on Service Provision. Our activity on these and the other areas of priority has been part of our developing pro-active role.

The National AIDS Trust participates in the development process in three main ways, through its grants programme, research, and co-ordination. Through grant aid, we have been able to encourage, for example, the establishment of the organisation Mainliners, a unique, grass roots service tackling the issues of AIDS and drug use at the sharp end. In helping to fund Brenda House, a residential centre for mothers and children in Edinburgh, we have helped to provide a desperately needed resource in an area where HIV infection among children is the highest in the country. Start-up and pump-priming grants have been a spur to many locally based groups providing a remarkable range of counselling, care and support services.

Our work does not stop there, however. Following the themes from the conference's morning session, we are addressing the urgent need for research into the most effective ways of providing help. This may come through other organisations with whom the National AIDS Trust has developed a constructive relationship: research into advocacy with the National Association of Citizen's Advice Bureaux, or into issues affecting AIDS and children with the National Childrens Bureau. Working in this way rather than working in isolation allows those with experience in their own field to apply that expertise to AIDS. Where appropriate, we also commission research which will inform our future work, as well as provide a valuable resource for all those working in the field. Our report on housing and AIDS, commissioned from housing consultants Raynsford Morris, is now completed and available.

Our co-ordination role recognises that when prompt strategic responses are vital funding individual projects are not the most effective way to work. The Trust's work on AIDS and prisons has been an example of such a response, bringing together a wide range of concerned bodies from the voluntary and statutory sector to address commonly held concerns about the need for action in this area. Such a forum for discussion and planning has created ambitious targets, particularly with the aim of stimulating constructive co-operation at a regional level between the prison service and the voluntary sector, to enable better care for those prisoners with HIV or AIDS, and prevent further spread of the virus. In bringing together people from government, the "AIDS voluntary sector"and those whose main concern is with prisons, the National AIDS Trust seeks to make concrete a commitment to national planning alongside local implementation.

The final session of the conference looked at the role of the voluntary sector, a role which the National AIDS Trust clearly regards as crucial, as has been demonstrated by the energy, commitment and style of organisations like the Terrence Higgins Trust, Body Positive and Frontliners with whom the National AIDS Trust has been fortunate to work alongside, and to co-operate. It is, however, inappropriate to expect these organisations to work alone: the wider voluntary sector also has responsibilities and immense potential in this area. It may be able to bring the message on AIDS home to people, where AIDS specific groups have been unable to get through. Many agencies already work with clients who may become affected by HIV: people who inject drugs, children and offenders. A more diffuse, but no less vital role, can be played by those organisations whose range of responsibilities and membership ideally places them to communicate the message at a local level. In Christine Reeves' contribution to the conference, she spoke of the impressive range of activities undertaken by the Red Cross in this field, including many ideas applicable to other groups.

The National AIDS Trust places a high priority on preventive activity. In those areas where there are currently small numbers of people with AIDS and HIV, educational work is of the utmost importance, arguably more so than modelling preparations for care on areas where the epidemic has advanced to a stage such interventions can prevent. There has, however, been a clear gap in the resourcing of local, community-based preventive work. The government has, in its 1989/90 allocation to Regional Health Authorities, included funds for such work, but we remain sceptical that many health authorities will have the flexibility to work with voluntary groups in a way which will actually reach the community. Mass media campaigns are clearly not enough, yet it is in such work that resources have been concentrated up to now.

The National AIDS Trust is seeking to fill that gap, and has provided grants to some innovative and exciting groups, notably a number of theatre and education projects, in an attempt to take the message to people in a relevant and engaging manner. We are working closely with Parkside health authority on an exciting initiative to bring the skills of the advertising and marketing industries to bear on local health education, but continue to be frustrated by the failure of government organisations to address the question of responsibility and finance for such work. Divided priorities such as those between the Department of Education and Science and the Health

Education Authority on messages to young people inside and outside school, and the separation of responsibility for drug education - based at the Department of Healths - and AIDS education - which rests with the HEA - create a bureaucratic muddle, in which a vital area of activity languishes unaddressed. The money which needs to be spent at a local level is slipping through a net of avoided responsibility. The National AIDS Trust is examining the possibilities of larger, locally based, community initiatives: a national "Spread Prevention" campaign. Undeniably, such work will be expensive, but nevertheless it will still be a fraction of the cost of television advertisements.

As we have pointed out, such community-based prevention is one of the priorities spelled out in the government's resource allocations to health authorities for AIDS for next year. Other priorities include the development of drug services to deal with prevention and care. Again, the National AIDS Trust has from the first offered direct, practical support to the very projects - community based drug agencies - prioritised by government in this area, and can already boast an impressive list of initiatives funded by our efforts. Central government money has also been offered to local authority social service departments to tackle the issue, raising questions for authorities on planning their services.

There is, however, a danger that such funding methods may not have the desired results. Small sums of money will be used for the appointment of "co-ordinators", who work in a vacuum, their only local contribution being their own, isolated existence. Even more disturbing is the possibility that, as a result of serious financial problems faced by health authorities from underfunding of their general services, extra money provided for AIDS will be siphoned into general expenditure. Central government is clearly unable to assess health and local authority activity on AIDS to the extent that this is needed, to make it most effective. The National AIDS Trust believes the role of the voluntary sector in monitoring is vital. From a knowledge of local needs the voluntary sector can ensure that resources relevant to AIDS and HIV are applied in the most effective manner.

The advice from government also encourages joint planning, but in practice this has often been difficult to achieve. Voluntary agencies must insist on, and be allowed, involvement at the planning stage for local services, question and evaluate the effectiveness of health and local authority programmes, and aim to develop fruitful working partnerships with the statutory sector on education and care programmes. This has already been highly successful in certain areas: the National AIDS Trust is keen that such voluntary/statutory sector co-operation should extend the length and breadth of the country, bringing together those with commitment and vision to stimulate new work in all areas. We recognise that in parts of the country the voluntary organisations has always been small and underfunded, and have through our grants programme attempted to break the vicious circle of under-funding and dependence which has often made it difficult for the voluntary sector to enter effectively into partnership with statutory agencies. The National AIDS Trust can act formally and informally as a "broker", between the statutory sector - which has most of the money currently provided to deal with AIDS - and the voluntary sector, which is often best placed to use that money. Such a role is welcome, in our experience, from agencies on both sides of the voluntary/statutory partnership.

Above all, this conference has demonstrated the need for action now, in order to avoid crisis in the 1990s. Already, as Professors Adler and Maynard make clear, there is sufficient HIV infection in this country to strain public resources: this can in the short term only get worse. We must break down the "phoney war" created by complacency which sees anything other than total disaster as an excuse to avoid the issues. With many more people infected than those officially recorded, and increasing numbers who will require care of some kind as a result, we face immense challenges under any circumstances.

We can learn from the experiences of the United States as we reject politically and morally the failure in public policy which allows people with AIDS to die in the streets of New York. We have in the National Health Service and local government public resources which, if adequately resourced and effectively planned, offer the chance for success. Taking a lead from the imagination and determination of the voluntary sector, government must produce a national strategy on AIDS, to see us through into the next decade. In this, as in the other areas raised by this conference, the National AIDS Trust intends to take a strong and active lead: we hope others will join us.

£2.50

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