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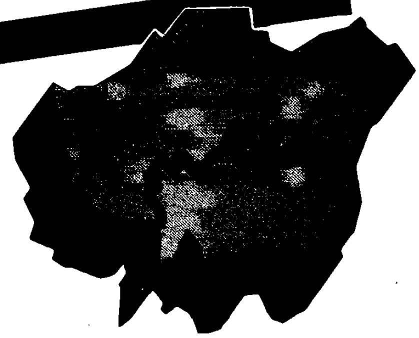

Report of a conference for local authorities, health authorities and voluntary organisations in London

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Editor: Penelope Clarkson

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Foreword

The King's Fund welcomed the opportunity to take part with the London Strategic Policy Unit and other agencies in the organisation of the conference 'AIDS: planning local services'. The Fund has a longstanding commitment to the improvement of London's health services. Better planning, a good standard of staff training and development, and support for carers apply in all its work: AIDS presents a major and urgent challenge to them all, but perhaps especially to the ways in which health services, local authorities and voluntary bodies can work together. The conference provided an opportunity for workers from all these agencies to come together, exchange ideas and compare experiences in an atmosphere of open discussion. In producing this publication, we have tried hard to give an accurate representation of the views expressed. They are not necessarily the King's Fund's own.

Martin Bould, Development Officer
Penelope Clarkson, Editor

1 AIDS: the local authority response

Opening address by Councillor John Austin-Walker, Leader, London Borough of Greenwich

There is no doubt that London is at the sharp end of the AIDS crisis with over 70 per cent of all British cases so far being located in the capital. It is also fair to say that local authorities in this country are way behind in preparing for all this figure implies. If the GLC had not been abolished, we would of course have had a strategic response far sooner. The London Strategic Policy Unit was created by a number of London boroughs to help fill the gap and I hope that it can provide an impetus for the strategic approach that is necessary.

Some councils have begun to provide services and to develop policies to deal with AIDS. In London detailed work has been done by a number of the London Strategic Policy Unit authorities, notably Lambeth, Hammersmith & Fulham, and Camden. The London Strategic Policy Unit itself has put forward a policy statement on employment for consideration and adoption by member boroughs. Before I come to discuss the problems which local authorities will face and how we can tackle them, which I shall do under six main headings below, I must put down two political markers which I believe are crucial. They relate to things that are often in the news these days. Firstly, local government finance, and secondly the equal opportunities policies of the local authorities which make up the London Strategic Policy Unit and others. The point I want to make on finance is very brief. Whatever ideas are developed on dealing with AIDS, unless central government gives us the cash to carry them through, they are to no avail. Up to this point, central government has not given one penny to local authorities for this task, and I want to make this absolutely clear, so that no one can ever say that they were in ignorance and that they did not know. In my view local authorities in London and in the rest of the country are presently not equipped to deal with this kind of community health crisis. If the government is serious about tackling AIDS, it must face this fact now. To slightly change the appeal of Bob Geldof – 'give us the money now'.

On my second point, the press have tried to make equal opportunities and anti-discrimination policies a stick with which to beat certain Labour local authorities. There has also been pressure from some quarters for us to keep our heads down on these matters. I believe that we must as local authorities resist any pressures when it comes to discussing AIDS. Racism, sexism, and discrimination against gay men and lesbians cannot be ignored by us as local authorities. We have to take these issues on board and re-emphasize our equal opportunities policies. There are of course plenty of good practical reasons why we must not allow these matters to be driven off the agenda. The anti-gay and anti-lesbian hysteria being whipped up by the press is aimed at driving people back underground. We are told that lesbians are a low risk group despite what the tabloids say, and yet we see headlines about police officers having blood tests after being spat at by lesbians who have been arrested. If gay men are to be terrorised by hysterical press, how can we in this country develop the idea of a gay community protecting itself, as gay men in the United States have been able to do? There is now a lower incidence of sexually transmitted disease amongst gay men than amongst heterosexual men in San Francisco, and a dramatic decrease in the number of new HIV positive people identified amongst the gay community there. That was achieved by open, honest discussion and not by moral outrage.

Moreover the spread of AIDS cannot be controlled amongst heterosexual people by putting the onus on women to be monogamous as some of the press would like to suggest. It is men who are the main distributors of the virus both to women and to other men. Circumscribing women's sexual activity is not the answer. Men – whether they be homosexual, heterosexual or bisexual – must be educated to take responsibility for their own sexuality. I noticed a comment recently by Edwina Currie that if men going abroad wished to protect themselves they should take their wives on their business trips. I wonder how those wives react to being seen as the universal all-purpose condom to accompany their husbands. It has been suggested that the experience in Africa is that programmes aimed at men have failed. I was struck by an article recently in the *New Socialist* (April 1987) by Lynne Segal, the author of *Is the Future Feminine,* who has argued that women are in a key position to aid the education of men. She argues that women's involvement in family planning, their concern for their children, and their responsible attitude towards health care and sexuality, make them the obvious agents for changing sexual practices. Despite the low rate of infection so far in this country for women, I think it is clear that women are just as worried about AIDS as men. As Lynne Segal suggests, 'This is hardly surprising when you consider that women, almost everywhere, have rarely been able to enjoy sex unaware of the accompanying dangers of pregnancy, venereal diseases, the health risks of the pill or, increasingly for younger women, of cervical cancer'. There have been reports that AIDS from heterosexual sex is one of the largest single causes of death amongst young women in New York today.

If we are to educate men and change sexual practice, is the propaganda which the government and other agencies have embarked upon right? Much of the reaction to AIDS is simply and straightforwardly anti-sex. Sex, other than heterosexual and monogamous sex, is now denounced not only as immoral but medically unsafe. Even the more progressive approaches have reinforced rather than questioned the most macho concepts of sexuality. I quote Lynne Segal again in her article in *New Socialist* in which she says, 'All the publicity around AIDS (not just the Government's) defines sex simply in terms of penetration – for women always the most hazardous, and not necessarily most rewarding, part of it. On every other billboard, as on nearly every TV AIDS "special", sex once again reduces to the activity of the penis, now newly attired in plastic. The thrust of the publicity is less sex and fewer partners. Instead, we should be talking about expanding people's notions of sexual relationships and about types of sexual practice which are both possible and pleasurable when we are uncertain whether we or our partners are free from the AIDS virus'. I think Lynne Segal's article is not just an important article for women, but also essential reading for men.

With regard to the other major area of discrimination, racists are already making their voices heard, with calls for screening of people from Africa at points of entry, and the totally unsubstantiated and suspect claim that AIDS began in Africa. I have not heard calls in the press for screening of Americans or Germans or French visitors to this country before they are allowed to land at Heathrow, though the virus was identified in both the United States and Africa at roughly the same time. Yet again for practical and not just moral reasons we must resist this racism. No section of our community can be alienated from participating in the task of stopping the spread of AIDS if we are to succeed. Local authorities and health authorities are going to have to tackle AIDS together. We will need to influence the social and the political climate in which we do that work. This brings me to the agenda for local authorities. How can we create a community response to preventing the spread of AIDS and how can we best assist those members of our communities who already have the disease, those who could develop it, and those who contract it in the future? I believe there are six major areas for local authority activity, and I shall discuss each of them separately below.

Joint action

There is an urgent need to collaborate and develop services jointly with health authorities and with voluntary organisations, some of whom are streets ahead of both the local and health authorities. I would also say, as Deputy Chair of the London Boroughs Grants Committee which is currently carrying out a review of funding of organisations in this area, that we must recognise as local authorities the very crucial role that the non-statutory sector has to play. The role for local authorities in joint action with health authorities may include the appointment of specialist AIDS advisers and counsellors. Lambeth, one of our member authorities, has set up an inter-directorate HIV Working Party headed by the Chair of the Health and Consumer Services Committee. Lambeth's response was initially a response to pressure from voluntary groups and local doctors to address the problems and issues in the borough. It was also one of the first councils in the country to begin to address the issues seriously when it organised a major seminar entitled 'AIDS – the local response' in June 1986.

There are clear responsibilities for local councils to develop and promote prevention under the provisions of the Public Health (Control of Diseases) Act 1984 and the Public Health (Infectious Diseases) Regulations 1985. Lambeth is one of the local authorities that has developed a series of initiatives which are geared to prevention. These include

- an information 'phoneline' with posters and advertising
- the commissioning and production of videos for internal council use and for community use in general
- an investigation of the feasibility of the council facilitating condom distribution suitable for use in high-risk contact
- the development of an AIDS awareness approach which features AIDS primarily as a public health issue rather than a 'risk group' issue.

Prevention and information

All councils have a clear responsibility in law to combat the spread of epidemic disease. Some groups of Londoners, according to present epidemiological knowledge, are at greater risk than other groups. However it is clear that awareness programmes should concentrate on highlighting the potential spread of the virus to all sexually active groups. They should alert the public to the risks of casual sex with unknown partners and how these risks can be reduced with prophylactic measures. Literature produced should avoid the use of words importing blame or implying moral judgement. In particular such words as 'victim' and 'promiscuity' should be avoided. The key issue is safety whether it be 'safe sex' or 'clean needles'. Just as important is the message of how you don't get AIDS. That message is an important one, not just for Dot in *Eastenders,* but for the community as a whole.

Care

Currently many health authorities are developing hospital care systems for AIDS patients. For most health authorities this has meant developing specialist dedicated units which require considerable staffing and resources. Local authorities have not been given additional government resources to meet the increased need to provide services. Social services departments will have to develop support mechanisms for people with AIDS leaving hospital and wishing to live at home. This will require additional and specialist services from social workers, home helps or even specially trained care teams. The services will have to deal with the medical and psychological needs at different points in the advancement of the illness. One of the most pressing problems for social services departments is the need to plan and develop services for children who are HIV positive or who have AIDS. The problem of isolation is one of the key issues which we need to discuss and debate fully. Councils can act to support voluntary initiatives by providing financial support to volunteer 'befriender' schemes; by supporting local self-help organisations; by developing dedicated community facilities for HIV positive people; and by supporting specialist housing associations.

Anti-racism and anti-discrimination

A person does not have to have developed AIDS or be HIV positive to suffer racism or discrimination because of AIDS. Black people have been blamed by racist association with the suggested but unproven origin of the virus. Gay men have been blamed by association with their sexual preference. Lesbians have been blamed by association with their sexual preference as well. Haemophiliacs and intravenous drug users who are seen as 'high risk' have been subjected to discrimination.

Local authorities should be addressing the issue of homophobia separately and urgently. The issue should in my view be progressed separately from a main AIDS strategy since any further association with AIDS may reinforce the 'gay plague' myth and may well serve to undermine health promotion efforts.

Local authorities will need to ensure that discrimination does not occur in housing, recruitment and employment. Councils could perhaps consider treating people with AIDS as disabled for the purposes of equal opportunities policy and deeming discrimination a disciplinary offence. This policy has already been adopted by Lambeth Borough Council and Manchester City Council.

The racist associations with the alleged origin of the virus and the consequent racism experienced by black people must be confronted by local authorities and we should not shy away from this. Councils should take the view that the origin of AIDS is entirely irrelevant since the views and assertions about its origin are adduced to support racist or homophobic arguments.

Employment issues

Over the last month media coverage has indicated that large UK employers are beginning to take specific measures against recruits and employees on the grounds that their work could contribute to the spread of AIDS at the workplace. British Airways admitted that it would screen all future applicants for jobs as pilots on the grounds that AIDS could affect concentration. Another example was Dan Air's attempted justification of its policy of employing only female cabin staff on the grounds of alleged homosexuality amongst male stewards. At a meeting of the Royal College of Nursing evidence was brought forward of positive discrimination against nurses both on the grounds that they may be HIV positive or on the grounds of their sexual orientation. These examples indicate that more serious issues will arise as private sector and public sector managements begin to address the employment issues of AIDS.

A set of principles for local authorities to adopt could be as follows

- trade unions need to be consulted and involved early in the development of any initiatives
- exposure to HIV should not be a barrier to employment in any job
- there is no reason to undertake any form of employment screening in respect of HIV
- normal council services should be maintained to those members of the public who may be HIV positive or AIDS patients
- the main emphasis of information or training in respect of HIV should be to consider misleading publicity and surrounding fears
- racist and discriminatory associations need to be challenged
- clear and unambiguous information is made available to staff and users of

facilities on appropriate safety measures

- managements faced with a disclosure from an employee of being HIV positive or having developed AIDS should take action to minimise any potential racism or discrimination and provide sensitive support to that employee
- medical information about employees and members of the public should be treated in the strictest confidence and should only be made available to other council employees on a strict and controlled 'need to know' basis. It should be emphasised that breach of confidentiality is in itself a disciplinary offence.

Training

The need for adequate training for staff is urgent. Training requires an emphasis on good, reliable information about the condition and explicit detail about the means and ways of contracting the virus. The training resources will need to include a range of media. It is appropriate that key staff such as management, trade union stewards, and staff who by reason of their post are most likely to come into contact with persons with HIV/AIDS, should receive special and intensive training. Although I come from a local authority that is not itself an education authority, I do believe that the education authorities also have a vital role to play, as does the youth service, in terms of educating children and young people.

In conclusion may I urge that the highest priority is given to strategic co-ordination across London in the fight against AIDS.

2 The New York experience

Patrick Hacker, Director of Supportive Housing, AIDS Resource Centre, New York

Whilst I have been working in the AIDS field for the past three years, I do not consider myself a specialist. I am a trained social worker who has been called upon to provide services to people with AIDS. I work with a very determined group of fellow professionals and para-professionals in New York City. Let me say at the outset how much we in New York at the AIDS Resource Centre, the Gay Men's Health Crisis, the People with AIDS Coalition, the Minority AIDS Taskforce of Harlem and the Hispanic AIDS Forum admire and applaud the ongoing effort the Terrence Higgins Trust has mounted over the last few years to alert both Londoners and the general public in this country about the impending AIDS crisis. Of all the challenges that I have faced in some fifteen years of social and youth work, AIDS is surely the most daunting. I cannot think of anything more urgent than the present crisis to bring us all together to share our experiences.

After working in local authorities and in voluntary organisations here in London and then in the not-for-profit sector in New York, I find my present involvement with AIDS by far the most testing assignment of my career. I moved to the United States in 1979 and began to work with people with AIDS in 1985, following the deaths of several friends. For two years I served as co-ordinator of the Intake Department at the Gay Men's Health Crisis – which we refer to as GMHC – before moving on to the AIDS Resource Centre, where I am Director of Supportive Housing. At this point we provide housing for approximately 65 people who would otherwise be homeless. Some are white, some are black. Some are young, some are old. Some are haemophiliacs, and some are intravenous drug users. Some 70 per cent are male. All are poor and/or socially rejected and/or physically or neurologically impaired to the point where they cannot live on their own. To put this housing effort into perspective, I have to tell you that New York City has approximately one third of the national total of people who have been diagnosed with full-blown AIDS. Of the officially estimated 11,000 cases in the city, there are at least 700 people without a roof over their heads.

I would now like to give you an overall picture of how New York has responded to being the city with the largest number of people with AIDS and AIDS Related Complex in the world. I will outline several main issues for you as clearly as I can. I shall first highlight the unwillingness of the statutory sector to confront the crisis. It was the voluntary sector which first identified the crisis – here I am referring specifically to GMHC – and addressed it. This incredible response, begun in 1981, continues to this day. As for the statutory sector, only a bandwagon of mounting statistics has forced them to act.

My second point will concern the problem of developing inter-agency services and structures, and how this problem has been tackled – or not tackled – by the city. Thirdly, I shall attempt to describe the incredibly slow development of educational and preventive strategies to inform and alert the public about the virus's destructive potential. Fourthly, I shall illustrate how racism and homophobia have aggravated the crisis even more. Finally, I will briefly address the specific problems of children with AIDS and the present crisis of their numbers in New York City.

The voluntary sector's commitment to the AIDS crisis manifested itself in 1981 with the foundation of GMHC. The mandate of this organisation was, and still is, to provide counselling, cooking, cleaning and shopping for clients, as well as financial and legal advice. GMHC also provides educational outreach to all groups affected by the crisis and has advocated politically on their behalf. This latter activity has increased in the last few months with frustration at the lack of action at federal level in America bringing about a far more sensitised political reality.

The response in 1981 and for the first few years of the crisis, when no one knew if the AIDS virus could be spread through casual contact, was quite remarkable. Today in 1987 GMHC has a staff of 70, approximately 1,200 volunteers, and a four million dollar budget. That budget is 35 per cent federally, state and city funded; 65 per cent still continues to come from private foundations and private donations. Its caseload since its inception in 1981 has been approximately 4,700 and the active caseload as of today is approximately 1,600. Of these 1,600, approximately 30 per cent are heterosexual. This assault on the crisis by the voluntary sector over the last few years has provided an opportunity for gay and heterosexual men and women, white, Hispanic and black, to constructively channel their personal frustrations, their personal anger, their personal hopes and fears surrounding the threat of AIDS. This phenomenal outpouring of concern continues to occur against a background of ignorance and discrimination. Not only did established institutions ignore the issues, they often actively discriminated themselves against people with AIDS. Hospitals turned patients away; staff refused to enter their rooms; social service and social security officers had clients physically ejected, or would only speak to them on the telephone. As a trained social worker, I have never been so saddened or disgusted at the lack of professionalism in my own profession.

However, as news of the heroic fight being waged in New York City became known, others responded. In a situation which resembled a state of war – and still does – where people with AIDS were, and still are, prisoners of war, hope at last had a vehicle to travel on. Visitors came to GMHC from towns and cities in the USA and even from other countries – Norway, Sweden, Japan, Germany, Australia and many others including, of course, the United Kingdom. They took home with them the role model of GMHC, but more importantly, they saw that people with a terminal illness could live with dignity and be empowered to fight for their lives.

One of the organisations that formed out of GMHC was the People with AIDS Coalition. This is a union of people with AIDS themselves who, while they do not want to be separate, want to be able to speak for themselves about what it is like to be experiencing that terminal illness.

As statistics throughout the world have continued to mount, presenting society with what I call a 'statistical bandwagon', statutory authorities everywhere have slowly, very slowly, been dragged, protesting, into confronting the reality that this crisis is not going away. Fortunately, one of the positive outcomes of the last few years has been the success of medical researchers in determining that casual contagion has no foundation in fact. Yet I still see in many of New York's local authorities and governmental institutions, as well as in the professions generally, a dismaying lack of perception as to what is at the core of the AIDS crisis. The lack of perception I speak of has complex causes, but its roots surely lie in the fact that the virus has to date primarily affected gay people in New York City. It may not have been a coincidence that the President chose April Fool's Day to make his first announcement about the crisis of AIDS.

Historically this subcultural group has never directly presented its own specific needs. Consequently, the caring professions have had little experience in delivering social services and support to this group, or even in identifying who and where they are. This problem is compounded by the fact that a disproportionate number of social service professionals, in my opinion, are themselves gay or bisexual, and of these, many still fear to publicly identify themselves as gay or bisexual. Only with the onslaught of AIDS have the negative implications of this become so obvious with regard to the delivery of services to clients. Many of these closeted professionals are restricted in their ability to deal with the crisis just because they fear personal exposure. As counsellors and social workers they may need to think through whether they are the most appropriate persons to be delivering these services to people with AIDS.

Admirable as the voluntary sector's efforts have been, there is no doubt that the role of local authorities and government should be enlarged, following the model established by GMHC in New York and the Terrence Higgins Trust here in London. The nature of the AIDS crisis demands the direct and immediate collaboration of all interested parties if we are to even keep abreast of what New York City's Health Commissioner, Dr Stephen Joseph, has aptly described as a 'continually moving target'.

This brings me to my second point – the development of inter-agency services and structures that can cope practically with the impending AIDS crisis. The role model provided by the voluntary sector, and typified in this country by the Terrence Higgins Trust, has to be duplicated at all levels of the caring professions. It will be crucial for this effort that all those concerned adopt the non-moralistic stance of the Trust. The success of such groups has depended on their close affiliation with those most affected by AIDS. To clients, they have communicated a simple message of support, advocacy and preventive education. Every statutory agency should set up its own AIDS outreach team based mainly on the 'buddy system'. This arrangement, used by the Terrence Higgins Trust in England and by GMHC, pairs volunteers with clients, one-to-one, to nurture a sense of personal responsibility on the part of the buddies. Their aim is to give clients a feeling of dignity and of being supported, but also a feeling of increased independence, and of being able to make their own decisions once given the options available to them.

While there are many people who will be capable of fulfilling this demanding role, they too will urgently require supportive counselling. Where are these buddies going to come from? One of the definite advantages that London has over New York is that there is already in place an intricate network of voluntary agencies with established access to the many different levels of service delivery within local authorities. There are voluntary organisations – London Friend, Body Positive, Parents' Inquiry, Metropolitan Community Church, the Albany Society, the Campaign for Homosexual Equality – these are the names which come to mind, that can provide the expertise and motivation required for the future war on AIDS. Such groups are especially valuable because they primarily represent the embattled gay and bisexual community so harshly singled out by the virus, by social discrimination and by quotes in the media. Let me emphasise that brand-new statutory programmes are not necessarily needed, but rather imaginative and innovative linkages with well-tested volunteer groups. If nothing else this strategy, by harnessing a volunteer structure already in place, will better control costs in the enormous effort required ahead. But in linking with the voluntary sector, the statutory authorities will have to ensure that they do not overload the volunteer effort with so much bureaucracy and accountability that administration requirements pre-empt the delivery of services. The frontline workers have to be able to get on with the job they wish to be doing.

This has, in fact, become a problem for me as a housing director of a voluntary agency in

New York. Right now, for example, I have an apartment available for three single individuals or a family of four, but because of the city's failure to identify eligible residents, it has stood empty for three months. We take on referrals from the statutory authorities in the city, and for three months they have been unable to make a referral to us because of bureaucracy. We do not have time for this sort of problem. As Camus wrote, 'Wars and plagues always take people by surprise'. In New York, we have been obliged to come to terms with the statutory system as we find it. In working within this system, some have grown concerned that our effort may be too compromised. Richard Dunne, Executive Director of GMHC, has answered this question most clearly, '. . . maybe, indirectly and unintentionally, we have collaborated in keeping the system going by patching up its deficiencies, but you can't build new systems in the midst of an epidemic'.

Moving to my third area of concern – strategies for education and prevention – let me begin by considering those who are living with a HIV positive diagnosis. This group and its needs should not be, in my opinion, or in the opinion of most of the agencies providing services in New York, approached negatively. What we must be able to do is to provide a vehicle of hope. We must tackle people's negative perception that their sexual lives are over, and that their fears of social rejection are justified. They must be able to harness positive hopes that they will continue to enjoy a fulfilling lifestyle. Safe sex, a lowered level of stress, good nutrition, good sleeping habits, along with regular exercise – these are the vital ingredients that are taught by all New York's voluntary agencies, to all our clients, residents or friends.

I really do hope that by now Londoners clearly understand that being seropositive for HIV is only that. It need not mean that one will contract AIDS. It does not predict the length, and more importantly, the quality of life that such a person can look forward to. Moreover, we must always retain their hope that effective drug therapies will become available soon. That is their wish and that is their need. Dr Mathilde Krim, a leading advocate for people with AIDS and an esteemed medical researcher, has repeatedly said that people who are being diagnosed today with AIDS should not reasonably assume that they will die.

I now turn to preventive education. We all know that there are several groups in the population who are at special risk of infection. Besides gay and bisexual men, these groups in New York include prisoners and ex-prisoners, intravenous drug users, haemophiliacs, their partners, prostitutes and the wives and girlfriends of gay and bisexual men. All of the above are, or will be, resisting the efforts of society and of the caretaking professions to change their behaviour. This in unquestionably the most challenging issue we face in New York. Not only are the target groups refusing our message, from the other side we are encountering enormous difficulty from the guardians of morality and from political opportunists who are exploiting the present dilemma. In New York, great damage and delay in educating the general public, especially teenagers, is being caused by the opposition of the archdiocese of the Catholic Church and other church groups to any form of gay sex education in the city schools. For example, the New York School Board, reacting to pressure from religious groups, has refused for over six months to release an excellent educational video made by young people for young people. In my opinion this is anti-Christian.

Nevertheless, and despite the problems of fighting a war on two fronts, some innovative approaches have been devised to reach the communities most at risk. GMHC has conducted safe sex forums in gay bars, discos and in bath houses. It has also tried to educate the correctional system where drugs are rife and homosexuality is frequent. Professional quality poster advertisements, with safe sex messages in both Spanish and English, well-calculated to appeal to their audience, are prominently displayed in all parts of the gay community. These advertisements, incidentally, present sexual opportunity as still an attractive option and a part of the whole lifestyle. In the Hispanic communities of the Bronx and east side of Lower Manhattan a group of ex-drug users is sending volunteers into the 'shooting galleries', places where IV drug users share needles, to distribute free sterilised needles. Special efforts are also being made in the black community where homophobia is, if anything, greater than elsewhere. These posters within the black community in Harlem and in other parts of New York carry the message that not only whites are affected by AIDS and not only gays.

In Britain such outreach efforts to ethnic minorities will, I sense, prove especially difficult. Here in the UK one senses that there is not the same degree of social interaction between the majority of society and the various subcultural communities. It is simply vital to communicate in the language and the style of the targeted audience. Mainstream language, as it is referred to in America, and middle class notions of self-interest such as mine, will often not be heard in New York's outer boroughs, or for that matter I suggest in Brixton in South London, in Newham in East London or in Southall in West London. The recent media campaign in the UK depicting icebergs and volcanoes illustrates another pitfall. The message about the transmission of AIDS and its potential problems must remain positive to be seen, heard and acted upon.

I have concentrated on efforts being made to reach target groups. This is because I think that general campaigns such as the ones just launched in Britain, in Australia and in Canada will only introduce the problem to the general public. Any real hopes of getting people to alter their intimate behaviour lie in more specialised, localised and persistent attempts along the lines I have mentioned. In New York there is a new term – 'afraids' – and it is another interpretation of what I see as the scare tactics of national media campaigns. Local radio, local television, schools, youth clubs, sport groups, adult education centres, private business and the unions are where the AIDS outreach teams have to do their work.

Homophobia and racism have been implicit factors in much of what I have discussed so far. As regards racism, it is clear in New York today that, despite the civil rights movement of the 1960s, political, social and economic equality have not been achieved by significant numbers within ethnic minority communities. But at least the issues have presented themselves clearly enough in New York to enable us to consider the next steps. In London, it appears to me, racism may be more subtle but at the same time, more difficult to confront. In a crisis situation, such as AIDS, the combination of racism and the lingering effects of the class system will surely make AIDS outreach to minority groups much more difficult. It is imperative, therefore, that statutory authorities and the proposed National AIDS Council be prepared to fund and develop liaisons, and to delegate actual responsibility for this task to community-based outreach teams with their own trained and counselled co-ordinators. For these groups to have a fighting chance against AIDS they must receive support at all levels, in order to enable them to do for themselves what outsiders will never be able to do. To put the matter in a London perspective: single-parent West Indian mothers of South London, the tightly-knit Indian and Pakistani families of West London, and the extended Jewish families of East London must all be reached by their own political, social and sporting groups.

In New York, GMHC took two years or more to become fully aware that it could not even begin to meet the rapidly growing problems of black and Hispanic communities of New York City on its own. Eventually the Minority AIDS Taskforce in Harlem was formed to develop a service infrastructure in the black community, and then the Hispanic AIDS Forum followed. I will not address separately the issue of homophobia as it has already been involved in most of what I have been discussing. I only suggest that the medical illness of AIDS and the social disease of homophobia, along with the social disease of racism, must be addressed completely and utterly if we are to develop an operational and timely response to the crisis.

Before I conclude, I would like to recount my experience as the supervisor of the GMHC paediatric team. In New York there are officially an estimated 180 cases of children with full-blown AIDS, according to the city's Department of Health. In the Bronx there is a doctor, Dr A Rubinstein of the Albert Einstein College of Medicine, who estimates that the figure is closer to 900 - 1,300 cases. At that hospital alone, inpatient and outpatient numbers are approximately 200 plus. AIDS cases in children are particularly hard to identify. Symptoms of AIDS mimic many other childhood conditions, and unless a specialist has been sensitised, he or she will often fail to recognise HIV infection or even full-blown AIDS in newborns and children. This is where in New York the district nurse, the health visitor, the homecare worker, the social worker and the other frontline service deliverers have identified and brought to the attention of the physician, the doctor or the specialist, that something else is going on. This is very valuable. The extended latency period of this virus means that children of six, seven, or eight may be at risk from inherited HIV infection.

The difficulties for the paediatrics team in New York have been compounded by the fact that 95 per cent of children with AIDS are from ethnic minority backgrounds; the majority of these were born with the HIV infection. Many of their parents have AIDS as well. I have worked with two such families and my responsibility as a social worker is to ensure that a will, the power of attorney and guardianship are all in place ready for the parents' own deaths. Not surprisingly, the challenge to a predominantly white and middle class volunteer group – GMHC – of providing buddy support services to outer borough ethnic minority children and their families has proved especially daunting. A large number of children – perhaps fifty – are living in hospitals in New York having been abandoned by families who were unable or unwilling to care for them. Some of these children have spent as long as two years, and some of them up to relatively recently, without being handled or even touched by fearful staff. These neglected children have responded remarkably to the buddy support system. I can describe a 23-year-old, white, gay male who has been working in Brooklyn for approximately two years with a mother who herself has AIDS Related Complex, a daughter of two who has just got over her sixth bout of pneumonia, and is doing very well, and a 14-year-old daughter who is also well. There is no doubt that the buddy support system has kept this family together.

This then is the picture of what is happening in New York City. Frustration is running very high, particularly at the moment, and people are definitely taking a more political stand. Here in London, I sense you have to create practical, workable liaisons between yourselves, as the people who are delivering the services, and the statutory sector. Barriers of communication have to be broken down at all costs. A London AIDS Council may be required to ensure that the action promised is the action that actually happens. I have tried to portray what has happened – and not happened – in New York City in my own very personal way. You will have to make it work here and you will have to make it work soon.

3 Planning services within the NHS

Dr June Crown, District Medical Officer, Bloomsbury Health Authority, London

Bloomsbury is one of the inner London health authorities which is dealing with a considerable number of AIDS cases. It is particularly important to stress, however, that our concern is not only the provision of services for patients with AIDS. We are also meeting the needs of the very large numbers of people who feel they may be at risk and who require counselling and testing. This has been a particularly burden since the government's health education initiative, indicating that it is having some impact on the community in general. We are, as a result, particularly concerned about future planning to deal with the disease, both for health services and for local authority and other agencies' services.

There have been about 730 AIDS cases in the UK. We do not know how many people are infected with HIV, but it could be up to 60,000. It could be quite a lot more. There is some evidence that there is a ratio of 100:1 of people infected to people who have actually developed the AIDS syndrome. Many of these people are well and have no symptoms; large numbers are unaware that they have been infected with the virus. Others, however, have physical, psychological, social and occupational problems which require multi-agency assistance. Patients with HIV infection and also those who have developed AIDS can remain well for long periods. The median incubation period, between contracting the infection and developing AIDS, has been calculated at about five years, though this may prove in due course to be an underestimate. Patients who have developed AIDS have two main types of clinical problem. Those who develop tumours (Kaposi's sarcoma) survive on average about two years from diagnosis of the disease, while those who develop lung infections (pneumocystis carinii pneumonia) survive about one year. The natural history is of recovery from the initial episodes of disease, but with gradual weakening between successive episodes. Over this prolonged time period there are going to be particular needs for services to be met. The disease has therefore a particularly long health and support component. We are now also seeing patients with neurological problems and dementia, and this may, in the long term, prove the greatest challenge to our joint services.

It is essential that we take account of the needs of all the individuals with HIV infection, who will require a wide range of assistance across all our services, as well as the tremendous task of prevention, which remains the outstanding challenge to public health. Both the health and local authorities can make major contributions to these tasks.

The epidemiology of HIV infection and AIDS

All service planning must be based on the best information we can obtain about the size of the problem. The most recent figures for HIV infection and AIDS cases in the UK (February 1987) have been published by the Communicable Disease Surveillance Centre (CDSC). The total number of people with HIV antibodies who have been reported is over 4,000. Their age distribution is shown in Table 1 overleaf. This shows the vast majority of cases among young adult males (25-44 years). These days, within the health service, and particularly within the acute services, we are not used to disease syndromes in this age range. We are looking therefore at areas of care which over the years have become rather unfamiliar to us.

Table 2 overleaf shows the transmission characteristics of people with HIV infection, showing that in this country the incidence is very much greater among homosexual and bisexual males than in other groups. Of the total cases of HIV antibody positive, over 2,000 are in this group. Nearly 1,000 are amongst haemophiliacs, and this is, of course, another major area of concern. We hope this latter group is now virtually under control through the protection of blood products. We hope therefore that this particular burden will be a static and diminishing one in terms of the provision of services for this group. Another matter of some concern is the development of HIV antibodies and AIDS amongst children. We have an obligation to put a major preventive stress in this field to see what innovative notions we can produce to control this particular area of transmission. Finally, Table 2 shows that the incidence is relatively low at present among intraveneous drug users.

Table 1

Cumulative totals of HIV antibody positive persons reported by age and sex

February 1987

Age (years)	*Male*	*Female*	*Unknown*	*Total*
0 – 4	15	4	1	20
5 – 9	41	-	-	41
10 – 14	56	-	-	56
15 – 24	652	65	2	719
25 – 44	1859	90	6	1955
45 – 64	314	5	-	319
over 65	24	3	1	28
not stated	996	28	20	1044
Totals	3957	195	30	4182

Source: CDSC

Table 2

Cumulative totals of HIV antibody positive persons reported by transmission characteristic

February 1987

Transmission characteristic	*Male*	*Female*	*Unknown*	*Total*
Homosexual bisexual	2158	-	-	2158
Intravenous drug abuser (IVDA)	163	85	4	252
Homosexual & IVDA	24	-	-	24
Haemophiliac	941	2	1	944
Recipient of blood	20	12	-	32
Heterosexual contact				
contact of above groups	6	30	-	36
contact of other groups	56	36	1	93
no information	1	5	-	6
Child of HIV antibody positive mother	5	4	1	10
Several risks	4	-	-	4
No information	579	21	23	623
Totals	3957	195	30	4182

Source: CDSC

Table 3 shows the geographic distribution of HIV infected people according to NHS regions. This, at the moment, is the best statistical information that is available to us on the distribution of the disease across the country. It confirms that the infection is most common in the four Thames regions, and we know from our own departments that it is concentrated in the London area. The information we have at present is only available on a regional basis. We do need to stress to the CDSC and other agencies that are producing statistics the importance to us as planners of having very much more detailed information. This applies more to HIV infections than AIDS cases, for if we are to be able to develop our services in a sensitive and appropriate way, and not always to be driving by the seats of our pants, we have to obtain data that will give us as much opportunity as possible to prepare ourselves. This applies even more to some of the more suburban parts of London where the problem has not arisen to the same extent as in inner London where we are already dealing with a major problem. There was originally some concern that the numbers involved in producing statistics at a district or local authority level would be so small as to provide problems with confidentiality. With the numbers of cases now reported throughout the country, this should no longer be a problem, and proper safeguards could be built in to deal with confidentiality. To help us help the patients we do need the best possible information that can be provided.

The effect of the publicity about AIDS is clearly seen in Table 4, which shows that the number of antibody tests done each month nearly doubled between July 1986 and January 1987. During this same time, the number of positives remained remarkably steady.

Table 3

Cumulative totals of reports of HIV antibody positive persons reported by region

February 1987

Region	*Cumulative totals*	*Region*	*Cumulative totals*
England		England	
Northern	212	Wessex	164
Yorkshire	194	Oxford	232
Trent	175	S Western	124
E Anglia	121	W Midlands	267
N W Thames	1361	Mersey	66
N E Thames	453	N Western	86
S E Thames	538	Wales	42
S W Thames	111	Northern Ireland	36
Total			4182

Source: CDSC

Table 4

Public health laboratory reports of HIV antibody tests

July 1986 - January 1987

	Category	
	Total no. tests	*Total no. initial positives*
July	5983	141
August	4919	157
September	4963	192
October	5680	182
November	9247	167
December	10545	192
January	10440	179

Source: CDSC

These figures, of course, represent an enormous workload, not just for laboratory services, but more importantly for the counselling and support of people who consider themselves at risk. In my view, everyone who is tested should have access before and after testing to proper and adequate counselling services. If they consider themselves to be at a high risk, they are undoubtedly in a high stress situation, and in a sense the result of the test from that point of view is irrelevant.

Tables 5 and 6 overleaf show the current figures for patients who have developed AIDS, indicating transmission characteristics and the geographic region of report. Again, this does not necessarily coincide with area of residence, and patients diagnosed and reported in central London may require services at a later stage in their area of residence. They may not want to stay in central London, nor indeed in the same area. The issue of choice is very important. At present, we have no access to this information, and therefore, our service planning is seriously hampered.

Table 5

Cumulative totals of UK reports of AIDS cases by transmission characteristic to February 1987

Transmission characteristic	*Cumulative cases* *Male*	*Female*	*Total*	*Number of Deaths*
Homosexual/ bisexual	640	-	640	317
Intravenous drug abuser (IVDA)	8	2	10	4
Homosexual & IVDA	8	-	8	4
Haemophiliac	28	-	28	22
Recipient of blood: abroad	4	4	8	6
UK	3	1	4	4
Heterosexual: possibly infected abroad	13	7	20	11
UK (no evidence of being infected abroad)	1	4	5	4
Child of HIV antibody positive mother	3	4	7	4
Other	-	1	1	1
Totals	708	23	731	377

Source: CDSC

Table 6

Cumulative totals of UK reports of AIDS cases by country and region of report and numbers known to have died to February 1987

Region	*Cumulative cases*	*Total deaths*
England		
Northern	20	14
Yorkshire	9	4
Trent	12	7
East Anglia	5	3
N W Thames	363	165
N E Thames	130	60
S E Thames	59	30
S W Thames	15	10
Wessex	16	11
Oxford	6	4
South Western	10	8
West Midlands	15	12
Mersey	10	10
North Western	31	16
Wales	11	9
Scotland	16	11
Northern Ireland	3	3
Totals	731	377

Source: CDSC

Planning services in the NHS

The service planning issues for HIV infection in the NHS are different in different parts of the country, reflecting the geographic distribution of the infection. Outside London, prime energy should be put into prevention, while there is still time *not* to develop a London-size problem. Those of us working in inner London have had to develop services on several fronts at the same time, and until recently, this has been within the framework of reducing resources. This is a pressure we have felt more in the health service perhaps than has been the case in the local authorities. If we were doing this as an academic exercise, producing statistics on a new disease and developing the services in response, we could all make our own plans and do our calculations to get all the components of the services planned and developed at the same time. It has not been like that. We have been forced in the health service to deal with acutely ill people, to deal with very worried people and with people who are not yet ill but are likely to become so. We have been doing this all at once, trying to scramble the resources together as best we may. The burden of this disease has come on those inner London authorities who are facing the most difficult problems in relation to RAWP allocation. We are losing a great deal of money for distribution to other parts of the region and other parts of the country. Trying to cope with this at a time when we are having to make cuts in our acute services anyway, to close wards and to close beds, puts a desperate pressure not only on the clinicians who are having to deal with AIDS, but also the clinicians dealing with all sorts of other things as well.

Over the last two years, special allocations have been made for AIDS-related services by the DHSS, though we do not yet know whether the sum available will cover all the costs. Even if it does, it will not necessarily buy or create extra space in already crowded hospitals. We are certainly not sure whether the money that has been allocated for AIDS is in fact extra money to the NHS, or whether this is some form of governmental top slicing which means that other parts of the NHS are going to be disadvantaged. If this is the case, I believe it is very unfortunate. We are not only dealing with AIDS as a problem, but with the problems of demography. We are faced with an ageing population who require long-term geriatric care, and who have a lot of acute needs such as acute arthritis, cataracts, and all the diseases of old age. We are trying to meet their needs decently at the same time. There is no point in trying to deal with one disease and then finding that the waiting lists for other life-threatening conditions, or conditions that greatly hamper the independence of people, exceed the expectation of life of individuals on those waiting lists. There are very real difficult areas of choice in NHS planning these days.

We have, therefore, to concern ourselves with the logistic issues of service planning for seriously ill patients and the impact of their needs on other groups of patients needing care. It is not any kind of service to people with AIDS, or to the clinicians who are looking after them, if part of the discrimination is the concern of the effect that their care is having on other patient groups. In Bloomsbury, we have developed a 'queueing theory' model to predict our future bed needs. This seems, according to experience so far, to provide reasonably accurate projections. We have opened an AIDS ward at the Middlesex Hospital which was formally opened by the Princess of Wales on 9 April. Our projections at the moment are that the ward will be full by the end of the year. Where we will spill over to after that is far from clear. At the same time, we have been developing the laboratory services needed for screening and diagnosis. We have also put resources into the whole field of counselling.

Throughout this period of pressure to treat those who have already contracted AIDS, we have been quite clear about the overriding importance of prevention. We are determined to do everything we can in this field, though obviously the contribution of the local district health services is only a small part of the preventive programme. The work being done at national level, in other regions, in local authorities, and by voluntary organisations is essential for the reduction in the spread of infection. We have been very encouraged by the evidence we have so far about the effects of joint preventive action. Studies undertaken at the Middlesex Hospital show that the prevalence of HIV infection in homosexuals attending the genito-urinary medicine clinic there has stabilised over the last two years, having risen quite sharply between 1982 and 1984. This suggests that in this particular 'high risk' group, behaviour has changed and people have been very responsible in reducing the exposure of themselves and others to infection.

Future planning issues

Although our work on the development of services within the NHS will continue, the priorities now must move towards the development of services in the community for people with HIV infection or with AIDS. Some of these services will be the responsibility of the NHS: health visitors, district nurses, domiciliary care teams and general practitioners. There have been particular difficulties with the proper involvement of primary care teams because general practitioners do not come within the remit of the health authority in the way other doctors and other health professionals do. We do not have the opportunity to plan their services or to influence their patterns of care. This poses a particular problem not only in relation to AIDS, but in relation to many of the aspects of care we are trying to develop in the health service. As with all other community services we will rely heavily on intersectoral collaboration. Ill people at home will need social services, support and assistance from neighbourhood communities and from voluntary agencies. Whatever the nature of their illness, we must be able to offer terminally ill patients the opportunity to die at home with dignity, if that is their wish, and if their medical condition does not require hospital care. We are at the moment experiencing difficulties in doing this in relation to AIDS patients which we have to overcome. There is no reason whatsoever why they should not receive the same domiciliary care as terminally ill cancer patients.

The problems of planning

The picture I have given so far is, despite all the emotion that is being generated, a relatively straightforward one in medical terms. The problems in relation to future planning fall into two parts. There are the structural problems – those of joint care planning teams and the joint committees between local authorities and health services. There are problems with being coterminous. We as one health authority have to relate to our adjacent health authority which is in the same local authority area. We also relate to another local authority (City of Westminster). The complexity of this in an area of central London, where people do not realise the major decision they are taking when they cross the Edgware Road, is not appreciated even by people in the DHSS, local authority agencies, or in the regions. We all respect each other and try very hard to work with each other, but the structure does not help. This is not something that we have just discovered with AIDS. In my experience, joint care planning teams have never worked very well even with joint finance to oil the wheels. It is imperative to use this as an opportunity to try and develop new, better, more effective ways of working together.

As well as these structural issues there are other more general issues in relation to HIV infection which we need to address. Our knowledge of HIV infection and AIDS is incomplete, but so is our knowledge of countless other conditions. What we do know about HIV infection gives us an excellent basis for planning services and for reducing the spread of infection.

We know the causative agent of the disease. We know the modes of transmission. We know the infection cannot be spread by casual and brief social contacts or by physical proximity (it is not like smallpox); we know that it is not spread by the activities of normal professional care (it is not like tuberculosis); we know that it can be spread by blood contamination and that proper training and standards of practice are extremely effective in preventing spread by this route among carers (it is like hepatitis). Why, then, are we experiencing difficulties in developing our service plans and persuading staff to participate in a normal professional fachion? There is of course understandable fear of the unknown. HIV is a new infection and AIDS is a fatal disease. The emphasis which has, quite rightly, been put by the government and the media on research, stresses in the public mind the lack of knowledge about the disease rather than the fact that we already know a good deal. A slight shift of emphasis could perhaps give us some assistance in this respect.

We are also, I believe, the prisoners of our own success in the treatment of infectious diseases during this century. The triumphs of antibiotic therapy in the treatment of previous killer-diseases, such as tuberculosis, have led to expectations in the public that all infectious disease can be conquered by chemicals. There is still an air of disbelief that the magical antibiotic is not going to be available tomorrow. The medical information about this is fairly clear, but it is a complicated message to get over. The diminution of infectious diseases as a health problem over the last couple of generations has caused us to become rather slack in our control of infectious procedures in the health service and in the community in general. Things that are not seen as a threat do not take up so much of our energy, and do not lead us to take the same level of precautions as our parents and grandparents did. Further, in spite of explicit health education material, there is still also a lack of public confidence in the evidence on the spread of HIV infection, and in particular in the belief about activities which are absolutely safe. This is a challenge which health education and information programmes must pursue.

Clearly, the biggest hurdle we have to overcome is in relation to public moral attitudes towards the largest risk group, homosexuals. The 'wrath of God' and 'divine retribution' views have been over-publicised, and there are undoubtedly many people, our NHS staff among them, who share these attitudes. There is also a very unfortunate 'they brought it on themselves' view – the victim-blaming approach – which can develop into a position of 'they don't deserve care'. It is surprising that those who express this view seem not to take the same stand in relation to cigarette smokers with heart and lung disease, or to alcohol misusers with liver disease.

It is essential in planning services that a great deal of our effort, therefore, is addressed to the education of all the staff who will participate in care. The newness of the disease and its nature mean that education will need to be more intensive than is normally the case in service developments. Both health authorities and local authorities are already embarking on major programmes of this kind aimed at specific staff groups. We can undoubtedly share our experience in this regard to improve their effectiveness in the future. These programmes, however, are likely to be more successful and faster in conveying scientific, intellectual and medical information to staff than in altering deep-seated emotionally-based attitudes. It is unfortunate that some of the attitude changes which would help us in developing services for HIV infected individuals have been hampered by those who have achieved publicity by taking extreme positions in favour of positive discrimination. They have served to engender a measure of suspicion in less radical sections of the population. This is an area where we can work together to ensure that our messages and our actions are optimally effective.

A prime task, therefore, for service providers at present is the development of sensitive and balanced education programmes, which address not only the information needs of staff and carers, but also their attitudes. This latter task will undoubtedly take much longer and a great deal more effort. If this is, however, seen as part of the long-term solution to the problems of planning comprehensive, sensitive and appropriate services for HIV infected people and AIDS patients, perhaps we should be asking the government to put resources into research and into the development of staff education and training, as well as into general public education and biological research. In this way the social, psychological and educational components of HIV infection and AIDS can be researched as well as the biomedical ones. These are not mutually exclusive approaches and the government ought to be able to find money for both. If the biomedical researchers are correct in their assessment that there is not going to be an effective vaccine or treatment in the near future, efforts to ensure that the services for patients are as good as they can be, should have some measure of priority.

Finally, there is one thing that I think all those who work in the health services, local authorities and in the caring agencies, should be totally aware of and committed to. We should not by our example, in dealing with patients or in developing services, make any contribution to the problems of either education or attitudes that are hampering some of our efforts now.

4 The community care challenge for local authorities

Denise Platt, Director of Social Services, London Borough of Hammersmith & Fulham

It has been said that three London boroughs, Westminster, Kensington & Chelsea, and Hammersmith & Fulham, are at the major point of impact of the AIDS issue in London. During the last year, and currently, Hammersmith & Fulham is supporting an average of 60 people in the community with either full-blown AIDS or AIDS-related conditions. (Both are a target for our services). As a local authority, we first became involved in supporting people with AIDS in 1985 when a member of our own staff approached us to say that he had full-blown AIDS. It was a very courageous thing for him to do in 1985 when the media was even more full than now of scare stories concerning how AIDS could be transmitted. We were concerned because he worked in our social services department and clearly the stress of the work was compounding what stress he felt about himself and the situation he found himself in. We were very concerned to support him in his employment.

Almost simultaneously, we read in a local newspaper that a client known to us had died of AIDS, having had a blood transfusion in the United States. We had been providing domiciliary services to this person and five of our home helps had been involved in going into his home. They were clearly frightened out of their wits by the things they read in the paper about the person for whom they had cared, whom they knew personally and whom they liked, and whom they had supported very caringly. They could not equate the stories in the paper and the task they had been undertaking.

We were concerned as a local authority that people with AIDS who lived within the boundaries of Hammersmith & Fulham should not be discriminated against in the provision of services. As an employer, we were equally concerned that employees with AIDS had their full entitlements as employees, had a right to employment and were treated equally to other employees of the council.

We set up at that time a corporate group to consider guidelines for the council in employment policy and in service delivery policy. The guidelines have now been completed and are formally adopted as our council's policy for all council departments.

In November 1985, we appointed the country's first Policy Development Adviser for AIDS, initially to design for the council, in the context of our health and safety machinery, a training strategy to inform our staff and so help remove some of the prejudices they were being fed through the media. This approach was fully supported by all our trades unions. I cannot emphasise enough that, without full trade union support and cooperation, our training strategy for staff would not have got off the ground.

Initially some of our meals staff were concerned about delivering meals-on-wheels to people with AIDS. We had people wanting to leave the meal on the doorstep or saying (at that time there was quite a significant charge), 'We won't take the money, won't you disinfect it'. For three weeks management and trade unions in Hammersmith set up a rota for delivering meals for people with AIDS so that our employees could actually see that we were not trying to be mealy-mouthed about the policies we were promoting. By example, we, trade unions and management, have been able to overcome a significant amount of prejudice amongst our staff.

We have, since 1985, been providing on a regular basis, timetabled in throughout the year, one-day awareness courses for all staff, followed by three-day courses which are predominantly counselling workshops for those staff who are likely to be directly involved in working with people with AIDS. The awareness courses in the first instance were targeted at managerial staff who were responsible for the allocation of work. We found that sometimes people's prejudices were being reinforced by the fears which our own managerial staff had. We were trying to equip them so that they could talk more responsibly with staff who might be working with people with AIDS, or who might have fears about working with people with AIDS in the future.

The three-day courses have been targeted at our home care staff, our hospital discharge schemes, those home helps working in areas where we know people with AIDS are currently living, hospital social work staff who are often the very first point of contact for people with AIDS, and area team staff working with local communities through a community social work approach. We have also involved housing and estates management staff from our housing department and our sheltered housing wardens who are not always dealing with the elderly, but who look after people who are vulnerable through a number of circumstances. My local authority does recognise people with AIDS as vulnerable under the Homeless Persons Act if they have a housing need.

It has all along been the intention of the local authority to equip staff with sufficient information not to feel afraid of any person with whom they are working, and to be able to provide services from a generic service base, including services to people in the community who may have AIDS. Coincidentally, our strategy of training our home help staff has had quite a major spin-off in the local community itself. Home helps tend to be community leaders, and we now have some very experienced people living in our local community who are able to dispel the myths of AIDS in the areas in which they live as a result of the training we have given to them.

Staff in local authorities are the most important resource that we have. In equipping our own staff to deal responsibly with the AIDS issue, and to talk confidently about it in an unafraid, non-discriminatory way, we are actually doing quite a major exercise in public education as well as being able to deliver our services more effectively. Certainly I have overheard some of our home helps on local buses very robustly arguing with their neighbours when things have been said which they know are not true.

I shall now turn to some of the major planning issues apart from the training of staff. Since Norman Fowler visited America, he has seen the light. He has viewed the comprehensive community care programmes which are provided in San Francisco. He has shifted some of the emphasis of his thinking away from a hospital-based AIDS service to community care for people with AIDS, and is looking to the San Francisco experience to provide information on different models of care. Inner London is however very different from San Francisco. It is quite clear in talking to people from San Francisco that there is a homogeneous community in that city which supports itself, and that San Francisco does not have the fragmented community problem we face here in working with AIDS. It is also clear that some of the models of care which work very well in gay communities, both in America and over here, are not as applicable for people who are drug users. This issue needs to be further explored. What the Americans call 'case mix' has to be looked at in a planning context.

Of particular concern to a local authority is the need to provide for a client group for which it has not had any time at all to plan, and for whom the statistics and the numbers game seem to change daily. The estimates broadcast at the beginning of April for the UK varied from 30,000 to 100,000 by 1990. The estimates within my own borough vary from 2,000 to 8,000 by 1990. Whatever the numbers, however, it is clear that local authorities are going to have to provide an increased range of services for a client group which is requiring services 20 or 30 years in advance of the time when they might have been expected to call upon their local authority for help and support. This is a client group for which neither central government nor any other body had provided any resources whatsoever to local government. Services which my local authority has been called upon to provide range from counselling to domiciliary care, home help services, the meals-on-wheels service, and day care for people who have become demented.

It is very difficult to find an appropriate model of care for people with dementia at a very early age and staff find it difficult to cope with them. Advice and support is also needed for people who have suffered early blindness as a complication of their disease. It is said, by the DHSS AIDS unit, that in the United States persons who are diagnosed as having full-blown AIDS spend an average of 18 days in hospital until the date of their death. For a similar situation in this country the amount of time spent in hospital averages 86 days. It is clear that planners in this country would wish to reduce that length of stay from 86 to 18 days and, indeed, we would support them. Most people prefer during illness to remain in their own homes in their own communities. This has very considerable consequences for local authority resources, and indeed, for planning, in conjunction with the local health authority and voluntary organisations, for appropriate models of care in the community.

It is significant that in all the discussions on AIDS, including those I have had with the DHSS AIDS unit, housing is not on the agenda. Hammersmith & Fulham has felt it necessary to set up a special needs housing team to look at the range of needs for people with AIDS. There is clearly a need for increased resources to be put into local authority housing departments if they are actually to deal sensitively with the range of accommodation needs that are likely to be presented. It is clear that the DHSS needs to talk to the Department of the Environment more closely than it seems to be doing at present in planning its resources. It would also be helpful if some of the capital controls were taken away from local authorities so that housing departments could plough back more than they can afford at present into building and into supporting housing associations. As a local authority we have also found ourselves having to create clear policies about the care of children, particularly our own children in care, teenagers and adolescents. We need to provide them with sufficient education to be able to cope in the great wide world out there. We also have to provide for children with AIDS in our services and the children of people who have died from AIDS.

The AIDS issue clearly exposes where current collaborative machinery is not effective between health, social services and voluntary organisations. The Hammersmith & Fulham experience is that we relate to the Riverside Health Authority together with Kensington & Chelsea, and Westminster. We also deal with the Health Education Authority (formerly the Health Education Council), the Paddington & North Kensington Health Authority, the Bloomsbury Health Authority, and two regional health authorities. It is a nonsense to ask for coordinated plans across this very important client group when you are dealing with such diverse health authority machinery and three local authorities with very different political perspectives as to how services should be provided.

From the start, when people with AIDS first began to be referred to local authority departments, collaboration between individual professionals at grassroots level in Hammersmith & Fulham has been very good. Their concerns about individual people have been paramount and services have been put together with speed and sensitivity. It is only within the last six months, however, that formal planning mechanisms have been set up between the health and social service authorities to examine the issue in a more strategic light, and to look at the range of services that are necessary to provide a continuum of care and support. It should not have been a surprise to us to find that our planning mechanisms were not always adequate to the task. The recent Audit Commission report of community care has pointed out several failings in joint planning. The urgency and necessity for London boroughs to move quickly on the AIDS issue has also highlighted some of the strains in the system. They range from resources of people to do the planning to vested interests between local authorities, health authorities and voluntary organisations. Vested professional interests about who owns the problem are also apparent. The health service in London has been faced with losing resources as a result of the ubiquitous RAWP (Resource Allocation Working Party). Simultaneously London local authorities have been called upon to reduce their costs substantially. Clearly these have both impacted very heavily upon the way in which the health service and local authorities can respond to the issue of AIDS.

What special services, however, is it necessary to plan? Do people with AIDS need very specialist services? What is special about their medical condition that might dictate that they need special services? Or is it that special services are required because staff request them and in that way they are let off the hook from delivering services in a generic and holistic fashion?

The issue is clearly special in the amount of adverse media attention which it attracts, the fear which it engenders in people and the racist views which adverse media coverage and inaccurate media reporting have influenced. It has surfaced personal prejudices and homophobia in many of our population because of the vulnerability of particular groups to the disease. Clearly, in dealing with some of these issues, people need to be able to respond and manage in a very skilled and sensitive way. But how special are the services that are required? I find that in discussing the work involved in caring for people with AIDS the debate centres more around what is good practice rather than what is special practice. It is clear that domiciliary care and other staff need to observe high standards of health and safety policy and procedure. They need to do this anyway. Dealing with people with hepatitis is much more dangerous to domiciliary care staff than dealing with people with AIDS. If good health and safety procedures are followed then people will not be at risk in either circumstance. Good counselling and good social work advice is clearly necessary, but good counselling and social work advice is necessary for everyone who approaches a social services department. What the AIDS issue has raised is that in dealing with this group of people it is not possible to 'cut corners' as it may have been in the past with some other client groups.

Good equal opportunities policies are clearly paramount in dealing with people with AIDS and so are non-discriminatory practices in the delivery of service and in employment. Staff will not always know when they are dealing with a person who has AIDS. All people in receipt of services are entitled to respect, consideration and equality from those who deliver services, and these are clearly messages which we need to hear ourselves and to get home to our staff. Some special services are clearly necessary, however, such as the provision of hospice care, some specialist counselling services, and 'buddy support' outreach teams. The carers and partners, too, should not be forgotten in the provision of services. These partners are dealing with situations which they may be facing personally themselves at some time in the future. Certainly one should assist people in partnerships to live their lives together to the full.

It would be easy for health and social services to plan comprehensive models of care providing multi-disciplinary community teams, additional district nurses, additional social work resources, additional helplines and drop-in centres, and additional day care. How do we establish, however, whether this range of services is what is required and what is relevant? We can discover from the American experience the type of resources that people have found helpful there. However, inner-city London is quite different from sophisticated San Francisco.

People with AIDS in my own borough are predominantly from a very settled gay community who have lived in Hammersmith & Fulham for some time. They are young and articulate, and are able as a group to contribute to their own service planning. We must be careful not to impose a middle-aged model of care on a predominantly youthful group.

It should be imperative therefore that, whenever health and social services get together to consider the AIDS issue, they include the relevant voluntary organisations and that people with AIDS themselves are part of those teams. In this way people with AIDS can review and give feedback to us about the way in which they currently experience the services we provide, and can help us to put together services which will be more appropriate in the future. It is important that individual care plans are developed with people with AIDS. Anyone with AIDS should have control right from the start of what happens to them, control over the progress of their illness and over when and how professionals intervene. It would be easy for us to become locked into institutional models of care. We would lose, however, the opportunity to develop more community support facilities and the opportunity to facilitate more personal control over their situation by persons with AIDS.

Money as we know is going first into the health service and into institutions. When psychiatric hospitals closed it was difficult to transfer money out of the health services and into community care. How much more difficult is it going to be to get money out of the health service for the community care of people with AIDS, especially when the health service needs all the money it can get on this issue? Consultants will begin to see the level of resource they receive as the appropriate level of resource, and community support services will again become the Cinderella.

Clearly resource implications are absolutely paramount. My own local authority is attempting to cost what servicing people with AIDS came to last year. To date we have only been able to do a minimal calculation in terms of the domiciliary services that we provided, and we are continuing to work out how much it costs us to train staff and the operational time that is lost during those training periods. According to our initial calculations we spent £120,000 in the last financial year. This may seem a small amount when the health service is talking in terms of millions. £120,000 for my small inner London borough is £1 per head of the population and almost a penny rate. My local authority is one that may be rate-capped in two years time and we could be facing a rate-cap of £28 million. So where, central government, is community care then? We can do forward projections with our adjacent London boroughs. Kensington & Chelsea, with a very similar population to ourselves, are projecting that they will need another £500,000 over the next two years, and in the next three years up to £1 million just to provide domiciliary care support in response to demand.

This raises issues about how local authorities are financed and the inadequacy of local government finance in the past. The answer is clearly not to put the burden of services onto voluntary organisations. They are playing their role very well in telling us how we should respond as local authorities. They have been the forerunners and the pioneers in getting us to acknowledge that it is our responsibility to make a response. People with AIDS have as much right to the services of a local authority as anybody else in the community. People's rights in this matter have to be recognised, and a mechanism must be found for providing the cash necessary for local authorities to provide models of care in conjunction with the health authorities. The money should come, however, direct to local authorities as well as through joint planning and joint finance mechanisms. Local authorities could then make their own response as well as contributing to a joint planned response.

AIDS has been considered the biggest public health issue of our time and this century. I would suggest that AIDS is the biggest and most complex community care challenge that local authorities will have to face. Can we cope with it?

5 Education and prevention

Workshop and plenary discussion

Educating all members of society about HIV infection and AIDS is a massive task. It will involve not just providing sufficient information, educational and training courses, but mechanisms for attitudinal and behavioural change as well. It will be to a large extent a process of re-educating the public who have received mis-information and been fed prejudicial attitudes through irresponsible media. It will be most difficult, of course, to educate those who do not want to learn either because they are not interested or because they are afraid.

Educational programmes are expensive; they require materials, resources and time. Bureaucracy often slows down educational initiatives within the statutory sector, and in a London climate of rate-capping and RAWP (resource-losing), local and health authorities have relied quite heavily on community efforts to promote education and prevention. Given limited resources and in response to the immediacy of the problem, it has been considered most important to educate first those who are most vulnerable. Targeting education to specific groups and activities has therefore been inevitable. This approach has, however, added to the association of HIV and AIDS with particular groups and heightened discrimination and prejudice against these groups. Counter efforts have also therefore become necessary to emphasise that AIDS is potentially a problem for everyone.

Much attention needs to be given to the methods used in mass education. A common assumption by the statutory sector in this country is that everyone speaks and reads English, and that no one is illiterate. The government's leaflets on AIDS were only printed in English and Welsh. It is rumoured that some old age pensioners, unable to read Welsh, handed in their leaflets to the DHSS hoping to receive a heating allowance in exchange. Efforts were made in many London areas to translate the leaflets into several minority ethnic languages including Urdu, Gujarati, Hindi, Tamil and Arabic. Funding was provided through community relations councils and community health councils, but not without resentment that the government had not shown sufficient interest in minority ethnic communities to issue the leaflet initially in different ethnic languages. It is essential that all groups receive information in their own language if it is to be both acceptable and understood.

Leafleting clinical information or lecturing to large groups of people is an inadequate and ineffective method for getting across the full message about HIV and AIDS, and to be helped to understand that discrimination is based on prejudice. People need to be told how AIDS can be contracted, and how it cannot. They need to know about good health and safety practices. Facts need to be separated from myths. Participatory methods of education need to be employed to help people explore their own attitudes, and to examine the effect the media campaigns on AIDS have had on them. Small groups or workshops are recommended, the use of videos and information packs, advice centres and phone-ins. Opportunities for counselling must accompany education to assist in attitudinal and behavioural change. For without the latter, education alone will not counteract the spread of the syndrome or the discriminatory reaction to those who have it.

Much emphasis is being given to the educational needs of young people in relation to AIDS, especially those in the 10 - 13 age group whose attitudes to sexual activities are not yet formed. Much of their awareness of AIDS has been gleaned from television coverage. Access to them through their schools may be restricted by recent legislation which places sex education under the control of boards of governors. Sex education is not part of the curriculum in many schools; some heads are reluctant to include it unless pressurised by parents; and many teachers are wary about discussing sex themselves. While AIDS is primarily a health education topic, discussing AIDS necessarily involves talking about sex and broader issues concerning lifestyles, moralism and attitudes to sexual activity. Teachers need training themselves, assertiveness training in some cases, to approach these subjects without embarrassment or prejudice. They will also need to be aware of the racist and homophobic implications of some of the discrimination surrounding HIV and AIDS. Schools alone will not be able to address the fears and misunderstanding that already exist within the minds of young people. The youth service also has an important role to play.

Access to other vulnerable groups, such as prisoners and their families, is also an area of concern. Victorian attitudes still pervade our penal system. The statutory guidelines laid down for the provision of services are not observed in many areas of prison life. The stress of AIDS and AIDS-related conditions, and the hostility of inmates and wardens alike, can only add to the enormous stress under which prisoners already exist. Some people believe that a first step would be to make condoms freely available within prisons.

There is concern that another group, intravenous drug users, who are considered particularly vulnerable to the virus, are also being marginalised in the campaign against AIDS. Information and help needs to be taken onto the streets, for many drugs users do not come into either the statutory or voluntary agencies that work on their behalf. As a predominantly young group they equally need safe sex education and the free distribution of condoms, in addition to the needle exchange schemes being piloted in some major cities.

Education for awareness must be coupled with education for prevention. Preventive methods can realistically and significantly reduce the number of new HIV infection cases. Awareness training to counter prejudice and to encourage empathy, and preventive education to control the spread of the virus need to be coordinated and joint funded if the required impact on a national scale is to be achieved. The new Health Education Authority (formerly the Health Education Council) could play a major role in the coordination of a continuing public health campaign.

It is also felt that the medical profession could assist if it were able to assure the public to a greater extent about the modes of transmission of the virus. There has been a hesitancy on their part to state categorically that the virus cannot be spread by 'normal social contact'. The general public are still not convinced that the medical profession is not concealing some of the facts, although it has been stressed that not a single case of AIDS has developed in this way. Some seek a clearer definition of 'normal social contact'. There are doctors who believe it is dishonest and patronising to simplify what is a complex syndrome for the sake of total public assurance. Fear and suspicion inevitably still remain.

There have been some suggestions that prevention could be assisted if there was universal screening for HIV, although its actual effects on behavioural change could not be guaranteed. Testing is expensive in terms of the supporting services that must be provided, including the availability of adequate counselling before and after screening. Singling out certain groups for screening such as pregnant women, intravenous drug users and travellers abroad has been suggested, rather than universal screening which is not considered justified in terms of the current prevalence of the virus, and might add to public alarm. Routine blind testing of persons has ethical implications. Who should have control over testing, and if tests that can be individually administered are developed, should they be sold over the counter in pharmacies?

First aid precautions should be taken not just by professionals who may have direct contact with infected persons in the course of their work, but by all others who may be caring for people with HIV or AIDS in a voluntary capacity. These precautions need to be no more stringent than those taken by anyone working with or caring for people with infectious conditions. The level of precautions required in the context of AIDS by firemen, police, ambulance drivers, undertakers and hospital ancillary staff has been unnecessarily exaggerated in the public's mind.

Examples of good practice in terms of developing educational and prevention strategies do already exist within several London boroughs. One borough has agreed an extensive programme with the trade unions, to include staff training for their own employees and outreach into the schools within their area. The cooperation of the health authority has been secured, and a policy on the involvement of voluntary organisations adopted. Most importantly additional resources have been allocated and specialist trainers appointed.

Educational task groups have been set up in some areas; training advisers, community outreach workers and researchers identified to take on the additional workload involved. Training courses within statutory agencies have been opened up in some cases to participants from voluntary organisations. There still remains the need to coordinate pressure on government to provide additional money, materials and resources (although in an election year, AIDS will not be a vote winner). The trade unions need to be involved in all stages of early planning, and the success of different strategies monitored and evaluated to ensure optimal use of energy and resources.

A joint local strategy for education, training and prevention might include some of the following components

- formation of a joint health education and collaborative training strategy between health and local authorities
- distribution of prevention services and policies through local information points i.e. libraries, noticeboards, GP surgeries, public amenities
- collaboration with local press to produce AIDS supplements, and close contact with the press to provide information and articles which avoid scaremongering
- combined use of expertise on staff training
- presentations and video-assisted talks to local groups
- collaboration between authorities to expand uptake of family planning services and the issue of free condoms
- links with drug agencies, prisons or other agencies dealing with groups facing higher risks.

Is there any danger that we might over-educate the public? Is HIV/AIDS becoming more of an issue of public concern than it needs to be? Some people believe that educators and activists are trying to move the public debate too fast. Immediate educational and preventive measures are needed to control the spread of the virus, and to combat actual discrimination. Attitudinal and behavioural change with regard to the many issues about sexual activity, moralism and lifestyles which the advent of HIV/AIDS has raised will take far longer to promote.

6 Prejudice, racism and discrimination

Workshop and plenary discussion

Discrimination is widespread and pervasive throughout all aspects of our society. To those discriminated against, it serves to deny access to employment, education, welfare, housing and other statutory services. It leads to social isolation, and very often to alienation. People are discriminated against on the grounds of their colour, gender, ethnic origin, sexual orientation, disability, religion or other personal characteristics. While discrimination is generally based on misconceptions, myths and irrational hostility, it does not make it any less effective.

With the advent of HIV and AIDS, discrimination against particular groups within our society has increased. These groups include those with HIV or AIDS, and the people with whom they are in contact, either personally or professionally; discrimination is also extended to those people who are suspected of being, but who are not necessarily, connected with these former groups.

This discrimination is largely based on fear of AIDS itself, a previously unknown and fatal disease. It is a fear that has been engendered by mis-information within the media about the transmission of the virus and its infectious nature. Some of the discrimination is based purely on existing prejudices about groups of people who have been labelled as 'high risk' in relation to the spread of the virus. AIDS has heightened homophobia, strengthened feelings about the alleged irresponsibility of intravenous drug users; and on the grounds of unsubstantiated allegations that the virus originated in Africa, increased the incidence of racism in this society.

The adverse effects of prejudice based on fear and ignorance, and the discriminatory behaviour that results from these feelings has been most clearly illustrated in the case of frontline workers who have been called upon to provide services to people with HIV or AIDS. Fear of the infection, shared by better informed and more senior colleagues in the health and social services, has led some home helps, for example, to refuse to act as instructed. Others have refused to associate with those who have co-operated. Some have felt torn between their own sense of duty and the pressure brought to bear upon them by their families and friends. The implications for them of working with people with HIV and AIDS have served to highlight their roles within a wider industrial relations context and led to wage negotiations beyond the immediate AIDS debate. While a few employers have made special efforts to inform and train home helps with respect to working with HIV or AIDS, it is telling both of the influence of the media, and the pervasive nature of personal prejudice, that some home helps, even after learning the facts of the virus, are still not prepared to care for those infected by it.

The employer's role in creating a safe and supportive environment for workers with HIV or AIDS, and in providing clear policy on non-discrimination on the part of all employees is therefore paramount. To date, few private employers, with the exception of a handful of American companies, have put forward clear policy statements and acted to put them into practice. The Terrence Higgins Trust has over 200 cases in hand of discrimination against HIV positive people at work. Much of this discrimination is based on myth, superstition and total ignorance. In 1986 the Trust reported a case of a woman who had been sacked because she knew a man with AIDS. There is no medical reason why people with HIV or AIDS should not continue to work while they are able, if proper health and safety procedures are observed. Stress, itself a factor in the onset of AIDS, can only be compounded by an employee's fear of losing his or her job, or being subjected to discriminatory behaviour on the part of colleagues as a result of any breach of confidentiality by their employer.

Both public and private managements have a responsibility, therefore, to reconsider their internal policies on health and safety, as well as their equal opportunities policy in the context of AIDS. The appointment of additional advisers, trainers and counsellors may be required to ensure that all employees understand both the medical and the social implications of HIV and AIDS. People learn through example, and the stance of those in authority and with responsibility will influence the climate in which behavioural and attitudinal change needs to take place. One of the major dilemmas facing policy-makers within the employer community is the relative advantages of combining or separating within an overall statement on HIV and AIDS, health and safety policy and equal opportunities policy. Reference to particular groups in the context of AIDS could reinforce prejudice about supposed 'at risk' groups, associating the virus with these groups. Many people believe, however, that the time has passed when HIV or AIDS could be considered simply as a health problem. For discrimination is taking place and has been heightened by mis-information. Including equal opportunities policy on HIV/AIDS within employer statements would give emphasis to the unacceptability of discriminatory practice within the workplace. Non-compliance by employees would then be a disciplinary offence, although training and counselling would have to precede any formal procedure to enforce behavioural change.

Many employers are turning to the trade unions for help. The unions, while their record to date in confronting discrimination in the workplace has been poor, could play a significant role in tackling some of the issues arising from the AIDS crisis. The major unions within the health and social services, including NUPE, NALGO and COHSE, have a particular responsibility to do so, and their co-operation and joint action are crucial to the success of non-discrimination strategies. The advent of AIDS is, in fact, forcing them to consider all forms of discrimination, not just that relating to HIV and AIDS. While NUPE along with the other unions has been slow to start, it has now produced a number of policy statements and guidelines for distribution throughout its membership. It has embarked on a series of courses for its members, ensuring in particular that convenors and shop stewards have the necessary information to pass on and advise members at all levels of employment. Emphasis is being given to grassroots membership, not just medical and quasi-professional staff, and efforts are being made to increase direct communication rather than relying on written material that is often not read or understood within the broader membership. Unions, as well as management, will need to determine procedures for assisting members who feel unable to change their attitudes or behaviour after adequate training and counselling. Joint understanding and action between unions and management will be essential. One of the early publications setting out the issues surrounding AIDS for trade unionists was an information pack entitled 'AIDS: a trade union issue'.

Discrimination on the grounds of race or colour, despite existing legislation, is still commonplace in employment. The uncertainty of the origin of the virus has reinforced racism and given rise to further attacks on the black community by prejudiced sectors within society wishing to apportion blame for the advent of AIDS. Statistics identifying the spread of the virus in Africa have been used as further evidence of the 'guilt' of the black community without acknowledgement of the limited resources in Africa to combat transmission, for example amongst the very mobile refugee population. Suggested strategies for screening immigrants from Africa, and black blood donors in this country, have led to the further reinforcement of racist attitudes.

The black community has long felt exploited in Britain; many black people have been excluded from statutory services or simply given low priority in social welfare terms. It is now apparent that the (predominantly white) response to AIDS is failing the black community again. Sufficient efforts have not been made to involve black people in the national fight against AIDS; nor to train and equip black people to challenge the spread of AIDS within their own communities. It is incumbent on those agencies with resources and responsibility to liaise with and consult the black community. To this end, bodies working to combat AIDS should adopt anti-racist policies to ensure that their language, their literature and their actions promote a truly national approach to the problems of AIDS.

Black participants at the conference drew attention to the potentially racist connotations of some of the remarks and references in the paper on the New York experience. It was suggested in the paper that in the black community in New York 'homophobia is, if anything, greater than elsewhere'. Reference was also made to stereotypical groups of 'single parent West Indian mothers of South London, the tightly-knit Indian and Pakistani families of West London, and extended Jewish families of East London'. Statistics such as the one quoted in the paper – '95 per cent of children with AIDS are from ethnic minority backgrounds' – can be misunderstood. These points were raised for consideration during the workshops.

One local group that is striving to redress the imbalance of attention being paid by the statutory authorities to AIDS within the black community is the Black Communities AIDS Team, recently established in South London. Its aims are to inform the black community on issues concerning the HIV virus, related conditions and AIDS; to provide support for people with the HIV virus, related conditions and AIDS, their families and friends; to challenge the structural and social reinforcement of racism through AIDS by the media and wider society; to challenge the prejudices and myths obscuring the facts relating to HIV and AIDS; and to establish links and to liaise with relevant organisations to challenge AIDS across the board.

The AIDS Team offers assistance to other agencies who do not have existing links with the African, Asian or Caribbean communities in London. Like many black groups, the AIDS Team has very limited resources but is seeking the opportunity to challenge AIDS on an equal basis to other agencies in the field. Unless groups such as this one are given this opportunity, the problem of AIDS within the black community is likely to remain marginalised, and racist attitudes will continue to obscure the unequal provision of AIDS services, with respect to both care and prevention, to all sectors of the community.

Racism and homophobia must be confronted, therefore, in the context of AIDS. Changing attitudes is a long-term process, and to redress the imbalance in health education strategies and service delivery extra funding will be required as well as redeployment of resources and re-evaluation of current approaches. It should clearly be a management responsibility within every workplace to ensure that this reappraisal occurs. Constructive and creative criticism is needed to ensure that those whose attitudes and behaviour must change are helped to understand the very complex nature of the prejudices on which their emotions and actions are based. Everyone who develops AIDS deserves the best care and attention possible in the final months or years left to them. Helping people with HIV or AIDS is an opportunity to show love and respect to those who are potentially ill and may be dying, irrespective of who they are. Everyone has a human responsibility to respond to this challenge.

7 Practical strategies for local provision

Workshop and plenary discussion

As a new problem confronting society, HIV/AIDS may require a new set of solutions. It will undoubtedly require joint action and integrated strategies on a London-wide basis as well as at local level. Action will need to be co-ordinated on three distinct fronts: public health measures, including health and sex education and AIDS awareness training; the development of an integrated and comprehensive network of community care; and finally the formulation of effective policies and positive action plans to counter actual and potential discrimination against people with HIV or AIDS.

The difficulties in achieving these aims are enormous. Many agencies, both statutory and voluntary, are already involved in the field. Efforts are being duplicated, professional cliques are being formed, and the public is left confused. As so often happens, those most in need of help are left on the outside. Health services are seen to be vying with social services, and in the climate of rate-capping and RAWP losses, competition for resources is rife.

The structure of London does not help. There are 33 London boroughs, and no all-embracing strategic body. There are four health regions, and 30 district health authorities. A recent DHSS survey which sought to identify and evaluate the London response to AIDS found very patchy provision across local authority areas; poor quality within some authorities, minimal or even nil response in others.

Action has usually been initiated in response to a crisis that has arisen within a particular authority. In some cases this has been the disclosure or death of a council employee with AIDS; in other areas incidences of difficulties faced by clients in obtaining council services have highlighted the inadequacy of the local authority provision; or staff have come together to formulate new service responses as unforeseen needs have become more clearly apparent.

Before considering the need for a more strategic response on a London-wide basis, it is important to examine the integrated approaches that should be adopted at local level. The formulation of a local strategy must encompass both statutory and voluntary agencies. There are a multitude of different groups who will need to be involved, which may make combined, general purpose meetings large and unwieldy. Cross-representation on a HIV/AIDS working party is a possible solution. As a general principle it is important to include the participation of people with HIV or AIDS. It might also be useful to assume that all working party members require information and/or training about the HIV virus.

The formulation of a local strategy will draw on the expertise and experience of the representative agencies in the area. A district medical officer, who most usually also functions as the medical officer for environmental health, is likely to lead the health authority's initiative on HIV/AIDS. Other health staff to be involved might include the health education officer, clinic staff, district nursing officers and unit general managers. From the local authority side, the lead is most often taken by the environmental health department. Some local authorities have appointed specialist staff, for example health advisers or health liaison officers, in recognition that HIV/AIDS is first and foremost a public health issue. Local education authorities also have an important role to play as young people are a major target for public health campaigns. In all the statutory authorities it is important that all departments have representation, and that policy development on employee-related matters is undertaken with the full consultation of staff unions.

Statutory agencies cannot combat HIV/AIDS alone. The role of the voluntary sector is vital, and in any local strategy their contribution should be fully recognised and encouraged. In fact, a small group of voluntary organisations, set up to work for and with people with HIV/AIDS, have carried much of the burden to date in terms of local education, information and community care. It is to the voluntary sector that many people with HIV or AIDS, their families and friends, have turned. People under stress or in need of help often will not approach statutory agencies. Voluntary efforts have however been poorly publicised, over-burdened, and under-resourced. Over time, HIV/AIDS self-help groups are likely to emerge in most of the UK's cities and towns, and other voluntary agencies may become involved in the prevention and care delivery process. Statutory agencies should consider how they can assist the formation of local groups and how they might be given financial assistance. Local groups are often far more able to work at grassroots level and to address problems of local deprivation and discrimination. They are often better at communicating and consulting, and are both more credible and acceptable within their immediate environment. Both staff and volunteers within community groups have the local knowledge and understanding that is vital for an integrated strategy at local level.

One further group should be represented on any HIV/AIDS working party – family practitioner committees. They organise GP and dental services which are often the first port of call for people who are worried about the virus. It is essential therefore that they know what the authorities are doing so that they themselves can sponsor good practice.

Having brought representatives from the statutory and voluntary sectors together to formulate an integrated local strategy, the first step will be to agree a full policy response to HIV/AIDS. An agreed policy is important because it sets benchmarks for action. No policy will stand in perpetuity and there must therefore be an agreed procedure for monitoring progress and reviewing policy and practice.

Next, local care services will need to be organised. At present the majority of patients are being treated in a small number of health authorities. Increasingly it is hoped that they will be treated locally in the community. Social services and housing departments will need to consider their policies for this new client group. Good practice will include the development of effective hospital discharge arrangements, and access to a full range of domiciliary services. Consideration will need to be given to what special services, if any, need to be provided. These may range from special refuse collection to welfare rights, and extended use of transport schemes such as Taxicard. Specialist housing associations might develop group homes. It is essential in all these service plans to ensure that user participation is at every level, and that efforts are also made to develop the participation of volunteers, for example through local befriending schemes.

One integrated model under present discussion is the HIV day centre. This might have the following purposes:

- to function as an activity and day centre for people with HIV infection
- to function as a 'wellness' or health maintenance centre, with an emphasis on nutrition, stress reduction, physical fitness, and so on
- to function as far as possible along self-help lines, actively seeking broader voluntary support for its operation
- to provide a base for counselling and advocacy activities to include a range of

issues, such as welfare benefits, and to provide advocacy for people experiencing discrimination and requiring emergency help
- to provide a social centre and a base for outreach activities
- to offer a referrals service for support from other agencies
- to provide office accommodation for centre management and voluntary agencies
- to provide a base for research.

If local collaborative strategies are adopted they will require considerable expenditure of time and financial resources. Both authority members and officers should be involved in decision making, and some evaluation of efforts will need to be undertaken. Achievement could be measured by a number of indicators including

- the degree to which authorities and voluntary groups have moved away from a 'panic' response and adopted consistent strategies within their own offices and across their joint field of activity
- the degree to which effective staff training has been undertaken, and procedures for confidentiality adopted
- the clear identification of lead officers with well understood roles
- joint projects undertaken and client referral patterns developed
- increased uptake of family planning and related services by men
- over the longer term, a fall in the rate of growth in the number of new HIV cases.

While collaboration within local areas is vital, the need for strategic co-ordination across London is also considered necessary. The idea of a London AIDS Council has been mooted. While there is not a pan-London body for any other medical syndrome, the immediacy of the AIDS crisis suggests that there needs to be some form of framework in which the London dimension of the problem can be considered. It is unlikely that any new organisational tier will be put in place in the short term, and it is perhaps not necessary. What is required is a forum for London in which health authorities, local authorities and voluntary organisations can come together.

The failure of the health authorities to work together has already been given some attention by the King's Fund in its report on 'back to back planning', *Planned health services for inner London*. Medical consultants and researchers are, of course, talking to each other within London and across the country in an attempt to benefit from lessons learnt and false moves made as quickly as possible. There is also an informal network amongst individuals within the voluntary sector. The London Strategic Policy Unit is already trying to co-ordinate the efforts of its member authorities in reinforcing a joint community care approach. All the authorities need to come together, however, with the voluntary sector in some formal way in order to avoid efforts being duplicated and to minimise competition for resources. It may be that a standing committee on AIDS established under the auspices of the King's Fund and drawing together the health authorities, local authorities and voluntary organisations, would be the best solution. The new Health Education Authority (formerly the Health Education Council) might be in a unique position to sponsor such an initiative.

A strategic approach across London could help ensure that at least the minimum standards of provision are available in those areas where demand is likely to be greatest. Joint efforts could be made to obtain the detailed statistics for London which are not currently available. Comprehensive monitoring of information could be undertaken if greater access to statistics from the DHSS, CDSC and the voluntary sector could be secured. Along with information and statistics, experience, models of good practice and policy statements could also be shared. An updated directory of resources could be maintained. Most importantly, available resources could be more equitably and effectively distributed. Co-ordinated efforts could be made to persuade government to provide additional funding to health and local authorities; they in turn could provide more resources directly to community and voluntary organisations. As far as possible red tape could be cut.

The solution is seen therefore to lie in all groups involved in the fight against HIV and AIDS coming together, working together and staying together. Senior managers and planners, professional staff and frontline workers, and people with HIV or AIDS need to link together to secure resources from central government, and from the corporate and charitable sectors. London is in the frontline; it will not have a second chance and it cannot fail. Planning, resource raising and service delivery must be tackled on a strategic basis, and tackled soon.

8 AIDS: future directions

Conference Afterword
by Geof Rayner, Health Liaison Officer, Lambeth

AIDS – planning local services was devised to allow frontline service workers, many unfamiliar with the issues, to listen to speakers involved in providing services both in America and Britain, and to participate in workshops to discuss the key issues of education and prevention, local service strategies and discrimination and prejudice. An additional point to be made is that there were people presenting workshops and participants in workshops who were antibody positive, had AIDS Related Complex or AIDS.

It is clear from the conference that we are not at a stage of laid down procedures. When dealing with issues around HIV/AIDS other unresolved problems come to the surface. For example, joint planning between the NHS and local government works poorly, many frontline workers do not think that information is getting down to them, and in many cases a policy stance does not exist. HIV/AIDS is not being dealt with as primarily a public health issue, and an ensuing service delivery issue, but as a range of perplexing, overheated 'problems', some of which appear invented rather than naturally arising.

The following situation, drawn from an actual case, shows how easily this can occur. A home help is visiting a young client. He is ill, but no explanation is given. Over time the home help suspects that he has AIDS, although she has not been told. The young man dies in confused circumstances, and the word is passed to the environmental health department. A team of EHOs are sent to his accommodation, dressed in protective clothing and proceed to cleanse his rooms, which includes burning the telephone. The home help, who had a caring relationship with the young man is now frightened that she has been placed at risk by her management, and she reports these events to her co-workers. The home helps thereafter refuse to enter the homes of clients whom they suspect to have AIDS. They will not believe management assurances that there are no environmental risks.

It is not possible to write a set of rules which would apply to every case to avoid problems like this. However, it is possible, and very useful, to define a set of principles which can form the basis of policy and action. Two emerge from the situation I have described.

The first is the need for preparedness. Failure to think ahead, to have an 'AIDS awareness strategy', means that management relations can be soured and services for clients damaged for months ahead. The second principle is consistency. This problem would never have arisen if a common stance towards health and safety had been adopted throughout the authority. The same rules should apply to everyone.

One of the most contagious aspects of HIV/AIDS is fear, which leads workers to make poor judgements and to adopt unprofessional behaviour. This can, over time, be avoided or resolved by good staff training, good publicity, good contact with the local press, and an authority-wide forum, such as an HIV working party, for making sure that the message gets through not just to managers, but to frontline staff.

Where the veil of fear has been set aside, other principles must be brought into play. Most of them are just the basic ones of running any service for any client group, but they always need restating. The first one is: the client comes first. The client is the one at risk, not the service worker. Furthermore, there is no point in devising services which further isolate this group, and which treat them as somehow different from anyone else. Not that there are not real differences and special needs: many clients will be seriously sick (but may also recover very quickly from bouts of illness); they will be young; and they are emotionally at risk. Clients will have to face the fear of dying, which most of the rest of us can simply ignore.

Alongside client-centredness is the key principle of confidentiality. This is a precious commodity, and once debased can have damaging results for the client. At present AIDS is a scare term, but over time this will subside. The same rule of consistency applies: all authorities have rules on confidentiality and these should be understood and if necessary reaffirmed to ensure they are used on behalf of the client rather than against them.

Preparedness, consistency, client-centredness, are some of the key principles for developing local strategies. But to make these effective will take resources and goodwill. An approach will need to be developed jointly between health authorities, local authorities, education authorities, trades unions, and voluntary bodies. This needs to be developed in full accord with a clear equal opportunities statement on AIDS. Some authorities, in order to make clear that AIDS affects everyone, have included this as part of an anti-discrimination statement on disabilities.

Over time, authorities will be able to move away from a war footing on HIV/AIDS. Until then, it has to be recognized that, particularly for London, spread of the virus is deadly serious; that it is a public health issue, not a moral issue. It will require resources, imagination, goodwill, and determination. It is not going to go away.

Geof Rayner was a member of the Conference Steering Committee

Appendix

THE EPIDEMIOLOGY OF HUMAN IMMUNODEFICIENCY VIRUS (HIV) AND ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) IN LONDON

Prepared by A Renton and A H Lewis, Immunity

Introduction

This paper aims to outline the apparent size of the current problem of HIV/AIDS infection in London and its likely progression. The data is largely drawn from the monthly Communicable Disease Reports (CDR) compiled by the Communicable Disease Surveillance Centre (CDSC).

The CDSC receives notification of cases of AIDS and other HIV related diseases and collects information on the results of voluntary testing at Sexually Transmitted Disease (STD) clinics, and data from screening of donor blood from the Blood Transfusion Service.

Background

The following points should be noted as general background to HIV and AIDS.

- the origin of the HIV virus is unknown.
- the first case of AIDS was reported in 1981 by the Centre for Disease Control (CDC) in Atlanta USA.
- HIV, the causative agent, was first identified in 1983. Subsequently AIDS and HIV infection have been identified in more than 75 countries, in all continents.
- the earliest evidence of infection with HIV is from blood collected in Zaire in 1959. [1]
- by the end of 1985 the WHO estimated that there were at least 25,000 cases of AIDS worldwide. [2]
- it is estimated that several million people worldwide are infected with HIV. [3]
- 20 to 100 per cent of those infected with HIV may develop AIDS at some time in the future.[4, 5]

National statistics

The CDSC data are probably the most complete for the nation as a whole.

People with AIDS – annual figures

Table 1 Number of patients presenting with clinical AIDS each year from 1979 to September 1986 reported to the CDSC.

	1979	1981	1982	1983	1984	1985	1986(Sept)
Patients	2	5	19	52	111	276	512

People with AIDS – cumulative totals

Table 2 Cumulative totals of UK reports of AIDS cases and numbers known to have died, to 28 February 1987. London is compared with the rest of the UK

Region	*Cumulative cases*	*Total deaths*
London	567	265
England (out of London)	134	89
Wales	11	9
Scotland	16	11
Northern Ireland	3	3
Total	731	377

Figures are given in the paper 'Planning services in the NHS' by Dr June Crown for HIV antibody persons by age and sex (Table 1), means of infection (Table 2), and region (Table 3). It should be noted that the HIV antibody test demonstrates that an individual has raised an immune response to the virus and has therefore been infected at some time in the past. It does *not* show that an individual will develop AIDS or that he/she is infectious.

London statistics

From these figures it can be seen that there is a concentration of reports coming from the London area. London has very particular features which make these figures unsurprising:

- densely populated
- relatively transient population
- concentration of medical services and extensive use by non-residents
- concentration of 'high risk' groups.

People with AIDS in London

Table 3 AIDS cases in London reported to the CDSC to February 1987

Region	*Cumulative cases*	*Total deaths*
N W Thames	363	165
N E Thames	130	60
S E Thames	59	30
S W Thames	15	10

People infected – Haemophiliacs

The Haemophilia Society estimate that there are 7,000 haemophiliacs in the UK. 50 per cent of seropositive haemophiliacs were reported in London [8]

Table 7 Reports of HIV seropositive haemophiliacs in London to CDSC by date

Period	*Cumulative total by region* *NW Thames*	*NE Thames*	*SE Thames*	*SW Thames*
To March 1985	1	0	1	0
To September 1985	3	29	8	0
To March 1986	22	74	57	4
To September	25	143	75	7
To December	26	169	90	8

(Regional variations largely reflect the location of major haemophilia centres). Now that blood products are being heat-treated in order to inactivate the virus, both haemophiliacs and recipients of other transfused blood products should no longer run the same risk of infection.

People infected – Heterosexuals

It is widely accepted that heterosexual transmission of the virus may occur in both directions, that is, man to woman and woman to man although there may be differences in the ease with which transmission occurs [9].

Table 8 Reports of HIV seropositive heterosexuals in London to CDSC by date

Period	*Cumulative total by region* *NW Thames*	*NE Thames*	*SE Thames*	*SW Thames*
To March 1985	0	0	0	0
To September	0	1	0	0
To March 1986	4	2	0	1
To September	8	3	1	1
To December	12	5	4	1

Published figures for rates of seropositivity for HIV in heterosexuals being tested at STD clinics are not available.

Table 9 Rates of seropositivity for heterosexuals of both sexes tested between June and November 1986 at the Praed Street Clinic [6].

Number tested	*Number positive*	*Percentage positive*
605	15	2.5

These data were not broken down by risk factors so that this does not represent individuals who necessarily contracted HIV heterosexually, that is, heterosexual IV drug users would be included.

To the end of February 1987, 17 seropositive female patients had been identified at the Praed Street Clinic. Of these only four had heterosexual contact as their only risk factor [10].

Other London clinics canvassed have reported similarly low figures for patients with heterosexual contact as a sole risk factor. This probably reflects an, as yet, small number of infected individuals in the heterosexual community.

Discussion

Any attempts to predict future trends are fraught with difficulty as they are based on the following techniques:

- extrapolations of current figures by comparison with trends experienced in other cities
- construction of mathematical models based on current understanding of modes of transmission and levels of infection

Limitations and inaccuracies in using these techniques arise from the following factors.

Geographical variation

Patterns of infection and disease differ strikingly with geographical location both between and within countries. Reasons for this variation may include

- cultural and behavioural differences
- different levels of general health
- levels of other sexually transmitted disease such as aiding transmission through open sores
- variations in other factors which may predispose to transmission and disease in those infected.

In Africa [5] HIV and AIDS prevalence is equally distributed between the sexes, virus transmission occurring predominantly through heterosexual intercourse. In Western countries there is a preponderence among homosexual men and intravenous drug users with a male:female ratio of more than 10:1 [5]. Regional variations due to factors such as concentrations of high risk groups in a particular city have been described in these countries.

Projections based on data from other places may thus be very misleading.

Means of collection of data

Neither AIDS nor HIV infection is officially notifiable. The CDSC data report only those positive tests notified and therefore necessarily underestimate the absolute number. Furthermore no figures are published on the number of negative tests, making ratios of positive to negative tests difficult to determine. Consequently no estimates of the prevalence of HIV infection in the various groups can accurately be made from these figures.

Differences in reporting behaviour between the different centres performing the test could potentially affect the figures, especially the distribution of cases of both HIV seropositivity and AIDS among the London regions. However the biggest distortion of the regional variation is probably introduced by the location of major centres dealing with the disorder such as the Praed Street Clinic in the NW Thames Region.

Sample bias

Except within the blood transfusion service, HIV antibody testing is at present done almost exclusively on request from the patient. This self-selection may lead either to over or under-estimates of the actual rates of prevalence in the particular groups within the community. Figures for the numbers of patients with AIDS are, in contrast to those for seropositives, not affected by changes in awareness and testing behaviour. Awareness of the syndrome among medical practitioners should no longer be a limiting factor in correct diagnosis.

Uncertainties about the natural history of HIV infection

The proportion of seropositive persons who will eventually develop AIDS remains unclear. Current figures support estimates ranging from 20 to 100 per cent[11]. It is unknown what proportion of those who are antibody positive are infectious to other people. The other major unknown is whether or when effective vaccination and/or therapy will become available.

Changing patterns of behaviour

The influence of public education campaigns on behaviour may substantially alter the long term trends.

Summary

Since 1983 newly presenting cases of AIDS have more than doubled each year, and it is likely that the number of new cases presenting in 1987 will exceed 1,300[11]. At present, the majority of seropositive individuals, and of people with AIDS belong to the already defined high-risk groups. However, a small number of people have been infected heterosexually. Without changes in behaviour, this group could become much larger much more quickly as the pool of infection increases.

Changes in behaviour may well limit the spread of the infection in the long term but the bulk of new cases of HIV-related illness in the next few years will be drawn from those already infected.

Figures for HIV test requests at the Praed Street Clinic[5] and at all London STD clinics canvassed, showed a tremendous increase during the months from October 1986 following the government's information campaign and widespread media coverage of the issues. Despite the approximately fourfold increase in tests performed, positive results barely increased at all. Testing is now being requested by individuals at relatively lower risk and by some at practically no risk at all. This increase should lead to more accurate estimates of seroprevalence in the population at large.

The question of heterosexual transmission

There is no evidence of significant levels of HIV seropositivity acquired through heterosexual contact in the UK. Those heterosexuals found seropositive have almost always had another risk factor such as IV drug use. The current concentration of infection among male homosexuals has led to the suggestion that bisexual men might provide a conduit between the two groups.

It has yet to be demonstrated that pure heterosexual transmission can sustain significant levels of infection in developed countries. Prostitute women have been cited in the media and elsewhere as a potential source of infection to the heterosexual community. Among a group of 70 prostitutes screened at St Mary's Hospital, only those with another risk factor (IV drug use) proved seropositive (about 2 per cent). It seems that at present, provided this sample is at all representative, prostitute women do not constitute a significant source of infection in London. IV drug users are another possible avenue of spread into the heterosexual community.

The increasing numbers of heterosexual men and women being found HIV positive in the USA should be cautionary. If this situation is to be avoided here, then heterosexuals must become aware that they are not insulated from any risk. It is to be hoped that it does not require a large number of deaths among heterosexuals for this to be realised.

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A NOTE ABOUT LANGUAGE

Prepared by Peter Holmes, Immunity

The real HIV/AIDS epidemic threatens to be not only a medical one but also one of discrimination against anyone perceived to be at risk or infected so it's important that we undermine prejudice before it gets started.

With the best intentions, even AIDS 'professionals' sometimes let themselves be seduced by the glib shorthand of AIDS and from time to time they say – and write – things of which they might be ashamed later.

The language of AIDS is important, because prejudice and discrimination against others are rooted in it. We are exposed to these phrases and labels over and over and their implicit meanings become a part of our belief system and attitudes toward people with AIDS.

At the risk of sounding sanctimonious here are a few suggestions:

USE 'someone (or people) with HIV infection' or 'someone (or people) with AIDS.

NEVER say 'AIDS victims' or 'AIDS sufferers'. The word 'victim' implies innocence and guilt.

DON'T call HIV 'the AIDS virus'. It can cause AIDS but doesn't necessarily do so. Some people with HIV infection may never develop AIDS.

CALL HIV 'the virus which can cause AIDS.

NEVER use 'AIDS virus carriers' or 'AIDS carriers'. Being HIV antibody positive may not necessarily mean a person is infectious to others.

REMEMBER that there is no 'AIDS test'. The most common test used at the moment is for the antibody developed to HIV by the immune system of someone who has been infected with the virus at some time in the past. Some hospitals are now using a test for the virus antigen itself. NOBODY can be found to have AIDS from a blood test.

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