# SELECT COMMITTEE ENQUIRY ON AIDS: SECRETARY OF STATE'S ORAL EVIDENCE

1. Education - what are you doing to prevent spread and is it working?

Since there is no cure or vaccine for AIDS, public health education remains the major weapon in the fight to contain the spread of infection. We therefore decided that there needed to be a campaign to raise the level of general public awareness about:

- the threat posed by AIDS
- the main methods of transmission of the virus
- methods of reducing risk with the objective of limiting the spread of infection within recognisable risk groups and the population at large.

We also needed to reassure those who had been alarmed by sensational or inaccurate media coverage.

The campaign has been closely monitored by market research commissioned by the Department and this has shown that it has been remarkably successful on a number of counts. The latest research shows that of those interviewed:

- \* 99% of people agree that you can become infected by sharing needles to inject drugs;
- \* 98% agree that you can catch the virus through sexual intercourse;
- 90% agree that the risk is greater the more sexual partners
   you have, and;
- \* 93% of young people agree that the risk can be reduced by using a condom.

This is a very substantial achievement in public education. is also evidence that the campaign is not only getting across the vital messages about how the AIDS virus is transmitted but is also helping to dispel some groundless fears. Although AIDS is a matter of great concern to most people, there is little evidence from the research that the issue is causing panic or alarm, and more and more people are coming to recognise that it This suggests is safe to associate socially with AIDS victims. that the campaign has struck the right balance by providing while at the same time informing and raising reassurance, people's awareness of the disease. We now need to turn knowledge into action by encouraging changed attitudes and behavioural so that people reduce the risk of infection to modification themselves and others.

aim of the first phase of the campaign was to raise the general level of public awareness about AIDS. The second phase aim to translate this knowledge into action. So far as attitudes to the use of condoms is concerned, market research has shown that, despite a generally high perception of the risk of infection and the part condoms can play in reducing it, there are continuing negative attitudes towards their use. Resistance to the use of condoms remains high among young sexually active heterosexuals but there is evidence that homosexual men have behaviour and monogamous to change their sexual has common. This change become more have relationships from an increased awareness AIDS about transpired in part resulting from the efforts of those voluntary bodies working with at risk groups, to which the Department has given financial assistance as part of its strategy in the fight against AIDS.

# 2. Estimates of likely spread since predictions conference?

You will recall that at the conference of international experts I announced that Dr Joe Smith was to chair a group to look at ways The group is considering both prevalence of improving our data. Although they have started on this work, and prediction issues. and they are looking at these problems urgently, they have yet to reach any conclusions or make any recommendations. So to that as I extent we cannot offer any new information. am However, the whole question ofyou will already understand, sure prevalance and predictions is very difficult.

#### [IF NEEDED]

relation to the estimate of 30-40,000 people infected by HIV the UK, the Committee will know that the Department's memorandum made it clear that this estimate was based on a pretty crude assumption that there was a simple ratio between the number of AIDS cases and the number of those with HIV. The memorandum it clear that the estimate could be out by as much as fold in either direction (para 4.8). We believe that it would be wrong to raise this estimate too often, both because approach would tend to suggest a greater degree of accuracy the estimates than is really the case and because we believe Government's public education campaign and also the work of voluntary groups may have had an effect on the rate of Moreover we think it sensible to await the views of Dr group who, we hope, will help improve the basis for estimates.

## 3. Risk to heterosexuals overstated?

In March 1986, a low key campaign was mounted comprising newspaper advertisements, the HEC leaflet "AIDS: What Everybody Needs to Know" and a telephone helpline run by the College of Health, now Healthline, funded by the Department.

However, it became apparent that a harder hitting and more intensive approach was needed and to meet this need the campaign was greatly intensified. In November 1986 I allocated £20M to be spent for this purpose covering the 12 months to December 1987: £7.5M was spent in the period November 1986 - March 1987 on intensive media advertising, poster displays and a household leaflet drop.

It is true that at present, the majority of AIDS cases and HIV infected persons occur within recognised risk groups in the UK. AIDS is a disease which is not confined to members of However, these groups and any man or woman can become infected as a result intimate sexual contact with an infected person. therefore necessary to target information about the disease population as a whole in the first instance. The phase of the campaign will also need to address the population in in order to sustain current levels of awareness and in general knowledge about the disease and to guard against complacency. People will also need to be kept informed of developments in knowledge about AIDS and its transmission routes. The campaign will also need to encourage more widespread behavioural changes in the heterosexual population and especially amongst sexually active young people, and to reinforce and further encourage, for example, the behavioural modification we are already seeing amongst the homosexual community.

4. Education - what further steps in the campaign and what targeting?

We are very aware that people with sensory disabilities, reading difficulties, or whose first language is not English, may not have benefitted in full from the campaign so far and that measures are needed to ensure that these groups receive the information in ways that are appropriate to them. Action is in hand on these fronts:

- \* Financial support has been given to the British Deaf Association and the Royal National Institute for the Blind for the production of AIDS material for the hearing impaired and visually handicapped.
- \* Consideration is being given to proposals for the dissemination of information to ethnic groups. Discussions with representatives of ethnic communities have reinforced our view that simple translation of existing AIDS leaflets would not be sufficient, and that it is essential that information is put across in ways that are sensitive to the cultural and religious mores of each of the communities concerned. Consequently we have commissioned research into the needs of the ethnic communities and how best AIDS information can be channelled to them. Strategy will be formulated in the light of this.
- \* Several proposals have been made, for example leaflets in cartoon form, for disseminating information to those with reading difficulties. We are seeking the advice of the DES as to the best way to proceed.
- \* Work is in hand to develop a campaign directed at homosexuals to achieve first attitudinal and then behavioural change. It will seek to discourage dangerous practices and promiscuity amongst homosexuals and seeking changes in the attitudes and behaviour of the more promiscuous sectors of the heterosexual population. Some of this can be achieved nationally by use of the mass media.

Increasingly, however, it is likely to call for the production of material which can be used locally by those in touch with at risk groups, by funding local campaigns and campaigns in the voluntary sector - the voluntary groups I must say have already done a great deal of good work - and by increased advertising of services providing help and counselling for those at risk.

#### 5. Screening/Testing

- i) Mass screeningMass screening has been proposed
- firstly as a way of providing additional epidemiological data
- secondly as a means of identifying every person infected with HIV so that their future behaviour can be controlled in some manner or they can be removed from society altogether.

We reject its use for either of these purposes. In respect of epidemiological data it is not a sensible approach. There are several other ways of obtaining the information we need which are far less costly in terms both of the infringement of individuals' liberty and of the resource and financial consequences.

various options are being considered by an expert group on monitoring and surveillance, that I recently set up. The group is chaired by the Director of the Public Health Laboratory Service, Their task is to consider the possible methods of Dr Joe Smith. information available to us on the present improving the the infection and to make spread ofand prevalance recommendations.

We are also firmly opposed to the idea that mass screening should be used as a method of finding and controlling the behaviour of those with the infection. Such a scheme would have the most profound implications both for the general public and for those who are infected. The key question here is what is to happen to those found to be seropositive? Having identified them, taking measures to control their activities seems to lead inexorably to arguing for their quarantining - a quarantine that would have to be for life.

#### ii) Anonymised Screening

Anonymised screening, sometimes called blind screening, has been proposed by a number of researchers. It is as well to be absolutely clear about what is meant by anonymised screening. In essence it would involve testing for HIV the blood of a sample of patients, for example hospital in-patients, whose blood needs to be taken for other purposes. However, to preserve the anonymity of those tested, the blood samples would simply record the age and sex of the patient, not the person's name.

This approach clearly offers some significant advantages. If carried out on a sufficiently wide basis it would provide information on the scale of the infection, geographical variations and on the rate of spread. This would increase our ability to evaluate the effectiveness of our public education campaign and would be helpful for planning services.

But it also presents a number of difficulties. From the epidemiological viewpoint the information provided is not complete. It would not be possible, for example, to ascertain the spread of the infection into the heterosexual population because those in the "risk groups" could not be identified.

In addition, substantial ethical and legal problems arise:

- first in connection with testing of blood for HIV without seeking prior consent;
- second, as a result of not being in a position to inform, counsel, or provide assistance to people whose blood is found to be positive.

These considerations require detailed examination before any decisions can be reached.

Dr Smith's expert group on monitoring and surveillance may well decide to consider the question of anonymised screening along with other possibilities and is currently actively considering this option together with others. But I, obviously, can not anticipate their findings.

#### iii) Selective Screening

There are a number of possibilities here. Two that have been suggested as being potentially valuable in providing useful epidemiological data are testing a sample of hospital patients on a voluntary basis and testing pregnant women in ante-natal clinics.

These groups comprise cross sections of the general population and would therefore provide a better measure of the spread of the infection among heterosexuals than could be obtained from screening small unrepresentative groups, such as prostitutes.

In addition, ante-natal testing has some justification on therapeutic grounds. It is known that pregnancy can lead to the onset of full-blown AIDS in those who are seropositive. Those women found to be infected could therefore be counselled about their medical position, offered the option of termination of their pregnancy and advised not to become pregnant again. I understand that some local pilot schemes for testing in antenatal clinics are being set up in Scotland.

These are two of the possibilities that Dr Smith's expert group is currently assessing. We expect Dr Smith's group to recommend shortly om the relative merits, from the scientific point of view, of these options. I shall then seek the advice of my colleagues on the policy implications and acceptability of the various proposals.

#### iv) Screening travellers

We have no plans to screen all people coming into this country or any particular group such as students. The evidence suggests that most of the transmission of the virus in the UK population at present is occurring inside the country, between people who live here.

Screening people coming in would have very little effect on the spread of infection here. It would also involve formidable practical problems. Screening in the country of origin would not necessarily be reliable. On the other hand, with the huge number of visitors to this country, screening at the UK port of entry would produce enormous congestion and lead to lengthy delays.

There would also, of course, be severe international repercussions; other countries could well take retaliatory action against our citizens.

6. Death certificates - should they indicate the underlying cause (eg AIDS), and if yes could it be kept confidential?

It is true that AIDS is not always given as the underlying cause in cases where the certifying doctor suspects or knows it to be so. The main reason for this omission is to preserve confidentiality. Death certificates are not confidential documents, and one could not sensibly institute a system of confidentiality only for those mentioning AIDS since this in itself would make the cause of death evident to anyone trying to find out.

However, the certifying doctor can indicate by ticking a box on the certificate that he has further information which he will make available to OPCS in confidence, and this method is well used.

OPCS/CDSC are also currently doing a research study of death certificates where the cause of death suggests that AIDS may have been the underlying cause but this is not stated. Even using this extra check CDSC judge that the total number of deaths attributable to AIDS is only very slightly in excess of the number notified to them.

This excess is so small that it cannot affect our understanding and appreciation of the AIDS epidemic, whether from the points of view of the public realising its seriousness, or public readiness to respond to educational campaigns, or government assessment of what publicity is needed, or of money spent on health care and research, or on the geographical allocation of resources now or in the future.

There is therefore no question that an artifically small number of AIDS deaths is being consciously accepted in an attempt to minimise to the public the seriousness of the epidemic. This is simply not so.

Not all deaths attributed to AIDS on death certificates are in fact due to AIDS - some have been shown to be due to conditions not fulfilling the criteria.

7. Sociological research - into effects of public education campaign and into how the disease is spreading?

I have already explained what we are doing in respect of research into the effects of our public education campaign. We shall continue to evaluate progress of the campaign and we shall match the research carefully to the shape and aims of the campaign at any particular time. Just as we need to be flexible in the direction the campaign needs to take, similarly flexibility is required in the accompanying research.

In so far as research into how HIV infection is spreading, the group chaired by Dr Joe Smith who are looking at methods of improving surveillance data, and at methods for prediction, may have an important contribution to offer. However we shall have to wait to see what they have to say.

Both the DHSS and the MRC are currently funding some behavioural studies and of course some of the work done by the COI is also relevant. These may prove helpful in increasing our understanding of behaviour which might lead to the spread of HIV. The ESRC is currently developing a programme of behavioural research in collaboration with the Department too. Further, we are also considering the need for a national survey of sexual behaviour which should contribute significantly to our knowledge on AIDS and also provide useful information for other services.

8. National information coordination - to the public and to schools (NAHT have said that schools have been inundated with material - often commercial - and they need guidance on what was most suitable).

So far as the general public is concerned, the Committee will be aware of our campaign of public education about AIDS. Literature directed at the public included a Health Education Booklet "AIDS: What Everybody Needs to Know" and the household leaflet "AIDS: Don't Die of Ignorance". Both gave basic factual information about AIDS and, importantly, directed people to agencies where more information might be obtained. The household leaflet also carried the telephone number of our two tier freecall AIDS Information and Advisory Services. The Committee may also be interested to know that we are discussing with representatives of other interested Government Departments the possibility of establishing a centralised literature ordering service for AIDS material.

Health authorities have now provided information about action they are taking on AIDS. This has been computerised and analysed and we intend to discuss with them examples of good practice and areas where further action is required.

The new Health Education Authority is currently assembling a data base of plans and initiatives for public education about AIDS being taken by health authorities, local authorities and other statutory and non-statutory bodies.

So far as schools being inundated with material is concerned, this is a question primarily for my Rt Hon Friend. However, I know that schools do receive all sorts of unsolicited material and it is for teachers themselves to consider in the light of their professional judgment what is suitable for presentation to children within the context of the school curriculum as a whole. Children need to be properly prepared to receive educational material about AIDS from both the moral standpoint and against a background of more general education about sexual and biological matters.

NEEDLE EXCHANGE SCHEMES - Are we confident they will reduce HIV spread?

#### Speaking Note

We hope they will. But on the existing evidence we can't be sure. That's why we've set up pilot schemes and will be monitoring them carefully to see what effect they do have on the behaviour of the drug misusers who use them.

#### EVALUATION OF NEEDLE EXCHANGE SCHEMES

#### Speaking Note

Our Major aim in setting up the pilot needle exchange schemes was to assess the potential value of such schemes in the fight against AIDS. We've therefore commissioned an independent research team led by (Dr Gerry Stimson of Goldsmiths College, London) to design and run a project to Monitor and evaluate the schemes.

Because of the long incubation period for HIV infection (and because we've not adopted universal screening) it won't be possible to measure changes in infection rates directly. But the project will examine changes in the behaviour of those drug users attending the schemes, covering:-

- their use of drugs and method of administration
- sharing of equipment
- sexual practices

'Hard' data will also be collected, eg on

- numbers of drug misusers coming forward
- numbers of syringes issued and returned
- trends in local infection rates eg for Hepatitis B (commonly spread by needle sharing and with shorter incubation than HIV)

We expect to get preliminary findings towards the end of the year with a further report early next year.

We have set up an advisory group of 3 experts to provide guidance for the evaluation team. It comprises:-

Prof Michael Adler - Professor of Genito Urinary Medicine at the Middlesex Hospital

Dr A Oppenheimer - A Social Psychologist involved with the MRC's AIDS sub-committee

Dr John Strong - A Consultant Psychiatrist in charge of Drug Dependency Services at the Bethlam and Maudsley Hospitals.

#### POLICY ON METHADONE SUBSTITUTION

- 1. In short, the position is that decisions on treatment for drug misusers, including whether methadene, or other drugs, are prescribed, are matters for clinical judgment in individual cases.
- 2. But we are acutely aware of the need to attract more drug misusers into treatment so as to reduce the numbers injecting illicit drugs. We have taken two steps to explore how this might be done.

First, we have been holding discussions with clinicians in the field about ways of making treatment services more relevant, accessible and attractive. These discussions have covered both prescribing policy and other aspects of treatment regimes and type of service provision [eg. whether we need more flexible opening times, whether outreach workers in the community would help].

 $\frac{\text{Second}}{\text{look}}$ , we have asked the Advisory Council on the Misuse of Drugs to  $\frac{\text{look}}{\text{look}}$  at this issue. They have agreed to set up a working group to make recommendations. These may well include advice on prescribing policy.

- 3. Our initial discussions with clinicians suggest that their approach  $\underline{is}$  becoming more flexible with regard to treatment regimes generally and prescribing  $\overline{practice}$  in particular. But we will consider urgently, when we receive the Advisory Council's recommendation, whether we need to take further steps.
  - I see this review of treatment policy as complementary to the other things we are doing to reach more drug misusers, namely:

First, the publicity campaign.

Second, the extra £1 million we have allocated this year to help drug misuse services reach more people and provide better counselling in the light of AIDS.

Third, the pilot syringe exchange projects.



#### Service Expansion

1. Over the last 4 years we have financed a major expansion of treatment and rehabilitation services.

First, we provided central funding of over £17 million since 1983 to pump-prime 184 local projects.

Second, from last year we have been allocating £5 million a year to health authorities specifically to finance continued expansion of services for drug misusers. Last year this money was used to set up or expand 169 projects.

Third, we have supplemented that £5 million with an extra £1 million this year tohelp services reach more misusers and provide improved counselling in the light of AIDS.

This is all additional to the service developments health authorher have financed from their Service Type

- 2. By working through both statutory and voluntary sectors we have provided a wide range of services from walk-in street agencies to drug dependency units and residential rehabilitation facilities.
- 3. We need to maintain and increase this diversity if we are to attract as many drug misusers as possible. We also need to ensure that treatment is flexible enough. We have work underway to these ends. [See sheet on 'Policy on methadene substitution].

# Treatment of Drug Misusers with AIDS and HIV Infection [for use if raised]

4. The number of drug misusers with AIDS is still very low. This gives us time to learn from the experiences of other countries in treating drug misusers with AIDS. It is clear that we will need to cater for the group. The ACMD will be looking at the problems which AIDS poses for drug misuse services. Drug misuse may also pose special problems for those caring for AIDS patients. We are looking at this now so that when the number of cases grow we are ready to cope with them.

10. Research staff - what are we doing about NHS reliance on clinical and academic research staff?

The way in which AIDS is dealt with in each district is a matter for local management. Most patients in London hospitals are at present cared for by teams led by doctors with academic appointments. It was in recognition of this that I funded an additional registrar post at St Stephen's, The Middlesex and St Thomas's hospitals. But, as I have said, this is a matter for local management. There is a limit to what can or should be done from the centre.

THESE IN RELEVANT SPECIALTIES?

Officials in the Department have already had meetings with representatives from Regional Health Authorities, who have responsibility for medical staffing, to discuss the medical staffing situation for the care of AIDS patients in their Regions.

My officials are fully aware that additional training may be necessary in certain specialties (for example, Genito-urinary Medicine, Clinical Immunology, Medical Oncology, General Medicine), and with this in mind have asked the Royal College of Physicians to consider what the likely demands for medical staff will be in the light of the AIDS epidemic.

The Joint Planning Advisory Committee, which advises the Department on the total number of senior registrars needed in each specialty for likely consultant opportunities, will take evidence from the Royal College of Physicians later this year with regard to the number of training posts at senior registrar level needed in England and Wales to give appropriate training for consultants who will be caring for AIDS patients in the future.

#### Background notes

We will expect Regions to review their needs for additional consultant posts in relevant specialties to deal with the increased workload brought on by caring for AIDS patients and to report this to us. The Joint Planning Advisory Committee will ensure that there are enough doctors in training to meet this demand by, if necessary, asking Regions to establish new senior registrar posts.

In some specialties there may be enough training posts, but Regions may find it useful to arrange for trainees to go on secondment to units which have a lot of experience in the care of AIDS patients. Regions are already considering this arrangement.

# 12. Training - what plans for training of GPs and health care staff in diagnosing and counselling?

shall be expending over a quarter of a million year we pounds on training centres. We have three for counselling, Bolton and Birmingham, and one for the clinical management of AIDS at St Stephen's hospital in Chelsea. provided the funding of the English National Board for nurse training and are providing a nurse training workshop in each region this year. We are also offering 14 fellowships to nurses, tenable for 3 months, for the study of care of AIDS patients. I have already mentioned the six part-time training appointments for general practitioners at London hospitals. For doctors, of course, the lead with training lies with their professional bodies.

Training will be equally important in the Personal Social Services field too. Our three counselling training courses, although hospital based, also offer training to social services staff. The Social Services Inspectorate undertook a survey earlier this year and established that most Social Services Departments had already mounted training courses for their staff. There is a sub-group of a working party looking at Policy and Practice Issues for Personal Social Services which is addressing itself specifically to training issues; and the Central Council for Education and Training in Social Work, the London Boroughs Training Committee, and the Local Government Training Board are all engaged with issues relative to AIDS.

13. Expert systems - what are we doing about developing computer 'expert' systems?

I assume you have in mind the system that Dr Roger Brittain has been developing. I understand he has been seeking funding for his project. However, he has made no formal research application to the Department nor has he provided the Department with sufficient detail. Nevertheless my officials are still in touch with him.

#### Background

There has been a series of correspondence between Dr R Brittain District Medical Officer, North Warwickshire Health Authority (NWHA) and the Department. Initially Dr Brittain wrote to CMO on 11 November 1986 and mentioned his computer-aided decision taking system for AIDS but no request for funding was made. on from this correspondence was received from Dr Brittain requesting funding of £10.000 per annum for 2 1986 years for the support of 2 PhD students working on the project. It is unclear where the original funding came from to initiate Dr Brittain enclosed a brief proposal with this project. this was felt however correspondence in December 1986, contain insufficient information on which to base an opinion Accordingly on 2 February concerning the value of the project. the Department sent Dr Brittain a research application form and detailed advisory notes in order to enable him to submit a Subsequently two members of the formal application for funding. attended a demonstration of Department's professional staff, Thus far no formal Brittain's system on 13 March 1987. application for funding has been received from Dr Brittain although three months have elapsed since the form and guidelines If a completed application and protocol is sent to him. received from Dr Brittain it will be subjected to the usual scrutiny by appropriate experts so that a decision over funding can be made.

#### 14. Voluntary Counsellors - funding training?

We are contributing in several ways.

First, we are funding two NHS centres, at St Mary's, Paddington and Bolton, to run courses in AIDS counselling. The training courses that they offer are open to those in voluntary bodies and a number of people in the voluntary sector have been on them. This year we are doubling the amount of our funding so that the centres can expand their programmes.

Second, we are providing increased levels of funding to voluntary bodies, such as the Terrence Higgins Trust. Our grants are intended to help meet their core administrative costs which may well include some of the costs involved in recruiting and training counsellors and of the various counselling activities themselves.

It is also worth mentioning in this connection the national AIDS telephone advisory service, NASA, which we set up earlier this year. This has relieved some of the pressure on the counselling services run by voluntary bodies. Moreover the expert counselling trainers we have employed to train the NASA advisors, have also given training to people in voluntary organisations, such as local helplines.

BACKGROUND NOTE FUNDING FOR VOLUNTARY ORGANISATIONS

How much money is the Government giving to voluntary organisations in the AIDS field this year?

We recognise that the contribution of the voluntary sector is vital in the fight to control the spread of AIDS and in the care of those who have been infected. AIDS projects will have a high priority for funding this year, and although final decisions have still to be taken on the total amount of resources that will be available, I can say that there will be a considerable increase over the £469,000 we provided last year.

I have also given a commitment to provide £500,000 for the new coordinating body, the National AIDS Trust.

15. Health authorities - what has their response been and are they able to fund services now and in the future?

The district response to our request for AIDS plans has, on the whole, been encouraging. Analysis shows that 90 per cent have trained counsellors and 83 per cent have made provision for health education on AIDS. About two thirds have an HIV action group and these authorities tended to produce the best plans.

The position is less satisfactory with regard to liaison with family doctors, local authorities and representatives of the main at-risk groups. We shall be looking for an improvement here when the plans are updated by this year's short-term programmes. We have stressed the importance of community care of people with HIV infection and AIDS in this year's planning guidelines.

So far as funding is concerned, for 1987-8 we have made a special central allocation of £7 million. This will fund a number of central initiatives and provided £4.4M to 'top-up' the three Thames Regions which together care for three-quarters of AIDS patients. But AIDS costs, like those of all hospital and community health services, are provided for in the annual budgets of health authorities. Included in those for 1987/88 is an extra £633M for the further development of services for patients, as well as £150M of efficiency savings.

16. Burn out - how are we going to cope with this (especially among health care professionals)?

This is a good example of an area where we can learn from the USA. The Visiting Nursing Association of the US told me about how it affects nurses involved in domiciliary care. We also know of the particular stresses on other health professionals, including doctors, hospital nurses and counsellors.

Part of the problem is to do with appropriate selection of staff who are to work full-time with AIDS patients. this is a question for health service management locally, it would be reasonable to suggest that only volunteer staff should undertake AIDS work, when this is to be the major part of their duties, as with other work involving terminal Training is important and especially so for patients. counsellors so staff learn how to protect themselves from Teams working with AIDS have their excess emotional strain. own support systems and senior staff should be aware of the need to allow more inexperienced staff time to talk through their emotional reactions with others in the team and specially trained outsiders. Even for those who appear to be coping well, there is a case for shorter attachments to that subject area than might be usual.

In all of this, the main lead lies with the appropriate profession or health service management. Our own role has been to assist with funding of some of the elements that are or are to be available nationally, namely courses for training counsellors and the provision of counsellors with the specific role of supporting health care professionals.

# IN THE

SOCIAL SERVICES FUNDING : SPEAKING NOTE

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Local authorities are generally preparing their staff to limit the spread of infection, not only for AIDS but for other (more) infectious diseases. Most local authorities are also training their staff to accept that AIDS does not endanger them or their families so long as simple hygiene precautions are taken and high risk behaviour is avoided.

We are currently considering, with the Local Authority Associations the increased pressures on PSS for 1988/89. Some recognition in the general rate support grant arrangements of additional work of this kind which affects all local authorities to a greater or lesser extent may be appropriate. But there are major differences between local authorities in terms of their current involvement with people with AIDS and we are also considering whether some more targeted allocation of funds might be required to recognise this. My officials are considering what mechanisms might best achieve this. Possibilities include the use of joint finance or the introduction of a specific grant. The latter would require legislation and is something which I would need to discuss further with colleagues and with local authorities. And of course the extent to which extra provision could be made available will need to be considered in this years Public Expenditure discussions.

Similar considerations apply to the funding of Primary Health Care services and Community Care services. Officials are working on these issues but as I have already indicated extra provision in these areas will need to be considered alongside other spending priorities.

18. NHS trade off - how will we ensure other aspects of health care do not lose out because of AIDS?

An epidemic, like a war, is likely to lead to some displacement of resources, at least in the early stages. It is not just a question of money. There are finite resources of manpower and training capacity. We intend to minimise the opportunity cost to other services. The estimated cost of £13 million for hospital treatment of AIDS patients this year must be seen in the context of the £1,000 million extra which we have provided for the Health Service.

#### 19. GUM CLINICS

How will we ensure they get increased funding?

We would expect that the needs of GUM Clinics, which are known to be in the forefront in dealing with AIDS, will be taken into account in allocating the additional funds which have already been given to those authorities with the greatest number of AIDS patients. We would also expect other authorities to consider the revised needs of GUM Clinics when they decide priorities.

## Will we revise manpower guidelines?

Staffing needs in GUM Clinics are also primarily a matter for the health authorities responsible for those clinics.

## Speaking Note:

We all feel the greatest sympathy for those haemophiliacs [and others] who have suffered the grave misfortune of AIDS infection.

There has never been a general State scheme to compensate those who suffer the unavoidable adverse effects which may arise from some medical procedures. Compensation can only be awarded by the courts when negligence has been proved. However all the facilities of the NHS and a range of Social Security benefits are available to those who suffer illnes, unemployment or loss of earnings as a result of infection with HIV or as a result of contracting AIDS itself.

Officials are actively developing an "Information Pack" for these haemophiliacs to help them both to get to know which benefits they would be eligible to claim, and how to go about doing so. We will do all we can to help in this way.

# Supplementaries:

- Q. What about compensation for those who were given infected blood transfusions?
- A. Fortunately only a very small number of individuals have developed AIDS from this source. Compensation would again only be awarded by the courts if negligence had been proved.
- Q. Were either the manufacturers or doctors negligent in providing these infected products for patients?
- A. I am not aware that such a suggestion has been made but it would be something for the courts to decide.
- Q. Does the Vaccine Damage Payments Act provide a precedent for compensation?
- A. No. Vaccines are given to the healthy as a matter of public policy to protect the health of all individuals. On the other hand haemophiliacs are treated in the course of medical care for their disorder. There is no public policy promoting particular drugs for their treatment.

Background briefing is attached.

# Compensation for Haemophiliacs

# BACKGROUND

Compensation for victims of medical accidents

Compensation to victims of medical accidents is payable only if legal liability is established on the grounds of negligence.

Compensation has to be claimed within a period laid down by law (usually three years) but this can vary in some instances.

The patient would need to obtain independent legal advice relating to wis or her individual case. An independent organisation, Action for Victims of Medical Accidents which is run by a lawyer, helps people to contact suitable lawyers and also holds a list of medical experts willing to advise in litigation cases.

## Other medical accidents

Individuals react to drugs in different ways and there are unfortunately circumstances where side effects are associated with many other commonly used drugs. It is not therefore practical to give specific examples.

## 'No fault' compensation

The idea of a 'no fault' compensation scheme based on loss of faculties rather than proving negligence in the Courts has been looked at previously.

The Royal Commission for Civil Liability and Personal Injury (the Pearson Commission) reported in 1978; it had considered a possible compensation scheme for personal injuries arising from medical 'accidents'. After studying evidence from other countries, the Commission concluded that such a scheme should not be introduced in this country at present and recommended that negligence should continue to be the basis of liability for most medical injuries.

## Vaccine Damage Payments Act 1979

Some people have suggested that there is a parallel under the Vaccine Damage Payments Act 1979, but this is not the case. Vaccines are given to the healthy as a matter of public policyto protect the health of individuals. The Vaccine Damage Payments Act recognises that a finite risk is incurred and provides financial assistance for those children who become vaccine damaged.

On the other hand haemophiliacs are treated in the normal course of medical care for their disorder. There is no public policy promoting the use of Factor VIII for their treatment.

#### Social Security Benefits Available

However all the facilities of the NHS and a range of social security benefits are available to those who suffer illness, unemployment or loss of earnings as a result of infection with HIV or as a result of contracting AIDS itself.

The sort of benefits which haemophiliacs could claim for example are:

Income maintenance benefits

available to people incapable

of work

Sickness benefit (contributory)
Invalidity benefit "
Severe disablement allowance
(non-contributory)

Benefits aimed at the extra costs of disability

Attendance allowance
Mobility allowance
(also invalid care allowance
paid to people caring for
AA recipients)

Income related benefits to top up other benefits which do not meet specified requirements

Supplementary benefit
Housing benefit

# 21. PUBLIC HEALTH AND INFECTIOUS DISEASES REGULATIONS

## Are the regulations necessary?

These regulations were introduced in 1985. They extended to AIDS some of the provisions of the Public Health (Control of Disease) Act 1984 that already operated in respect of some other diseases. These include powers for medical examination, and for the removal to hospital and detention there of people suffering from AIDS. The regulations also provide for restrictions to be placed on the handling of the bodies of AIDS sufferers.

I should stress that these powers are intended to be used only in the most exceptional circumstances where an individual represents a real danger to the public and needs hospital care and attention. They have in practice been used in only one case so far. Nevertheless, they are useful fall-back provisions which would enable appropriate action to be taken in those very rare, extreme cases where it might be needed.

# Will the regulations be extended to cover HIV?

I understand that the power to order medical examinations in the public interest, or in the person's or his family's interest already technically extends to HIV. Like the other powers, however, it is intended to be used only in the most extreme circumstances.

We have no plans at present to make any changes to the regulations, but we will keep the position under review.

# 22. Strategic Plan - have we got one for the next 5-10 years?

AIDS is an international problem and the Government believes we need to share our knowledge internationally so each nation can learn from each other. Nevertheless each nation needs its own plan of action tailored to its own particular circumstances.

In the UK the overall strategy for dealing with AIDS has four parts:

- \* Public Health Measures, such as screening blood donations.
- \* Public Education, so that people can learn how to avoid infection.
- \* Research into vaccines against HIV infection and treatment for those who are infected.
- \* Development of Services for those who are infected or who have AIDS itself.

There is currently neither a vaccine against HIV infection nor a cure for AIDS. There is a massive worldwide programme of research to find both a vaccine and cure and major advances have been made, particularly in understanding and isolating the virus. Most experts agree, however, that it will be at least five years and may be much longer before a mass vaccine is developed.

Moreover, because of the way the AIDS virus enters the genetic material of body cells, it may not be possible ever to achieve a real cure, that is to eliminate the virus from those who have been infected. There are, however, treatments being developed which prolong the life of patients with AIDS.

This means that for the immediate future the top priority is given to measures to prevent or slow down the transmission of the virus.

Continued....

#### The NHS

We are working now on national policies and planning guidelines for the next 5-10 years for issue in due course. We have also finished the analysis of the District Plans for AIDS, which are updated annually in short-term programmes. One of the most difficult problems is projecting future cases, not just of AIDS but of pre-AIDS conditions, which also make considerable demands on health care.

We do not yet know what the effect of our intervention strategy will be, the likely impact of new drugs or the extent to which the disease may, or indeed has, spread into the population at large. We may have to produce a number of scenarios, but they will all aim at a much higher proportion of care in the community.

#### The PSS

Most Social Services Departments are addressing the question of The Department is working on this too. A Deputy Chief planning. Inspector of the Social Services Inspectorate is chairing a Working party, which is currently sitting, on policy and practice for the personal social services. The Vice-Chairman is Brian Roycroft, Director of Social Services Newcastle. This group is They are covering a wide expected to report later this summer. range of issues such as counselling, confidentiality, illness, mental handicap, domiciliary care, etc. The PSS will be an important area and we aim to build on the work that is already under way.