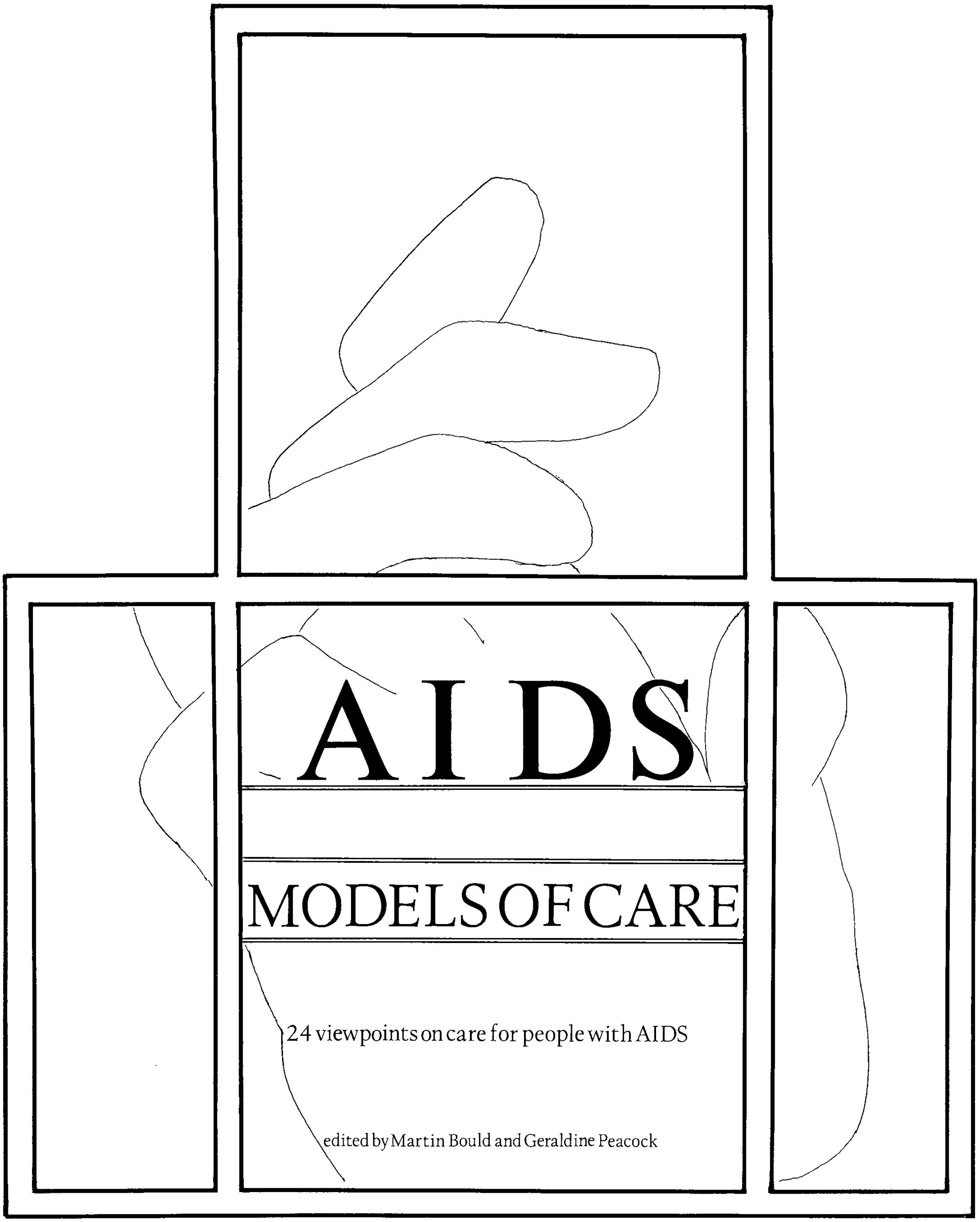

AIDS

MODELS OF CARE

24 viewpoints on care for people with AIDS

edited by Martin Bould and Geraldine Peacock

King's Fund
LBTC
FRONT LINERS
The Terrence Higgins Trust

AIDS: Models of Care

24 viewpoints on care for people with AIDS

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arising from two conferences jointly organised by the Kings Fund Centre for Health Services Development, the London Boroughs Training Committee, the Terrence Higgins Trust and Frontliners in May and June 1988

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SECTION ONE

OVERVIEW

1

Introduction

GERALDINE PEACOCK

In May and June 1988 the King's Fund Centre and the London Boroughs' Training Committee, in conjunction with Frontliners and the Terrence Higgins Trust, organised two national conferences — 'AIDS: Models of Care'. Whilst there had already been many national conferences about AIDS, these were somewhat different. They were concerned with bringing together planners and managers across sector boundaries to share developments from their regions. Formal presentations were minimised and the days were designed to promote collaboration in a workshop-type atmosphere. There were no 'experts', just contributions from many people intimately involved in planning and managing sensitive, informed and relevant systems of care for people with AIDS and ARC.

The special emphasis was in care in the community. It became clear that AIDS has no fixed progression. Different people experience it in very different ways, and consequently need flexibility and choice in the services offered to them. Although the impetus for treating people with AIDS and ARC has been mainly hospital based, it has become clear that long periods of good health occur intermittently with the need for periods of hospitalisation, creating a growing need for community care. AIDS is a terminal disease and people have a right to choose how to die; well integrated systems of hospital and community care mean that carers can respond to each individual's own definition of the care they need rather than presenting them with an 'off the shelf package'.

Because of the particular spread of AIDS and HIV infection in this country, two places, London and Edinburgh, have had the most experience in developing models of care to date. With other authorities and agencies planning ahead to provide suitable systems of care, it seemed sensible to try to promote an interchange of information so that authorities about to plan, or in the process of reviewing provision, could do this in the light of others' experience. The conferences were therefore designed to bring people together across the country who could learn from each other.

The conferences were specifically targeted at planners and managers because without policy commitment and high level backing, effective services never get off the ground. Many of the training opportunities around AIDS have been for grassroots staff to provide information, examine health and safety issues and provide some practical skills. All this is wasted if organisations do not have informed and strategic management approaches to support these workers. For care in the community to become a reality, new directions in training are needed. It was a main hope that these conferences would bring together senior people to look at how effective collaboration could be achieved across sector boundaries. The aims of the days were consequently:

a) To provide information about different models of care.

b) To examine the implications of these models for implementation in different settings.

c) To explore the possibilities of coordination and multidisciplinary approaches to the provision of services for people with AIDS.

d) To examine the policy and planning initiatives necessary to achieve such service development.

In planning the conferences we decided to focus on AIDS and ARC, although we fully appreciated that people who are HIV positive also have specific care care needs. We felt that we could not tackle everything in one day and should consequently focus on the sharp end of need. Spurred on by reports from America where hospital care has been effectively lessened by the growing community programmes, the conferences were designed to show that although AIDS and ARC are medical conditions there are also strong social and emotional implications which demand integrated systems of care. Unfortunately in this country, although the calls for joint planning and care in the community have been great, the reality has been disappointing. Planning for work with AIDS and HIV is a new challenge, one far reaching enough in implication to produce innovative planning and set an example for other models of care and service provision.

The impetus for the conferences came from discussions between the King's Fund and the DHSS. The King's Fund called an early planning meeting and provided a background paper on issues raised by AIDS and HIV infection. This meeting was well attended by a wide range of agencies from many sectors. From this emerged the need to focus on planners and managers and the suggestion that the conferences should be jointly planned with the London Boroughs' Training Committee, who were already running and evaluating a wide ranging multidisciplinary programme of training around AIDS and HIV, and the Terrence Higgins Trust and Frontliners who would represent the needs of the voluntary sector and consumers. This proved to be a rewarding collaboration for all agencies concerned and made for effective results on the day.

This volume is not intended to be an instructive text or 'source of all wisdom'. What it represents is a series of inputs and background papers which emerged from the two conference days; as such they are personal descriptions by professionals and users of their involvement in a range of models of care. Some of the readings are edited transcripts from contributions made on the day and these we have deliberately left in a personal style because we feel they make lively and vivid reading. The collection does not attempt to provide answers or blueprints for service developments but rather present themes, and ideas and models.

We have organised the range of contributions into sections. The first section presents an overview of the current situation facing providers of services for people with AIDS. Anne Johnson looks at the challenges posed by shifts to community care and how these might be met, whilst Deirdre Cunningham sets the scene by identifying some key issues in planning such as the principle of choice, cost and finance, joint planning, and management commitment in developing strategic district plans. This section also contains two contributions from people with AIDS describing their direct experiences (good and bad) of care.

Section Two looks at developments in Edinburgh starting off with an overview and followed by specific contributions from George Bath and Ray Brettle on planning and delivering hospital services whilst developing links with the community. There is also a thought-provoking introduction to issues about accommodation and community care by Les McEwan, Depute Director of Social Work in Lothian Region who raises pertinent questions about the appropriate use of hospitals, and residential amenities in community care, whilst identifying the problems and possibilities of providing enough suitable accommodation.

The third section focuses on London based initiatives in the statutory sector. The contribution from Denise Platt, Director of Social Services in Hammersmith and Fulham, emphasises that people with AIDS do not require special services and that issues around AIDS are a microcosm of every other problem social services departments deal with. She looks with insight at the needs for housing, support for staff and antidiscriminatory practice as well as the importance of providing appropriate training. Rob George outlines the approach of one health authority (Bloomsbury) to setting up a community AIDS Team, which has the user's right to determine their care as its central focus. His experience shows multidisciplinary provision to be essential and evaluation as the key to success in creating a flexible system of care linking home and hospital. Such a care system must cater for emotional, social and spiritual needs on an equal footing to physical ones.

Surinder Singh and Ronald Lande look at models which link with general practice and the potential role of the GP. Lande shows that the GP's ongoing responsibilities are very much in line with how care for people with AIDS living in the community might be provided. He suggests that the GP role has been neglected so far, maybe because GPs themselves need training or because of issues of confidentiality; people do not want their doctor to know. Singh points out that GPs can help adapt existing services and provide continuity of care through medical monitoring, feedback, continued support and counselling. He outlines a model of care set up at St Stephen's Hospital which attempts to link hospital staff to primary care teams.

Voluntary organisations in London have done much to establish community systems of care for people with AIDS. In Section Four, some of these organisations, The Terrence Higgins Trust, Frontliners, Landmark, and the Black Communities AIDS Team, provide an overview of the work of their organisations and show how they can combine effectively with statutory agencies and resources to create effective networks and relevant services. Finally, two new centres with hospice facilities have opened recently in London for people with AIDS and this section contains inputs from the Mildmay Mission and the London Lighthouse emphasising the need for high quality community based care provision providing unconditional acceptance and compassion combined with high quality medical and nursing care for people with AIDS and ARC. Their focus is on holistic care.

The fifth section of this publication is called 'Using Existing Structures'. Deirdre Cunningham emphasises the need to guard against incremental and uncoordinated services by making the best of what already exists in adaptive forms. AIDS does not necessarily fit any one existing model but draws on bits of many different ones. However, she also identifies funding as one of the major hurdles to overcome. Joyce Leeson gives an example of how this was approached in North Manchester where she helped develop services which emphasised that the prevention and treatment of AIDS should be managed as in any other disease, but with some special additions, e.g training roadshows, open access testing clinics, the appointment of an AIDS coordinator etc. She also identifies funding, choice and evaluation as major issues to be tackled.

The two other contributions in this section are examples of particular initiatives to provide additional advice and relevant services to people with AIDS. The Community Support Centre in Newcastle aims to help existing services respond sensitively to the needs of people with AIDS in what is, at present, a low prevalence area. Andy Cooke's contribution on the benefits structure provides an example of an existing system which people with AIDS have to fit into. He explores which benefits might apply but stresses how difficult it often is for people with AIDS to get the system to recognise and meet their needs.

The last chapter presents a brief selection of issues raised by participants at the two conferences in their workshop discussions and provides some ideas to be considered in the development of any joint initiatives to plan care for people with AIDS.

We do not anticipate people will wish to read this publication from cover to cover; indeed, it is not designed for that purpose but rather as a reference and information resource to dip into when planning your own service provision needs. It might well offer some short cuts or ideas not already considered; most importantly it offers a catalogue of achievements (and failures) to inform the work of anyone involved in planning or managing community linked systems of care for people with AIDS.

2

The Shift to Community Care for People with AIDS

ANNE JOHNSON

The care of people with AIDS and the development of appropriate services presents a challenge to managers and clinicians; to health and social services planners in statutory and voluntary sectors; and not least to patients, their families and lovers. We owe a great deal to those who have been on the receiving end of services, for acting as a pressure group for the development of integrated services as well as for raising funds, developing support groups and hospice care to provide resources which in an ideal world might be provided by the statutory sector. An intense discussion has surrounded the development of services for people with AIDS and has emphasised the need to respond to consumer demand. The intensity of this debate provides lessons for other areas of the health service such as mental health and handicap, geriatric and cancer services where much still remains to be done in the provision of integrated community and hospital services.

In this paper I will consider first what factors are fuelling the debate about a move to community care, then consider some models of care from the United States and finally discuss how services have been developed, and might be developed in the future here. This paper will inevitably focus on my own experience in Bloomsbury Health Authority. This is just one example of an attempt to develop services, which has been a learning process with successes and failures.

The term 'community care' is loosely used. To some it means all care outside hospital, including hospice care and hostel care, to others it concerns only care in the home. But hospitals, though institutions, remain part of the community. However much care is developed outside hospital, people with AIDS will continue to place high demands on hospital beds for acute, high technology management. The organisation and planning for those beds needs to be made hand in hand with the development of other services. Thus, this paper discusses the development of integrated services as well as a shift to community care.

It is worth considering what motivates the desire to reduce hospital use and develop services elsewhere. Firstly, there is increasing pressure on hospital beds, particularly in central London at a time when beds are being closed. Secondly, there is a desire to develop services which are both appropriate and responsive to people's needs. Thirdly, there are economic arguments about reducing costs per case. Studies of hospital costs per case in the United States (US) and the United Kingdom (UK) have been shown to be highly dependent on the length of stay per admission. In the US it is estimated that by 1991 the personal medical care costs for people with AIDS will amount to 1.4% of health care expenditure. The lowest average stay in the US - of around 11 days per admission - has been recorded in San Francisco and many have turned to the model of care in that city in developing services. The major components of that model were to develop a dedicated ward for people with AIDS early in the epidemic in order to centralise expertise and coordinate services and to develop, largely through the voluntary sector, programmes outside hospital. These include the Shanti project which provides emotional and practical support at home as well as working with hospital staff. In addition, hospice and hospice-at-home services have been developed which may contribute to the low length of stay. However, it must be emphasised that many of these services have been developed through the massive contribution of donated voluntary labour. In 1984-85 nearly 7,000 volunteer hours per month were contributed to the Shanti project, with a further 4,000 paid hours per month. In translating the American experience to the UK, it must be remembered that we have the advantage of a highly developed public sector health service, free at the time of need. This provides not only in-patient services, but through family practitioner and community health services, structures also exist for care at home. Thus while we can look at the principles of the American experience we need also to look at our ability to use existing structures and maximise integration between health authorities, family practitioner services, local authority services and the voluntary sector.

In planning services, there is a tendency to think only about those with the most severe manifestations of HIV infection. However, many people will be well for most of the time. Much of their care will therefore be developed on an out-patient basis. The model of care that we have tried to develop in Bloomsbury is schematically outlined in figure 1. In-patient care has been developed in a dedicated ward, and while this has been a very useful contribution to the integration of services, many centres in the future may choose to manage people with AIDS in general wards. Out-patient care is centred on the sexually transmitted diseases (STD) clinic. Community care involves general practice, hospice care and the development of services at home through the home care team. The pattern of care requires tailoring to each individual since people with AIDS may have very varied requirements for both in-patient and out-patient treatment. Many people with AIDS are in employment and after an acute episode requiring hospital admission will be back at work and relatively well. Those with Kaposi's sarcoma may require only out-patient treatment during much of the course of their illness. What we are attempting to do is to make the transition from in-patient to out-patient care as rapid as possible and thus diminish the amount of time people have to spend in hospital. This in particular requires good coordination with services outside the hospital.

In this country we have a primary health care system centred on general practice, which often gets forgotten in the context of planning services for people with AIDS. This is partly because many people with HIV infection have been diagnosed and managed through STD clinics. General practitioners are showing an increasing interest in sharing care with STD clinics and hospitals. This is perhaps one of the major areas that needs to be developed because general practitioners have considerable expertise in care at home: in the use of existing facilities such as district nursing services, meals on wheels and home helps; as well as experience in the management of terminal care at home. There can be little doubt that terminal care facilities along hospice lines are a component of the management of people with AIDS and have already made some difference in our hospital use. Mildmay Hospital has beds open and facilities will shortly be available at Lighthouse. Nevertheless, this is only one aspect of terminal care since many people will die in the acute phase of disease and not go through the terminal phase associated with some types of cancer. However, terminal care facilities are important for those with neurological disease and chronic wasting syndrome. Most recently in Bloomsbury, we have developed a home care team with the specific role of integrating services between in-patient, out-patient and general practitioner facilities. However, in planning community services financial costs need to be considered. One plan of such costs presented by Dr Cunningham and her colleagues in the British Medical Journal suggested an annual cost for community and hospital care in the order of £22,000 per case of which only £7,000 was for in-patient care. However, this particular plan suggested rather a heavier requirement for care at home than many people with AIDS experience and there is a need to quantify the exact use of resources.

Since the opening of the AIDS ward in Bloomsbury, there has been a substantial reduction in length of stay per episode. At the beginning of April 1987 the average length of stay per episode was 21 days. However by March 1988 this had fallen towards 14 days, close to the 11 day average observed in San Francisco (figure 2). There are a number of possible reasons for this fall in length of stay. These include a greater experience in patient management; influence of the home care team; the role of Zidovudine in reducing admissions for pneumocystis carinii pneumonia; and the gradual improvement of social services and community services in London.

Currently 15-20% of the people with AIDS cared for in Bloomsbury are in hospital at any one time. In San Francisco the equivalent figure is 10%. Thus there still seems to be scope to reduce length of stay by developing the services mentioned. One further possibility is to develop day centres which provide both emotional support and acute treatment facilities for blood transfusion and investigation. All these services need to be evaluated and examined carefully in terms of their appropriateness for consumer needs, their costs, and their impact on in-patient stay.

Lastly, coordination and development of services means crossing boundaries both between the different statutory and voluntary agencies and between geographical areas. Many of the patients cared for come from all over London and may receive much of their treatment outside their district of residence. This requires that there is good communication between different districts so that early discharge to appropriate community services can be facilitated.

In conclusion, the future planning for the care of people with AIDS and for those who are HIV positive is a huge task for both formal and informal sectors but it also presents a major opportunity. That opportunity has been made clear to service providers by those who suffer from a disease that has touched many young lives and presented them with a struggle against prejudice and stigma and we are reminded of the human right to optimise the quality of life, even during the terminal phase of disease. The opportunity for planners and health care workers is to put into practice the ideals and not just the economic arguments which lie behind the concept of community care. That is: to integrate and optimise the use of finite human and financial resources and to maximise the quality of care offered, not only to people with AIDS but also to all those that seek care and support throughout our communities.

Figure 1

CARE FOR PEOPLE WITH HIV INFECTION OR AIDS

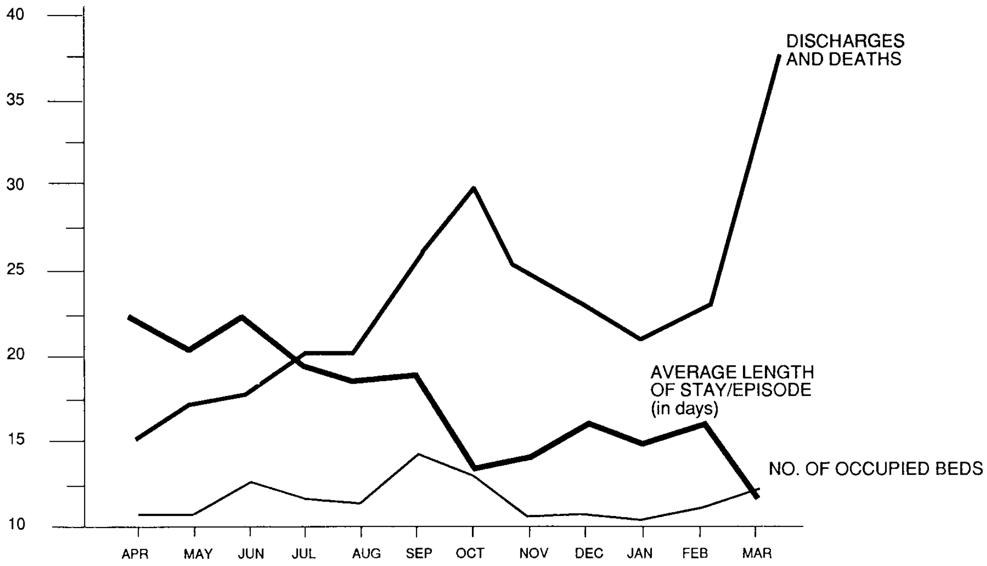
	Facility						
	Community				**Facility**	**Hospital**	
Progress of Infection	GP/DN	Hostels	Hospice	Home Care Team	Day Care Centre	Out Patient Clinic	In Patient
HIV							
Asymptomatic/well	■					■	
Symptomatic (PGL/ARC etc)	■					■	▨
AIDS							
First acute infection or tumour						▨	■
Convalescence	■			▨	■		
Subsequent acute infections/other problem	■			■	■		■
Terminal care	■	■	■	■			■

Note: lighter shading indicates that the type of treatment is sometimes appropriate

Reproduced with kind permission of Professor M W Adler

Figure 2

AIDS and HIV-RELATED INPATIENT CARE in 1987/88
The Middlesex Hospital



3

Key Issues for Planning

DEIRDRE CUNNINGHAM

Care for people with AIDS to date has been concentrated in the main centres where it has grown up as a rather hospital based service. Yet there is evidence from many sources that people prefer a community-based model: people with AIDS prefer it, paid carers prefer it. So how can the current model be changed?

Two arguments for change can be put forward. First, people with AIDS are now becoming a more diverse group and their needs are more diverse. With more experience people realise that AIDS need not be kept as special and separate from generally accepted concepts of good practice (as I argue in a subsequent chapter).

The second reason is logistics. In the earlier years of this decade, the numbers involved could have been coped with as little specialties in hospitals, but we must now face projections based on relentlessly increasing reports. In Paddington and North Kensington, we calculated that if we continue with 18.5% of people with AIDS in an acute hospital bed at any one time, we face a requirement for 592 beds for them alone by 1992. This compares with a figure agreed with the Regional Health Authority of 550 acute beds in all. This is a very good way of convincing hospital clinicians and others that things have to change, and we have now agreed that we will shift towards community care which we believe is more appropriate anyway for people with AIDS.

Role of the hospital

There are two distinct sets of considerations here: one for the low prevalence areas and one for the high prevalence areas where models have already been developed. In the former, the fact that there have not been many reported cases means there is time to set up good systems; in particular good ways of liaising with local authorities and other agencies and good prevention programmes. These districts should bear in mind, however, that there may well be more cases than they know about, since there is ample evidence that people come from far afield to central London for testing and treatment.

In areas of high prevalence, especially London, services for people with AIDS have grown up in response to urgent need, but may have become somewhat entrenched. To change them to accommodate different ways of working is challenging, and may involve asking people who have hitherto provided a very good service to do things differently.

Cost

The work we have done shows it is remarkably difficult for the NHS to cost accurately the care that an individual person would receive over a year in hospital, both as an in-patient and an out-patient. Our systems have not been set up on the same lines as American or fee-paying systems. So we have to try to estimate the total quantity of care we provide. We no longer accept that people with AIDS necessarily pass through a clear succession of stages in their illness, nor do we now think they will be quite so dependant for their last year as perhaps once we did, so we must face up to the difficulty of costing community care. Whilst services do not exist, we must inevitably rely on theoretical costing exercises. An example would be the terminal care facilities planned in the voluntary sector. How do we cost them?

Funding

Services have so far developed around central funding. The allocation of £2m to London local authorities, for example, has been very much welcomed by health authorities, although the way it was allocated from the DHSS has not necessarily made for the best in joint planning in London. Health authorities and other agencies are becoming concerned about setting up new posts and new capital developments which they will have to fund into the future.

Choice

We all wish to uphold the principle of choice for people with AIDS when planning services. The Wagner and Griffiths reports have recently underlined the importance of choice. (Sir Roy Griffiths, *Community Care - Agenda for Action* and Lady Gillian Wagner, *Residential Care - the Research Reviewed* - both HMSO, 1988.) But other priority groups such as elderly people or those with psychiatric conditions cannot necessarily choose the hospital where they are treated.

Choice of GP is an important issue. In Paddington and North Kensington we want to involve GPs in all aspects of care - prevention, primary care, and shared care. But we have not cracked the problem of how people with AIDS can find out for themselves which GPs are particularly interested or have the necessary expertise. Nor have we cracked the problem of the GPs' choice not to have someone on their list.

Individual choice of elements within the care plan remains largely theoretical when so many elements are not necessarily available. In practice we cannot offer much choice. In many areas there are unresolved difficulties: staff recruitment has not been a major problem in the past, but there may be shortages as services for people with AIDS become absorbed into the general provision of services. Already certain authorities have only a few home helps who want to work with people with AIDS. Another difficulty is the choice not to tell. People do not have to tell their GP or local authority if they have AIDS or HIV infection. But if they do not tell, can they still be offered services? And what happens if they are being treated away from their normal area of residence?

An outline of the approach in Paddington and North Kensington

The starting point has been an agreement reached between health and local authorities in one of our joint care planning teams that the principles of community care which apply to priority care groups should apply to people with AIDS. This means that we aim to have shared medical care between the hospital and the general practitioner and the terminal care team or hospice. Nursing services should be provided in the community as part of the normal district nursing service. There should be a multi-disciplinary approach and a key worker system, with supervised counselling and individual care plans for each person which reflect their wishes. Financial and legal advice, day care and housing are other important parts of the package. Terminal care should take place in the community with hospice care available where necessary.

Beginning to develop a district strategic plan for HIV infection was the main tool to get people to change their attitudes. Of particular importance in bringing about change were our projection of our present practices to the future and our proposal for a model designed to alleviate the anticipated problems. This approach helped us to get commitment from within the authority and get a framework for discussion on how improvements could be made. It acted as an agenda for discussion so we could undertake proper joint planning with all the other agencies involved.

Obstacles in Paddington and North Kensington

Our strategic approach is not perfect. It includes some intrinsically difficult areas: a key worker system for people with AIDS is no easier to operate than it is for any other group. It was hard to get agreement about counselling. We found that counselling was going on everywhere. In a survey of work, everyone said they were providing counselling, all meaning different things, so that at the extreme almost analytical counselling was going on unsupervised.

Providing housing and services for people who have travelled for treatment to St Mary's presents another unresolved issue. We have tried to agree with two of our local authorities that there should be some arrangement whereby housing can be provided for those people who need it, i.e. those who have travelled a long way and have already been accepted as a responsibility of the health service. Clinicians feel they cannot send people back to districts where no services exist. Local authorities feel unable to provide housing for these people from their normal budget; they are faced with a reduction in their own housing stock (see Denise Platt's comments on p 29). Yet the difficulty of securing housing in London for people with AIDS is so great that we are hoping that next year money allocated for dealing with AIDS may be given to local authorities for housing for these people. This could possibly be done through joint planning mechanisms.

A further practical problem has been how to disseminate expertise within the hospital system. Often this expertise has been gained by clinicians and nursing staff in GU clinics, which are at the periphery of hospital services. Yet the expertise must be disseminated throughout the hospital because (at least in the main centres) there is no service - not even geriatrics - where HIV infection hasn't made an appearance. We are developing a number of ways of tackling these problems and then ensuring wider dissemination to new centres and to community services, including setting up genito-urinary clinics more widely through the regions, arranging joint appointments between the main centres and the new clinics, rotating staff between hospital and community, and setting up new in-patient centres in the more peripheral hospitals.

There are many areas which must still be tackled. Our strategic plan has not adequately covered the needs of babies, children and pregnant women or equal opportunities. We still need to ensure proper consumer input. Our staff support has been effective amongst one group of health advisers over the past year, but we still need to extend it systematically to other groups. As with so many of our changes, we must win total managerial commitment, or nothing will happen.

4

My Experience of Care

PETER THOMSON

It was 16 months ago that a man in a white coat turned around to me and said - yes, it is what you think it is. But what had happened before then. As, I hope, a responsible gay man, I used to go for fairly regular check ups at my STD clinic and particularly one time when there was a very, very slight chance that I could have been in contact with somebody who had subsequently developed syphilis, so I was very keen that they check me out very thoroughly. At the time they thought that it would be a good idea that I had a test for the HIV antibody. This was in November 1986. After a lot of discussion which I subsequently found out was called counselling, we decided that it would be a good idea in my case as we seemed to think that, from the number of people who I knew had already been diagnosed with HIV infection, the chances are that I would almost certainly come out with a positive result.

After that things happened very rapidly. I woke up one morning to find that my collar size had changed from 14.5 to 17.5 and because I had become fairly used to trotting into my STD clinic by this time, I went there and the instant reaction from the hospital doctor was, "oh, that's fun". They said it was nothing more than swollen glands, don't be worried, but we would like to photograph it as well. I am not going to do the usual thing of saying that I have changed the names to protect the innocent because I hope what I am going to present to you is a very positive image of the sort of care I have received in my 16 months.

I am treated by Westminster Hospital in the Riverside Health Authority. During my time, I have just worked out that I think I have seen 20 doctors. The doctor who has been my principal doctor has changed about five times. Always they have managed to keep together some kind of continuity. Surprisingly enough they have only ever lost my notes once and then it was partially because I was changing departments so rapidly that my notes couldn't actually keep up with me. In the December of 1986 after the episode of the glands, everything went well for about 3 or 4 weeks, the glands went down and then the purple blotches appeared. So I went back. By this time I had done a bit of reading and learned a lot. I began to realise what AIDS was. I was still very green and very wet behind the ears in those days when it came to AIDS issues but ultimately on February 6th 1987 they diagnosed me as having Kaposi's sarcoma. This was done with the most, the greatest, amount of care I can possibly describe to you. The doctor actually gave me the diagnosis, I was then escorted very quickly from the consulting room straight into the health advisor who began to tell me that all wasn't lost. People with KS diagnosis can carry on for years and years and years and years, it was really up to me to use my own free will to seek what ever support I felt that I needed. The health advisor, June Francis, dictated phone numbers and I still keep the page in my Filofax today of all the phone numbers she gave me, one of which was Frontliners, the fledgeling Frontliners in those days. Throughout that very difficult period, it was always as I left, "now if you are worried come back, if you are worried about anything call us, if you think that something is going on, come in". From time to time you develop a cough and your first thought is PCP and you ring up. "Yes, no problem, come in, we will fit you in somewhere, don't worry about it." You go in and you are nervous, palms are sweaty, are they going to have to do a bronchoscopy, will the lady with the x-rays forget to give you a gown, will you be pressed up against the cold screens of the x-ray machines, stupid things like that. Your mind is in an absolute turmoil. But I must compliment Westminster in saying that at all times, although the adminstration has broken down on a number of occasions and some departments seem not to have wonderfully good communication with others, the quality of care that I have received has been first class. They have had me now on AZT for a little over a year, I am fortunate that I can still hold down a fulltime job and for some crazy reason this is how I have decided to spend my holiday!

Bravo Westminster, thank you very much Westminster. Thank you ladies and gentlemen for hearing my story.

5

My Experience of Care

JOHN MORDANT

My name is John and I am not a responsible gay man. I am a straight man and an ex addict. I would love to be able to say to you that the quality of my care since I have been diagnosed with HIV infection, then ARC and then AIDS has been exemplary. It has been anything but exemplary. It has been horrendous, that is the only way I can describe it. It seems to come down to the impression that because I am an ex-addict I am untrustworthy and therefore should not be told anything about my own health status. I will just mention that on one occasion I entered a North London general hospital which was not admittedly a teaching hospital and I was a patient on a side ward, and I asked for a glass of milk and the person put on a gown, mask, gloves to give me a glass of milk. This was not three years ago, this was nine months ago. I think she must have thought I was going to bite her. I can't think of any other reason, it is totally incomprehensible to me.

I am a patient at the Middlesex which has a pretty good record but for myself as a patient at that hospital it has been a series of blunders, mistakes and lies. That has been my experience with the hospital. The diagnosis of Kaposi's sarcoma from Dublin was kept secret from me, I found out about my diagnosis by reading my notes myself. I was not told about it. After it came out of course there was a lot of gnashing of teeth and wailing and apologising. But it didn't actually help to be sitting down at the skin clinic reading through your notes while you are waiting for the doctor to come along and find out that you were diagnosed with Kaposi's sarcoma. It seems to be a general fact that gay men receive much better treatment than addicts. That is a fact. I am a member of Frontliners, a director of Frontliners, I have been a member for over a year and it is great to be in a group where I am accepted for myself, but the medical profession does not accept me for myself. The medical profession sees me as a problem, sees me as something to be shunted to somebody else, because at any moment I may fall off the wagon and go back to my addictive outrageous behaviour. This does not help me as an individual to come to terms with my diagnosis. I live on a daily basis with the knowledge that my immune system is compromised and it seems to me that there is a lot of work that needs to be done to change people's attitude towards those people with AIDS who are not, 'responsible gay men.' We are responsible people, we can be trusted if given the chance but we are never given the chance. In service provision we come last. Nobody wants to work with us. Very few people want to work with us. It just really hurts me as a person with AIDS that when I go into hospital I do not feel that I am receiving the same level of care that my other Frontliner colleagues are receiving. It always seems that myself and my addict friends are being pooh-poohed. What ever problems we are experiencing, we are told it is down to our drug addiction. It is something from the past. Very little exploration and very little experimentation and general practices are done on us to try and find out what exactly is the underlying problem or what is causing the problems we are suffering. I don't know what we are going to do about this difference in the treatment that gay men receive and that heterosexual addicts receive, or addicts in general receive. It is something that is a blight on the service and it does nobody's reputation any good to have me up here very very angry and upset about the treatment I have received and people like me receive from hospitals in general. There have been doctors who have been exceptionally good but they are the exception rather than the rule. The rule is that generally if you are an addict you are disbelieved, what ever you are going through is taken with a pinch of salt. This cannot continue any longer. The face of AIDS in England in 1988 is changing radically. We are the new client group and you have to begin making service provision for us because we exist and we are not going to go away. We need understanding, consideration and a little bit of TLC because it goes a long way. Basically we need to be believed and we need to be given the same dignity and rights as anybody else because we do not get that at the moment. We do not. Hospital treatment for me has been a series of nightmares, almost Clouseau-like in their ridiculousness. Peter Sellers could not have been better at doing some of the things that have been done to me. But I live in hope, I hope that by maybe coming and speaking at conferences and speaking to anybody I can, I can help to change the image that drug users have. We are not monsters, we are not irresponsible people, we are people with two problems when we have HIV infection. One problem is the HIV infection, the other problem is our addiction which is as well a fatal illness.

I think I have run out of time now but I hope I haven't been too hard on you - but you need it.

SECTION TWO

EDINBURGH

6

Planning for Aids in Lothian — an Introduction

GEORGE BATH

Lothian is the administrative region containing Edinburgh city and three other local authority districts. It has a population of about 750,000. Most of the people with HIV infection and AIDS live in the city of Edinburgh (population around 400,000). As well as containing a capital city and many tourist attractions, Lothian contains several areas of multiple deprivation.

The HIV epidemic in Lothian is different from that in England. The rates of HIV infection (based on people tested) are higher even than the Thames Regions, and the infection affects predominantly people who have used drugs, either currently or in the past. Other transmission categories are represented but are much less affected. We calculate that about 50% of our drug users are infected with HIV. It should be noted that the bulk of the infection spread in 1983 and 1984 — later than in most English cities. This means that the number of people diagnosed with AIDS in Scotland is only 3% of the UK total. About half of them are in Lothian. In future more people will become ill from symptomatic HIV disease and AIDS, and the proportion of drug users amongst them will increase. The different problems of people from a drug abusing background are described elsewhere, by Steve Cranfield and Ray Brettle (pages 44 and 20). To complete the picture, it should be pointed out that Lothian has been a net loser in the reallocation of NHS resources.

Our services must be planned to meet a demand that is not there at present so they can be available in time for the right numbers and types of users. The projections estimate that in 1991 between 140 and 310 people will be living with AIDS in Lothian. Not only is that a wide range, but of course there is the possibility that our projections could be wrong, especially given therapeutic advances, so our planning must be adaptable to cope with variations in demand as well as to the different needs of our diverse client group. It is, of course, hard to gauge the wishes of our future client group.

We want our services to be sympathetic and high quality, but in order to achieve this we must take into account the anxieties and expectations of our staff, whether they are ill-founded or wellfounded. Services must be acceptable to our client group and also to local communities. In neither case is this straightforward: past and present drug abusers are not necessarily immune from societal homophobia, for example, and some gay men will have fixed ideas about drug abusers. We have also had some unpleasant experiences when attempting to site hospices owing to lack of acceptance by the community.

The organisation of our care system has evolved rather than been planned. The presentation of people with HIV infection — who are at this stage predominantly unsymptomatic — is either to the genito-urinary clinic if they have become infected through sexual transmission, or to the infectious diseases hospital unit (mainly those who have become infected through needle sharing), or else they are identified through the community services. In the future we think we will not have enough facilities in any of these services to cope with the demand. We calculate that at any one stage 15% of people with AIDS will be in hospital. In practical terms we plan to provide an extra 15 beds by 1991.

This is why we have decided to centralise our services in an infectious diseases hospital. Some of the arguments for and against this are presented by Ray Brettle (page 21): on the one hand, the risk of 'ghetto-isation', the inhibition of local effort, and problems of access and staff burn-out; on the other, the development of a range of expertise in clinical and nursing care, better liaison with community services, and a quick response to the needs and wishes of users.

A centralised unit is not only about in-patient beds. We expect an increasing reliance on outpatient and day care facilities and we place great emphasis on links with other services, including medical back-up, community nursing, psychology and psychiatry (especially for addiction problems), social work and voluntary agencies. Integration with housing policy and hospice and hostel provision is a crucial area since the housing circumstances of drug users with AIDS are often very precarious: Les McEwan describes accommodation issues in his paper (page 23). There is an intention to run satellite clinics which will be nearer where people live, but these will not offer a comprehensive service and the high default rates make it preferable to have all services on one site. We also plan an outreach component which could help local community services with new treatments with which they are not familiar, help to educate local services, and contribute to continuity of care.

Finally, at any one time quite a large proportion of the population who have HIV infection in Scotland are in prison. A lot will be locked up in prison when they get sick so it is necessary to coordinate closely with the prison authorities for both out-patient and in-patient services. We do not yet know the actual extent of this problem but it is likely to be considerable.

7

Planning Hospital Services

GEORGE BATH

This paper addresses the planning of hospital services for people with AIDS. I would emphasise that there is probably no one perfect solution, but a number of different approaches that are appropriate in different settings. What is ideal may vary considerably from place to place owing to local considerations.

Outlined below are the major points to be decided when planning hospital services.

A statement of need - both now and in the future

In predicting requirements for AIDS services, it is necessary to have an idea of how many people will need treatment for AIDS or HIV related disease. In situations where the epidemic has already begun and cases are apparent, future case numbers can be arrived at by the process of projection while, if the epidemic has not yet begun in major measure, as for instance in Scotland, it is necessary to made predictions. The techniques used to make either projections or predictions are rather too lengthy to go into at this time and those interested can pursue the matter in the *Report of the National Working Party on Health Service Implications of HIV Infection* ('The Tayler Report') published by HMSO for the Scottish Home and Health Department. However, at the end of the process one will have arrived at a likely estimate of the number of people who will have the condition and therefore require hospital services.

The second factor to consider is the characteristics of the group that will require care. The age and sex structure of the group, the social background, the transmission category and the socio-economic circumstances of the people concerned all have to be considered. These are comparatively 'hard' characteristics but even then may be difficult to predict in advance of the time when cases become apparent. Other information which is equally necessary but even more difficult to obtain is an indication of the wishes and needs of the population and the disease patterns that they will experience in addition to HIV infection. (For instance, drug abusers will suffer a number of injection-related infections while gay men may experience sexually transmitted diseases other than HIV). Lastly, an idea of the home and family support that is likely to be available to the potential patient group is something that one would really wish to know about.

What is required to meet the need for services

When these points have been established, it is helpful to examine what has been found necessary elsewhere to care for people with AIDS or HIV infection. It is possible by looking at other places in the country or elsewhere in the world to predict what sort of facilities will be required. However, when looking at experience elsewhere it is always necessary to be slightly sceptical of accepting models wholesale. One has to ask, for instance, are there appreciable differences between the situation that we are planning for and the situation under observation? For instance, experience in the USA may be considerably coloured by the absence of a National Health Service. In other situations, the transmission category of patients may differ markedly from that in the situation we are planning for. Equally, less tangible considerations, such as differences in public attitude to AIDS or to people with AIDS may make a considerable difference in what will be required to establish care facilities.

It is also desirable to attempt to predict future trends in treatment. These might prove of considerable importance in planning, since introduction of successful treatment might either prolong or shorten the time that patients need to be in hospital, may make a marked difference to the number of people with AIDS living in the community, and will have a direct influence on the activities that hospitals have to undertake.

Present facilities: an assessment of what is available

Once a projection of need and a 'best guess' of factors, including treatment trends and the characteristics of those who will be the patient group, have been arrived at, we have to look critically at what facilities are available at present.

It is necessary to consider the physical facilities available to us, a comparatively simple task. The in-patient hospital facilities must be assessed both in terms of their quantity and their suitability, as must the back-up facilities such as neurology, dermatology, oncology, genito-urinary medicine, psychiatry and other medical and paramedical services. When looking at these facilities it is necessary to ask if they are suitable for dealing with AIDS cases, whether there is scope for their expansion, and what alterations, if any, will be needed to make them appropriate to meet the needs being considered.

In the same way, the availability and suitability of staff for dealing with AIDS and

HIV infection must also be considered. This would include medical staff, nursing staff, physiotherapists, occupational therapists, psychologists and psychiatrists, and both numbers and the training of staff must be taken into account.

Since hospitals do not operate in isolation, it will be necessary to examine what non-hospital facilities are available in the geographical area under consideration. This relates largely to the question of support in the community. If it is adequate, it will tend to minimise the length of hospital stay, while if it is poor or absent, it will be necessary either to create better support in the community or to make available facilities that will allow people with AIDS to stay in hospital for a longer period, although this latter option is definitely a second best.

Briefly, one will need to consider social work services, the community nursing service and the non-statutory sector, which can range very widely from 'buddies' to drug counselling services. In addition, the role of primary care must be emphasised as being critical to the support of patients in the community.

'Pulling it together': the formation of a practical plan

At this stage, one will have an indication of the ideal solution in terms of both physical facilities and staff requirements. Almost invariably this will require more resources than are available at present. In addition, there may well be an indication of the need for additional staff training or additional support facilities in the community.

Once the resource implications of the ideal solution have been determined, these must be compared with what will in practice be available in terms of money, buildings and staff. If, as is almost inevitable, there is less than would be required to meet the ideal situation, it is necessary to arrive at a system of priorities and to devise a compromise plan.

The essential questions are "which of the components of the plan are most urgent or important?" and "which elements of the plan can only be taken forward in combination with others?" At this stage it is also relevant to assess possible constraints to meeting the plan. These are likely to be numerous and dependent on local circumstances. They may include official inertia, uncertainty about the future of other medical and nursing services and perhaps pressure from the local community against siting 'AIDS units' in the location that would seem ideal for them. In addition, estimates of available resources for the future may be unavailable or vague.

AIDS and AIDS planning: is it 'special'? Are there any special features about AIDS planning? I think the answer is that it depends on what you compare it to.

AIDS is a terminal illness. It runs a protracted and often indefinite clinical course with, in many instances, multiple presentations and problems, and it tends to affect young people. In most circumstances, infection control to prevent either staff or other patients becoming infected will be an issue, although not a major one because as we know AIDS is not highly infectious and is, in fact, very difficult to contract by casual contact.

These features are unusual but certainly not unknown in the health care setting. For instance, if one looks at cancer services, chronic neurological disease such as multiple sclerosis and a number of chronic diseases in young people, they share many of the features that have been listed above. In fact, in the days before chemotherapy was available for tuberculosis, virtually everything that could have been said about AIDS could have been said about TB. In addition, of course, work with TB patients was a real and substantial risk since it was not uncommon for staff to contract the illness and die from it due to their contact at work. For these reasons, it is probably true to say that there are few features arising from the medical aspects of AIDS that are unique.

The novel features of AIDS, however, are the sociological and psychological ones. The incidence of the disease in many countries is highly concentrated in particular groups in society. For instance, it is disproportionately a disease seen in gay men, drug abusers, haemophiliacs and people from certain African countries.

While this pattern of disease incidence may well be only a temporary phenomenon, it means that at present there is a unique possibility for bad attitudes and stigmatisation of those with the disease by the general public. Another feature which may, in some circumstances, be important is the fact that carers may have a disproportionate tendency to have been drawn from the 'risk activity' categories that experience the disease most. For instance, certainly in America, there has been a noted tendency for physicians and nursing staff members specialising in AIDS to be drawn from the gay community. From a practical standpoint, this perhaps means that the staff members are better able to empathise with their patients and may feel more emotional drain on themselves because of this. The incidence of 'burn out' and other symptoms of stress may hence be greater.

Because of all these factors, there is probably a greater requirement with AIDS than with other similar chronic terminal diseases of the young to consider psychological and emotional support both for the patients and for the carers. There is a need to consider practical support, since stigmatisation may remove societal and community support that would otherwise be present. In the case of drug misusers, who tend to make poor use of medical facilities available to them, it is probably necessary to give greater consideration to 'enhanced convenience' to counter default rates and non-use of facilities.

Lastly, it is probably necessary for all those involved in Health Service provision to become aware of the needs of the groups in society - drug misusers and gay men - who are likely to be our patients in future. Often this awareness can direct us to fairly small but significant things that can make a huge difference to the happiness of our patients.

For instance, an awareness that addiction is likely to be a considerable additional problem in those who contracted their infection by drug abuse is likely to make us more sympathetic to the provision of services to deal with their addiction. In practical terms, this may mean providing substitution therapy with either oral or injection drugs to those who are in hospital for treatment of their HIV infection. This is not something that has been commonly done in the past.

In the case of gay men, some major mistakes have been made in the past over not recognising the place of lovers in the lives of our patients. For no particularly good reason in the past it has been common practice in hospital to accept as next of kin only a relative or spouse and not a same-sex lover. This unintentional snub has undoubtedly caused great anxiety and suffering to homosexual men who are admitted to hospital in a seriously ill condition. Merely acknowledging small issues like this can make a tremendous difference to people's happiness.

Care of haemophiliacs

Briefly in conclusion, I would just mention the case of haemophiliacs who have HIV infection. There is no real difference in the facilities they need in relation to AIDS, but we must acknowledge two things:-

1) They have a serious medical condition in addition to HIV infection - haemophilia.

2) They often have a long-term connection with the haemophilia unit and in many instances the haemophilia unit is well able to cope with the medical problems that arise in those who are infected with HIV.

For this reason, it is often appropriate for people with haemophilia to be cared for, not in the facilities that will care for others with AIDS, but in the haemophilia unit. Naturally, it is necessary to look critically at the facilities which are available there, since in the past counselling on some issues that are important in AIDS and HIV have not featured in the management of haemophilia. For instance, the sexual counselling of infected people is a new skill that must be acquired by haemophilia units dealing with HIV infection.

8

Delivering Care in Hospital

RAY BRETTLE

Care systems for HIV tend to reflect the needs of the particular people who use them. In a homosexual/bisexual community, there is likely to be a good information system and a lot of self help groups, contributing to a well-developed group voice which can comment on deficiencies in services. Use of existing services, such as the sexually transmitted disease (STD) unit, is likely to be high and the consumers are essentially health conscious and interested in their health generally. As a consequence, the care system for these groups had been characterised by an emphasis on the involvement of voluntary organisations, a lot of home care and community care systems, a positive response to hospice care and an even more rapidly evolving health consciousness.

This must be contrasted with the problem that exits in Edinburgh. In a drug misusing community, active and current users are still engaged in an illegal activity. Unfortunately, there is a tendency to be manipulative; there is also a natural distrust of organisations - the DHSS, the social work department and hospital services - because current drug users are living amongst an underground set of activities. Even worse, all those organisations distrust addicts because they all have had experience (as far as they are concerned) of being ripped off. There are very few addicts' self help groups and there is virtually no organised community voice. There is nobody saying, "why haven't you done this, why haven't you done that." This is the bad side of the equation.

Drug users have a very immediate type of life style. There is a problem, they like it sorted out and that is the end of the matter. They are not particularly health conscious. They have very poor use of existing services and high late presentation for antenatal care. Women do not necessarily present until 23 or 24 weeks. There tends to be a very large use of accident and emergency facilities for abscesses and other problems from drug misuse - emergency first aid care, if you like. There is a default rate as high as 30% for most clinics. If you give people appointments, they don't come back. If you say, "fix your teeth", they don't turn up.

The people who provide these services find such behaviour very difficult to cope with. Without doubt there is a problem of aggression that one simply cannot get around. Last Thursday in our infectious disease ward, we had two people, one an in-patient and one an out-patient, kicking each other and scratching each other to death in the ward, so that they had to be separated by staff. They happened to be two women and not men. One of my staff was injured in trying to separate them. We have had very little aggression against ourselves: most of it is verbal, but the aggression does exist. (However, it must be pointed out that the verbal aggression towards staff and the chaotic behaviour were worse in the early days of the service and now appear to be settling, perhaps helped in part, as far as the behaviour goes, by enforcing an appointment system.)

Many of these individuals live in a violent society. I have patients whose brothers have murdered brothers; whose friends have been clubbed to death over drugs; prostitutes who have had Stanley knives thrust into their throats. We live in a very non-violent society in general, but for these people violence is a very real phenomenon.

Not all the people using our service are drug misusers, though. We have an increasing percentage of people attending because of sexual contact. The study that we are currently undertaking shows that 60% of our users have non-using sexual partners. So it is a very wide field. The other important thing that I want to emphasise is that at presentation only about half our patients are currently using drugs which is why I prefer the term 'drug misuse related', because the other half are no longer using drugs in the sense that they are addicted. Unfortunately, the half that are still using do tend to take a lot more than half of the resources and half the time. This is a particularly difficult problem in Edinburgh because of the lack of care facilities for addiction. What we have tried to do is to develop a care system which is reasonably user-friendly, that is, we try to emphasise the fact that we are interested in these patients as people, not as cases, and that we are willing to address both their addiction problems and their HIV problems. We regard that as a very important point. Other systems may avoid their addiction, but we believe that you cannot say: "I will treat your HIV but you will have to go down the road to sort out your addiction problem," or "I cannot give you Methadone but I can give you AZT and you can sort out the rest of your problems yourself". You have to address both problems.

We have tended to centralise services on one hospital site because it has made it easier for communication and enables us to provide dental care, contraceptive advice, ante-natal care or family services on the basis of "do as much as you can when they do attend". In certain situations it is important to have good lines of communication to GPs because otherwise both of you will be prescribing drugs and the people will be receiving twice the amount that everybody thinks they are receiving. That is one example of how communication can help avoid some of the problems caused by manipulative behaviour. The same principle applies to others involved, too. We respect confidentiality where it is necessary, but in other situations the information we pass on may be considered as coming close to an infringement of confidentiality.

In this context I should briefly mention our out-patient services which include counselling, medical services and drug misuse related services such as the issue of needles and Methadone. The philosophy here is to attempt to move towards a safer drug use — abstinence, non-injecting drug use or, at worst, injecting drug use with clean equipment — and away from injecting drug use with unsterile and shared equipment. Close links with Lothian Region Social Work Department enable problems such as accommodation, fostering and adoption, DHSS allowances and diets to be dealt with more easily.

We believe that through concentrating on one site we have developed a working in-patient system. It enables us to build up the high degree of medical expertise which is required to manage a new and complex disease, which is, after all, a life long illness. Within the space of six years you develop a totally new service for a new illness with many opportunistic infections, with the additional complications of treating drug users. Contact with the hospital does provide a certain amount of continuity. We do our best to minimise the problems of changing doctors. As a consultant I see most of the patients that I try to look after.

However, I must confess that centralising services for people with AIDS at one hospital in Edinburgh, the City Hospital, is contrary to the ideas I originally set out with. Nevertheless it is a policy I believe to be realistic at present. It allows the development of a readily identifiable source of expertise which is available to government agencies, NHS planners, voluntary organisations, GPs and the general public. It makes sense while health education for workers, patients and public is given time and resources to make much greater progress, especially on the crucial areas of infection control and means of transmission. Centralising in one hospital happens to be cheaper initially and also reflects the power and influence consultants have in developing services as compared to other groups in the health service. These considerations may help to explain why our model of care has taken its present shape. We have now reached the point where we can say that Edinburgh's record as a hospital based system has shown that it is possible to deliver health care to past and present drug users with HIV infection and AIDS.

There are some difficulties facing us. One of the main obstacles to a policy of treating people with HIV infection and AIDS wherever they appeared seeking treatment was the problem of getting other hospitals to adopt appropriate infection control procedures. This may be an important point for districts outside London to consider. The examples of inappropriate isolation techniques from Edinburgh are appalling: women being delivered who never saw a face at all — staff are always covered with masks, gloves and gowns; a senior nurse, on finding a patient out of her room to fill in the menu chart, putting on disposable gloves, taking the pen then throwing it in the bin — in front of the patient. These incidents happened two years ago and I think a lot has changed, but these things happen. We have had experience of patients being distrusted or feeling rejected for a variety of reasons, but not least because they are drug users. Another problem was the response of the other patients to people with AIDS or HIV infection. We have had situations where people with AIDS have been rejected by the other patients. You can keep hammering away at staff education but the ward patients change every day and on the education of the patient population is a massive task. Unique to Scotland, insofar as other people haven't yet had to face it, are the dilemmas arising when patients have to be removed from the ward owing to unacceptable behaviour associated with drug use. It is difficult for other patients to have their lockers rifled by people with HIV infection looking for money when they are in overnight.

It is the need rapidly to accumulate experience and offer advice which led us to develop a specialised service. If there are only one or two people with AIDS per year, as is the case in some health districts, it still takes a lot of resources to educate everybody in your district. At the moment I am talking purely about managing HIV illness. If people present with neurological or respiratory problems, I think it helps if there are a group of nurses and doctors who have decided to look after these people. The main precondition for success is that the team has to be committed. If you allocate somebody and say: "you will look after the AIDS patients" or "you will look after HIV", I think it fails because they are not interested and this tells very rapidly. The necessary medical expertise is also, of course, required which in turn needs reasonable time for training in internal medicine because the doctors are going to deal with a variety of presentations from literally every system you can think of. A further prerequisite is reasonable infection control, and also adequate training in infection control so that people know when it is appropriate to put gloves on and to know when it is necessary to use gowns. A lot of this may just mean telling the patient, especially those with central lines, "I am going to put a drip up on you, this may involve a certain amount of blood spillage, so I am going to get dressed up". On my ward rounds, for instance, none of us gets dressed up to see people with AIDS, whether they have drips up or not, and I think that is very important.

Without doubt as AIDS and HIV infection become more generalised the expertise has got to spread down. It will become impossible to depend solely on a centralised unit, although that unit will be needed to provide the experience and expertise to other people. The lessons learnt in a single centre about practical things, for example, such as how to deal with the home helps and how to get the linen service organised can then be passed on. The stage is now set to explore the possibility of increasing the use made of community support services.

However, there are the opposite problems. If you centralise you are looking after three or four people currently using drugs in one area. We elected to centralise and demonstrate to these patients that to gain experience with dealing with them, we have to make quantum leaps in knowledge in two years. Before HIV came along, most users were contacted because of hepatitis B. But hepatitis B is a transient event and only 10% remain carriers. Hence the users' contact with the hospital was fairly brief.

The advantages of a centralised service have to be balanced with the dangers of stigmatisation. There is the risk of people saying: "that's the AIDS unit and if you go in there you have got AIDS", or "if you go to see that doctor you have got AIDS", and so on. In a district general hospital, there is the advantage that most of your clinics will be taken along with all the other clinics, so that in an out-patient department it will be much less easy to make such comments.

9

Community Care and Accommodation

LES McEWAN

The purpose of this paper is to examine the issues concerning accommodation which an authority must address when it plans community care for people with AIDS. I have some experience derived from my work in Lothian but I am not an expert - there are no experts in planning for AIDS. I am fully prepared to admit we may have got our thinking wrong. It is certainly changing over time.

In addition to being the Depute Director of Social Work, I chair an AIDS co-ordination group which covers the four Lothian district councils which are housing authorities, and the health board, the police and the non-statutory sector, including housing associations.

Key principles for community care

Is care in the community desirable or possible? Before that question can be answered, 'community care' must be defined. I would use a shorter statement of objectives for community care for the purpose of this paper, and that would be the first sentence of the House of Commons Select Committee's definition (which Griffiths adapted). But I would add the word 'permanent' so it reads:

"To enable an individual to remain in his own home wherever possible rather than being cared for permanently in a hospital or residential home".

This definition helps us see that hospital care and residential care both have their place in our scheme of services. Whilst accepting that community care for people with AIDS is desirable, we still have to focus on the appropriate use of hospital and residential care.

In planning services we must start with some basic principles - a vision of how things ought to be so that we can measure what we've achieved and what still needs to be done. The principles which apply to all people apply equally to those with HIV and AIDS, that is:

- that they have the right to live independently in the community in a home of their own choice;
- when they are ill or disabled they should be given encouragement and support (and the services they need) to retain independence and control of their lives, in accommodation and living conditions of their choice, and which meet the needs of their medical condition;
- only where they do not wish it or it is no longer feasible to offer support, care and treatment in their own homes, should alternative forms of accommodation and care be offered.

There should not just be two alternatives - when well, home; when ill or disabled, hospital or residential care. There is in fact a continuum between the two and there should be a range of choices of accommodation which offer different forms and degrees of care. The continuum between ill and well is also the continuum between dependent and independent; and between no care and total care.

Whether community care is possible is entirely dependent on two things: attitudes on the one hand and resources on the other. The old adage "where there's a will, there's a way" is apt, but Griffiths' analogy again from his report adequately sums up what community care feels like at present: "The Israelites faced with a requirement to make bricks without straw had a comparatively easy and routine task". Certainly, community care is very difficult to achieve in resource terms north of the border.

What do these principles mean in terms of the practical requirements for accommodation for people with HIV and AIDS? When they are well, their accommodation needs are the same as any other person's. When they are ill or develop full blown AIDS, they will need accommodation suitable to their medical needs, again just as any other person in the community who may be ill or disabled. But that accommodation must be in a suitable location, for example, it has got to be near the hospital where the person is being treated, near to his relatives, near to local services and on a local bus route. The property itself must be easy to get into, and easy to move around in. This is particularly important if the person is non-ambulant in which case the building must be ramped or have a lift. They must have basic facilities, running water, means of cooking and decently effective heating. There are some properties in this country still which don't have these. Also the accommodation must be available. The person must not be debarred from applying for housing because of HIV or AIDS. I don't believe this is the case anywhere in Britain but the person may be ineligible for housing because they are single or because of a previous poor tenancy record.

Finally, it must be possible to arrange care at or around the person's accommodation. There is no point in accommodation being in the right place and suitable in terms of access and facilities if the care is not available. Certain characteristics of a person's home will make it more or less suitable for intensive domiciliary support to be given there. It is possible to get around the absence of certain facilities. For example, if there are no laundry facilities, a domiciliary laundry service can be used; if a person has inadequate cooking facilities, meals-on-wheels can be provided; if there is no lift, it is possible to carry someone up and down stairs if there are sufficient people to do that. But the lack of certain facilities will not only be felt to be degrading by the people themselves but will make it difficult to provide care; for example, if there are no or poor bathing facilities or if there is a lack of privacy owing to overcrowding. There are very few ways you can get around these basic problems.

Clearly, a balance of the right kind of accommodation and care will be what determines whether community care is possible or desirable for the individual. It will be the absence of suitable accommodation or the inability or inpracticability of providing the level and type of support required on a domiciliary basis that will lead to alternative forms of accommodation being offered and considered. Getting that balance right between accommodation and care necessitates a basic understanding of what people with AIDS need and of the barriers to providing that care.

To make policies and provide services, we would expect planners to assess, measure or confirm need. We have tried to project the total number of people with AIDS, and then adjust the total to allow for the number currently in hospital and the number of people who have died.

Next, these people have to be divided into relevant groups. You have got to know how many mothers and children are involved, how many families there are with more than one member with AIDS, how many single homeless people there are and how many are active drug misusers. Then the dependency levels of those people has to be estimated.

Each of these factors requires prediction of future events, and in some cases the scientific basis for this is simply not there. Estimates of dependency levels require an understanding of the progression of AIDS itself but even with this, certain planning assumptions about the need, say, for residential and hospice care have had to be clutched from the air.

Not only is there an absence of hard data about our future population, but we can only guess at how many people may be living in unsuitable accommodation at present. An estimate of the numbers is a crucial factor which is missing from our plans. So as well as the normal processes of planning, it is necessary to do a bit of guessing.

What this amounts to is forming assumptions through consultation with people with AIDS, and turning to a number of sources of information to test ideas.

There are are a number of sources. One can ask professionals in the field; obtain information from elsewhere including abroad; you can ask the AIDS organisations such as the Terrence Higgins Trust in London, or the Scottish AIDS Monitor north of the border, or one can ask people working in the drugs projects. Individuals or self help and support groups such as Body Positive and Frontliners can be approached. But in all these cases, it will be important to check whether those who have been asked know for certain or whether they are simply predicting too. Many people go to San Francisco, Sweden and Italy - or indeed to other parts of the country - to try to find out what to do. Will the experience they learn there be relevant to what is going on at home? If you ask self help groups, will they represent a broad enough spectrum of views? We have not done very well on consumer research in Lothian to date. The fact is that we are trying to plan in anticipation but it is equally true that there aren't that many people around with AIDS yet in Scotland or Lothian to ask. Further, getting access to individuals or even self help groups is not easy. We have no Frontliners set up in Scotland but we have a Body Positive group, with whom we are in close contact, but direct access to Body Positive members themselves is for very understandable reasons restricted. The views we have had expressed to us by these members through the co-ordinator are varied and I have to say often are at variance with each other. Body Positive people clearly know what their needs are now and are better able to guess what their needs might be in the future but these are still predictions and they may not be representative of the needs we are going to have to meet in the future. Although consumer research is difficult it must definitely be undertaken. Otherwise we will overlay our planning with too many professional views about what's best for others.

Planning a range of accommodation

I have already stated that in Lothian we only envisage alternative accommodation being considered where a person has no accommodation or where support and care cannot be organised around his or her existing accommodation for whatever reason. In such circumstances a range of accommodation types will be necessary to meet the variety of needs of those with AIDS. The types of accommodation would be those available for other groups of 'people in need' (as defined in Scotland under the Social Work (Scotland) Act 1968) but would cover more than the range we have at present for each single group of persons in need. We have nine babies in our care in Edinburgh at one end of the spectrum and we are talking about people aged 50 at the other end - quite an age range and therefore a needs range.

Figure 3 illustrates the range of accommodation we have been envisaging and planning in Lothian. Accommodation is arranged around the continuum of care discussed above. The type and degree of care increases as we move from right to left and the type of accommodation moves increasingly from independent living to group living, again from right to left. In terms of support in a person's own home, we have all the facilities on line at present. Some things such as wardened housing, family facilities and a hospice are not in existence yet, although we have got political backing to introduce them. On the treatment side and the total care side in the hospital and in the support we can provide in a person's own home, we are relatively well provided given the size of the problem now. We see a need for supported accommodation and we have got a supported accommodation team with my department working with the housing associations, district councils, housing agencies like Scottish Special Housing, and development corporations to obtain and provide supported tenancies and shared tenancies. We are also looking at shared landladies and we hope to have money for wardens later this year so we can add wardens to the accommodation we get through normal housing stock. We have already got a drug rehabilitation hostel which has 12 places, all of which are occupied with people who have HIV. We then envisage a hospice which we put under the nursing home category. There are also two existing hospices in Lothian who say: "we will give you some places" but because of their charters or deeds they are *not* able to say: "we will specifically concentrate on people with AIDS".

This range of provision through different degrees of care and independence leaves unanswered a question which is very important - can the needs of different groups of people be met in the same provision? In Lothian, we haven't got it right; we haven't answered the questions yet about whether integration is possible or not. In practical terms, as things are at the moment, frankly we would be pleased to get a residential facility off the ground and leave the question of who goes in there for the future.

Can different groups of single people be mixed in the same accommodation?

The arguments for integrated provision of residential care start from the case that what matters is the illness itself not lifestyle, and not prejudices about other people's behaviour. Indeed groups are already mixing and differences may erode as the epidemic progresses. We must also be aware of the danger of perpetuating stigma and prejudice through separate provision. And of course the self-identity of users may be different from the labels we seek to attach to them. For example, former injecting drug users may no longer identify themselves as drug users, and some homosexuals may not wish to be identified as such.

On the other hand, different groups may in fact remain prejudiced against each other, which would lead to conflict within integrated units, and to some people being unable to accept services.

In particular, the needs of active drug users may encroach on the care and treatment of others. Even if such difficulties could be overcome for single people, there is a strong argument that parents and children need family life. Finally, we have to remember that the management of a 15-bed facility is already complex without adding these additional tensions brought about by integrating different groups. Certainly a policy of integration will present a major challenge to staff where it is adopted.

We have concluded that three groups do need separate group living, supported accommodation, or residential and hospice care facilities. These are families, mothers and children, and active drug misusers. Whether ex-active drug users and others could be accommodated together depends on the scale of residential provision you are making and the type of residential facilities you have got. The successful answer to the question of mixing client groups has eluded us for the moment.

Housing criteria

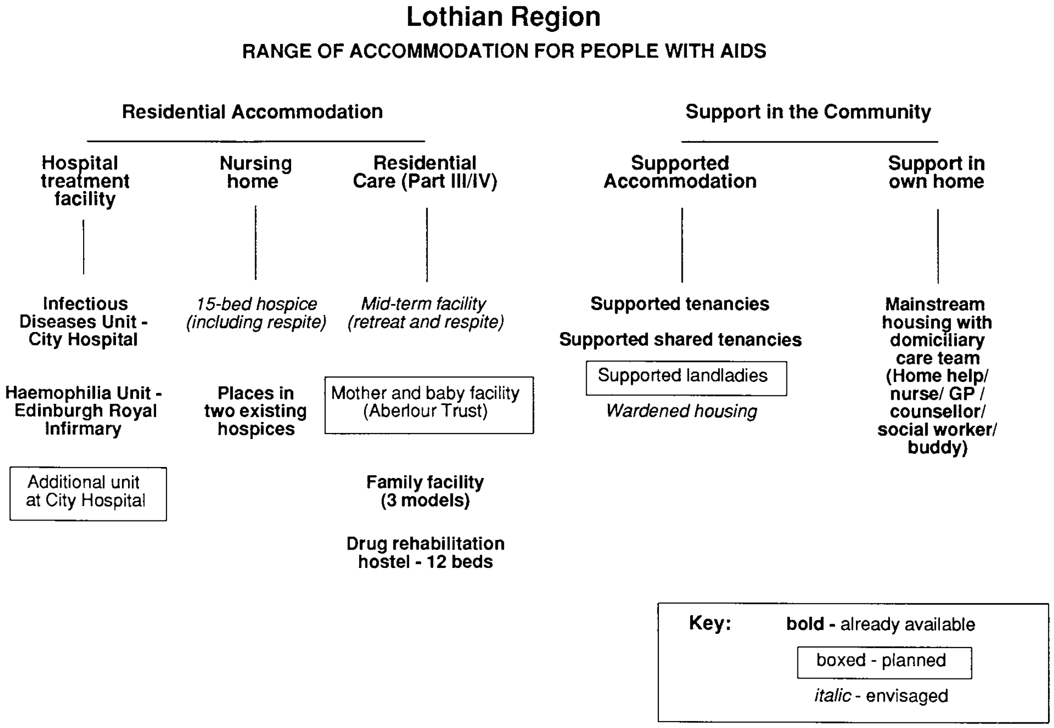
Do we need to change housing eligibility or priority criteria? Housing is not my specialist field so I cannot give you an informed over-view. Our experience in Lothian may not be typical. It is essential to have housing authorities, housing agencies and housing associations in partnership with all other agencies. We have four housing authorities who sit around the table with other agencies in joint planning and there are a number of standing consultative arrangements. For AIDS, Edinburgh District Council represents the four districts in Lothian because the others do not yet have the problems. The response of the three other districts to the proposals on non-residential accommodation has been one of interest but one of pragmatism — "we'll get into that when we have to."

Edinburgh District has not formally considered its housing policy in relation to HIV and AIDS. The officials wonder whether this is necessary as they believe all needs can be met within existing policy and procedures for mainstream housing and they are anxious to avoid any emotive response arising from the overt allocation of a house to someone with AIDS. The following points have been made:

- People with AIDS would be eligible for medical priority both for housing and re-housing (this would entail a medical report and there are concerns on the part of people with AIDS about confidentiality).
- People who are homeless would be classified as 'vunerable' to bring them within the scope of the Housing (Homeless Persons) Act.
- Single people make up over 50% of the district's housing waiting list — allocation policies are already being revised to take account of this and 3-apartment houses and furnished lets are being made available. Single people with AIDS should not have any more difficulty getting housing than other single people.
- The district is sympathetic to voluntary organisations wishing to take over tenancies for special needs groups - provided this is done in a low-key way.

Although these considerations do not amount to a formally adopted policy position, there are advantages in this ad hoc approach since it avoids raising issues of discrimination in favour of people with AIDS over other groups with particular needs.

Figure 3.



SECTION THREE

LONDON : STATUTORY SERVICES

10

The Local Authority Response

DENISE PLATT

Hammersmith and Fulham is a very small London borough, perhaps one of the smallest. We have a population of around 150,000 people. I can walk from the top to the bottom of my borough in about one-and-a-half hours. We are a very small part of London and we have a significant number of people with AIDS living in our community. Over the past two years the Social Services Department in Hammersmith and Fulham, of which I am Director, provided direct services to about 160-200 people with AIDS living in our local community. So we have a growing body of knowledge in the department about how we can support people at home. It is very difficult to tell how many people with HIV-related disease or who are HIV positive live in the borough because all the statistics are produced on health authority boundaries. In terms of community it is quite difficult to relate to health service administrative boundaries: the local authority has to deal with Riverside Health Authority, the Parkside Health Authority, the Bloomsbury Health Authority, the Hammersmith Special Health Authority and the North West Thames Regional Health Authority. So there has been considerable difficulty in co-ordinated planning. I am told by the Riverside Health Authority that the number of people in Hammersmith who fall within the health authority boundary who have HIV related disease could be between 8,000 and 10,000. Another formula tells me that by 1990 everybody who lives in the borough will have HIV-related disease. So I therefore have to plan on the basis of people who present to us and from our knowledge about them.

The clients who have received most services from us have been white and from the gay community. We know that we do have drug users living in Hammersmith and Fulham, and we have a drug clinic at Charing Cross Hospital, but as yet we have had few actual requests for service from people who have acquired HIV infection through present or past drug misuse. This is perhaps because we are a statutory organisation and people are concerned what we might do. That is particularly an issue in relation to women. People think that if as a drug user if they approach us the first thing we will do would be to take their children into care. There are eight babies and young children with HIV infection living within my borough boundary whom we know and support in the community. They are not in care.

As well as experience of clients coming to the department, to whom we have subsequently provided services, we also have experience of members of staff working elsewhere in the council who have HIV-related disease and AIDS. We found, when we were confronted with our first referrals and a member of staff who presented to us with AIDS, that it was essential for us as a local authority to adopt the principles on which we were going to operate in the delivery of services. This applied across the local authority as a whole, not just in social services. The philosophy and principles which have been adopted are, first, that every person who lives within the boundaries of Hammersmith and Fulham is entitled to equal access to the council's services; second, if the services are available, we should help the people to make use of those services; and, third, that employees' rights are equal and there should not be discrimination in employment for somebody who has HIV-related disease. We also have a cross party approach to the issue of HIV-related disease. The issues are too urgent for party politics to enter into it and our philosophy has been carried across two different sorts of administration in Hammersmith, so all those myths about politics getting in the way of local authorities delivering services can be demonstrated to be myths.

From the start, we adopted the approach that we were going to deliver our services from the generic base, the department. We didn't set up a specialist service. If we had, we would not be able to cope by now. It is only because we have been trying to enhance the services that exist and to make them sensitive to people in the community that we have been able to absorb the work that has come forward to date. Until the recent allocation of £2m from central government to local authorities, we were having to face some very difficult priority issues about where to allocate resources. Some people who had traditionally received services from the department were having to wait longer for the service because the needs of the people with AIDS were very substantial and we had to divert resources to their care. So we haven't been providing a special service as such. However, we have discovered that in providing services to people with HIV-related disease we have a microcosm of every other issue that social services departments and local authorities have tried to duck away from for years. In providing services to this client group you cannot cut corners. They won't allow you to! They tell you very quickly when they think you are not delivering the service in the appropriate way. AIDS finds the weakest spot in your organisation very fast. In terms of my own organisation it was health and safety policies.

We found ourselves initially having to adopt a training strategy for our own staff. This proved to be the prerequisite for any service delivery that we could provide: people, particularly those in our domiciliary care services, had all read the *Daily Mail,* especially the headline which says "home help dies of AIDS". That wasn't very helpful when it was printed on the day of our first training course for home helps. So we made the best of that opportunity. We tried to develop a training strategy for all our employees and to target it in the first instance on managerial staff. There was nothing that said that our managers had any less prejudice than our workers on the front line. Secondly, we found ourselves developing health and safety policies in conjunction with the trade union which put HIV in the context of other health and safety issues. Our domiciliary care staff and residential staff are much more at risk from other things than from HIV-related disease. I must say if it hadn't been for the very good support from our trade union in everything that we have tried to do in terms of health and safety in the service, I don't think we could have made the strides that we have. By involving them at the start we have been able to make a significant amount of progress in relation to the services we have delivered. We also have found ourselves developing very strict confidentiality policies in the department. This is a total reversal of the usual culture. People in social services tell everybody everything and the person at the next desk knows all about the caseload. However, until we can actually guarantee that people with HIV-related disease will not be discriminated against because of their diagnosis, our confidentiality has to be very tight. We have also had to look at issues concerning civil rights of clients living in our residential care and testing issues in relation to children in care.

The services that we now provide are:

- Social work and counselling
- Proper assessment with the person concerned, not around the person concerned, which allows the person with HIV-related disease to dictate the pace as and when a statutory organisation becomes involved. Sometimes that involves them telling us to get stuffed for a while, which we will do.
- Practical action and social care planning, ie putting together packages of care for people.
- Advocacy. The Social Fund is already proving quite a trial for anyone who has managed to get income support in the first place. An enormous amount of time and energy goes in to trying to help people to

find their way through the new social security system and to get community care grants. People who are permanently incontinent and living at home need community care grants but it is increasingly difficult to get financial help. The local DHSS officers with whom we have met had not themselves thought about AIDS as an issue in Kensington, Westminster and Hammersmith. They have now.

We also have been providing day care, occupational therapy, assessment and support, telephones, bus passes, specialist workers with technical skills around visual impairment, respite care, meals and domiciliary care generally. I may say that our views about the provision of all those services have been changed by the feedback we have had from the clients who have received them, and we have found ourselves rethinking very traditional models of services to try to respond to people.

Housing is a vital issue in care for people with AIDS. There is no point providing counselling if people haven't got a roof over their heads because they have been evicted. But we must see the local authority response in context. My local authority currently has 800 homeless families on its waiting list. To accept people because of their HIV status means in some ways that they leap-frog that list. The cost of keeping someone in bed-and-breakfast accommodation can range from £12,000 to £15,000 a year. We have rehoused 30 people with ARC or AIDS because they are vulnerable. I invite you to do the calculation so that you can see how much the cost works out at. We have currently placed around 600 of those 800 families outside our borough in leased accommodation from Pinner to Wimbledon. We cannot even house our own homeless families within our own borough. The thought of finding accommodation in the borough for people who have no connection with the borough while they seek treatment at a London centre is quite mind-boggling — and all the more so in the light of the Housing Bill which is currently going through Parliament. This does not mention anywhere vulnerability or homelessness. It seeks to hand over housing stock to social landlords and to housing action teams. Not only is the right to buy diminishing local authorities' stock of accommodation, it is also current government policy to hand over housing to other agencies. Given that tension, it is difficult for us to think of ways of meeting our care in the community commitment for a whole range of client groups, although central government would presumably look to voluntary housing organisations in these circumstances.

I want to say what is special for us as local authorities about providing services for people with HIV related disease. Firstly, the problem is new, and it needs new resources; secondly, the age of the client group the — clients are asking for our care a good 20 years before they might have been expected to do so; third, the discrimination that the diagnosis arouses is a challenge to anybody in the provision of services. I am talking about homophobia, racism and I will add 'drugaphobia' as well. It is important for councils to develop equal opportunities policies, not slogans, which are supported by anti-discrimination strategies. Support mechanisms for staff are the fourth new area: we have found ourselves setting up a variety of groups for staff and their partners. Fifthly, in policy planning we have a variety of planning groups. Within the department we have a planning group which is chaired by the deputy director. I sit on it, but as I am not chair I can speak, and it includes the home help who actually delivers the service; so it spans the hierarchy. We find it necessary to do that because the issue moves fast. There is a similar group in the housing department and also one which involves the health authority. These groups have representatives from health, housing, the family practitioner committee, two consumers and housing associations. The consumers are chosen by the voluntary organisations and there is nothing that concentrates the mind more than when an AZT alarm goes off in the middle of a planning group. We have to work fast because time is running out for some people.

Finally, there is consultation with the community. One of the ways we have been trying to tackle homophobia and racism has been to go out into the local community and talk to tenants associations about issues for people living in their community. We have had a small experiment in consultation using our community workers. This involved meeting key leaders of tenants' associations, tenants' groups and so on and talking about the services of the department and trying to enlist the community's support with us in providing extended networks of care. On the broad front, this is a health education matter. More specifically for us, it is an attempt to operate the community networks in a supportive way. The small experiment is rolling into a bigger public meeting and is proving to be quite an exciting way of involving local people. Although consultation has come last in this list, it should really have come first, as it must happen from the very beginning and continue throughout.

11

Bloomsbury Community Care Team

DR ROB GEORGE

This paper outlines some key principles for the care of people with AIDS, and then proceeds to describe the multidisciplinary functions of the Bloomsbury Community Care Team. It looks at some of the practical issues we deal with within terminal care in London, and closes with some thoughts on evaluation.

To set the scene, however, it should first be mentioned that the Bloomsbury team was set up at the end of 1987. It received funding from the health authority (approximately one-third), and from various charitable sources (a further third). The final third came from the King's Fund, and is intended to fund the evaluation aspect of our work.

Key principles

The acronym AIDS can be taken as a useful mnemonic and changed into more productive and positive terms. The first of the two illustrations I will use here applies to key principles for management: Autonomy, Integrity, Disease and Surroundings.

Autonomy: The person with AIDS, in conjunction with his or her family unit, is very much the centre of a multidisciplinary approach. Autonomy means that the client has— perhaps for the first time— the ability to determine the level and type of care, and retains control of medication and management strategy.

Integrity: people must be seen in the context of their relationships, their lifestyle and the physical needs they have with regard to their jobs. Hospital practitioners can all too easily view someone as a person in bedclothes, horizontal, part of the structure concerned with managing in need patients, and with an illness that is a scientific problem. People must be understood in an integrated way as they are in their community and home life.

Disease: we must not only seek to meet people's physical needs by controlling the symptoms of the disease and providing comfort; equally, and perhaps more importantly, we must be aware of their emotions and spiritual needs.

Surroundings: the physical surroundings we can provide for people are tremendously important in order to allow them to function and to restore the whole of themselves as they look ahead to the time when they will face the issues of death and dying. We have to be aware that different groups may require different strategies in this respect.

Besides these principles to guide us in managing a service for people with AIDS, we need to bear in mind some key ideas about how we as individuals provide care. The needs of individuals, the support networks they have, and their whole axis and psycho-social context are very important in determining how we should respond to them. Many of the carers involved — be they partners, family or health care workers — suffer from paranoias or the emergence of personal problems which have been highlighted by getting involved in this whole area. We need to think about that in a productive way and to realise that many of us experience a vicarious and chronic bereavement process. I am bereaved of people I look after at least once a week, and a lot of the issues outlined above are ones that I have had personally to address.

To use another mnemonic, we can describe our goals as carers as *acceptance* of the individual, an *intimacy* of involvement, meaning a sense of contact and humanity, *diversion* to a "living mentality," and mutual *support* between statutory sector professionals, voluntary sector workers, and partners or family.

The diversion of people to a living mentality is particularly important. We are all in a sense on a death curve; it is just that most of us have not identified that fact. But many people are coping with dying, rather than living until the time comes for them actually to die. I recently reviewed a paper from America which showed that suicide is 36 times more frequent amongst people with AIDS in New York than amongst an age-matched, carefully controlled population.

The multidisciplinary approach

As our principles have stated, we see the person with AIDS at the heart of the multidisciplinary team and at the centre of the coordinating network. But that individual will have different needs, from the time of confirmation as HIV positive, through various stages as the virus manifests itself, and ultimately to terminal care and death. Those needs may include friendship, counselling and advice, finance, accommodation, respite care, diagnostic inputs and so on.

The function of a multidisciplinary team is to integrate and facilitate the various services, both statutory and voluntary, which are available to meet these needs. Some services such as counselling may come from either or both sectors; friendship— which I would put above counselling since people want friends in many cases, rather than counsellors — is likely to come from the voluntary side. Diagnostics would be an example of a service which is provided by a statutory agency. But at different times, the most appropriate type and source of these services will vary. Operating in this flexible way and arranging inputs to meet individual needs at any given time is the prime function of our multidisciplinary team.

Although it is called a community care team, it is important to stress that we do not attempt to undertake hands-on care to the exclusion of other providers. On the contrary, we try to work as much as possible with the primary health care services — the GP and the district nurse — to use them and help educate them. Nevertheless, our main area of activity is to provide continuity between respite and terminal care, and to provide care and symptom control at home. We discuss with the individual how they want to spend the rest of their life. For example, do they want to go into a hospice or stay at home come what may?

Bloomsbury has a large problem: 700-800 individuals who are HIV positive, of whom about 200 have AIDS and will eventually require symptom control and terminal care. Only about 20% of the people on our books live within the boundaries of our district. The others come from as far afield as Exeter or Paris. This means that our facilitative role with primary health care teams is very important. For example, if someone came from on the South Coast, we would set up the links with local primary care and general practice that are appropriate to the individual, confidential and adequate in amount and quality. Advice, information and education will become a major part of our work, and we would even see ourselves expanding to provide a telephone advice service within North East Thames Region, were that appropriate and feasible. In these ways, we can disseminate our knowledge and experience about terminal care and even, in the long term, educate ourselves out of a job.

In setting up our community care team in Bloomsbury we drew on existing care models, and in particular the terminal care services we were providing for people with cancer. That provided a starting point, a model grounded in experience, and a credible basis for funding.

The team comprises two specialist nurses, a physician (myself), a social worker, an administrator, and a researcher who is evaluating our work. In addition, we are aiming to have available as part of our team a member of Frontliners, that is, a person with AIDS who can give us input say one day a week. This would help us to provide a service when a patient specifically expresses a wish to speak to a person who has AIDS. Often people are unable to discuss some things to do with AIDS or HIV with the team because they feel we do not understand. They may prefer to talk to someone who is in the same position as they are, although perhaps at a different stage, and we recognise that.

The social worker is an essential part of the multidisciplinary team. He or she can provide experience of the welfare benefits system, and in our case can add skills in bereavement counselling. The latter area is one at which I think we need to look at a lot more carefully in the future.

One of our specialist nurses is trained in terminal care, and one was previously a senior district nurse, so that we have credibility with colleagues in both those areas, and can encourage them more readily to begin to work with people with AIDS. Similarly, having a doctor on the team is helpful for relating to general practitioners, understanding the confidentiality issues, and involving them in care, even if only at a basic level initially.

The researcher is a member of the team because we feel we have a major responsibility to describe and to evaluate the systems we are using. We use an established evaluation procedure adapted from the work of the Bloomsbury Cancer Team. A key feature is that it employs non-intrusive methods of investigating how effective we are being. The client is not involved in a lot of interviews or other intrusions on his or her privacy.

In the future we are thinking of including occupational therapists (as at St Stephen's) and physiotherapists in the team. We also need to ensure we are able to bring in consumer views not only from Frontliners but also from groups specifically representing black communities and drug users.

Practical issues facing the community care team

The team's aim to use existing primary care structures has already been mentioned. In many cases the people with AIDS we have spoken to have been able to report good experience of their GPs, where they have used them. There are exceptions: some people will refuse to see a GP. I am very keen that everyone on our books has a GP of their choice, and if they wish to change GPs they can do it easily.

We have just finished planning for shared care cards which will allow people with AIDS to carry their own notes. They can then give their notes to a GP to write in and contribute to, so GPs do not need to record in general practice notes HIV status and clinical details of problems related to HIV and AIDS. The notes carry documentation of individual needs and selected test results. Experience from abroad suggests that the notes do not get lost and are always available when needed, and of course district nurses and voluntary agencies can have access to the notes if the person with AIDS wishes them to. The control of the confidentiality lies with the people themselves.

The wide catchment area has already been mentioned. This can cause confusion with different and arbitrary administrative boundaries. Certainly social services provision and local authority policies (for example on refuse collection) differ widely between boroughs in London. If you move to another area you may find that a home help is not available. The amount of liaison work generated by these differences has been a problem for our team.

However, we have begun to make progress in some ways. There are now instances when we are able to pass on care to another team in another district. We have worked with community health councils to keep them informed. Sharing problems between different statutory teams happens at a quarterly meeting where people discuss problems and mistakes in their work, and colleagues help them look for better ways of handling matters. Only those workers who have a 'cock up' to report attend the meetings.

Discharge policy is an example of an area where we still do not get it right. We are trying to work with Frontliners and with other teams to ensure that common procedures are used and that there is uniformity of practice across London. One aspect of this is to help hospitals explain better what the various departments do and what people with AIDS can expect. We are developing a pack which will take people through the things they need to think about, the services available, contact points and so on. Another aspect of good practice in discharge is to guard against a simplified medical way of looking at people — the tendency to say that once the pneumocystis has been treated, or there is a central line in for the CNV retinitis, there is no longer a problem. We must make sure that hospital staff are thinking about whether the home is adequate, whether there are facilities at home for caring or for preparing meals, whether social work or counselling back up exist for the person with AIDS and his or her relatives, and so on. The time someone is in hospital may be the first time that the family has discovered the person has HIV, is a drug user, is gay, or whatever. These points need to be structured into an adequate discharge policy.

One issue we have not got to grips with yet is our services for drug users. Bloomsbury has been developing a number of services such as a needle exchange, a health team at the Drug Dependency Unit, and an outreach team called CLASH — Central London Action on Street Health. But I do not know the answers on providing appropriate housing, home care or hospice facilities tailored to these groups of past and present drug users with HIV infection and AIDS.

Finally, I want to consider at some length the issue of surroundings appropriate for people with AIDS as they approach death, and to set in this context discussion of the work of hospices.

First of all, some people want to finish their life in a hospital. There are a number of people I have cared for who have been discriminated against and have found that the first and only place where they have been accepted has been in a hospital environment. They are secure in that environment and wish to finish their days in that hospital. There is nothing wrong with that at all.

Many people wish to stay at home, and their needs have been touched on throughout this paper. Our aim is to provide 24 hour cover at home. But the practical challenge that is entailed should not be underestimated. A person on their own at home and wishing to end their life there may tie up as many as ten people — the GP, home help, two community nurses, a member of my team, and three or four volunteers. That is a major logistic issue.

Finally there is residential provision, hospice or hostel. Although these are associated with terminal care, their function is much richer and more diverse. They are an alternative and sometimes more appropriate form of the bed back up which is an essential adjunct to any kind of home care team. There must be, for the person with the illness, the definite assurance that if they cannot cope at home, there is a bed available for them, providing institutional care and taking pressure off the home situation. For many people, just knowing that they can have relief if they need it is sufficient to empower them to cope with any situation they came across.

Similarly it is important to stress that none of these are one way streets. A hospice is not a one way street. The meaning of the word 'hospice' is a resting place for travellers. In AIDS, the patterns of symptoms, the patterns of progression and the patterns of death are not easily described. Perhaps because of the environment of the hospice, we are finding at Mildmay that many people are going in there with a label of so many weeks to live; but as soon as they are in there, they start to eat, they feel better, their depression lifts. They become mobile, so that on two or three occasions we have found that individuals whom we had expected to die, are in fact going home a month later. If people want to travel back home from the hospice rather than travelling through death, then so be it.

In fact, a major part of a hospice's work is providing the possibility that people may go back home. We provide a bed for one man during the week because his mother needs to work. He goes home to his parents for the weekend, has a good weekend with the family, and then goes back into the hospice for the following five days. That is a very productive way of using a hospice bed facility. Similarly, the partner of another person we care for needs a break once a fortnight so we provide respite care in the hospice. This means that the whole structure of care for that individual is kept under control, and balance is maintained.

People need to have space and the environment to explore issures connected with death and dying. There may be a need to resolve their own views of themselves and their relationships with their family. People may wish to reassess their world view. In a non-directive way, people need to be allowed to express and consider these issues. If you come from another spiritual background, you need to be allowed to express and explore that background. It is not a problem that people have different world views; what is a problem is when they are not allowed to talk about it. If people need to explore how they are approaching death and dying, and what it means to them, they need to have an environment where they can do it.

It is very important that this element is part of the structure of any service you are providing. Certainly organisations like the Lighthouse and Mildmay could be said to come from specific world views. That may influence the environment, but I can speak for the Mildmay when I say we do not in any sense proselytise or impose any views we may have. We are totally open to the fact that this is an issue that needs to be addressed individually.

Last of all, I would ask you to remember that these strategies of respite, rehabilitation and resolution of issues concerning death and dying are all active strategies. By allowing discussion of issues of relationships, family, world views, where people want to live, and so on, we are assisting in a therapeutic strategy. The notion that when a person stops having medication, you stop actively caring for them is nonsense. Providing an environment where a person feels tranquil, at peace and comfortable is an essential part of an active strategy of care.

Evaluation of palliative and terminal care in people with AIDS

We have very little data on symptomatology and patterns of disease in the terminal phases amongst people with AIDS. At the moment it would appear that needs in terms of physical disability fall fairly evenly between neurology, chest disease, gastro-intestinal problems and malignancy. However, more than 50% of patients have significant involvement of more than one system. In the Bloomsbury Community Care Team, we are documenting physical needs and symptomatology in an attempt to discern patterns and I see this as the bedrock of care planning.

We have adapted established techniques employed by Dr I Higginson, of University College, London, in order to build up a meaningful profile in the next 12 months or so. This work will include the in-patients and community services at Mildmay. We are also in early negotiations with the St Mary's team who are incorporating similar protocols in their research programme.

As part of any process of evaluation, it is important that assessments made by professionals should be matched by improvement in quality of life and satisfaction of people with AIDS, their partners and family. Again, there are proven schedules that have examined this in the area of cancer therapy and it is obviously necessary for us to apply them in our work. This would require audit either internally or using independent agencies such as the DHSS or academic departments of community medicine. Bloomsbury and Mildmay hope to work with the academic department at University College, London to this end. Other home and terminal care teams using compatible methodology will extend the potential data base.

Because AIDS is in large part a constellation of potentially treatable diseases manifesting themselves in the immune deficient person, much of conventional medicine has been directed at treating infection and malignancy with often rather toxic and unproven drugs. For many people the idea of stopping treatment is associated with the loss of hope and rapid death. In consequence many people continue with management late into the disease, despite unpleasant side effects, and their quality of life is compromised. Where possible, the effects of drugs upon quality of life and symptomatology should be documented in an attempt to rationalise how and when to modify drug regimes. Obviously in planning assessments it must be fundamental that people are not disrupted by objective measurement and that, at all times, their quality of life should be in the forefront of the minds of those seeking to document the effects of a drug.

It will be important to document the effects of any AIDS initiative upon existing nursing, medical, social service and housing provisions. Examples are changes in bed occupancy, the delay in acquisition of facilities from community nursing services and social services, provision of accommodation and so on.

We should also examine the relative benefits of community care teams, the multidisciplinary approach to care and the effectiveness of advisory, interventionist, hospital based or community based services in meeting the needs of people with AIDS.

I certainly welcome the diversity of models available but I would urge that there is a high level of collaboration in establishing evaluation procedures so that we can pool data at an early stage. This will allow teams and individuals to share information and experience and allow an overall improvement in care.

(Note: the last part of this paper draws on extensive discussions with Dr Moss and Mrs Sims of Mildmay Mission Hospital).

12

Liaison with General Practice

SURINDER SINGH

As Community Medical AIDS Fellow at St Stephen's Hospital, I am general practice trained, but I have never been a principal. My post is duplicated at St Mary's Hospital in the former Paddington and North Kensington Health Authority (now Parkside) and both posts are funded by Help the Hospices charity, whose support I acknowledge.

Outline of the model of care at St Stephen's Hospital

The hub of the model of care developed over the last few years at St Stephen's is the full utilisation of our multidisciplinary team. The team comprises the medical officer (helped by the GP fellow); the HIV liaison sister; the occupational therapist; skilled counsellors and social workers; health advisors; the ward sister or the ward charge nurse; and a representative of the Terrence Higgins Trust. The team meeting takes place weekly and the treatment of the people with AIDS currently in the hospital is discussed. The objective of the meeting is to discuss plans for discharge, with emphasis on integrating services and ensuring smooth transition from treating illness in the hospital to maintaining improved health at home.

Transition from hospital to home and integrating services requires comprehensive co-ordination. A home assessment of daily living activities, continued support and counselling, and arrangements for medical follow-up all need to be integrated into the final discharge plan.

In team discussions, input usually comes from the medical officer (again with the help of the GP fellow) and the HIV liaison sister, since they attend the daily rounds at 8 am, although further input comes from other team members. A period of time is set aside in this forum to discuss people who have recently been discharged to the community and those who are being followed up in the out-patient department. The key element in this model of care is that it is a team approach for the care and the continuing management of the person with AIDS, and representatives from the community have vital knowledge of a wide range of services. If the services most suitable to the various needs of individuals cannot be found, then inevitably the focus of care once again shifts or is biased towards the hospital. In our team there is a physician and an occupational therapist who are community trained.

A further key element is the great emphasis being placed on the use of existing services. No service that we use has been specially developed, although many have been adapted or modified to provide the level of care needed for this client group. There are, however, gaps in the various services, particularly when we are liaising with other boroughs. A large percentage of our patients are actually from outside the health authority or even outside the region. One of the extended roles of the team is to identify those deficiencies in services and make them known.

An invaluable input to this group comes from the representative from the Terrence Higgins Trust — particularly with regard to the buddying service. Sometimes the buddying service is the only type of care or help acceptable to people with AIDS. It can ensure that a basic level of help is possible when perhaps statutory services have been refused.

That is a summary of the model of care adopted at St Stephen's Hospital. Next I want to discuss the problems as I see them in four main categories: case management; community perspectives; domiciliary care services and general practitioner training.

Case management

Two major elements in case management are continuity of care and ultimate responsibility. If the person with AIDS is monitored in the sexually transmitted disease clinic, is that the most appropriate place? Often all that is required is a routine blood test or a repeat prescription. Could not an interested general practitioner provide this care just as well? Feedback is another important aspect of care and should be a two way process. We have heard that communication with local general practitioners around St Stephen's is improving. However, it is important to stress that the process of patient follow-up and monitoring requires information to be relayed to both parties involved in the care, that is, the GP and the hospital. The best way of ensuring this is a type of shared care system. In summary, who can be responsible for the person with AIDS other than the person himself or herself? But we can move towards a client orientated package, where shared care includes access to notes to ensure that necessary information is available to all who need it, whilst still respecting confidentiality.

Community perspectives

Management of the care of people with AIDS must not be seen solely from the hospital's point of view, but must recognise the potential of health services in the community. There is a problem of differing perceptions of consultant responsibility. Even within Riverside, there is often a problem about identifying who is responsible for patients because the patients will often be attending neurology clinics or dermatology clinics as well as their general practitioner. A second problem about perceptions of responsibility is that exclusive provision of care for individual patients by the hospital can occur at the cost of the primary care system as a whole. If the general practitioner is marginalised, his or her ability to provide care is undermined, for example, in cases where people with AIDS enter the terminal phase of their illness, and where symptom control is mandatory in order to maintain their quality of life.

The same point could be made with reference to staff training; sometimes there is a feeling, especially for those with experience of community services, that there is a failure within the hospital to appreciate what can be achieved in people's homes. One way of combatting this is to encourage hospital staff to visit primary care teams, district nursing services or community nursing services. For example, in the last two months there have been something like 25 health workers visiting the dedicated ward at St Stephen's. These health workers will be on the ward for between two and five days and will gain 'hands-on' experience in the care of people with AIDS. However, this type of arrangement is not reciprocated: the hospital staff don't usually visit primary care teams and that is an area of concern, both to me and ultimately to clients.

Domiciliary care services

One of the main problems, and a familiar one although restricted to London, is the sheer number of boroughs, health districts and family practitioner committees we deal with - none of which seem to be co-terminous. As previously noted, a large number of our patients come from outside the region. Now in London alone there are 29 district health authorities, four regional health authorities and many FPCs. As a result, planning services for individual patients is rather a haphazard business and more dependent on the patient's address than on anything else. It is impossible for the key worker to know about the resources available in all 29 health authorities. A central co-ordinator might have an important part to play here. The co-ordinator could identify local services which could be used for individual clients. The co-ordinator would perhaps be responsible for making an initial assessment of people with AIDS and their informal care network, and for establishing effective liaison between hospital and community. He or she would have an important role in collating information, which is also of great importance if we are to monitor this epidemic.

General practitioner training

Finally, general practitioners need better training to help prevent them from being marginalised. What I suggest is that clinical attachments by post graduate general practice trained doctors should be actively encouraged; not only at recognised HIV or AIDS centres like St Stephen's but also at other hospitals which treat significant numbers of people with AIDS. These attachments would be for a minimum of six months and would not only familiarise the doctor with the physical, psychological and social problems of HIV disease in patients but also bring benefits to the AIDS unit at the teaching hospital by providing more doctors who are willing to support patients in their own homes. These doctors will be the new cohort of general practitioners in the years to come. In this way the doctor can ensure that the full potential of community care is realised and that local resources are used efficiently, appropriately and cost-effectively.

13

The Role of the General Practitioner in the Care of People with HIV Infection and AIDS

RONALD LANDE

Although the care of people with AIDS should be conducted within the normal patterns of NHS services, there are a number of factors to be considered in the future development of general practitioner services.

The pattern of care to date has tended to minimise the role of the GP. In fact, AIDS is the only fatal disease where someone can, over months or years, attend hospital or follow up clinic at any time, directly and without any letter of referral, bypassing the GP. Sexually transmitted diseases clinics have tended to retain a role in all aspects of medical care of people with AIDS or HIV infection, including primary care of these patients.

Some people have not wanted their GP to be involved. This may be because of the GP's attitude, or because of fears concerning confidentiality, or because of other matters such as consequences for life assurance cover or employment.

However, some GPs have felt excluded from participating in the care of people with AIDS. This feeling has been made worse by the lack of any suitable forum for discussion of areas of responsibility between hospital doctors and GPs. There have been conflicts over failures of communication and the interpretation of confidentiality.

This background does not give a very positive picture. We know also that more people with AIDS and shorter hospital stays will place a greater workload on GPs. The urgency will be even greater in those cases where the person with AIDS becomes homeless or changes address due to eviction, breakdown of informal networks, loss of employment or unsuitability of existing accommodation. Rehousing will in all probability mean finding another GP, perhaps at a time of acute illness.

On the positive side, the GP has a unique opportunity in the field of prevention. Virtually every member of the population has a GP, and access is in most cases easy, immediate and free. The informed GP can provide accurate information about HIV and AIDS, on a personal level and over a period of time, to the whole community. Where patients attend routinely for family planning, or foreign travel innoculations, the GP can discuss with them safer sex, risk avoidance and lifestyle issues. This role could also include pre- and post-test counselling for HIV tests. If GPs undertook this work, inappropriate use of hospital resources could be reduced.

Of course, GPs may be approached for treatment by patients in high risk groups who for whatever reason do not attend an STD clinic. Some patients may have symptoms indicative of HIV infection. The GP must be fully aware of all the diverse ways in which symptoms can present, so that he or she can offer appropriate and accurate advice.

Patients who are HIV positive will usually be attending a hospital clinic and will usually be well. In these circumstances they could be cured before a crisis arises whether or not they are happy with their current GPs. If not, they can consider changing. Hospital staff should be familiar with the registration procedures so they can offer advice and assistance.

There should be no need for the hospital to inform the GP of HIV status if the patient is well. But if the patient is attending the GP for the treatment of any illness, he should be consulted and advised to inform the GP. The reason for this is to enable the GP to consider whether any presenting illness is HIV-related.

To outline these functions is simply to underline the GP's existing responsibilities in primary health care. Where someone is diagnosed with AIDS or ARC, it must be readily acknowledged that acute episodes and relapses are best dealt with in a hospital setting. This permits full assessment, counselling, treatment plans and management. The full expertise of the hospital team and the full range of hospital services can be brought to bear. With the introduction of new drugs, tests and treatments, no single GP can have comparable up-to-date experience.

However, there are great opportunities for the GP to play a full role in the care of a person with AIDS between acute episodes which necessitate hospital admission. The GP can be involved in medical care such as prescribing, home visiting, arranging nursing care and so forth. He or she can also offer vital support to the family and friends of a person with AIDS receiving care in the community.

Some necessary steps must be taken for this arrangement to work. The earlier the GP can be involved, the better. Otherwise he or she may not know the patient has been attending hospital. The consent of the person with AIDS to inform the GP must have been obtained, and effective admission and discharge procedures should be agreed.

As people with AIDS approach the terminal phase of their illness, similar considerations apply to the GP's role. There is no golden rule: people should as far as possible retain control of their illness and choose services that meet their needs. Some will want to go back to hospital, perhaps because they or their family and friends wish to feel that everything possible has been done.

Others will wish to die in their own home. People with AIDS are usually young and often have never had a significant illness before. The GP will be closely involved with other members of the primary health care team in providing formal care at home, but should be aware that the age and previous history of people with AIDS means that management problems will be significantly different from those in cases of, for example, terminal carcinoma.

Where a person with AIDS chooses to die in a hostel or hospice, their own GP may be involved. However, a GP appointed or attached to the hostel or hospice may be able to offer additional skills in, and knowledge of, the care of people with AIDS and HIV infection. This may be the most appropriate arrangement for some people.

The GP and primary health care team will inevitably become involved with the family, friends, and lover of a person with AIDS, and, after that person's death, will have an important role in supporting them through their bereavement. The GP can help them come to terms with the case of a usually young and previously healthy individual, dealing with feelings of guilt and of relief that it is all over, and adjusting to new directions in life.

This paper has outlined a number of ways a GP can play an active and appropriate part in sharing the care of people with AIDS with other professionals and informal carers. What help and resources are needed? First of all, GP's should have access to more education about AIDS and HIV: teaching, clinical demonstrations, courses, etc. A suitable GP 'helpline', for example, to an AIDS clinic, would enable the GP to get advice on any particular problem that might arise. Then some small practical improvements could be considered. Where GPs undertake counselling for HIV tests, open access to pathology laboratories would be helpful. Latex gloves are expensive to purchase, and FPCs could agree to supply them for venepuncture and care of people with HIV infection in the home.

Finally, better consumer information is needed. GPs should be enabled to obtain leaflets and booklets about AIDS, HIV infection, safer sex, etc, in the same way as hospital clinics. Those produced by the Terrence Higgins Trust are good examples. FPCs should take a lead in maintaining a list of GPs with a special interest in AIDS and HIV infection, so people could find another GP more easily if there was a problem with their own.

There are many ways in which GPs could provide a better service to people with AIDS, and many of them wish to do so. Health authorities and GPs should work together to develop guidelines on acceptable standards and procedure in primary care. Shared care between GP and hospital would both reduce pressures on the inpatient and outpatient services and enable the person with AIDS to remain in the community for as long as possible, supported by family, friends voluntary organisations and local authority services.

SECTION FOUR

LONDON: VOLUNTARY SECTOR INITIATIVES

14

The Terrence Higgins Trust

NICK PARTRIDGE

The Terrence Higgins Trust is constituted to provide information, advice and help on AIDS and HIV infection. We provide information through our leaflets, helpline, speakers, training, conferences and media work. We have a national remit and aim to produce information which is easily understandable to the general public and more specific groups in society, primarily gay men and intravenous drug users who, so far, have been most affected by the spread of HIV. We are looking at the needs of the heterosexual community, with particular reference to women.

All our advice and counselling work is based on a non-judgemental and non-directive approach. We aim to provide information and advice which will enable people to make the personal behaviour changes necessary to slow the spread of HIV in the UK. For those who are HIV antibody positive, either with symptoms or not, we provide advice which presents the choices of action which could help to promote their health and well-being.

The direct services we have established for people with AIDS or ARC are intended to supplement statutory service provision. The fear and stigma that have surrounded AIDS has often prevented the proper provision of these services. Our training and information work is, however, steadily breaking these barriers and we intend to continue to work closely with hospitals and social services in order to provide the highest possible quality of community care for those who are living with this devastating illness.

The services of the Trust are described below. They are available to anyone who is affected by AIDS or HIV, irrespective of the mode of transmission, their sexuality, race or creed. The problems which have been created by AIDS are complex and diverse. Imaginative and multi-faceted responses are necessary. The wide ranging work of the Terrence Higgins Trust will continue to synthesise dynamic community based action so that we can effectively fight what has been rightly recognised as the greatest threat to public health we currently have to face.

Buddy Groups

AIDS is a highly stigmatised illness which currently affects gay men more than any other group. This has meant that people who are ill have not always been able to call on informal support systems such as neighbours, families and so on. Misinformation has bred fear amongst statutory service givers, sometimes preventing service provision.

People with AIDS may be isolated and unable to attend to basic needs. A buddy fills the gaps by being a befriender who will cook, clean, walk the dog or simply provide company and comfort. In short, their role is one of befriending people with AIDS or ARC.

We are currently buddying mostly gay and bi-sexual men, two heterosexual couples, eight drug users and four heterosexual women. The numbers and up-take of buddies are set out in the table below.

	Male	Female	Total
Trained buddies	89	68	157
In buddying relationships (on 1 April 1988)	80	54	134

As well as training our own volunteers we have also trained about 35 people from outside agencies around the country who wish to set up similar schemes. As the number of people with AIDS grows, so will the demand for this service.

Current trends indicate that people with AIDS are now asking for buddies earlier in their illness, so a longer term relationship will develop, which requires us to train greater numbers.

Telephone Helpline

The Helpline provides help and information on all AIDS and HIV issues, and acts as the entry point to the majority of our other services. Opened in February 1984 and the first in the country, it has consistently received more calls than it can answer. The need for helpline services is amply demonstrated by the growth of similar local lines around the country. These provide a local response while the National AIDS Helpline is able to provide a free, 24 hour service. The Trust has been involved in the training programmes for most of these lines.

Our service operates every day from 3pm to 10pm, on four lines on the main 01- 242 1010 number. In addition, we provide a VISTEL line for the deaf and hard of hearing. There is a priority line for those diagnosed with AIDS or ARC.

Currently we are able to answer an average of 1500 calls per month. We are limited by the length and complexity of the calls, and the number of volunteers available to staff the lines in the afternoons.

We intend to expand the hours of operation to a 12 hour service, from 10 am to 10 pm. As the demands from the growing number of people who are diagnosed increase, we will develop the priority line service. This will be particularly important for calls referred to us from the National AIDS Helpline.

Counselling services

The wide range of social and medical problems associated with AIDS and HIV have created very diverse demands for counselling and support. We have responded to this by developing the following services:

FACE-TO-FACE COUNSELLING is offered in one hour sessions, on a short term basis (usually 3-6 sessions). If clients need longer term counselling or therapy we refer them onto the appropriate agencies. We currently see on average 30 new clients each month.

FAMILY SUPPORT NETWORK responds to the needs of parents and other family members by putting them in touch with other families who have had to cope with AIDS. There is a monthly group meeting in London and regular telephone contact is maintained with those living elsewhere in the country. So far 70 families have used the network.

LOVERS' SUPPORT GROUP recognises that the needs of the lovers of people with AIDS are often overlooked, yet the emotional traumas of caring for someone with a terminal illness can be enormous. We currently run two groups every week, with both groups having 10 members.

WOMEN'S SUPPORT GROUP was set up in November 1986 for women with HIV, ARC or AIDS. It meets once a week, is limited to ten members and is not currently full. Although the number of women who are affected by AIDS is still small, we are examining why this service is not better used.

CHOOSING LIFE provides daytime support for people with AIDS in a group setting. As most of our buddies are in work, daytime care has always been a problem and Choosing Life is our solution. There are now two groups of ten people each, and by October 1988 we expect to have at least five groups operating.

PEOPLE WITH AIDS SUPPORT GROUP is the longest established group in Europe. Meeting fortnightly, with about eight members, it now offers information courses about living with AIDS for those who are newly diagnosed. These six week courses regularly fill the twelve available places.

DRUG USERS' SUPPORT GROUPS are included in the section on drugs education (see page 42).

All our support groups have trained and paid facilitators. The volunteers involved with face-to-face counselling must have a background in counselling. They also receive special training to develop the skills they must have before they are accepted as a counselling volunteer.

We expect the demand for all these services to expand rapidly. It has often taken time for groups to become established, but as their reputation has grown so has the demand. We will also intiate new groups as the need arises.

Helper Cells

People with AIDS often need assistance while they are out-patients. This help typically includes shopping, cleaning, cooking, transport to medical appointments and a variety of other requirements. These services can be of a one-off nature or regular scheduled help.

At present three or four requests for service are processed daily but it is anticipated that as the service becomes more widely known the demand will increase considerably.

Helper Cells are divided geographically in the Greater London area to facilitate easy localised service. Although this is a new project among Trust activities there are close to 100 people prepared to assist in this capacity.

Helper Cells are used when there is no Buddy available, when a person with AIDS does not want a full time Buddy but needs occasional help or when there is only short term or temporary disability.

It is felt that much of this home help service is properly the responsibility of social service agencies and health authorities. However, in view of budget cuts, it seems unlikely that adequate help will be forthcoming. It is essential therefore that the Helper Cells project should prepare to expand and enlarge the range of service to meet future needs that will doubtless increase.

Legal Services Group and Legal Line

The service was set up in 1985 as a response to the increasing number of legal and social welfare problems that were being reported by people with AIDS and HIV infection.

The service is provided by sixty qualified lawyers, and is professionally constituted by the General Council of the Bar. The major areas of work cover insurance, social welfare, housing, employment, wills, power of attorney, debt and financial advice, immigration and international travel. The Group also provides information and advice to other authorities, and works closely with law centres and advice agencies.

The Legal Group has published leaflets on insurance and social security and is currently writing leaflets on wills, the social fund and income support.

The number of legal cases and referrals dealt with 1985-1987 are as follows:

1985	42 cases
1986	244 cases
1987	643 cases

The Legal Line telephone advice service will open every Wednesday from mid-April 1988. It will be staffed by volunteer lawyers and provide access to the other services of the group as well as telephone advice.

It is anticipated that the 643 cases and referrals in 1987 will grow to over 2,000 in 1988. The Legal Services Group will be considering a law centre to provide a better service delivery for this increasing workload.

Financial help

As AIDS largely affects young people who expected to live for many years, they have often taken on financial commitments which their illness prevents them from fulfilling. The Number One Fund has been set up to provide people with AIDS and ARC with financial assistance to help meet the costs of living with AIDS.

Since April 1987 we have made grants to a total of 258 people. Some have received more than one grant. We make payments for fuel and 'phone bills, furniture, special health care, rent arrears, holidays, fares to visit families and so on. We maintain close contact with other grant making charities (Crusaid, Mark Ashton Trust, Frontliners) to ensure we are not duplicating payments and to share the cost of larger claims.

In the future, due to the Social Security changes we expect an even higher demand on the Fund. The already strict grant making protocol may have to be tightened. A Number Two fund is to be set up to meet the particular needs of HIV prisoners and drug users, both as inmates and on release.

The health education work of the Trust

The Health Education Group at the Trust aims to:

- Reduce the incidence of HIV transmission by facilitating personal behaviour change.
- Promote the well being of those with HIV antibodies, both with and without symptoms.
- To establish styles of health education which embody good practice and can easily be adapted for use by other groups.

The Trust has in the past been involved in promoting health education for the general public and gay men in particular. As other bodies have taken on this role, the group has begun to develop strategies for groups with special needs in health education. These include the young, men who have sex with men but who do not define themselves as gay, people with learning disabilities, those involved in the sex industry and other marginalised groups.

One of the main aims of the Trust is to provide accurate, non-sensational information about AIDS and HIV. The demand for our leaflets following the 'Don't die of ignorance' campaign was enormous, and in the past year we have printed and distributed over one million leaflets and posters. We have also helped many other organisations to prepare their own leaflets, often directly using our material.

We are working closely with the Health Education Authority and other community groups on a campaign for men who have sex with men. We are developing and funding theatre as education, safer sex workshops, training packages and printed and audio visual materials for the general public. All our work is aimed at promoting health education at a community level.

The Roadshow is a travelling AIDS/HIV information and safer sex display which was started for use in gay pubs and clubs. As the overall campaign has grown the Roadshow has developed to meet the growing demand for information. It is now working on new displays for libraries, youth clubs, theatres, hospitals and work places. It is involved in the development of various projects, such as those for young heterosexuals, and of new display materials to adapt the approach to the changing needs of gay men.

An important development is the Black Community Project which will work more closely with the various groups already established in the community. The main aims are to encourage self help and the production of materials in other languages.

Drugs Education Group

This group aims to provide accurate information about HIV and AIDS to current and ex-injecting drug users, specialist, generic and other workers in the drug field, and to Trust workers, volunteers and the general public. It also aims to provide support services to drug users with HIV and AIDS in the community and in prison.

We provide information, education and training on drug use and HIV, servicing the needs of the Trust and outside. There is a prison visiting service to inmates with HIV and we advise the Home Office on prison training around HIV and AIDS issues. About 30 HIV positive inmates have been visited and several hundred counselled.

The Drug Users' Support Group began in September 1987, and 43 people have attended the Group since then. Attendance ranges from 2 - 14. The Group meets weekly and has two professional facilitators.

The Italian Drug Users' Support Group is a new service which has met twice in April 1988 and has seen 5 attendees. It is facilitated by two Italian speakers. It was set up because we were advised of a drug using problem in the Italian community in London. We shall in time set up similar groups for other minority groups as needs become defined.

A full-time drugs counsellor will be in post from May 1988. We intend to develop the support groups as we gain experience in their usefulness. We intend to set up a special fund for HIV positive drug users in prisons and further expand our prison visiting service. It is possible that a development officer will be required to look at the needs outside London, and we propose to train and fund support groups. Our leaflets and posters will be continually assessed and up-dated.

Women's Group

The Women's Group was formed to tackle the issues raised by HIV for women. The group is developing materials on safer sex from a woman's perspective, pregnancy and AIDS, and prostitution and HIV.

Interfaith

The Interfaith Group brings together a number of faiths to provide a nation-wide network of people who are able to respond to the spiritual needs expressed by some people with AIDS.

The Group also runs training days for clergy, looking at the religious debates AIDS has fuelled and contributing much needed factual information.

Liaison with other organisations

The past year has seen a rapid growth in the number of organisations involved in AIDS work. Resources are, however, still very limited and it is vitally important that we do not just avoid the duplication of services, but actively ensure that the services we can provide are properly co-ordinated and planned.

To this end we have developed close links with all the major hospitals in London and the home care support teams based at St Mary's and St Stephen's. In the coming year we intend to employ four full time Buddy Co-ordinators who will ensure that our services continue to be integrally involved in the out-patient, in-patient, social work and home care services provided by the hospitals.

The more diverse nature and spread of local authority services has resulted in patchy local authority service provision and co-ordination. It is primarily dependent on whether an authority has employed an AIDS officer. Where this has happened it has become much easier to access services for people with AIDS, and we expect to work closely with these officers in the future.

With voluntary sector organisations, we maintain close links with the Mildmay Mission and London Lighthouse, the Haemophilia Society, the Standing Conference on Drug Abuse (SCODA), the Black Communities AIDS Team, Body Positive, Frontliners, the National AIDS Helpline and London Lesbian and Gay Switchboard.

At the London wide level we sit on the North West Thames and the North East Thames Regional Health Authorities' AIDS/HIV Working Parties.

Nationally we are represented on the National AIDS Trust, the Network of Voluntary Organisations in AIDS/HIV (NOVOA), and the National Association of AIDS/HIV workers. To co-ordinate our fundraising work we are involved with the AIDS Alliance.

We continue to work closely with a number of other organisations on particular projects. With the Health Education Authority, we are committed to developing a health promotion campaign aimed at men who have sex with men. We sit on the Home Office Advisory Committee on AIDS in Prison. Together with the National Association of Citizens Advice Bureaux we have produced a training video and information on the implications for people with AIDS of the introduction of the Social Fund.

One of the major achievements of the Trust has been to encourage the development of a local voluntary response to AIDS throughout the country, aimed at creating community based care. We remain committed to ensuring that these initiatives are offered adequate training and support to enable them to provide the services that will be vitally important in the years to come.

15

Responding to the Needs of Drug Users with AIDS

STEVE CRANFIELD

Because the majority of drugs agencies in England and Wales were set up before the advent of HIV-infection, services for drug users with AIDS and AIDS-Related Complex (ARC) have tended to be based on modifications of available resources. There has been a lack of co-ordination in planning service provision and, perhaps because funding in the main has gone to health service initiatives and drug treatments, there seems to have been conspicuous lack of response from many social services departments (where failure to provide basic support services is still all too common).

In addition, because many drug treatment centres and AIDS treatment centres are concentrated in or around London, many drug users from other parts of the country and abroad have come to London seeking help with their drug dependency and/or AIDS. This has led to problems of homelessness for many drug users with AIDS and has placed added burdens on already overstretched drugs agencies. It has also created culture and language barriers between clients and workers.

Statutory drug clinics are beginning to move away from the (hitherto almost sacrosanct) immediate goals of abstinence towards those of harm reduction. This has meant in practice that most drug users with AIDS gain access to priority treatment in drug clinics, with more individualised treatment programmes. Long-term or maintenance methadone treatment is commonplace. Since drug users with AIDS are at present a minority group in all treatment settings, and also for reasons of confidentiality, most counselling is one-to-one: no group or day care treatment programmes have been initiated to date within a drug clinic (although in terms of cost-effectiveness alone this is desirable). This treatment is unlikely to continue in its present form if resources fail to match the increase in AIDS cases. Drug clinics are also beginning to act as focal points for the community care of drug users with AIDS: one clinic in North London, for example, has set up a dedicated medical team to offer primary health care to all clinic attenders. Some clinics report a reluctance of physicians to include drug users in AZT treatment (due to an assumed poor patient compliance). Many drug users fail to get adequate dental treatment (dental care is a significant problem).

As mentioned above, homelessness or inadequate housing is a major problem facing this group. Drug users are low housing priorities. Most hostels refuse to accept people with AIDS, active drug users and drug-free alike. There is at present only one housing association in London offering permanent accommodation to drug users with AIDS: this is massively over-subscribed. Housing is often a significant factor in a drug user's choice to enter residential rehabilitation. Many residential treatment centres have adapted to the arrival of residents with AIDS by modifying programmes, placing increased emphasis on physical well-being and arranging for appropriate aftercare in the community. Some have set up specific support groups for people with AIDS and two projects have plans to set up separate houses for people with AIDS.

The majority of drug users with AIDS report feeling a tremendous sense of isolation, not only from the community at large but from family, partners and drug-using friends. The sense of solidarity shown by the gay community in response to the threat of AIDS has yet to be repeated in the drug using community. Consequently most drug users feel that their medical/drug treatment, however good, is inadequate to meet their needs for emotional and practical support, which can be overwhelming The voluntary and non-statutory sector has attempted to address this problem with varying levels of success. The first agencies to meet these needs were mainly those working with the problem of AIDS as it confronted gay men. This has required many agencies to modify or extend their services to meet the needs of drug users: often experience and skills have had to be imported from specialist drugs agencies or self-help groups like Narcotics Anonymous. Others continue to feel de-skilled or uninterested in drugs and AIDS issues. Where these services have been created they have taken the form of support groups, group or individual counselling, befriending, advocacy work and financial support. Many drug users find counselling per se of limited use: they are more likely to benefit from counselling if this occurs in a set-up where their practical problems (clothing, housing, benefits etc.) can also be dealt with. Even where support groups have been set up (e.g. within the Trust, which now also has an Italian-speaking support group) this has required a high level of commitment from participants and facilitators alike. An encouraging development is the emergence of groups of drug users and ex-users (often with HIV) determined to set up support networks and cells, such as Frontliners, the Terrence Higgins Trust, the Aled Richards Trust and the Moorhouse Group of Narcotics Anonymous. These are often much more successful than statutorily-funded services and, interestingly, seem to have less problem exploring the issues of sex and sexuality, which many drug users express resistance to in more formal counselling.

Drugs and AIDS agencies have also been active in advocating improved medical treatment for people with AIDS in prison (mostly drug users). Most inmates with AIDS report unfair and degrading treatment in prisons and continue to be inadequately prepared for discharge. The Terrence Higgins Trust provides a prison visiting service for such people and helps with aftercare. Workers from all sections continue to report feelings of exhaustion and burn-out in the field of drugs and AIDS. Training (particularly in the areas of psychosexual counselling and welfare benefits) is still inadequate and the lack of staff support is reflected in high staff turn-over rates.

16

London Lighthouse: A Centre for People Facing the Challenge of AIDS

CASPAR THOMSON

London Lighthouse, Britain's first major residential and support centre for the growing numbers of men and women living with HIV, ARC and AIDS will be officially opened on 23 November 1988. It is based in a £4.85 million, purpose-designed building in North Kensington. It is committed to providing the best possible care, support and facilities so that people affected by AIDS can live well throughout their lives. Its range of integrated services include a social centre, counselling, health programmes, home support, respite and terminal care. London Lighthouse also provides support to the partners, friends and families of people affected by AIDS and runs training courses for statutory, private and voluntary organisations and for individuals concerned with AIDS related issues.

The project was established in 1986 by a group of people who, as a direct result of having HIV or AIDS themselves, or knowing people who were affected, identified the need for a centre where people with AIDS would be supported, have control over their lives and be central to decisions regarding the organisation and the quality and range of services it offered. People with HIV, ARC and AIDS work at all levels of the organisation.

London Lighthouse provides a range of services for people affected by AIDS. It has a drop-in centre, which will be open seven days a week, and will provide a relaxed and informal meeting place for people with HIV, ARC and AIDS, their partners, families and friends. In the summer months outdoor seating will be available in the garden. The cafe will serve drinks and meals throughout the day and a shop stocking relevant books, videos and audio tapes is planned.

London Lighthouse offers crisis intervention, one-to-one bereavement and group counselling as well as support groups and residential programmes for people affected by AIDS. The counselling sessions aim to provide a safe environment so that people can deal with the emotions and issues that arise. People with HIV, ARC and AIDS facilitate and participate in this provision.

In conjunction with specialists, London Lighthouse runs a series of Health Programmes aimed at enabling people to make informed decisions about diet, exercise and relaxation techniques as well as providing information on orthodox and complementary healing methods.

The Home Support Services provide domiciliary non-medical nursing care and support through a network of trained neighbourhood teams. The teams are supported by the Neighbourhood Teams Development Officer who ensures that the services are linked into other domiciliary support services. By October 1988, 120 volunteers were working with over 60 people with ARC and AIDS in London. London Lighthouse also operates Nightlights, a core of volunteers who are able to spend the night, often the most isolating time, with people with ARC and AIDS.

London Lighthouse runs external training courses for individuals and for statutory, voluntary and private organisations who are concerned with providing services to people affected by AIDS, or who wish to know more about the issues involved. Its North Kensington Centre has four fully equipped training rooms and a resources and information service staffed by a team of professional trainers.

The residential unit is open to anyone with ARC or AIDS who requires nursing or non-acute medical care, who does not wish to go to hospital or who is unable to remain in their home. Situated on the top floor of the Centre, its 24 bed unit is staffed by 17 (soon to be increased to 27) trained nurses and offers a choice of single and multi-bedded rooms. Each room is designed and furnished to a high standard and has its own bathroom with shower and toilet facilities. Other facilities include two day rooms, an assisted bathroom, assisted toilets, a treatment room, a counselling room, and a small kitchen where family and friends can heat up prepared meals and make hot and cold drinks.

The aim of the unit is to create a safe, supportive and non-institutionalised environment where the residents are in control. The role of each staff member, therefore, is that of a guest there because s/he possesses the skills which can help the resident to be in charge of her or his own life. Residents can have visitors 24 hours a day and the furnishings include reclining chairs to enable people close to the resident to stay overnight.

London Lighthouse anticipates that the residential unit will be most suited to those who would like to be at home but

a) are convalescing from an acute illness and are unable to go home at that point,

b) their usual carers need a break,

c) they are no longer in need of acute medical intervention in hospital, but require other nursing and medical care, or

d) for practical reasons they cannot be nursed at home any longer.

Lighthouse will consider referrals from people with HIV infection, their carers, general practitioners, hospital nursing or medical staff and community workers, but the Unit is not appropriate for people who request admission solely on the grounds of poor housing.

Volunteer workers are central to London Lighthouse. Without them the organisation would not have grown so rapidly, nor would it be able to provide such a wide range of services. Over 160 volunteers are working for the organisation either in the Home Support Services or at the Centre, handling a wide range of jobs from fundraising to working in in the Residential Unit. Training courses are organised for all volunteers.

The full cost of purchasing the Centre, extending it by 1,600 square metres, furnishing and equipping it was £4.85 million. London Lighthouse is particularly indebted to the DHSS, NW Thames Regional Health Authority, SE Thames Regional Health Authority, The Monument Trust, AIDS Crisis Trust, Ian McKellen, London boroughs, charitable trusts and many hundreds of organisations and individuals whose financial support enabled the Centre to be built.

In the 1989/90 financial year London Lighthouse will need £2.3 million to run its services. A significant proportion of this will be funded by the four London Regional Health Authorities, the London Boroughs Grants Scheme, the DHSS and charitable trusts. In order to maintain a high level of service provision and to develop new facilities however we need to raise at least £1 million each year.

London Lighthouse is now just two years old and about to bring on stream its full range of support, counselling, training, domiciliary and residential services in a purpose-built building of great distinction and beauty. The organisation is well staffed, structured and managed and, for the moment at least, fairly adequately funded. We have successfully raised nearly £4.8 million to pay for the capital project, but face revenue costs in excess of £2 million in the next financial year.

New problems require new money and it has to be recognised that the provision of high quality community-based care for people affected by HIV, ARC and AIDS will continue to require substantial funding from statutory sources, as well as a great deal of fundraising effort by the wider community, for many years to come. At this stage we have been assisted by the upward curve of the disease, by the general sense of emergency about AIDS, by being the first project of this kind and by being based in Central London where there is more money. But we know that there may well be harder times ahead.

We are breaking new ground and learning from our mistakes as well as our success. We are developing best practice policies and operational procedures, including vigorous equal opportunities and anti-racism policies, backed up by in-service training. We are poised to expand our existing services substantially, as well as to develop new ones, for example in the field of housing, advice work and support services for drug users, and for the lovers and families of people with AIDS. We are also expanding the work of the Training Department, to address the issue of black people and children with HIV.

We have put a high priority on building good working relationships with other AIDS organisations. We believe that there is validity in a range of organisational responses to AIDS and that, while duplication and competition should be avoided, as far as possible there should be choice in the provision of services. This balance can only be achieved if the people in organisations take time and trouble to get acquainted with, as well as respectful of, one another's work. We are currently working on plans for Lighthouse to provide an access point for other organisations like Frontliners, the Black Communities AIDS Team, the Citizens' Advice Bureau, Immunity and the local Law Centre.

As far as we know, London Lighthouse is unique in the world and it is designed to offer a replicable model of care in other population centres as the disease spreads, either as a full range of interlocking services or in its component parts according to differing local needs. Aspects of our services are already being reproduced in projects elsewhere in this country and abroad, and we intend to set up a consultancy service to expand this area of work.

In order to do so, and to be sure that our services are meeting the needs of people with HIV, ARC and AIDS, we intend to subject the range, efficiency and cost-effectiveness of our services to rigorous monitoring and evaluation. Internally, there is a continuous audit, and a consultative structure involving representatives of services users, voluntary workers, paid staff, management and the Board of Directors (known as the Council) monitoring different aspects of the work and making recommendations. Externally, discussions are now underway with the Department of Health, King Edward's Hospital Fund and other interested parties with the intention of setting up an independent research project.

When HRH Princess Margaret opens the building on November 23rd 1988, she will unveil a plaque in the reception which describes the Centre as having been "Rebuilt by many hands for London Lighthouse, a Centre for people facing the challenge of AIDS". It is a challenge which is constantly developing and one which the organisation will continue to meet with energy, an openness to change and commitment.

(Revised and expanded by Caspar Thomson and Christopher Spence from the background paper provided for the conference information pack by Caspar Thomson.)

17

Mildmay Mission Hospital - Continuing Care for People with AIDS

VERONICA MOSS

Present and planned provision

Mildmay Mission Hospital opened the first hospice or Continuing Care Unit for people with AIDS in Europe in February, 1988. A third floor ward had been completely restructured and refurbished to provide nine single rooms with en suite toilet and wash basin; a large communal day room with coffee and tea making facilities and a microwave oven for the use of visitors; and a large roof garden. All the usual medical and nursing equipment enables good professional care to be given in an environment designed to be comfortable and home-like. However, the Unit is set in the context of a small community or GP hospital and there are no laboratories and no intensive care facilities.

The next phase of development will provide a further eight single (or double) rooms, a Day Centre and home support team.

Care is given by a multidisciplinary team. A staff of trained nurses provides 24-hour nursing care, and there is 24-hour medical cover, with the Medical Director at present dealing with the day-to-day care of the patients. The Clinical Nurse Specialist co-ordinates the team which consists, as well as the nurses and doctors, of a counsellor, social worker, occupational therapist, physiotherapist, chaplain, and a housekeeper to the Unit. The team meets weekly to discuss the care, and to share information and understanding of the people with AIDS and their individual situations.

The counsellor is responsible for the support, family therapy and bereavement counselling that may be needed. She is also responsible for the recruitment and training of volunteers to work initially with the team on the unit, and later out in the community. They are all trained to provide practical support and care, and some are selected to undertake further training in bereavement counselling. A staff counsellor, a different person, provides support for the team through weekly meetings with the nurses, and by being available for confidential counselling sessions.

Objectives

The objectives of the Unit are to provide accommodation in the hospital for terminal care; respite care, usually for one or two weeks, but sometimes for a weekend; and convalescent or rehabilitative care. Admissions are limited to four weeks.

Day care for people who wish to stay at home but whose carer has to go to work daily or who requires respite on some days in the week is also provided. Patients may attend for diversional or specific therapies, maintenance infusions of drugs, or company and supervision. There is a home care support service through a specialist team which can advise or provide hands-on care if necessary and as requested by GPs or district nurses.

Basic philosophy of care

Mildmay aims to care for the whole person with unconditional acceptance, compassion and with the highest appropriate standards of medical and nursing care, regardless of race, creed, culture or lifestyle. Our emphasis is on living with AIDS, not on dying, through a patient-directed, multidisciplinary and holistic approach to care. We aim to improve, wherever possible, the quality of life through good symptom control and active treatment where appropriate (as perceived by the staff in consultation with the person with AIDS and his or her loved ones). The person with AIDS's wishes are the first consideration. For the dying, we aim to enable a peaceful and comfortable death to take place with dignity, with continuing support and counselling being offered to those who are bereaved by the person's death, including the staff. We do not aim to prolong life, but this may happen as a result of the approach outlined above and the person may find that his or her role as the 'dying patient' needing total care has changed, willy-nilly to that of 'the rehabilitated person' with renewed possibilities for independent living and a resumption of responsibilities. This is a difficult role reversal that takes time to adjust to, especially for the person who has come to terms with dying, and has completed or handed over his or her affairs.

Mildmay Mission Hospital is staffed mostly by committed Christians from the whole range of Christian denominations, who find here a unique opportunity to work together to translate their faith into action, and most people join the team with a sense of vocation. The emphasis is on sharing their faith through high professional standards of care coupled with an unconditional love and acceptance of each individual as he or she is. Spiritual care and counselling are available as required and initiated by the person with AIDS. We have found that, given a safe and accepting emotional atmosphere, many patients and their loved ones can begin to explore spiritual conflicts and needs in a way they have not been able to do earlier.

Definition of terminal care and boundaries between acute and terminal care

This is particularly difficult in the care of people with AIDS as the course of the disease is unpredictable, and patients sometimes make very unexpected and spectacular recoveries from a state close to death, albeit for a few weeks or months. The aim of care must at all times be to enhance the quality of life and to enable people to live out each day as fully as possible within their limitations and wishes. However, the boundaries between care that promotes this and that which constitutes acute intervention are difficult to define. For example, the I-V infusion of Foscarnet or Gancyelovir undoubtedly prevents the progression of CMV retinitis to blindness in many cases. However, the insertion of a Hickman line and the initial therapy with necessary monitoring of renal function must count as an acute intervention. It is justified when and if the person feels that his quality of life is enhanced, and who could doubt that prevention of blindness will enhance the quality of life? However, some people may choose to do without the hassle and take their chances. These are the kind of dilemmas that are specific to this particular field of terminal care; there are, of course, also many areas of overlap with traditional terminal or hospice care.

Links with other terminal care or home support teams

There is a growing network of these teams and it is very important that they forge close links and co-operate with each other. This may be through visits, regular meetings and maintenance of good communication at other times. Co-operation regarding the care of people whose primary hospital may be very inconveniently placed for continuing community support once they have been discharged will ensure that patients can remain in their own homes as long as possible.

The Mildmay Home Support Team will expect to co-operate well with all community services, and to maintain close communication with the hospice or hospital under whose overall care the person with AIDS is being treated. It will provide advisory or hands-on care if requested by GPs or district nurses, and will liaise closely with them at all times.

Allocation of residential places

Referral forms are designed to give sufficient information about applicants for assessment of need to be made. Daily meetings to discuss referrals take place to allocate places to those who are appropriately referred and who are judged to be in greatest need of such a place at the time of referral. We have no exclusion criteria except in the case of those who may be violent or disruptive to other people or where people are referred for inappropriate reasons, such as homelessness in someone who does not require skilled nursing and medical or rehabilitative care.

Prevention of bed-blocking

It has become obvious that this can be a major problem, especially so when people have become homeless as a result of their illness, or because they expected to die soon and gave up or sold their accommodation. Unexpected recoveries have therefore, at times, meant that beds have been blocked by relatively well patients with nowhere to go.

We have found that early planning for improvement, rehabilitation and discharge are essential, where people show signs of unexpected recovery. It is also important that limts are set for admissions for respite and convalescent or rehabilitative care, and that arrangements are made and adhered to for discharge where possible.

There is an increasing number of people who require supervised hostel accommodation or sheltered housing. Housing associations, churches, charities and other voluntary agencies, as well as local authorities must get to grips with this growing problem. Mildmay is establishing links with those presently providing such housing, but much more is needed.

Differing needs of different groups

As a result of the care received by patients referred for terminal care, some have made remarkable recoveries, and we have therefore developed an expertise in rehabilitative care. We have also been forced to reassess our provisions for activity and diversion and to expand these considerably.

However, deaths do, of course, occur, and these have highlighted some of the problems that occur when people with AIDS live with each other, get to know each other relatively well, and then some die while others are undergoing active rehabilitation. They grieve for each other, and are forced to face, time and again, their own precarious and unpredictable situation. It takes considerable skill, good team work and forward planning to cater for the needs of people (and their loved ones) who are at such different stages of their illness.

Respite care poses fewer such problems as people are in only for a short period and are not necessarily aware of all the other residents.

At Mildmay we have found that the single rooms provide privacy for the terminally ill or those who prefer it, for relatives or lovers to spend time with the patient, or to say goodbye when viewing the body after death. Those who want company can use that communal day and dining room or to go to the therapies department or the activity centre. There is a roof garden and people are invited to participate in its care if they wish. Many choose to go out into the local community to go shopping, to visit a pub or a market or are taken out for a drive or a visit.

The day centre will provide for the needs of those who wish to be cared for at home and for the needs of their carers, as will the Home Support Service.

18

The South London HIV Centre ('The Landmark')

JONATHAN GRIMSHAW

Background

By 31st March 1988, 126 people were reported to have AIDS and 782 were reported as being HIV antibody positive in the South East Thames region. Most cases are in the inner south London area covered by West Lambeth Health Authority and Camberwell Health Authority. It is commonly agreed that this data under-represents the true level of infection in the community.

This area of London has a large gay population and a large drug-injecting population. In the latter, local studies have shown a very rapid increase in the incidence of HIV infection, as well as a high incidence of needle-sharing and 'unsafe' sexual practices. Local studies have also revealed a significant number of HIV people who are antibody positive who have central African connections.

In south London, as in other areas, statutory service development has been hampered as much by lack of understanding of the disease, and the needs of the people affected, as by lack of human and financial resources. The AIDS voluntary sector has the expertise and skills in health education, counselling, emotional support, advocacy and domiciliary support because it is closer to the people most affected. Very often in this case, the voluntary sector is made up of the people most affected.

Against this background, it was clear that the care and support of people with HIV, ARC and AIDS living in south London — outside hospital — and the provision of credible health education could be vastly enhanced by optimising the development and contribution of HIV-related voluntary activity in the area. It was also clear that if the voluntary and statutory services could be integrated and co-ordinated, a more complete service could emerge.

The project

A voluntary group was established— Lambeth AIDS Action — which had on its steering committee health authority representation (GU Consultant, Community Unit General Manager, Authority members), local authority representation and voluntary/consumer group representation. Local needs were identified and a strategy developed to meet them. The main component of this strategy is the development of premises to provide social and recreational (day centre), counselling, health promotion and advice facilities for people with HIV, ARC and AIDS.

A building has been made available by Camberwell Health Authority, located in Brixton, which will provide a large recreation area, kitchen, counselling rooms, quiet room/library, meeting/group room (which can also be used for recreation), massage therapy/rest room, office accommodation and garden. Capital funding (of approximately £105,000) has been obtained from South East Thames Regional Health Authority and private charitable sources. The building will also provide a base from which to develop and train a team of home-support volunteers. Volunteers from the Terrence Higgins Trust, Body Positive and London Lighthouse are already doing very good work in south London, but they do not have a local base and their work is not locally co-ordinated. It is hoped to draw in new volunteers from the local community and that the presence of such a centre in the community will encourage this.

The Centre will have a core staff for administration and for organising and supporting volunteers. Much of the counselling and advice work will be one on a sessional basis by statutory sector workers: benefit/welfare rights advice workers, legal advice workers, employment advice workers, housing advice workers etc. The aim is to provide a comprehensive advice service, covering all the social problems that people with HIV, ARC or AIDS may encounter, on one site.

The Centre will have a full-time health education worker to develop community involvement in HIV prevention work. Both West Lewisham Health Authority and Camberwell Health Authority are appointing drugs outreach workers and these will be based for 50% of their time at the Centre. In addition, the Centre is providing accommodation for the Black Communities AIDS Team — a voluntary group whose aims are to provide HIV-related health education to the black communities and support for black people with HIV, ARC or AIDS.

The Centre also aims to develop housing provision for people with HIV who are homeless. From discussions with local agencies and housing associations, it is becoming clear that the Centre's role may be two-fold: to assist in co-ordinating new, independent projects and to become a management agency for projects which it develops in association with other agencies.

Revenue funding is being provided by South East Thames Regional Health Authority, joint finance from the health authority and local authority and charitable sources. The centre will be managed by a committee representing users, staff and volunteers.

Co-ordination with statutory organisations is being achieved by representation on health authority and local authority HIV policy and planning groups, as well as co-operation at operational level. For example, it has been agreed that health authority district nurse (AIDS) co-ordinators, local authority home care co-ordinators and the Centre's volunteer co-ordinator will meet weekly at the Centre to draw up a home care plan for each individual client. This will ensure better communication between disciplines as well as ensuring that the client gets no more, or less, support than he, or she, wants.

The centre will become operational between May and August 1989. The services provided for people with HIV infection, ARC and AIDS will be evaluated by independent academic researchers under arrangements currently being negotiated.

19

Two More Voluntary Organisations for People with AIDS: Frontliners and the Black Communities AIDS Team

Frontliners

This description of their work was supplied by members of Frontliners

Frontliners is a group of people living positively with AIDS and ARC and working for the benefit of others who are diagnosed. Counselling, publications, information and fortnightly socials are just a few of the services provided. Frontliners are now an established, respected and reputable organisation with both voluntary and statutory bodies.

Frontliners helps people with AIDS discover that they are not unique and do not have to face the world by themselves. People with AIDS now have another family for those who have been rejected by their own. They have a loving, caring and understanding group of people they can relate to. Through the group, new friends can be made where old-established friendships have been dissolved. Only a person with AIDS knows what another person with AIDS is going through. A non-diagnosed individual, however sympathetic, is unable to comprehend the full emotional implications of what it is like to have AIDS.

They are able to walk away from the problem if they choose, whereas a person with AIDS is living with AIDS 24 hours a day.

When work becomes impossible for one reason or another, people with AIDS may face state benefit problems— where, what and how to claim. Frontliners can help here. Individuals can also get help with housing problems. At another level, Frontliners is actively trying to tackle the shortage of housing for people with AIDS through discussions with housing associations, local authorities and church groups about both crisis housing and long term solutions.

Frontliners are not trying to take over the responsibilities of other organisations but to highlight the services that are available to people with AIDS. Apart from monitoring services and providing information, Frontliners actively participate in training of carers and helpers in the community. They give talks on issues that are important for people with AIDS to nurses, district nurses, social workers, GPs and many others. Organisations, whether voluntary or statutory, are encouraged by Frontliners to use their own resources more effectively to help alleviate the plight of people with AIDS.

One of the major achievements of Frontliners is to write and publish a book called *Living with AIDS — a Guide to Survival by People with AIDS* (available from Frontliners, free to people diagnosed with AIDS or ARC; £9.95 to others including post and packing.)

The main aim of Frontliners is to give to people with AIDS the basic tools to remain positive and live well, so they can live out their lives with dignity, and with the human rights they are entitled to.

Frontliners UK Ltd is a company limited by guarantee. It has over 400 members and one paid worker. About 25 members volunteer to work for Frontliners on a regular basis.

Address: Frontliners UK Ltd, 52-54 Grays Inn Road, London WC1X 8JU. Tel 01-831 0330

Black Communities AIDS Team

The Black Communities AIDS Team (BCAT) is a voluntary group of Black men and women from the Asian, African and Afro-Caribbean communities. It was formed in January 1987 and aims to provide suport to Black people with HIV infection, ARC and AIDS, their families and friends.

BCAT also aims to counteract myths and prejudices in relation to HIV and AIDS, and to challenge the structural, social and media reinforcement of racism through AIDS.

BCAT therefore undertakes work to inform Black communities on issues concerning HIV and AIDS, and to establish links with relevant organisations to ensure Black communities' needs are met.

It plans to provide volunteer befriending and community care services, telephone advice, information and counselling.

Address: The Landmark, 47a Tulse Hill, London SW2 2TN. Tel 01-671 7611

(adapted from information supplied to the editors by BCAT).

SECTION FIVE

USING EXISTING STRUCTURES

20

Don't Set Up Anything New

DEIRDRE CUNNINGHAM

My title reflects the basic argument that AIDS and HIV infection were seen as very special at the outset, and special services developed accordingly; but that in the longer term this is not necessarily the right approach. We may have to move to using our existing services and this highlights some of the issues involved.

Suggesting that we shouldn't set up new services may appear to run counter to some obvious facts: the human immunodeficiency virus is new to man, the illness it causes is new, the client groups and the whole nature of the problem are very different. But setting up special services has itself created quite considerable problems. We have seen services grow by disjointed incrementalism, though the reasons are very understandable. Initially, in 1982 and 1983, I think the approach in this country was one of fire fighting. People presented themselves with problems, so services were developed; they didn't necessarily get planned; they arose, and weren't necessarily plugged into the other services. Certainly from the health service point of view this created a growth of hidden specialties. The health service has a history of developing services from the skills and commitment of a few interested individuals. These services grow up perhaps in a slightly idiosyncratic way, often around charismatic figures. What we have seen is a very hospital-based model of care and in London an urban teaching hospital-based model of care. This may be appropriate for certain circumstances but I am sure that users of these services would feel that there is more to it than that. One result has been that mistrust has grown up between individuals providing services for HIV infection. We can see several reasons; partly mistrust between individuals; partly because the funding mechanisms have meant that people have been bidding for the same pockets of funds; partly because nobody could exchange information on individuals and so nobody really knew exactly what was going on. We have also seen a bit of mistrust growing up between agencies, so that there is a risk of setting up alternative overlapping services. Most basic of all, the problem has been immeasurable. It is amazing how much you can do together if you know the size of the problem, what the main issues are, how many of something you have got. But because of the problems of confidentiality and information exchange we have not actually been able to quantify the size of the problem. So any anecdotal evidence that people can give gets bandied around but still nobody really knows what we are dealing with. Hence you get uncoordinated services. For example, in counselling services, certain individuals may receive three counsellors even in one morning, whilst others receive nothing. This has already been found in other services, for example the young chronic sick, but now it appears to be happening again in services for HIV infection which haven't been formally planned.

Separate planning, management and delivery of services

My district was the smallest health authority in the country, the old Paddington/North Kensington, which is now being merged with Brent to become a larger authority called Parkside. An example of service plans specifically for HIV infection and not part of the larger planning process is the expansion of services for drug users. Expanding drug dependency services in Paddington and setting up a needle exchange scheme has drawn in large numbers of drug users who then use facilities not related to HIV infecton. This has had resource and other consequences for many services, not only in the health service but also for the Local Authorities, the police, probation officers and others. All these agencies are now having to pick up some of the issues in a post hoc way.

My view is that there is evidence that if services for HIV infection are expanded without reference to the overall balance of care, either in health authorities or between agencies, this may cause problems in the future. We are certainly having to monitor the use made of our services for drug users to make sure that we are able to ascertain the impact on our Health Service. Another example in the drugs field is when reductions of other people's services occur without prior consultation. There is quite a lot of reduction of services for drug users in many parts of the country and in London at the moment. If you are actually providing one of the few drug dependency units and needle exchange schemes you will obviously pick up the problems which are not able to be dealt with in other places.

Setting up separate management for services for HIV infection goes against the fact that people with HIV infection are identified in all parts of the health service. There is really no way they can be managed separately and in fact separate management may result in overlap. This can mean considerable problems arise in implementing any decisions. Quite a lot of planning can be done, but unless you are plugged into the existing system nothing actually happens. So that is an argument for using existing management structures and existing methods of operation.

Finally, with regard to delivery of services: many examples spring to mind of special services for HIV infection which have caused boundary problems. For example, in the old Paddington district we set up a home support team which originated in a hospital and consists of nurses, other professionals and the Help the Hospices Fellow. The idea was that this would operate across other district boundaries because of confidentiality problems. The team would liaise with people in the districts in which the patients live and assist them along the Macmillan model to treat their own patients. Although this was a commendable immediate response, it has caused some boundary problems.

Some home help services have also had some similar problems, when local authorities have tried to set up their own specific home help service for patients with HIV infection because other home helps weren't willing or able to treat people in their homes. This may produce burn out and stress in those home helps. There can sometimes be problems of over-identification which recipients of this service find difficult to cope with. Other difficulties include lack of consultation on operational problems and inability to adapt to the changing nature of the client population.

Specialist services may also militate against achieving the long term objective for everybody to deal with HIV infection as part of their normal duties, insofar as it is appropriate. I am not saying that we shouldn't have special services at the moment but perhaps not necessarily in future.

Why have services developed like this?

Initially the very small numbers involved meant that people didn't feel that a specific effort should be made to produce strategic plans. The time it takes for the number of cases to double is 10 or 11 months and I think the numbers have only just reached sufficient size for us actually to be thinking about the long term consequences.

HIV infection is transmissible but the public did not realise earlier on exactly how it was transmitted and what the level of risk was for them. I still think that many members of the public don't realise that it cannot be transmitted from person to person directly in the normal course of social life. It is sexually transmitted which means that it is a closet illness and produces secrecy, stigma, and moral judgements. AIDS is fatal and there is no immediate cure on the horizon. All this means that there is no perfectly analogous condition in the health service or local authorities to slot services for HIV infection into. If there were an analogous condition, it may be that an existing model of care could have been adopted immediately, but AIDS does not really fit into the young chronic sick mould. Nor does it fit into the terminal care mould because in terminal care the age group is generally older. So it doesn't readily fit into a way we have already of doing things, and the information barrier has meant that people have not passed information on to each other. There still has not been an agreement of who needs to know what and precisely why. A lot of people feel they need to know things that others don't feel they need to know in order to be able to do their job. This really needs sorting out.

Funding has been central and having to put in bids has made people stress the things about AIDS that are unique. It has also created rivalry. Of course central funding makes sense while the Health Service and the local authorities can't respond rapidly to a very expensive issue out of their existing funds at a time of contraction of everything else. But it does militate against drawing services for HIV infection into existing services.

Finally, up to the present, although this is now changing with the advent of AZT, once people actually develop ARC or AIDS, the illness has been of relatively short duration which has meant that it has predominantly grown up around hospitals.

Applying existing principles of good practice

What I am now going to suggest is that I think there are short term solutions and long term solutions. Let me make it clear that in the short term, special services are the answer because I don't see how we can act quickly and reach our goal of plugging services for HIV infection into existing services without doing a bit of bridging work. But equally there are plenty of models of care and concepts of good practice which could be applied to HIV infection. Not only do these make sense in the longer term but I would argue they should really be applied very quickly. Health promotion and prevention of HIV infection can be coordinated using principles embodied in *Health for All by the Year 2000.* The most crucial elements of this are the drawing up of targets and intersectoral collaboration. I know that in delivering health promotion as a health authority in London we have been guilty of overlapping with other authorities and we have been guilty of not liaising sufficiently at the right level with voluntary agencies who are delivering health promotion.

Joint planning is another key area where we could use existing structures. One example will illustrate how we actually got our planning wrong, admittedly in the face of boundary problems relating to our health district. Over a year ago, we set up what we called a community policy group which was designed to plan services jointly on a district basis. We knew that both local authorities we related to had their own groups each planning services on a local authority basis. But we felt that we ought to plan the services on a district basis, so we invited representatives from voluntary agencies, from two local authorities, social services, housing, environmental health departments and surrounding health authorities. At this meeting the views expressed were: why set up something new, why not use joint planning mechanisms. But we felt we couldn't use two separate joint planning mechanisms, instead we thought we could amalgamate the two joint care planning teams into an ad hoc working group to solve problems for the district. We went through the whole laborious process of putting proposals through two joint care planning teams, getting them ratified by two joint consultative committees, and forming an ad hoc working group from these two systems. The working group met once and never met again. It was obviously quite unworkable. The solution we have now fallen back on is to return to the existing joint care planning teams, even though they have never really done very much planning. They have dished out the joint planning funds, the joint finance, but haven't done the planning for a long time. We have now got both joint care planning teams to set up two project groups and are trying to rejig the joint planning mechanisms so that we have voluntary representation for the appropriate issues. Again what slightly militated against this was the central funding from the DHSS to local authorities asking for direct bids to the AIDS unit without going through our methods of joint planning in the district. We have informal arrangements with these joint planning groups to consult us when they make future bids.

Primary care can be developed along the lines suggested in the recent White Paper *Promoting Better Health.* This White Paper could be interpreted very usefully in the field of providing services for HIV infection. Some problems must be solved first, such as how general practitioners can actually provide services when at the moment they are not all experienced dealing with problems presented by people who are HIV positive or who have AIDS. Again there are difficulties for primary care teams where not all members know who is HIV positive and who isn't, and when they haven't got a very good liaison with hospitals. We will obviously have to find ways of tackling this problem and a lot of this will have to be done centrally. For infection control, I still think we have got to get the message across that Hepatitis B virus is infinitely more transmissable than HIV and that if they were actually taking proper precautions for Hepatitis B then there should be very few precautions or none required for HIV infection. For continuing and community care, the concepts of good practice for priority care groups should apply to people with ARC and AIDS. This means multidisciplinary care, with individual care plans and a named or key worker responsible for coordination. Care (including counselling) should be provided by all authorities at all stages of the development of symptoms of the infection. Eventually care should be provided in people's own local authorities of residence. Although there are some issues which cannot immediately be addressed, we have to find some system for providing housing and other aspects of local authority care for people near the major centres until we have disseminated expertise to all other districts and local authorities. People cannot be sent to their borough of residence until we are quite sure that all the elements of the packages of care which they require are available there.

Terminal care is another area where we may not have plugged the existing expertise into the system for people with AIDS. Concepts for good practice in terminal care really ought to apply to HIV infection. Experience such as that of the Help the Hospices Foundation and The Kings Fund/NAHA publication can be drawn on for AIDS, although there is not always a clearly identifiable terminal phase. Another relevant concept in terminal care is the way of selecting and managing the stress of staff. With HIV infection I don't think there are very many difficulties in recruiting staff to deal with people who are HIV positive or who have AIDS in London. But there are great difficulties in recruiting health visitors and other sort of workers in the community for people with other conditions. Eventually we may have to look at ways in which we select staff and provide staff support in relation to HIV infection and this may mean we ought to provide these services as part of our normal services rather than as special services.

In conclusion, in terms of planning, managing and delivery of services to individuals, AIDS should not be treated as special. Well developed models of care and concepts of good practice must be adapted to AIDS. If existing models of care cannot cope with HIV/AIDS, that fact may say quite a lot about our existing models of care in relation to other conditions as well. If they are not appropriate for consumers who have HIV infection or AIDS, are they appropriate for other consumers? If we have problems about confidentiality and information exchange in relation to AIDS, is this a reflection of problems in other areas? If we have problems about antenatal testing and informed consent, are we doing these things in other areas, should we not look at what we have been doing for a rather long time on many fronts and ask whether AIDS can be used as a way of adapting, or even improving our other systems?

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The North Manchester Approach

JOYCE LEESON

Who could but agree that applying existing models of good practice and using existing structures are great ideas and exactly what we ought to be doing? But there are a few questions that we ought to sort out first so that we know how far we have got.

Is AIDS the same, or is it different? What models of good practice do we have? I am always telling my authority and anyone else who will listen that AIDS is just like any other disease, but we do need special policy statements to say how we will treat it as such, and we don't accept that the HIV test should be carried out just like any other test. Moreover, we do need earmarked funds to meet needs — even more than we have at the moment. Guidelines have come out nationally defining HIV virus as a dangerous pathogen with a need for very detailed and highly protective procedures. And of course we are also faced by the biggest epidemic the world has ever seen — of AIDS seminars, AIDS conferences, AIDS papers, AIDS journals, AIDS books and so on. So we can say AIDS is just like every other disease but there are some potentially contradictory positions, which need clarification.

What is there that is different about AIDS? It is a new disease and we are still learning about it. We still haven't got an entirely clear idea about its natural history and the natural history of HIV infection, nor indeed about all the manifestations of HIV infection and their different proportions in different groups of the infected population. Some of the things that have been said authoritatively in the past have not been borne out as time has gone on. So we are still learning and still tentative about some of the things we are saying. Not only is AIDS new, but it is the end result of a transmissible infection, as many diseases are, so that the protection of the community at large is an important consideration, especially perhaps amongst paid carers in health and other services. In that, it does not differ from a number of other conditions, such as tuberculosis, or Hepatitis B. Unlike tuberculosis we haven't got a cure yet for AIDS and unlike Hepatitis B we haven't got a vaccine. On the other hand AIDS is much less easily transmissible than Hepatitis B and appears to need a larger infecting dose. Perhaps the most relevant factor is that AIDS in the UK has occurred first of all in certain groups who are already stigmatised in our society, in particular gays and drug users. This isn't unique — it is similar to sexually transmitted diseases and Hepatitis B in that respect — but it does give scope for a lot of prejudices to enter into any discussion.

For most diseases, prevention is better than cure; rather more so in diseases where you haven't got a cure. Therefore we have to address the prevention issue. Prevention is very fashionable these days; everybody is doing it but not always to the satisfaction to those who know a little bit about it. One thing for sure is that the approach of "tell the plebs what to do" is of very little use in the AIDS field. Health education messages must offer some advice, but it is advice about how to have sex more safely and how to take drugs more safely and, as we have seen, experts' advice in this field may be overruled by moral guardians. Contraceptive advice, prevention of venereal disease in general and drugs advice also run into similar problems, and if we were more sensitive to the failures of the 'tell them' approach, we might succeed better in preventing not only AIDS but other diseases too.

So while there is clearly an overlap between HIV, AIDS and many other health problems, there are undeniably certain unusual features which are problematic about AIDS. These have lead me to assure my health authority that although AIDS presents no special danger and its prevention and treatment should be managed as in any other disease, there are some special things they must do about it. Everyone must, for example, attend the one hour training programme that we are running for all our staff, called the AIDS Road Show; open access testing clinics must be offered; a standing action group on AIDS must be established; a counsellor and an AIDS co-ordinator must be appointed; relevant employment, control of infection and staff training policies must be developed. Again it seems to me that it isn't really the scientific attributes of HIV that are the difference, but the myths we are having to deal with. Our response to AIDS has exposed some shortcomings in our general services, but perhaps the issue is best summed up by Mark Twain's remark, "it ain't what folks don't know, it's what folks do know that ain't so".

Should AIDS services be district services? The case for this is very strong and certainly the North Western Regional Health Authority's policy is quite clear, that patients with HIV infection should be managed in their home district. Yet this is not happening at the moment, and as far as hospital care is concerned it is hardly happening at all. We are in the early stages of the epidemic; the North Western Region had 52 cases reported by May 1988, three-quarters of those reported from the hospital in my district which is the Regional Infectious Diseases (ID) Unit. I have risked being somewhat unpopular in the past with the staff in that Unit by advocating the region's policy that district general hospitals should be caring for the AIDS cases. I have now come to see that this is probably not appropriate at this moment. My worry was that we were stigmatising and making the services less accessible if we allowed them to develop in the Regional ID Unit. We might give other health staff, particularly doctors, an excuse to say, "AIDS is nothing to do with me, send them to the specialists," if we concentrated services in the ID unit. In practice we have managed to develop expertise in that hospital which is not available elsewhere; people are voting with their feet — they are leaving hospital elsewhere in the region and coming in a taxi to ask to be taken into the care of our Unit. This is partly because the AIDS telephone advice line is letting people know that this is where they will get high quality service. That is a compliment to our services and although there is still room for improvement we have sweated blood to get as far as this. Now we are building up a model of good practice for hospital care which we hope can diffuse to the other districts, together with the skills of all the staff involved. This will happen as the number of cases grows and it becomes no longer feasible to concentrate them in one place.

The first and easiest diffusion is already happening when our staff work with community staff in other districts — the general practitioners, the community nurses, and local authority staff and so on — to enable people to go home. It is easier to get the attitudes right when a particular person with particular needs is under discussion, rather than a theoretical approach. We find that this liaison is going fairly well, although because the numbers are small, we are still in a position to offer a fairly detailed back-up to other districts.

There are some ways in which HIV and AIDS services are just like those for other illness, only even more so: for example, very large numbers of people are professionally involved in the planning and delivery of services. Community medicine has been given responsibility for co-ordinating the district services and, although we don't have genito-urinary medicine in our district we do have infectious diseases, general labs, the regional virus laboratories, control of infection staff, a community drugs team, terminal care nurses, health promotion officers, psychologists, nurses, a medical officer for environmental health, and general practitioners. All these interests are brought together in the health district's standing action group on AIDS. There is a fair potential for cultural clash in such a diverse group and we have had some fairly difficult times working our way through. This was greatly multiplied by the contribution from the voluntary sector, AIDSline and Body Positive and for a while the Haemophilia Society. There is a parallel city wide group which includes even more representatives such as the blood transfusion service, the public health laboratory service, the city council and the community health council. This group reports to the joint consultative committee since that covers the whole of the city, not just our district. So there is a great number of people involved in debating the way forward and this has helped us to iron out some of the problems and establish the right model of service for the moment.

We have now got some dedicated workers in post and I use that word in both the jargon and the human senses. We have a counsellor and a half-time trainer/co-ordinator, and a half-time social worker and community nurse have just been appointed.

This planning arrangement has some parallels with other planning groups but the presence of such varied and powerful people has made it a little different from most of the others. The decisive factor has been the major input from the voluntary groups. They are articulate and well informed interest groups who often know more about aspects of the topics under discussion than some of the professionals present. I think that this has given us great advantage, and we have also had the input from the voluntary groups into service provision. From the very outset they have provided counsellors for our testing clinic. This has enabled them to influence not only the planners, but also the providers by working alongside them. They have won the admiration and respect of the many groups of people who are on the delivery end of the service. I should add that we recruited our dedicated workers from the voluntary organisations as well when we came to advertise the posts. So we are not only following established models but creating new sorts of models which could be established in other areas.

Most of our early cases were gay men and the original focus of the Manchester AIDSline was very much concerned with the interests of gay men, but as the virus began to arise amongst drug users, new challenges have arisen for both the health authority and for AIDS line. Our district drugs team (as do most of those in the North Western Region) includes a worker from Lifeline, which is a voluntary organisation in the drugs field. They have a considerable and growing interest in AIDS which helps us get the interest of our other drugs workers in the field. AIDSline itself is developing a commitment to working with drug users and has got a Manpower Services funded worker with that particular remit. On the whole drug users are not a very well organised pressure group and we are therefore trying to patch together ways of getting closer contact with the potential clients. The Regional Drug Training Unit and Lifeline both play a major part. For example, they have recently produced an underground comic addressed to drug users. It is fairly explicit and we hope funny and entertaining in trying to convey appropriate messages to the users. There is a move under way in the North Western Region for drug users to form a union which is being supported by various of the bodies mentioned above.

I should add that our district is not a supra-regional centre for haemophilia, so I have not tried to address that particular issue.

To conclude I want to raise some questions which might help to assess how well models of practice are being applied.

First, joint planning: is joint planning a reality in your district? Is there equal input from the local authority, the voluntary organisations and the health authority?

Second, counselling: is real non-directive counselling available to patients and their carers and loved ones in your services?

The word 'counselling' is used to mean many things. It appears in our disciplinary procedures. The first stage of the disciplinary procedure for the staff in our district is that you get 'counselled' and I have a nasty feeling that counselling is sometimes a little like that. That won't do really. We realise it won't do in the AIDS field, but perhaps we have let it go by in other fields without challenging it as we might have done. On the same subject, I read that people are advocating testing of the whole of the ante-natal population in Britain, 600,000 women each year, with 'informed consent, following counselling'. I suggest you pay a visit to your ante-natal clinic and see how much counselling is likely to be available in that setting without an enormous injection of staff and training and so on, not to mention a change of culture.

A third issue to highlight is choice. Do we give patients the choice about where to be cared for and how much hi-tech intervention they want, with full information about the pros and cons? Do we try to listen and to respect wishes on these matters? Do we seriously train staff to understand the predicament that patients find themselves in and to respond appropriately? These questions should apply not just to AIDS but across the board. I can say 'yes' for a few of our services, for example, our resettlement services for people who have been long stay mental patients. The service we are hoping to develop for terminal care will be based on such principles. But I would not like to have to answer the question too closely for some of our other services and it is hard to say why you should have to either be dying or to have been incarcerated for years or to have AIDS before your own wishes for dignity and privacy and autonomy should be taken seriously. A model of good practice would be planned and monitored jointly by the users and by the statutory agencies concerned, and would involve continuity and integration between hospital and community, between local authority and health authority, between statutory and voluntary. It would be designed to meet the needs and wishes of the individual users and would rely on close touch with, and feedback from, users' representatives. It would involve volunteers in care and offer them the support that they need to be able to participate. I believe we should continue to try to develop models of care like this for people with HIV infection and AIDS, and to apply what we learn to other services too.

The question remains as to whether the Health Service at present is able, and has the money, to meet these standards of care. Our district allocation for AIDS was £15,000 for 1988/89 with just over £100,000 for the hospital service, which is classed as regional. We are going to have to stretch that a long way to meet the needs that I am identifying.

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The Community Support Centre

CHRIS MEARNS and PAT TYSON

The Community Support Centre is a pilot project resulting from a joint initiative by the Northern Regional Health Authority and Newcastle Social Services and is funded by the DHSS for a period of three years. The aim is to develop services to people with HIV, ARC and AIDS, their partners, families and personal as well as professional carers. In addition the Centre operates as a consultation and resource base on AIDS and related issues. The Centre became operational in December 1987. It is staffed by a team — office manager, clinical psychologist, nurse advisor, social work counsellor and community worker — which encompasses a range of non-medical services.

The team is currently arranging and providing direct care to a number of men and women who are antibody positive, and a few with active HIV infection, including AIDS. The interests and preferences of the individual in receipt of services is of paramount importance in determining what support they receive, and how and by whom it is delivered. Few people with AIDS have tended to use the existing range of statutory and voluntary care available, partly because as a young and marginalised population, they may be unfamiliar with them, but more importantly because most are sceptical about the goodwill, usefulness and respect for confidentiality they could expect. Whatever confidence they may have in their carers is usually invested exclusively in the hospital team.

At the time of writing, five months into the project, we have direct contact with 21 individuals. 7 have received diagnoses of ARC or AIDS, 3 are parents or partners of people with AIDS, the remainder (11) are antibody positive, 8 of whom have had at least one hospital admission. 2 antibody positive asymptomatic people have been seen as a consequence of extreme or problematic psychological responses to a positive test result. All risk groups apart from haemophilia are represented, and we are involved with men, women and children.

The vast majority were diagnosed as HIV antibody positive between 1984 and 1987, two were diagnosed earlier and two within the last three months. Six antibody positive drug users form something of a subgroup within the caseload as they are part of a psychotherapy group with which one of us is working. Three of these individuals are not otherwise known to local health or social services. Of 18 individuals with HIV infection, only two are employed, and only six have any contact with their families. Four individuals have moved out of the area since being referred.

Six referrals have been made to us by doctors at Newcastle General Hospital, mostly by the consultant physician under whom people are admitted for in-patient care. Three referrals have come from AIDS counsellors (to the psychologist in the team), five referrals of antibody positive asymptomatic people have come from clinics in other parts of the region. Seven are self- referrals.

At this stage it is possible to report only preliminary data on the provision that we have made available to the individuals concerned, and outcome data is not yet available.

Excluding the psychotherapy group referred to above, nine individuals (physician and counsellor referrals) sought psychological help; nine (including the bulk of self-referrals) sought help for problems relating to social need. Four referrals involved consultation with individuals and their professional carers which have enabled the provision of local services — these were people living in other health districts within the region. Seven cases involve two or more team members. All of the individuals have been offered specialist help from a welfare rights officer, and housing issues (and related claims) have been pursued on behalf of the people concerned.

We find that good experiences with immediate carers engender trust and it becomes possible in some cases to involve community based providers. This process builds bridges between different providers and users so that everyone's trust and confidence grows, and so does the quality of provision. This benefits the individual and allows us to build up a pool of non-hospital based, non-medical providers with growing experience. We are also working intensively with providers not yet involved in practical care in order to develop their contribution and refine their training procedures so they can win the confidence of people with AIDS in the future.

Ward based acute medical treatment has formed the basis of statutory provision in the region. But community provision cannot be described as 'ready and able to cope', any more than medical teams could be so described when their first people with AIDS started to come in. Increasingly effective medical management has not been matched by developments in knowledge and awareness of all the other aspects of what it is to live with AIDS. We believe it is essential to increase the influence of people with AIDS and HIV infection on our developing health services, while at the same time getting other kinds of care and support into place, such as advice on welfare rights, sub-acute health care, social services provision, housing, child care services, volunteer services and so on. Excellence of care and support for people with AIDS depends heavily on such developments.

The Community Support Centre is tackling these issues in the Northern Region in a number of ways. Our first task has been to inform key people about our work and our existence. This includes managers and practitioners in the health service, workers in other organisations concerned with AIDS, and most important, people with HIV infection, ARC and AIDS, their partners, families and carers. Once contact has been made through posters, cards, and information sheets, we aim to raise awareness of the range of social, emotional, welfare and non-medical considerations which need to be taken into account in providing care. Our role will be to promote close cooperation between agencies and to identify changing patterns of need for services outside hospital. Finally, we aim to set up training sessions for a wide range of bodies. We have already organised several courses which are adapted to the different needs of different professions and organisations.

Gaining acceptance within the network of existing provision has not always been easy. Inter-agency conflicts which arose in the planning of the project (no team members were involved) continue to reverberate, often affecting our relationships with other workers, and complicating the process of team management. In addition, some providers seem happier with ideas than their implementation, as if to say "Community care is the answer... but not for my patients". They have not always grasped that a change in one part of the care network would create differences in another.

There also exists a kind of 'possessiveness' — "They're my guys..." — which maintains the status quo by keeping new providers under-involved and therefore marginal. The associated 'veterans' culture is sometimes evoked to invalidate new ideas and different viewpoints. It has occasionally been necessary to risk increasing the possessiveness by politely but purposefully 'pushing in'.

Declarations of respect for confidentiality and choice sometimes conceal an unwillingness to accept influence by people with AIDS on the support they receive.

The early stages of the project have reminded us of the importance (for ourselves and others) of promoting one's own beliefs without devaluing alternative views. It is more constructive to see change as growth rather than criticism, and to recognise that each other's knowledge and skill was hard won, needing time to adapt and deserving respect. We all need to care for people without disabling them, and to avoid feeling indispensible.

Organisations have their own dynamics and it is often easier for groups to engender friction rather than cooperation, particularly when the cultures of those groupings are divergent, eg: medical/non-medical, volunteer/salaried, hospital/community, gay/IV drug user and so on. Despite this, cooperation can break out. For individuals as well as organisations, there is inherent tension between continuity and change and this is heightened by the intensity and urgency of our tasks in relation to AIDS. Understanding and surmounting the obstacles to progress that we encounter often helps us to grasp the value of existing provision, to discern unmet needs, and to refine our contribution.

We need to utilise different strands of support — professional, personal, voluntary — and to view the range of provision available as complementary rather than mutually exclusive. We need to have structures which empower people with AIDS and which can accommodate developments in provision, variety in the needs of users, and transitions in the level of demand.

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BENEFITS FOR PEOPLE WITH AIDS - THE NEW FACE

Andy Cooke

For people with ARC and AIDS, the old supplementary benefit system had some advantages, because 'additional requirements' formed the building blocks around people's disabilities and special needs. A personal picture could be built up showing the way that AIDS had affected a particular individual. The new system of income support that replaced supplementary benefit at the beginning of April 1988 makes it almost impossible to provide a claimant with the financial resources accurately to meet his or her needs.

The criteria for eligibility for income support are similar to those for supplementary benefit, but the so-called additional requirements payments have been replaced by a series of premiums, the most relevant to people with AIDS being the disability premium of £13.05 per week. To qualify for the disability premium the claimant must meet one of the following criteria. The claimant must either be getting one of the following benefits: attendance allowance, mobility allowance, mobility supplement, invalidity benefit or severe disablement allowance, or to have been certified as incapable of work due to sickness for twenty-eight weeks or more (a gap of eight weeks or less will be ignored). A severe disablement premium of £24.75 is available to those who have been awarded attendance allowance.

The social fund replaces supplementary benefit single payments, which included items such as clothing, bedding, furniture and travel costs and is divided into budget loans, crisis loans and community care grants. The full details of the new system cannot be described here.

To be eligible for a budget loan for essential items such as furniture and household equipment, the claimant must either be receiving, or have claimed and be entitled to, income support for a continuous period of twenty-six weeks excluding any break of up to fourteen days.

Crisis loans are available to meet emergency expenses. A crisis loan may be made if it is the only means of avoiding serious risk to the health and safety of the applicant or a member of the applicant's family.

It is essential to remember that these loans are repayable on a weekly basis directly from benefits the claimant receives. The amount available for loans is cash limited at each DHSS local office, and therefore only those claimants deemed to be of the highest priority by the Social Fund Officer will be granted budget loans. The Social Fund Officer must take into account the ability of the claimant to repay the loan. This does not bode well for someone with a life-threatening disease like AIDS.

Community care grants are intended to assist the return to the community from hospital, nursing or residential care homes or to help a person to remain in the community and avoid going into any of these.

Payments from the social fund are discretionary and the claimant has no right of independent appeal. This unfortunately may leave any discrimination in payments on the grounds of prejudice unchecked. It is essential that all people who are advising claimants monitor the DHSS attitude to AIDS carefully.

The other benefits relevant to people with AIDS are the mobility, attendance and invalid care allowances. Mobility allowance is £23.05. It is aimed at people who are unable or virtually unable to walk, or who would be put at risk from walking any distance.Attendance allowance may be paid at a lower rate of £22.10 a week or a higher rate of £32.95. It is awarded to those who need substantial attention to help with washing, dressing, bathing, etc. Invalid care allowance is an award of £24.75 and is payable to the carer. It is necessary for the carer to have given up work to look after the sick person, a case that may arise with a person with AIDS.

The new system of income support only makes allowances for the 'average' needs of a disabled person. The resources required by a person with AIDS are usually much greater than this average. Potentially, people with AIDS stand to lose out considerably under the new system. It is therefore essential that they are encouraged to seek advice and are made to feel welcome by advice agencies, and that such agencies equip themselves with AIDS-related knowledge to enable them to offer advocacy skills sensitive to the specific problems. For those paid carers not able to offer welfare advice it may often be appropriate to test the water with an agency as to their attitude to AIDS on behalf of a client, or to make sure that the client is not the only source of information about AIDS to the advisor, and that the services provided by organisations, such as the Terrence Higgins Trust, available to other advice agencies are publicised and used.

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Issues for Planners and Managers

GERALDINE PEACOCK

During time spent in workshop discussions at the two conferences participants were asked to consider four issues and provide feedback on these. We thought it would be a useful conclusion to this publication to collate the responses and suggestions which emerged from this initiative. The following are issues which appeared on all workshop agendas

1. What objectives do we wish to achieve through service planning?

- the identification of clear targets and policy statements.
- the provision of comprehensive/flexible and appropriate services for people with AIDS, for example, information and education about HIV and AIDS, free testing facilities, family support services etc.
- the provison of staff training at all levels in the NHS and Local Authorities, and also for informal carers.
- the achievement of a high quality of life for people with AIDS.
- the development of systematic ways of evaluating levels of satisfaction with services.
- the provision of staff support.
- the development of planning systems which actively hear and represent the users voice.

2.What are the key elements in effective collaboration?

- identification of clear roles for agencies in respect of the needs of consumers.
- the development of an efficient national information exchange and effective communication between agencies.
- effective co-ordination between all agencies involved in the provision of care for people with AIDS.
- the identification of key workers.
- effective joint planning between the NHS, all relevant local authority services (housing, education, environmental health, social services), other statutory services (police, prisons, probation) and the voluntary sector.
- effective use of joint funding.

3.What structures already exist and how can we use them?

- review what already exists to avoid duplication nationwide and not just locally.
- build on existing effective training and management structures.
- use joint care planning teams but reorient them away from health and medical approaches.
- build on good models of multi-disciplinary practice that already exist.
- develop existing systems for case conferences, monitoring and evaluation.

4. What resouces are needed to develop collaborative work in this field?

- an educational update at all levels.
- a high level of consumer involvement in planning and training.
- more funding, particularly increased central government finance, for training, preventative work and direct service provision in the community
- redistribution of resources away from health authorities and more towards social services, to ensure equality between sectors.
- a nationwide information exchange.

The overall feeling from workshops was that although much good work is being carried out in all sectors around the country, it is often achieved in isolation. There is a lack of coherent information or consistent funding from central government. There were fears about direct provision by voluntary organisations creating a model of 'care on the cheap' and a strong feeling that a lead from Central Government in providing resources information and the co-ordination of care provision for people with AIDS was long overdue. This followed from the fact that funding so far has been divisive, producing health-led service provision, and that the views of consumers have not always been heard.

The days did not end on a negative note but rather with optimism that even in these short periods of time a lot had been shared and openly expressed. It is now up to senior staff from all organisations concerned with service provision for people with AIDS to pursue these goals and ensure that in planning services in their areas they do not ignore experience available elsewhere.

The days served to clarify and identify goals, share experiences and motivate people to develop collaboratively across sector boundaries with users' needs very much in mind, and that must be a good start!

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Care for people with AIDS increasingly means care in the community. As numbers rise, health districts, social service departments and voluntary organisations will have to adapt to meet the challenge of AIDS, and to provide the best care in the most effective ways.

AIDS: Models of Care presents individual viewpoints from 24 people who organise, provide or receive care. Their experience in areas with high numbers of people with AIDS will be invaluable to all those involved in planning or managing services, both in statutory and voluntary agencies.

The book contains sections on

- the shift towards care in the community
- planning for AIDS in Edinburgh
- responses in London by health service, social services and general practice
- leading voluntary sector initiatives in London
- using existing structures

The 24 papers share a strong concern for involving people with HIV infection and AIDS, and for multidisciplinary working between agencies. They were presented at two conferences in May and June 1988, organised by the Kings Fund Centre, London Boroughs Training Committee, Terrence Higgins Trust and Frontliners.

AIDS: Models of Care is published by the Kings Fund Centre in association with London Boroughs Training Committee.

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