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Project Paper NUMBER 87

AIDS strategy in Northern Ireland: low prevalence, high cooperation

Report of a Working Party

EDITED BY PAULA KILBANE

AIDS STRATEGY IN NORTHERN IRELAND
LOW PREVELANCE, HIGH COOPERATION

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King Edward's Hospital Fund for London

Typeset by J&L Composition Ltd, Filey, North Yorkshire
Printed by GS Litho, London
Distributed by Bailey Distribution Ltd

ISBN 1 85551 067 7

King's Fund Publishing Office
14 Palace Court
London W2 4HT

Contents

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Acknowledgements

The authors wish to acknowledge with thanks the contributions of the many people whose dedication and hard work brought these initiatives to fruition. In particular thanks are extended to:

Members of the School Writing Group
Northern Ireland Council for Educational Development
Belfast and South Eastern Education and Library Boards
Down and Connor Diocesan Board
Governing Bodies Association
School Health Staff, EHSSB
Central Training Team, EHSSB
Unit Training Teams, EHSSB
Unit Management Groups, EHSSB
AIDS Helpline, Northern Ireland
AIDS Steering Group, EHSSB
Area Department of Health Education, EHSSB
Genito Urinary Medicine Clinic, Royal Victoria Hospital
Colleges of Nursing, EHSSB area
Northern Ireland Hospice
Beaconsfield Marie Curie Home

Foreword

AIDS is the greatest challenge to public health seen in the latter part of this century. Epidemiologically there is enormous variation in the rate of HIV in populations worldwide and, paradoxically, the problem is worst where resources are least available. Within the foreseeable future, the only means of curtailing the epidemic is through promotion of safe behaviour and avoidance of risk. The danger is that in areas where prevalence of HIV appears to be low, AIDS prevention initiatives will have little or no priority. Too often efforts are mobilised only when the problem is irreversible. The nature of the disease and its mode of transmission also focus attention on the sensitive areas of sexuality, homosexuality and death. In socially conservative cultures this presents personal and political dilemmas which may contribute further to the avoidance of action on prevention.

This project paper outlines some of the initiatives undertaken in the field of education and prevention of HIV infection in an area of low prevalence and attempts to adduce some of the factors critical to achieving implementation of the programme, planning for which started at the end of 1986 following the development of a comprehensive strategy on AIDS by the health authority.

CHAPTER 1

Introduction and background

Setting the scene

Northern Ireland is a predominantly rural area with a population of 1.5 million people. It is bounded by sea to the north and east and on the south and west by the Republic of Ireland. The total area is small: 90 miles north to south and 140 miles east to west. Many outlying parts of Northern Ireland are sparsely populated, with the major concentration of people in Belfast (300,000) and its commuter hinterland. It is well served by road networks, has major ferry ports in Larne, and two airports in Belfast. There are also two universities with a student population of 21,000.

Within the last 20 years media reports have focused, understandably, on civil unrest within Northern Ireland. Yet it is important to appreciate that despite this situation the majority of people lead normal lives with commonplace activities, such as working, playing sport and attending school. There are strong family links which bring those now living abroad home on frequent visits to their relatives, and some 2.7 million tourist nights were spent in the province in 1986. Major arts events, such as the annual Queen's University Festival, also attract a number of people from outside Ulster but, in general, the civil unrest has caused a diminution in the flow of people into Northern Ireland. In contrast there is a steady cross border flow of Northerners to the Irish Republic. Some go there to work, but the majority go for holidays or major sporting events such as international rugby fixtures. In summer it is calculated that some 150,000 Ulster people go abroad for holidays and, in addition, a quarter of a million business trips are made annually by air, 95 per cent of these to England and Scotland.[1]

Legislation within Britain does not automatically apply to Northern Ireland. For example, the 1967 Abortion Act specifically excluded Northern Ireland and the legislation in regard to homosexuality which was passed in Britain in 1967 was not introduced here until 1982 and only then as a result of a case

brought to the European Commission of Human Rights. The people in Northern Ireland could, in general, be said to be fairly conservative in behaviour.

It is not a society in which there is much open debate on issues such as sexuality and little evidence is available, as elsewhere, about sexual mores and behaviour. But some recent studies into undergraduate behaviour have indicated that 60 per cent of second year students have never had sexual intercourse. Among the other 40 per cent, few have had more than one partner. Religious beliefs and regular church attendance were thought to be important factors in explaining these findings.[2,3]

Research shows some differences in alcohol consumption: for example, average weekly consumption is lower in Northern Ireland than in England, Scotland and Wales with drinking taking place on fewer occasions. There are also high levels of abstinence: almost 40 per cent of the total population are non-drinkers.[4]

There are 39 registered intravenous (IV) drug users in Northern Ireland of whom 11 are injecting pethidine; none uses heroin. The policy of the drug addiction unit of the Eastern Health and Social Services Board is to offer detoxification only. Methadone or other maintenance programmes are not available. While it is very difficult to ascertain the true prevalence of drug abuse from published statistics, exhaustive enquiries both at official and 'street level' tend to indicate that IV drug use is very low indeed. There is evidence of marijuana use and small quantities of cocaine sniffing but no organised IV drug culture. The absence of accident and emergency (A & E) attendances by patients with IV drug overdose or other complications of abuse tends to support this.

Why is intravenous drug abuse so low in Northern Ireland? Possible reasons may be the conservative culture and close family ties, together with a high security profile. Certainly the high degree of stopping and searching of vehicles provides a major disincentive to those trafficking in drugs. The drug squad in Northern Ireland, from time to time, find small quantities of soft drugs but, in their view, the paramilitary organisations prevent the introduction of hard drugs. It is thought that the paramilitaries perceive that drug

addiction would make the local population more susceptible to 'informing'.

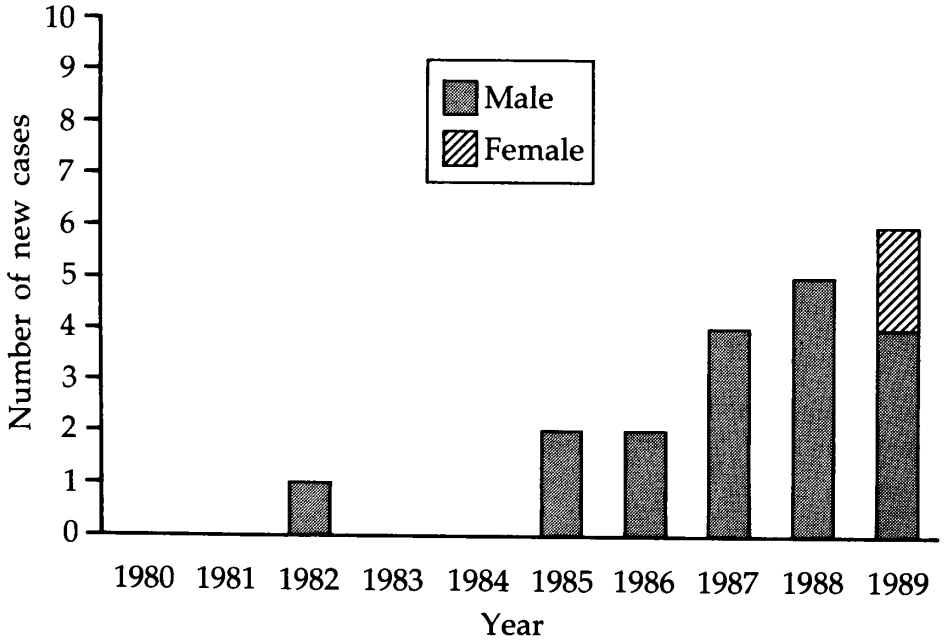
As previously noted, Northern Ireland forms but a small part of Ireland as a whole and its substantial border is shared with the Republic. In very many respects, the societies in the two parts of the island share social and cultural characteristics. However, it has not proved possible to prevent the introduction of hard drugs to certain parts of the Republic, notably Dublin, where it has been estimated there are over 3,000 heroin users living mainly in areas of social deprivation in the inner city.[5]

Prevalence of HIV infection

In demographic terms, the population of Northern Ireland is similar to the remainder of the UK, although slightly younger. Standardised mortality rates are higher overall, particularly for ischaemic heart disease, but the picture in relationship to HIV infection and AIDS is one of low prevalence at present.

By the end of March 1990 there were 74 individuals who

Figure 1 Number of new cases of AIDS seen per year 1980–1989 in Northern Ireland



were seropositive and 21 cases of AIDS under medical care in Northern Ireland. Eleven of those diagnosed as having AIDS had died by that date. These rates (14 with AIDS per million population) are the lowest figures for any region in the UK. Nevertheless, when trends over time are compared, it is clear that the Northern Ireland rates are following the same path as those in the remainder of the UK and Europe (see Figure 1). In terms of the epidemiological pattern of both seropositives and cases, this is a disease that primarily demonstrates the western pattern. The breakdown of those who are HIV postive is as follows:

homosexuals and bisexuals: 37
haemophiliacs: 16
heterosexuals: 6 male, 8 female (14)
intravenous drug users: 2 male, 2 female (4)
others: 3

In respect of the haemophiliacs, just over 16 per cent of those in Northern Ireland who were treated with factor VIII have been infected. This is the smallest percentage for any country in Europe due to the fact that the concentrate used in Northern Ireland was, in the past, drawn from predominantly European sources.

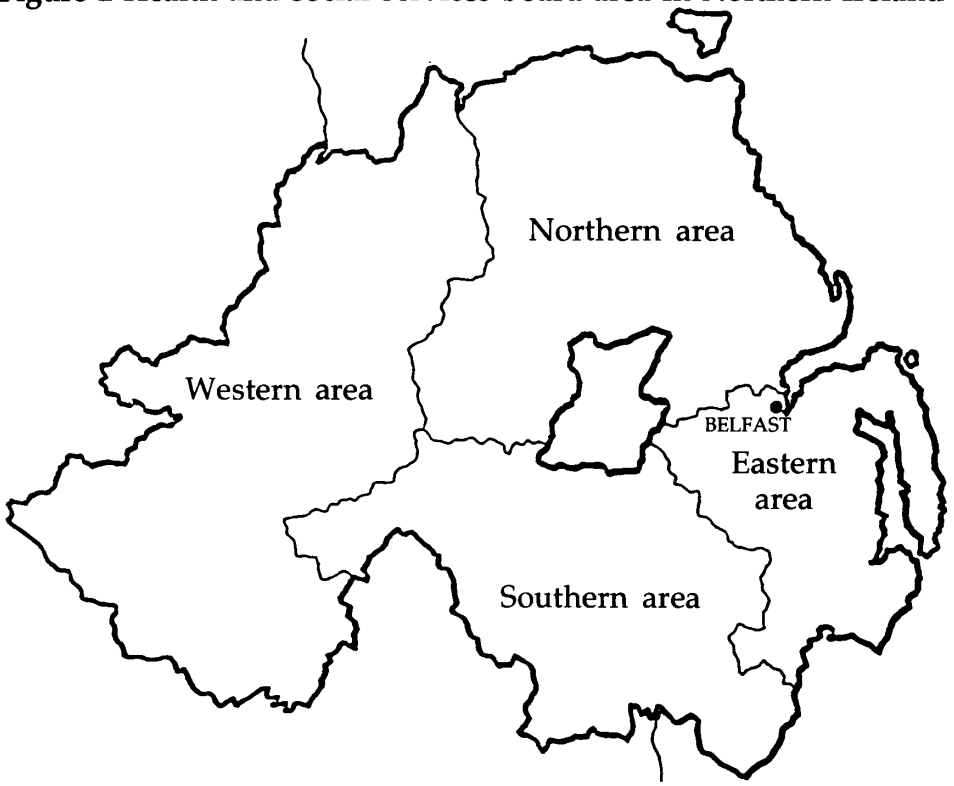
A current cause for concern in Northern Ireland is the relatively high rate of heterosexual infection among women in particular. Of the eight women found to be HIV positive, five were second generation cases – that is, they were not infected abroad or by partners with identifiable risk factors.

The picture in the Irish Republic is substantially different, with 142 cases of AIDS in April 1990 and over 934 persons known to be seropositive, including 65 children. The difference in pattern and scale is directly attributable to the infection of over 500 intravenous drug abusers. Of the remainder, 112 haemophiliacs (21 per cent of those tested), 126 homosexual or bi-sexual males and 73 heterosexuals have been found HIV infected.

Organisation and structure

Northern Ireland is divided into four health and social services boards: Northern, Southern, Western and Eastern. The Eastern

Figure 2 Health and social services board area in Northern Ireland



Board is the smallest in area but has the largest population because it includes Belfast and its hinterland to the south (see Figure 2). The population of the Eastern Health and Social Services Board (EHSSB) was 636,000 at the time of the 1981 census and the organisation is a major employer with a staff of 32,000.

Health and social services boards in Northern Ireland have a responsibility for providing all social services, including child care services, services for the elderly and the mentally handicapped, as well as home-help services, meals on wheels and a comprehensive range of health services. This differs from the situation in England and Wales where the provision of social services is the responsibility of the local authority. Each board is divided up into smaller units of management which have consensus-type multidisciplinary management teams or groups (UMG). There are 14 such units in the Eastern Board varying in type from community only, to teaching, mixed (acute and community) and specialist (for example, pyschiatric). There are major advantages in terms of planning integrated

approaches where such joint health and social services structures exist.

Some regional functions are provided by the Department of Health and Social Services (DHSS Northern Ireland) since there is no regional tier as such. The DHSS Northern Ireland sees its role as coordinating initiatives to do with AIDS on a province-wide basis and keeping the boards in touch with developments in England and Wales through the Northern Ireland Committee for AIDS (NICA) which has representation from public health medicine, from each of the health and social services boards, together with clinical and health education representation. Until recently this Committee was responsible for decisions on which aspects of the British public education campaign would be taken up in Northern Ireland.

The Health Promotion Agency (Northern Ireland) which is analogous to the Health Education Authority, has now been established with a remit to develop material for public education and to support as appropriate other preventive initiatives; the unit will take over this area of responsibility from NICA.

The organsation of education services in Northern Ireland will be detailed elsewhere (see Chapter 3). It is sufficient to say that while a controlled sector exists in the form of education and library boards similar in role and function to local education authorities, separate management structures exist for Catholic or maintained schools and independent grammar schools. In effect, therefore, consultation with three bodies is needed for the introduction of a common programme.

The involvement of the voluntary sector is crucial in the field of AIDS, and Northern Ireland is fortunate in having the AIDS Helpline. This had its origins in Carafriend – a gay befriending and counselling service. It is now fully established as an independent counselling and advice service staffed by men and women volunteers both heterosexual and homosexual. The Helpline provides a telephone service four times a week and has close links with service providers. The chairperson of the Helpline is a full member of the Eastern Health and Social Services Board AIDS Steering Group and liaison is therefore closely maintained. The Helpline is funded mainly by DHSS Northern Ireland but also raises some monies locally. The importance of the link between statutory and voluntary sectors will be detailed elsewhere (see Chapter 6).

CHAPTER 2

Development of a strategy

Background

Until 1986, initial responses to the challenge of HIV in Northern Ireland were focused on laboratory testing, particularly in relation to blood transfusion services. Testing of all blood donated via transfusion began in 1985. Subsequent to this, discussions about health education took place between representatives of health education, public health medicine, interested clinicians and the voluntary agency Carafriend which subsequently set up the AIDS Helpline. However, it was not until the autumn of 1986 that mechanisms were put into place to formalise a coordinated approach to strategy. At that time, the Chief Administrative Medical Officer (CAMO) of the Board set up a multidisciplinary advisory committee. The remit of this group was to provide the policies needed for a comprehensive AIDS strategy. Working groups reported on the following:

1. health promotion and prevention;
2. treatment and care;
3. control of infection;
4. screening;
5. confidentiality and other issues.

These working groups reported by November 1986 and the strategy was put before the EHSSB and agreed in December 1987. The recommendations put forward the need for:

1. *Health promotion and prevention* as the priority area not only to address the general public but to focus efforts on particular areas or groups thought to be at risk. It made explicit the need for certain practical steps, for instance the free provision of condoms at the genito urinary medicine (GUM) clinic and the specific requirement to provide counselling to people whose behaviour repeatedly brought them to the GUM clinic with recurrent infections.

2. *Treatment and care* to be focused in the first instance in

centres where expertise was being developed, with the important proviso that in the long term people should be treated as close to their homes as possible.

3. *Recommendations on control of infection developed elsewhere* to be adapted for introduction within the EHSSB. (Those from ACDP and St Mary's Hospital were adopted.)

4. *Re-affirmation of certain fundamental principles about screening.* For example, that there would be no compulsory HIV screening for health service employees or others, and that informed consent, with proper counselling, would be required for individuals who were considering having an HIV test.

5. *A re-emphasis of the importance of confidentiality,* particularly among the care providers. The stragegy made explicit the important principle that none of the Board's employees should be discriminated against on the basis of their HIV status.

It was clear that specific mechanisms were required for the implementation of the AIDS strategy. The Board, therefore, set up a multidisciplinary AIDS Steering Group to facilitate this. It was chaired by a public health physician with representatives from nursing, genito urinary medicine, social services, administration, finance, health education, public health medicine, dentistry and general practice. In addition to statutory membership, the chairperson of the newly established voluntary group, AIDS Helpline (Northern Ireland), was also invited to be a member of the Steering Group. The intention was to take into account what was happening in hospital and community services through feedback from the voluntary sector on the experience of the consumers. This information proved extremely useful in planning.

Role of the AIDS Steering Group

Its role was:

1. The development of a training strategy to establish AIDS education and awareness programmes for each unit of management using multidisciplinary training groups.

2. To develop and undertake preventive initiatives in the

wider community with other major agencies such as the education and library boards, trade unions and youth services.

3. The development and dissemination of models of good practice.

4. Provision of appropriate outpatient and inpatient (short term and long term) accommodation and services such as counselling.

5. To prioritise bids for resources for AIDS and approve on behalf of the Chief Administrative Medical Officer (CAMO) the allocation of monies (within agreed resources).

6. To develop a positive relationship with the media.

7. To keep under review the Board's AIDS strategy and documentation.

It was proposed that the AIDS Steering Group should report quarterly through the CAMO to the Area Executive Team (AET) on progress and developments.

The climate in January 1987

Since there was the opportunity to keep incidence and prevalence relatively low in Northern Ireland, the AIDS Steering Group took the view that health promotion was an overwhelming priority. It was very fortuitous that the UK-wide public media education campaign about AIDS and HIV was taking place at that time. While the methods used may have been criticised by many, the fact remains that the iceberg advertisements and the household mail drops opened up widespread debate on AIDS for the first time. Even in Northern Ireland AIDS became an acceptable topic of conversation and the word 'condom' could be mentioned. This seemed an ideal time to bring forward a preventive education initiative. The other advantage of the government campaign was that it removed the need to think immediately about education for the general public as a whole, a task undoubtedly very difficult for a single board to perform.

Priority setting

It was necessary to select priority targets for specific initiatives. School children were an obvious choice as the first target group, the advantage being that school children were less likely, as yet, to have fully established patterns of sexual or other behaviour likely to place them at risk. Therefore, primary prevention was a real possibility. Secondly, as an easily accessible group concentrated together, maximum advantage might be obtained from minimum staff input. Given the absence of agreement to sex education in schools at that time there were reservations about whether this subject, involving as it did discussion of sex, sexuality and death, would be acceptable to school education authorities. However, the decision to place the subject in the context of infectious disease may have helped to alleviate this problem. Concern on the part of many educationalists about the real threat of AIDS and their sense of responsibility in relation to the welfare of young people may also have been helpful. Fortunately there were well-established health education links between the health board and its respective education and library boards. These had been strengthened since the province-wide introduction a decade earlier of the schools council health education project (SCHEP). Health education officers are involved with educationalists in the provision of joint training of teachers in health education methods. One outcome of this is that a network of teachers with health education skills maintain close contact with health education officers and the health visitor attached to their schools. This proved very helpful in the implementation of the Schools AIDS programme which is fully integrated into schools.

A regional body called the Health Education Liaison Group, comprising relevant staff from the health and education boards, the Department of Education (Northern Ireland) and DHSS, has been in existence for a number of years and has helped to consolidate working relationships. This group was identified by the AIDS Steering Group as an important source of contact. From the outset, the AIDS Steering Group endeavoured to ensure that clear ownership of the AIDS education programme was vested with the education authorities, with health personnel providing a supportive presence. This has been

reflected in every step of the process – from the very beginning in meetings with senior education personnel right through to the development of the AIDS pack in all the meetings with school principals and teachers.

The 32,000 individuals employed in health and social services within the Board formed the second target for education. The principal reason was their need for awareness about AIDS because of their role in delivering services. This was not only to ensure the best possible quality of care for patients but also to reassure staff about the correct procedures for their own health and safety at work. It was hoped by means of training to address the very sensitive issues associated with AIDS and to demystify and destigmatise these as much as possible. Another important reason was that many Board employees or their relatives are young and have a personal need to know. In addition, because of the nature of their work, health and social services staff have a powerful informal role in positively influencing and educating their own communities, and in helping to inform opinions. The contribution in this respect could be substantial, since one in five households in the area has a member employed by the Board.

Practical steps in implementation of the strategy

The AIDS Steering Group decided that it would be necessary to appoint an officer with designated responsibility for coordinating and ensuring the implementation of both these very large programmes. It was considered that it would not be possible for existing staff to carry out a task of this magnitude alongside other duties. To that end, an AIDS education coordinator was employed on a fixed term contract for a two-year period. The duties of the post were to liaise with all those involved in the education programmes, in schools, education and library boards, trainers, units of management and multidisciplinary groups. The development and piloting of suitable materials was a major activity for the coordinator initially, in addition to the organisation of training programmes themselves. This appointment was absolutely critical to achieving and maintaining these programmes.

Another initiative taken in the field included the provision of

free condoms and information leaflets to attenders at the GUM clinic with counselling for those who attended with AIDS related problems and/or repeated sexually transmitted diseases. The AIDS Steering Group allocated additional resources to the GUM clinic to supplement inadequate levels of staffing and facilities for the sexually transmitted disease service. Additional nurses, junior medical staff, social services staff, laboratory staff and a clinical psychologist were made available. There was also capital investment required for the extension of the GUM clinic facilities. Although it is the policy of the Board not to isolate individuals suffering from HIV, nevertheless it was felt that there was a need for a small dedicated inpatient facility for those who were terminally ill or had distressing or overwhelming symptoms. A two-bedded unit was therefore planned for conversion from existing space in a medical ward.

It must be emphasised that it was essential to have a comprehensive strategy and a wide-ranging policy for AIDS formally approved by the Board. This provided a framework for future action. It made explicit statements in certain controversial areas – for example, employment – and provided an important reference point to which the many interested members of the organisation could refer.

CHAPTER 3

AIDS education programme for schools

Background

Young people were identified as a major priority group in the strategy on AIDS and school children were the first group targeted to receive AIDS education.

In January 1987, discussions took place between representatives from the Eastern Health and Social Services Board and from the Belfast Education and Library Board and South Eastern Education and Library Board regarding AIDS education. From these discussions a joint initiative was undertaken to produce teaching materials for use with 14–19 year olds in Northern Ireland's schools and to develop and implement an AIDS training programme for teachers.

In Northern Ireland, public education (apart from unversity education) is administered centrally by the Department of Education (Northern Ireland) and locally by five education and library boards. These boards are broadly equivalent to local education authorities in England and Wales. Post-primary education in Northern Ireland comprises three main sectors:

Controlled Schools managed primarily by education and library boards which are secular and largely Protestant.

Voluntary Maintained schools managed primarily by boards of governors (and in this area by Down and Connor Diocesan Board) and are largely Roman Catholic.

*Voluntary grammar schools** Non-maintained schools which are independent and can be Roman Catholic or Protestant.

With such a varied management structure it was clear that the materials and training would need to suit the needs of all three and negotiations had to be conducted in a tripartite fashion.

A preliminary analysis of the situation identified the need to resolve the following dilemmas:

* The secondary and grammar schools system still obtains in Northern Ireland.

1. How to make AIDS education acceptable to churches, schools and parents in a culture which is dominated by a religious teaching that proscribes sexual activity outside marriage.

2. How to prevent a negative reaction from parents and leading public figures.

3. How to achieve high priority in an already crowded curriculum for the inclusion of a subject based primarily on health rather than education needs.

A literature and resource review of the current educational materials had been carried out in 1986 to assess their suitability for use in Northern Ireland's schools and colleges. It was found that those that were available were considered only partly suitable for a society which is generally conservative and in which sexuality is a sensitive issue; where there is relatively little officially recorded drug misuse; and where there was reported prejudice towards people who were not heterosexual.

Approach and implementation

To take account of these concerns a two-pronged approach was adopted. A joint writing group from the health and education sectors was set up to produce materials. At the same time, members of the AIDS Steering Group evolved a strategy for securing commitment for the initiative. The AIDS Steering Group and the writing group worked in parallel, and while the latter began to write the materials the former engaged in a consultation process designed to set the climate for acceptance of AIDS education. Communication between the two groups was maintained through the newly appointed AIDS/HIV coordinator (see Appendix 1 and 2).

The full membership of the writing group is outlined in Appendix 3. Members were selected on the basis of their expertise and skills in specific areas. The Northern Ireland Council for Educational Development (NICED) played an important role in the development and dissemination process. NICED was a body set up with the specific remit to develop educational and inservice training in Northern Ireland schools and was thus essential to the project.

Initially, the AIDS Steering Group arranged consultations

between the General Manager and Chairman of the EHSSB, the chief officers from Belfast and South Eastern Education and Library Boards, and representatives from the Down and Connor Diocesan Board and the Governing Bodies Association. Consensus was reached about the importance of including AIDS education in the curriculum and encouragement was given to proceed with development of the package. Then the consultation meetings were extended to gain the support of education advisers and school principals and a commitment was made to keep them informed of developments throughout the year it took to produce the package.

During the development of the AIDS pack, school health staff were kept closely informed of the strategy and their potential role for supporting the initiative was explored.* This resulted in their willingness to promote the AIDS programme when speaking to teachers and parents. It also ensured that a single clear message about AIDS education was coming from influential health service staff.

It was recognised that school health staff would be of crucial importance in supporting teachers when the programme started in schools, particularly at parents' meetings.

The pilot process

The package was piloted in draft form in six schools in Northern Ireland representing the full range available (maintained, controlled, grammar, comprehensive or secondary) as well as with pupils with a wide range of abilities. The response was very positive from teachers and pupils. The main concerns of the teachers about implementing AIDS education in the

*The School Health Service (SHS) is concerned with the health of school children and regular medical inspections and immunisation programmes form a major part of their work. The service consists of a number of teams comprising a medical officer, a health visitor and a school nurse. Each team is responsible for a number of primary and post-primary schools. As a result of the ongoing nature of the work, strong relationships exist between the teams and their schools. Health education is also a recognised element of the work of the SHS and the health visitor in particular carries responsibility for this by liaising with teachers and providing advice and support.

curriculum were how to involve parents and how to deal with their own personal feelings about the subject.

All teachers felt they needed time to explore their own attitudes before taking the package into the classroom. These findings were taken into account by the writing group in the next stage of development.

All schools have their own mechanisms for contacting and consulting with parents on school matters. The teachers involved in the pilot study used a variety of approaches. Some involved parents' evenings where parents were taken through the lessons as pupils. Other teachers simply informed parents by letter about the programme. In the pilot scheme, only one parent asked for further details and, after a meeting with the teacher, fully supported the programme. Teachers who held the parents' meetings reported positive benefits in terms of increased understanding and gaining support. Parents spoke of greater confidence in themselves about talking to their children about HIV and AIDS. One teacher described how the positive response from the parents raised the principal's commitment to integrating AIDS education into the curriculum.

The product

The outcome of the writing group's work was *AIDS education for schools: a Northern Ireland package on AIDS awareness,* which was published in March 1988 by Longmans.[6] It contained a teachers' handbook, a set of pupil material for photocopying, materials for interactive games and transparency masters for overhead projection. Since much of the package dealt with attitudes and feelings, an active learning approach was employed throughout. Teachers were given a two-day briefing on the application of this approach and the materials appropriate for each activity.

The aims of the programme were to provide accurate factual information about AIDS and HIV infection; to encourage the pupils to explore their attitudes to the disease and personal relationships; to promote responsible behaviour based on self-respect and respect for others; and to identify sources of help and advice in the community outside the school.

There are three units in the package, each outlining activities

for two class sessions. In unit one the pupils are helped to understand the defence systems of the body, obtain knowledge about infections and transmission, and to identify AIDS as a sexually transmitted disease.

The second unit aims to identify their existing knowledge about AIDS and HIV, to consider the myths and misinformation and to present them with accurate information.

The third unit uses small group work and discussion to explore attitudes. This unit requires sensitive leadership and it is crucial that it is undertaken in an atmosphere of trust and mutual understanding. At the beginning attention is drawn to the necessity that teaching within this unit is consistent with the ethos of the school.

Introduction of the schools' pack

A prerequisite for using the package is that pupils will have already had basic sex education, although this has not been provided within all schools. It can stand on its own but, ideally, it should be included in an integrated health education programme or as part of a general studies course or integrated into subject training where, for example, the medical content could be covered in biology and the moral and ethical issues discussed in religious or social studies.

The EHSSB is one of four health and social services boards in Northern Ireland and is responsible only for health education in its area. To ensure a Northern Ireland wide implementation, NICED coordinated the training and dissemination of the package throughout the region. Two places were offered to each school initially on the two-day briefing programme. A complimentary copy of the package was made available to teachers who attended the briefing, while each principal was already in receipt of a copy.

By the end of the first round of briefings (May 1988) the level of attendance for the inservice training had been unprecedented in the area of health education in spite of a good local record. Some 76 per cent of post-primary schools in the EHSSB had one or more teachers trained. Furthermore, 46 per cent of special schools and 62 per cent of the colleges of further education released teachers for the training.

As a direct result of the training, teachers from special schools voluntarily formed a working group to adapt the package for use with children with special needs. This version of the package is also available to teachers now.

Advantages of the method over previous training initiatives in health education

Until the AIDS programme, the impetus for specific initiatives in health education tended to come from the education authorities and were supported by health education officers. In this case the approach originated from the health service and, from the outset, negotiation took place at the highest level with education authorities. The advantages of this were that the programme was implemented with the utmost speed and efficiency and it achieved the highest level of training uptake of any health education programme to date.

The process of developing materials locally allowed all involved at every level to share concerns and to participate in discussion about implementing the programme. This led to a greater confidence and trust in the programme.

Evaluation

In Autumn 1989 an education member of the schools' writing group carried out a survey of all schools in Northern Ireland in the post-primary sector to ascertain use of the pack in 1988/89 and proposals to use the pack in 1989/90.

Response varied from board to board with 83 per cent in one education and library board to 37 per cent in another. However, since only 41 per cent of the institutions overall responded it is difficult to gauge the overall impact, and alternative methods of ascertaining coverage are now being employed. There was marked geographic variation in response rate and in response by type of school – for example, grammar or secondary schools.

Discussions are taking place with the education authorities about updating the pack and producing guidance as to how the materials will fit within the new curriculum. This illustrates the importance of being able to adapt to a rapidly changing environment with a product which not only meets the requirements of health education but will be taken up only if it is tailored to fit the requirements of the education sector.

CHAPTER 4

AIDS awareness programme for health and social services staff

The approach

Early in 1987, the AIDS Steering Group looked to other countries to see what had already been done in the field of education about AIDS for health and social services staff. It became apparent that while others were dealing with crises, Northern Ireland was still in the fortunate position of having time to plan as the known seroprevalence was still at a low level. However, it was recognised that the task was ambitious because the EHSSB is one of the largest public sector employers in Europe and, in common with the other boards in Northern Ireland, has a combined health and social services structure. A training model was needed which could be absorbed into the ongoing work of the services using the skills and expertise of existing staff.

The rationale for this approach was that the long-term responsibility and ownership for AIDS awareness must lie with local unit of management groups. The strategy adopted by the Steering Group consisted of two strands: first, creating a climate for acceptance of the programme and, second, organising the training. The approach concentrated on raising the awareness of units of management groups about the importance of AIDS education in order to gain their support for implementing the strategy. While this was happening steps were taken to develop materials and design the training.

Organisation

A Central Training Team (CTT) was established with a remit to train multidisciplinary teams from each of the 14 units of management. This involved:

1. designing suitable training materials;
2. designing and providing training for the unit teams (UTs);
3. monitoring progress and providing ongoing support;

4. evaluating the effectiveness of the training programme.

The members of the multidisciplinary Central Training Team were selected on the basis of their individual expertise and skills in specific areas. To equip them for the task of training others in AIDS awareness they themselves underwent a three-day residential course which covered medical facts about AIDS and HIV infection, sessions on values and attitudes, and a two-day course on communication skills.

Following their training, the skills and knowledge of this multidisciplinary team were shared to ensure a consistent approach and philosophy in the design of the training for unit teams.

A model was developed to utilise individuals' skills and resources at a local level; it was based on a 'training of trainers' approach. The training was based on adult learning principles using participatory methods and was learner centred, thus recognising that individuals have valid knowledge and experience which in turn reflects how they act and feel.

Members of the unit teams were selected by their respective unit of management group (membership is shown in Appendix 4). Their role (when trained by the Central Training Team) was to plan and provide training for all staff in their respective units so that all 32,000 staff in the EHSSB would eventually have undergone AIDS awareness training.

Because of their key roles, the five colleges of nursing in the Board's area, the Northern Ireland Hospice and Beaconsfield were also included in the AIDS awareness programme. It was thought necessary to design an additional model for primary care which is currently being developed based on a GP facilitator approach.

The aims were:

1. To have staff who are fully informed about AIDS, thus ensuring that the quality of care given to people with HIV infection or AIDS is of a high professional standard.

2. To reduce to a minimum any occupational risk of HIV transmission.

3. To raise personal and community awareness about the risks of the spread of HIV infection.

As a spin-off, the additional skills attained by the unit teams would be of lasting benefit to the unit of management.

Feasibility issues

An education programme on this scale had never been attempted before by the Board and presented many challenges for all involved. For example, in the planning stages a few of the concerns were: how could units of management be persuaded to release staff to do the training; would the issue be taken seriously enough; was it feasible to do this in a multidisciplinary fashion?

Issues for trainers

The primary concern was to ensure that those in the unit teams had the skills and confidence needed to carry out the training. It was anticipated that few of those in the teams would have formal training in group work, or experience of planning education programmes; the multidisciplinary nature of the teams would also be a new way of working for many. These factors were taken into account in the planning of training by the Central Training Team. Clearly the method of selection of the unit team members was a crucial matter. The AIDS Steering Group considered this important and met representatives from the units of management groups and the trade unions to devise on a personnel specification for the members of the unit teams. Non-judgmental attitudes towards AIDS and related matters, good communication skills, commitment, sensitivity and an ability to deal with anxieties and discuss difficult issues such as death, sex and prejudice were considered to be important criteria. It was preferable but not essential if those selected had some background in education or in training. In practice, not all units observed these criteria for selection but it is worth noting that those that did so appeared to have the more stable teams. (Appendix 4 illustrates the wide variations in the composition of the unit teams.)

Development of training

Once the personnel had been nominated by the units of management, the first step in preparing them for the task was to assess their own training needs and to get them to identify priorities and resources in their units. Each team compiled a profile of staff and resources in their unit – both human and material. This process had a number of objectives, apart from the stated one: it also made the members and the team's future role known to key individuals in their unit, gave them identity as a unit team, encouraged them to identify the skills within their own team and, ultimately, strengthened them as a team.

Training was offered in three parts:

1. *Working with groups** This was a two-day course which gave participants a greater understanding of group processes and confidence in running their own sessions. The course explored and developed an appreciation of the skills required to work with adult groups. It emphasised the central importance of participatory learning in adult education.

2. *AIDS awareness* This was a three-day course designed to allow the team to explore their own values and attitudes about AIDS and HIV. It provided a forum for discussing important issues about AIDS as well as giving up-to-date information on the virus, its transmission and disease manifestations. Finally, it was an opportunity for the teams to formulate plans for implementing AIDS awareness locally.

3. *Presentation skills* This two-day course took participants through the practical skills of presentation. This was an occupational course for those who felt they needed additional support in this area.

A training manual was developed by the Central Training Team as a resource for UTs. This contains four sections: medical facts about HIV and AIDS; the methods and techniques for use in AIDS awareness sessions; values and attitudes; sources of further advice and support. This is augmented by

* Working with groups: a course on group work and participatory teaching methods. Developed by Antoinette Saton and Martin Evans. HEC/TACADE, 1983.

regular updates on local data, as well as circulation of an AIDS news sheet and journal articles.

Impact and implications

Seventy people were trained in the first phase and, since then, an additional 50 have been trained to supplement some of the teams. It was found that as training started in units it generated a new interest in the overall programme and, as a result, the teams expanded and now regular training is provided for new recruits to teams. Each team has been assigned an experienced trainer from the Central Training Team to give ongoing support and advice. This also acts as a direct source of feedback on progress for the Central Training Team, the AIDS Steering Group and, ultimately, the Board. Regular meetings between groups and unit teams and an AIDS/HIV coordinator are held to share information and to give mutual support. This has provided a valuable way of maintaining morale and overcoming problems.

The teams provided training on a rolling basis, selecting groups in order of priority. As units vary in size, no deadline for completion of training was set centrally but each UT developed its own timetable. While some units formed teams immediately, others did so following the issue of a memorandum from the general manager highlighting the seriousness of AIDS and stressing again the high priority attached to it by the Board. This was followed up by another memorandum from the general manager at the time the AIDS (Control Northern Ireland) Order 1987 came into effect and this spurred the remaining units into forming teams. It took almost a year to get all 14 teams in place and all of them are now operational. The colleges of nursing representatives have taken steps to train their colleagues and to introduce AIDS awareness into the curriculum of student nurses; the hospice team has trained staff in anticipation of their key role in community care. The effect of the successful programme and its implications for the workload of the Central Training Team had not been anticipated and, as the teams in the units gained momentum, additional staff volunteered to become trainers. The Central Training Team now provides ongoing training which means that an

extra burden has been placed on the few members who act in a direct training role. To ameliorate this an increase in direct trainers has been planned.

The unit teams have their difficulties too; for example, finding the time for planning and training alongside other work commitments. In some instances, unit management groups have released staff from some of their normal duties while other teams find they have had to do administrative work in their own time. To try to overcome this, the AIDS Steering Group has issued 'one off' sums of money to each unit management group to assist the teams with administration and resources.

Difficulties have also arisen in cases where the perceptions of the team did not meet traditional expectations, such as staff groups not being trained by a member of the same discipline.

Factors in success

Unlike previous health education initiatives by the Board, the AIDS programme operates on an organisation-wide basis. The multidisciplinary approach coupled with 'training the trainers' had already been widely used in health education in the Board but never on such a large scale. From the beginning, the aim was to ensure ongoing commitment to the programme in units of management. Therefore, it was considered important to integrate the programme into the system with ownership and responsibility resting with the UMG. Previous approaches used outside trainers (albeit employed by the Board) who left once training was completed; in the AIDS programme the trainers consist of existing local staff.

Members of teams have reported great satisfaction from working in a multidisciplinary way and have described how the experience and contact with other disciplines is having a direct benefit on other aspects of their work.

Other important factors which show the teams that their work is of value are the 'spin-off' effects on practice. For example, many units have made appropriate changes in ward practice; resurrected control of infection committees; made resources more available, such as sharp boxes and rubber

gloves; and, in addition, individual members of staff are more safety conscious. Some teams found they have had to make changes to their programme to take account of the fact that staff receiving training later are well-informed through informal education from their colleagues who have undergone training and changed their practices accordingly. One unit has directly attributed the good management of a particular incident to the training they received from their unit team.

While unit teams were being trained by the Central Training Team, there was not always consensus about the inclusion of issues like safer sex and sexuality. The resistance was an expression of individuals' discomfort with addressing personal issues in the training. Consequently, the Central Training Team found much more time was spent than originally anticipated on putting the social and personal implications of AIDS into context for the unit teams.

The overriding factor in the success of the programme appears to have been the commitment of the individuals involved and, in particular, the loyalty of the members of the unit teams which may in part be due to the efforts made to develop team spirit in the early training. In spite of the practical difficulties, time constraints and occasional setbacks, the teams have continued to fulfil their commitment to AIDS training. They are also encouraged by the positive feedback they received from staff who have undergone the programme.

Other factors have been important, such as the existence of a Board strategy which provided a policy base for the initiatives and consultation with management and unions in the early stages giving them the oppportunity to influence the proceedings. The provision of training and a comprehensive training package, including help with preparation for planning and prioritising, gave the unit teams the confidence and skills required. Ongoing support networks appear to be important if not vital.

Evaluation

An independent evaluation of the programme has been commissioned. This took the form of a case-control study with a sample of 660 staff matched for occupational grouping, grade

and unit of management. The response rate was 75 per cent. All respondents were interviewed by a specially trained team using a standard questionnaire and also undertook a self-completed questionnaire which included questions on more sensitive personal feelings and issues. The data items collected covered knowledge, attitudes and values and sought to elicit some data on intended behaviour. The survey took place over a three-month period from June 1989.

Analysis of the data shows consistent statistically significant differences in knowledge and in attitudes between those trained in the programme and those untrained. Detailed findings are being prepared for publication elsewhere. These findings have important implications for the introduction of training programmes for staff both in the NHS and in other large public sector organisations. In particular, they demonstrate that such a large scale programme is feasible, and that it can bring about changes in attitude which have an impact on industrial relations and health and safety at work.

The evaluation also highlighted areas in which further work is required in the training programme itself and pointed up certain deficiencies in the routine administration systems. For instance, there is a need to keep detailed and legible records of staff undergoing training and to design the evaluation method at the same time as the implementation of the programme.

As of 1 April 1990, 11,560 staff had been trained, so there is still a considerable task ahead. New members of UTs continue to be recruited locally and have mandatory three-day training. Support groups have been formed to assure quality and keep up morale and a series of special workshops and seminars with experts have been held to update staff on new developments and help to enhance and develop training skills.

CHAPTER 5

Role of the genito urinary medicine department

Background

Throughout the United Kingdom, the care of patients with HIV disease has been undertaken by clinicians from many different medical specialties: for instance, general medicine, gastroenterology, immunology, and respiratory medicine. Genito urinary medicine departments have played their part to a greater or lesser degree – from simple diagnosis, transfer of the patient to other colleagues, to outpatient care only of HIV disease. Yet others have undertaken the management for both outpatient and inpatient care, with referral to specialist colleagues when indicated.

The role adopted by GUM departments has probably very much depended on the profile of the medical personnel in the departments, the other clinic staff available, and the services provided locally in terms of clinic facilities, bed availability, laboratory back-up and access to specialist colleagues, to mention but a few of the considerations.

Almost certainly, all GUM departments see themselves as having a role in the education of patients and the public on matters related to HIV. They would also have taken a view on the traditional practice of contact tracing of this sexually transmitted disease and its role in prevention of the spread of infection.

This chapter deals with the approach adopted to the medical care of patients with HIV infection in Northern Ireland, with special reference to the role of the GUM department.

Local policy and provision

The DHSS has recommended that all district general hospitals should be able to cope with cases of HIV infection, and this principle has been adopted by the four health and social services boards in Northern Ireland. To that end, personnel from different departments have attended courses in Northern Ireland and in Great Britain on the management of HIV

infection. It was felt that, for a new problem such as this, a centre where expertise could be developed was a logical step. The GUM department in the Royal Victoria Hospital, Belfast, stated a willingness to perform this role. The GUM service in Northern Ireland consists of clinics in Belfast, Londonderry, Coleraine and Newry. Only Belfast has a full-time clinic; the others (all outside the EHSSB) are part-time, managed by local GPs with weekly visits by one of the Belfast-based consultants. These clinics have been made available for HIV outpatient visits, with referral to local physicians or the department in Belfast as seems appropriate.

Clinical facilities in Belfast, as elsewhere in the United Kingdom, had been coming under increasing pressure in the decade between the mid-seventies to mid-eighties because of the relentless increase in sexually transmitted diseases in the community. At the time when a strategy for the care of HIV patients was being formulated, the medical personnel consisted of three consultants, one registrar and one senior house officer with some clinical assistant sessions. The nursing complement consisted of a sister, three full-time staff nurses, and a VD supervisor. One health adviser/contact tracer was employed and there was one secretary for the department. Additional services also provided by the clinic included colposcopy, wart treatment and impotence clinics. The department had access to inpatient beds and the Royal Victoria Hospital, the major teaching hospital in Northern Ireland, had most specialties represented on site with good laboratory and radiological facilities.

Service response

The demands envisaged by the extra load on the GUM department led to the appointment of additional staff – a senior house officer, a social worker, a clinical psychologist, a staff nurse, a half-time secretary and a half-time health adviser (this post has not yet been filled as there is no physical space available for the appointee). Extension of the physical capacity of the clinic was also recognised as being essential (even without the demands of HIV). An extension is currently being built.

Consultants in the department felt that this clinic was the

natural place for many patients with HIV to gravitate to and they were committed to the outpatient and inpatient management of their patients in cooperation with their other specialist colleagues. The GUM department has hence evolved as the centre where specialised care has been developed in the EHSSB and, so far, this has proved to be a satisfactory arrangement.

Policy issues

Taking on this role has meant the acquisition of some new skills and the reevaluation of well-established practices. Sexually transmitted disease practice aims to prevent the spread of infection by diagnosis, treatment, contact tracing, prevention strategies and education. In the context of HIV, a diagnosis of late disease may not necessitate an HIV test, but asymptomatic and early disease make testing invaluable for diagnosis. The policy formulated by the department was that no patient should be tested without their informed consent. Both pre- and post-test counselling was to be provided by doctors, a health adviser, a social worker or psychologist, depending on the needs of the particular case. When persons with high-risk behaviour (whatever the sexual orientation) attending the clinic did not initiate the subject, it has been the policy for the doctor to do so (often to the relief of the patient). Patients are counselled on the potential effects of either having or not having an HIV test, and the implication for their life if the test is positive. Equally important is the opportunity for counselling those who are negative, or do not have a test, on risk reduction strategies.

Although no cure is available for HIV infection, the benefits of early diagnosis, treatment of disease manifestations, prophylaxis and counselling on healthy lifestyle are all now apparent and are actively pursued by the department. Differing views have been put forward on the value or otherwise of contact tracing of HIV infection. Staff of the GUM department have taken a traditional approach on this subject. They have felt that attempted prevention of spread to uninfected persons is a priority and, therefore, that all possible contacts should be traced and counselled on testing and risk reduction. The possibility of prophylaxis strengthens this argument.

Confidentiality would, of course, be respected. Should persons traced be positive, they can be provided with all the facilities available and will usually endeavour not to transmit the infection. Those who do not wish to be tested can be counselled on reducing the risk of potential transmission in the future.

Prevention of the spread of HIV and education are presently synonymous. The only physical method of prevention presently available is to counsel on the use of condoms for sexual contact carrying a risk of infection. To this end, the GUM department has been providing free condoms from 1985, with advice on their use.

Contribution to prevention

Physicians working in genito urinary medicine have a number of advantages when dealing with problems such as HIV. The most important is that they are used to dealing with sexually transmitted diseases and with gay male sexual behaviour. This lack of familiarity is often a great obstacle to other medical practitioners when taking a good medical history and examining people without embarrassment. Genito urinary physicians also have an advantage in that they are used to speaking publicly on the subject of sexually transmitted diseases and should therefore be able to communicate effectively and with credibility to the public and professions alike.

One of the physicians in the department is a member of the Board's AIDS Steering Group and Central Training Team. He has taken a special interest in the development of the Board's education strategies. He has provided medical information for the schools' pack and the trainers' pack. He also provided all clinical input to the unit training teams and addressed other relevant staff groups, including social services staff and general practitioners.

The GUM department has made a substantial contribution to establishing communications with the local voluntary body involved in HIV work – for example, the AIDS Helpline and Carafriend (the gay befriending and telephone helpline). These links have taken the form of talks, question and answer sessions given by the consultant at the gay men's club, and less

formal social meetings. The female health adviser attached to the GUM department has also established an excellent relationship with both these voluntary bodies and has played a key role in gaining the confidence of this community. A recent development of the clinic role has been to extend the health promotion and education activities onto the streets. In collaboration with AIDS Helpline volunteers, the clinic health adviser is undertaking a programme to contact prostitutes and advise them on HIV, safe sex and condom use.

The input of the GUM physician has been critical in the formulation of many operational policies – for example, procedures following needlestick injury and employment policies. In addition, the GUM department collaborates actively in the multi-centre trials of new drug therapy (the Concorde trial, for example) as well as conducting its own research programme[7,8] and collaborating with various Board research initiatives.

Treatment and care

The care of haemophiliacs in Northern Ireland who are HIV positive continues to reside in the department of haematology in the Royal Victoria Hospital. Counselling and support for them and their families is provided from this source. Northern Ireland is notable for having the lowest incidence of HIV positivity in Europe among haemophiliacs dependent on factor VIII.

Patients other than haemophiliacs with HIV infection have mostly been managed as outpatients by the GUM service at the Royal Victoria Hospital, although some attend GUM clinics in Altnagelvin and Coleraine. These patients have open access to the clinics and to the counselling and social services provided. A designated HIV clinic is in operation at the Royal Victoria Hospital. Inpatient management has mainly been handled by the GUM physicians, with close cooperation with relevant specialties, notably gastroenterology, immunology, neurology and respiratory medicine. Some initial misgivings were voiced by nursing, paramedical and ancillary staff about the care of patients and handling of specimens but, with explanation of the epidemiology of the infection, familiarity with day-to-day management and the advent of the EHSSB staff

education programme, these misgivings have largely been addressed.

With a few exceptions, all patients have consented to their general practitioners being notified of their diagnosis; there has been only one instance of a general practitioner not wishing to care for a patient because of HIV infection. Three patients with AIDS have now been successfully managed in the community, with the cooperation of general practitioners, community nursing and social services. Two of these patients received terminal care at home. Cooperation from the undertaker services has been exemplary, both in the community and for patients who died in hospital.

CHAPTER 6

The voluntary contribution

Development of the AIDS Helpline Northern Ireland

In late 1985, a small core group of people from Carafriend (the voluntary befriending organisation for gay men and lesbians in Northern Ireland) decided to take some action on AIDS. During the early months of 1986, the core group was joined by others from outside the organisation with experience in psychology, social work, voluntary counselling, medicine and direct contact with people with HIV and AIDS. On Friday, 16 May 1986, the Helpline was officially launched; a telephone counselling service was provided one night a week. Initially there were nine volunteers and, in 1986/87, there were 477 phone calls. In 1989/90, 667 calls were received and the Helpline was running three nights a week and Saturday afternoons. The DHSS supports the Helpline directly (£26,000) and additional resources are obtained from fund-raising initiatives.

Aims and objectives

By the end of May 1987, the AIDS Helpline Northern Ireland had a written constitution, had held its first annual general meeting and was in a position to clearly articulate its broad aims and objectives. These are:

1. To work in a complementary way with Northen Ireland's statutory bodies responsible for health education.

2. To develop such services as would be necessary to afford support and counselling to anyone affected in any way by AIDS/HIV.

Out of these two aims, a third arose which can be said to combine elements of both:

3. To liaise as closely as possible to develop a network, particularly with other voluntary groups whose field of interest brings them into contact with people affected in any way by AIDS/HIV.

By September 1987, after negotiation with the DHSS, the Helpline was in a position to appoint and employ its first full-time employee as services coordinator. At the same time, new premises were found in a building situated in the centre of the City of Belfast which already houses an umbrella organisation for many of the major charities and voluntary groups in Northern Ireland. This was a very symbolic move in that it gave the Helpline a presence at the very heart of the voluntary services sector. During this period, emphasis was focused on the development and refinement of the ongoing training programme for volunteers in order to prepare for future needs and demands which had yet to be felt here. Unlike their counterparts in Great Britain and the Republic of Ireland who have found themselves thrust into a crisis management situation, the voluntary sector in Northern Ireland had time to plan and train. In 1989, it expanded to employ both an administrator and a development officer.

Development of links with statutory sector

As an organisation, AIDS Helpline has a full and prominent role in the local network of statutory health and social services agencies involved in AIDS and HIV and in the wider voluntary network of AIDS organisations in the United Kingdom and the Republic of Ireland. In Northern Ireland, individuals from the AIDS Helpline have developed a continuing and maturing relationship with the Eastern Health and Social Services Board. For example, the Helpline has played a key role in direct training of EHSSB staff in their AIDS awareness programme and in the design and production of materials. As this programme has matured, the Helpline has increasingly been contacted for advice and information. It also contributed to other subcommittees formed by the EHSSB – for example, on issues such as publicity and the needs of young people. In addition, the AIDS Helpline formalised its cross border relationship by holding a major conference in conjunction with the AIDS Action Alliance in the Republic of Ireland. This was supported by input from and attended by staff from the statutory sector in Northern Ireland.

A cooperative relationship between the voluntary sector,

DHSS and EHSSB was established in early 1985. This enabled concurrent development of policy and planning, and thus avoided elements of conflict which could arise in situations where key bodies become involved at different times and/or develop divergent positions.

Between January and March 1986, close links were established through meetings to discuss mutual concerns about AIDS with the core group, the health education unit, and the departments of public health medicine and genito urinary medicine in the EHSSB. The Helpline played a very active role in the sub-committees formed to advise the Board on strategy during the autumn of 1986.

The foregoing account of the relationship can in no way capture the dynamic nature of the relationship. In 1987 and 1988, as well as formal meetings there were many informal meetings between all concerned. As a result, they are in a better position to work constructively and creatively together.

Benefits of liaison

Some of the benefits accruing from this relationship of mutual regard and reciprocation include exchange of resources – for example, EHSSB uses every opportunity to publicise the Helpline which in turn is totally available to the Board for information and advice. For instance, the Helpline contributes to EHSSB training programmes and vice versa. Ongoing dialogue takes place in order to present a unified point of view in relation to key issues surrounding AIDS/HIV, particularly in response to enquiries from the local media. The EHSSB's AIDS education coordinator works closely with the Helpline to ensure a flow of communication and mutual resourcing of information and materials. The desirability for voluntary and statutory agencies to work together is highlighted by such major organisations as the World Health Organization (WHO) and the Health Education Authority (HEA) and has been locally endorsed by the DHSS (NI) regional strategic guidelines to health boards in Northern Ireland (1987–92). Experience in Northern Ireland shows that close liaison between statutory and voluntary organisations can be attained.

What has been experienced by the Helpline as a result of the relationship with the EHSSB

The Helpline feels it has benefited from the enhancement of its reputation within the wider health service in Northern Ireland and in the DHSS. Acknowledgment by the statutory sector has been an important factor in giving the voluntary group confidence, self-esteem and in helping it to maintain its energy levels. Because communication is good, due to the Helpline's close and active involvement with the EHSSB, there is an assurance that a sensitive service is provided for those with HIV or AIDS. Savings must be considerable, although the contribution made by voluntary, unpaid effort has never been costed in this country.

The role of the voluntary sector – the relationship now

In simple terms, it is hoped to continue to work independently but together towards a unified goal. More specifically, because of the flexibility and absence of organisational constraints, the voluntary sector can act as the 'tigers of wrath' in a constructive fashion by:

1. lobbying government;

2. advocacy on behalf of those who are marginalised and who cannot safely speak out for themselves;

3. highlighting needs and inequalities;

4. communicating these back to those with statutory responsibility.

It is the role of the Helpline to ensure that those affected by HIV or AIDS play a part in determining the nature and quality of their care.

In relation to public health education, the role of the voluntary sector is to institute experimental, innovative projects, some in conjunction with the statutory authorities and others that may well be impossible for statutory bodies to carry out.

Helpline initiatives

The most recent examples of these outreach projects involve increasing preventive health education services in gay discos in Belfast by distributing safe sex materials and leaflets. Two female volunteers from the Helpline have also started an education programme with prostitutes on a regular weekly basis. This project has the support of the GUM clinic staff.

Helpline has also become much more proactive in terms of support for those who are HIV positive by enabling the development of a body positive group which meets in the Helpline's premises. In addition, a home support services group has been formed made up of a number of Helpline volunteers. This aims to provide practical and emotional support to people with AIDS and HIV. Its continued success depends on the maintenance and development of good relationships with potential referral agents, such as GPs, nurses and social workers.

Helpline is also piloting projects in the four Northern Ireland boards on community awareness initiatives on AIDS. The basic concept is to encourage local informal discussion in community groups. The access and facilitation of this scheme is largely through health promotion staff involved in community development projects. There is clearly much merit in this approach, as it parallels the Board's strategy for promoting health in general from the community level.[9]

From a Province-wide view, AIDS Helpline and the Northern Ireland Health Promotion Unit have collaborated to set up the Northern Ireland AIDS Forum. This brings together interested partners to share ideas and ensure consistency and coordination throughout Northern Ireland.

Perhaps the most important benefit of the relationship between the voluntary and statutory sectors has been the absence of competition. There are no AIDS 'camps' in Northern Ireland; no agency is striving for a monopoly over the other in terms of expertise and understanding. The spirit of cooperation allows the dovetailing of activities and this has exciting implications for an integrated, holistic approach to the health issues surrounding AIDS and HIV. Naturally from time to time there are

differences of opinion on some matters – these may even surface on radio programmes. However, to date, it has proved possible to accept and understand these differences and move forward towards achievement of shared goals.

CHAPTER 7

Conclusions

The AIDS training initiative is by far the most ambitious and comprehensive of its kind ever undertaken in the EHSSB. In the process, many issues have emerged which will be useful in planning further stages of this and other programmes.

The major challenge was to gain priority for an issue such as AIDS which, as described, has a low prevalence in Northern Ireland and which, given its associations, could have been anathema in this community.

Critical factors: general

It is felt that the critical factors in the success so far achieved were:

1. The development of a comprehensive strategy on AIDS by the EHSSB which subsequently underwrote all the programmes undertaken.

2. The strategy was developed by a number of working groups comprising established figures in Northern Ireland, from fields such as virology, immunology, haematology, genito urinary medicine, public health medicine, nursing, social services and health education and was chaired by the Chief Administrative Medical Officer (CAMO) of the EHSSB. The high degree of consensus thus achieved lent credibility to the document which has proved invaluable at many stages since in discussion with colleagues in the health service and from other sectors.

3. The adoption of an explicit set of goals by the AIDS Steering Group clarified its role for all members and contributed to the unity of purpose that has been demonstrated since its inception.

4. The appointment of the AIDS/HIV education coordinator had symbolic importance to those inside and outside, and highlighted publicly that AIDS was being singled out as a

priority issue within the Board. It also forced the Steering Group to address what could be realistically expected of one person and highlighted the support which the coordinator would need. In addition, it gave the immediate means to begin prioritisation and implementation of the strategy.

Critical factors: school programme

1. It was recognised that AIDS is more complex than many other health issues as it has major moral and ethical dimensions. This was identified early on as a potential stumbling block and was overcome by explicitly involving a moral philosopher in the design of the material.

2. In addition, it was made clear that the material could be flexibly used and adapted to meet the prevailing moral ethos and values of the type of school in which it was being used. So, it had universal applicability.

3. The uptake of the training by teachers was outstanding and their evaluation of the training and package was extremely favourable. Involvement of school principals in the early stages may have been a factor in the high uptake.

4. The willingness of the Northern Ireland Council for Education Development to negotiate with the Department of Education for teachers' release for training is a reflection of the degree of goodwill that was established and demonstrates a way of working between health and education authorities that maximises resources and effectiveness.

5. The level of cooperation between all the agencies may be a reflection of the value of building on existing goodwill.

Since the school package was introduced it has been reviewed in a number of Journals.[10,11,12] In general, these reviews were favourable about its approach, production and education materials, particularly for the first two modules. Module III has been criticised for being somewhat 'tame' in exploring personal behaviour, such as discussing condom use in a relationship. The authors would accept that, without the benefit of inservice training, a 'user' might manage to dodge some of the difficult issues. This points out the need to train trainers to explore the

sensitive issues but also reflects the necessity to provide an acceptable product.

If the experiences in Northern Ireland were to be used by others it would not be necessary for all districts to generate their own packages from 'scratch'. But adaptation of existing material to suit the locality is vital and has the advantage of involving negotiation with local education authorities to generate ownership and commitment. The Northern Ireland school package has served as a model for development in the Republic of Ireland, for example, with considerable amplification on IV drug use.

On the negative side, there is disappointment that evaluation of the package implementation has been more difficult than anticipated. To some extent that has been due to major changes in the structure and the new curriculum which has preoccupied most schools. On the other hand, the Board engaged in joint development with the objective of giving long-term ownership to the education authorities.

As a result of this approach, the right to direct intervention has been forfeited. Nevertheless, the AIDS Steering Group continues to talk to education authorities and is adopting a ground-up approach again in the light of the new curriculum.

Critical factors: staff programme

1. If the AIDS education programme for schools was one of the most comprehensive ever undertaken here, the programme for health and social services staff must be the most ambitious. In many respects it has broken new ground. For example, it is the first inservice programme which has ever been offered to all staff in the Board. Multidisciplinary training is rare in the service; the development of training teams from different levels in the organisation is unusual in hierarchical organisations and the transformation of practitioners into trainers while maintaining their practitioner status is not common.

2. 'Ownership' of the AIDS awareness programme by unit management groups was the aim of the Steering Group when it first embarked on the consultation process with them. The rationale was the recognition that AIDS will be an issue for a

long time so it needed to be integrated into the work and training of all staff. It was believed that training structures which were not rooted in practice would be ineffective and wasteful of resources.

3. The encouraging results from the evaluation of the AIDS awareness programme have given new impetus to all concerned to carry the task through to completion. Some units of management have almost finished and are involved in training 'newcomers'. Others, particularly in very large units, have a major task still ahead of them. Symptomatic of the creation of this 'new climate' in the organisation was the specification for AIDS awareness training for outside firms applying for competitive tendering contracts within the Board for catering, domestic service and so on.

Other factors

The close cooperation between the AIDS Steering Group and the GUM clinic and the deep involvement of the latter in all aspects of the education initiatives has been mutually beneficial; so has the relationship which has been developed with the AIDS Helpline.

The voluntary/statutory relationship should be distinguished by its dynamic nature; voluntary agency members should not get locked into relationships that are predicated on a committee structure. It has been found that once personal relationships based on mutual trust are established, the possibility of a two-way consultancy role becomes a viable mechanism for developing an integrated, cooperative approach.

Has anything been learnt that may be applicable elsewhere?

There are two outstanding principles that have contributed to the development of relationships between the voluntary and the statutory sectors, the health and education sectors and between different disciplines involved in the AIDS education programme. These are:

1. In planning any action which requires intersectoral and voluntary involvement, it is crucial to 'audit' the environment

thoroughly before taking the first steps. This means identifying allies and potential obstructions and knowing where power and influence lie in the different parts of organisations and in the different sectors.

2. The next stage is to cultivate interpersonal networks and to build and consolidate key relationships on an ongoing basis as the 'actors of the piece' change.

What is clear is that there is an enormous amount of untapped talent and ability in all sectors. Our experience shows that this can be tapped in the interests of AIDS education by: the development of policy; good leadership; clear goals and objectives; imaginative planning; the provision of appropriate training and resources; and ongoing support and recognition for the teams in this field.

CHAPTER 8

The next steps

As well as continuing to nurture and develop the school and health and social services programmes there is a need to develop programmes for other groups in the community. The current priorities include education programmes for young people outside the school system, and the development of model programmes for community care.

Youth programme

At organisational level the youth sector appears to have potential for developing good programmes. There are well-established links with this sector and some health workers have been involved in providing training for youth workers. This allows access to youth clubs, YTP schemes, further education and voluntary groups outside school. A pilot programme for youth has now begun in which the object is to adopt informal methods which are appropriate to the needs of young people. The basic approach is the identification of a group of young people to carry out training. This peer group training approach is successfully underway with a built-in evaluation of the pilot scheme. In parallel has come the development of AIDS training modules for inclusion in the curricula for youth work training – with both statutory and voluntary sectors. The effort required to implement, evaluate and promote these programmes is considerable and funding was obtained for a youth education post on a two-year fixed term basis.

Community care

A developing initiative in this area is the appointment of a part-time GP facilitator for AIDS. A survey was carried out among all GPs in Northern Ireland in 1988 to ascertain level of knowledge and practices in relation to HIV and AIDS.[13] As a result of the survey, GPs identified the need for further training in practical control of infection measures

and also issues such as counselling and confidentiality. The GP facilitator was appointed in response to these findings; the post holder conducts tailored multidisciplinary sessions for practices and these have now been recognised for training points under the new GP contract. This is a vital step towards the widespread extension of care into the community.

Because of the low prevalence of AIDS/HIV in Northern Ireland, community care has not become as pressing a problem as in areas of high prevalence. This presents an opportunity to explore and develop models of good practice. The close relationship which has developed by the inclusion of Beaconsfield House and the Northern Ireland Hospice in AIDS awareness training would prove valuable in developing this model, which will also incorporate the skills and expertise of the AIDS Helpline and staff from the GUM clinic, community nursing, social services and general practice. A secondment from the voluntary sector may be a possibility.

Although the spread of AIDS in Northern Ireland is, relatively speaking, at an early stage, a trend is already developing whereby Northern Ireland people who are living elsewhere are coming home to die. Rapid action in terms of community care is therefore needed. A step in the right direction has recently been taken by the introduction of a confidential direct-line telephone service within the social work department of the Royal Victoria Hospital. The BC Homelink gives individuals an opportunity to discuss their concerns about the emotional and practical implications of returning home. It offers an information pack about services and benefits and can be provided if needed.

Planning and resources

These chapters cover some aspects of the AIDS programme in the EHSSB in great detail and comment only briefly on others. It is now apparent that some three years into the AIDS strategy vital components are becoming institutionalised and new initiatives such as the Homelink are becoming essential. Although prevalence of HIV remains relatively low there is now an acceptance, at least in the EHSSB, that AIDS programmes are legitimate and important. This is manifest by the continuing

funding of developments. Currently, funding is provided for screening services for blood transfusions (80,000 units pa) and the regional virology laboratory (3,500 pa). It has supplemented the GUM staff, both outpatient and inpatient, as required and allowed modest capital developments. The health promotion and training initiatives are funded on a fixed-term basis to allow the employment of the AIDS education and youth coordinators and a part-time GP facilitator with support staff. However, financial pressures are now emerging with respect to the funding of AZT and other prophylactic and anti-viral therapies. This is currently under discussion with the DHSS, Northern Ireland.

It is impossible to cost the overall programme, since a large burden has been borne by existing staff in the NHS who train without pay, and by other sectors such as education and youth. Their commitment and hard work has made much progress possible.

Much still remains to be done in Northern Ireland. We are still only scratching the surface in understanding the cultural and social changes needed to provide and care for those already infected. The challenge of promoting relevant behaviour changes among young people in particular is just beginning. It is the paradox of prevention that if we are successful our efforts will be deemed to have been unnecessary.

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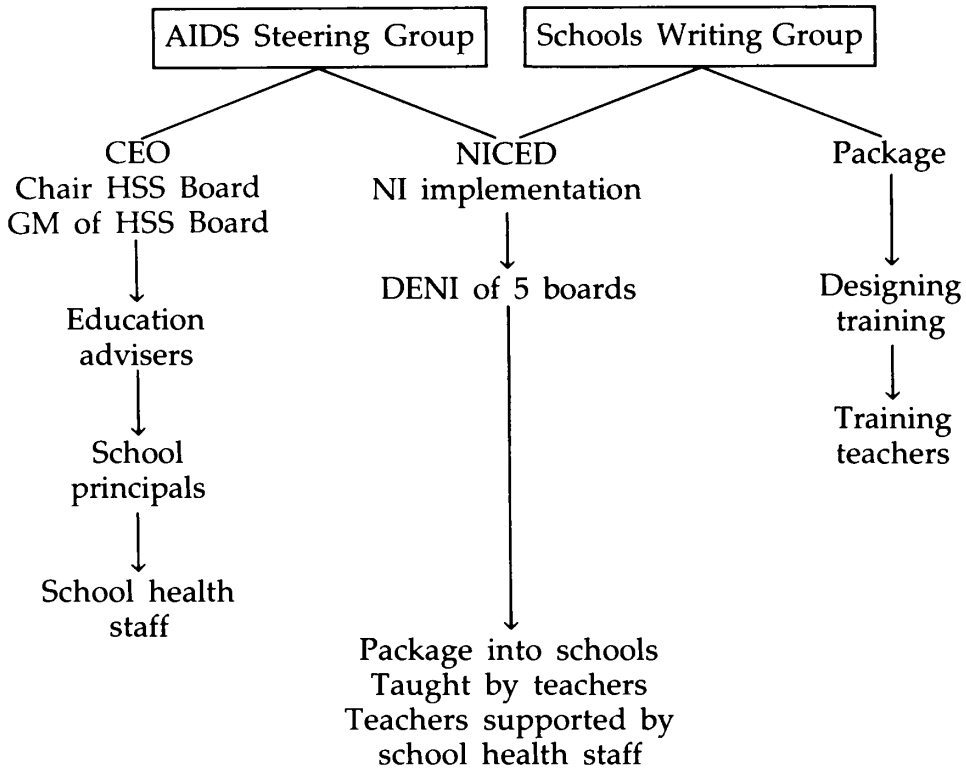
APPENDIX 1

Strategy for implementing schools AIDS package



CEO – Chief Education Officer
DENI – Department of Education, Northern Ireland

APPENDIX 2

A timetable for the two-pronged approach to AIDS awareness for schools throughout Northern Ireland

Month	*Aids Steering Group activities*	*AIDS Writing Group activities*
January 87	Review of literature and resources.	Multidisciplinary writing group formed.
February 87	Brief produced for writing group.	Writing began – group divided into 3 sub-groups.
March 87	Met with chief education officers from BELBs and SEELB. Representatives from the Down and Connor Diocesan Board and the Governing Bodies Association. This meeting was hosted by the GM and CM of the EHSSB.	Sub-groups met regularly to feedback on progress.
May 87	Met with education advisers from both ELBs. Seminars for school principals were held to inform them of plans, outline the pack and to discuss practical or moral issues.	Draft materials near completion.
June 87		Teachers from six pilot schools were trained in the use of the draft materials.

Month	*Aids Steering Group activities*	*AIDS Writing Group activities*
August 87	Members of AIDS Steering Group and Writing Group met with Director of NICED. It was agreed that it should be responsible for dissemination of the package throughout NI. Host lunch for Writing Group. NICED agreed to coordinate the publishing of the pack.	Materials rewritten in view of lessons learnt from pilot.
September 87	Seminars × 8 organised for school health staff to brief on pack and on their possible roles.	
October 87	Update for CEOs, Down and Connor Diocesan Board and the Governing Bodies Association.	Rewritten materials – final draft.
November 87	Update meetings chaired by respective CEO for school principals, adviser from ELBs to preview draft materials.	
December 87	NICED/ASG – begin process to involve the other education and health boards in NI.	

Month	*Aids Steering Group activities*	*AIDS Writing Group activities*
January 88	Package sent for printing.	
	NICED/ASG – negotiate cover leave for two-day training.	
February 88	Schools sent advance information about the package.	
March 88		Writing group and education advisers plan training for teachers.
April 88	Cover leave granted for two-day training for teachers.	
		Members of writing group start training of teachers in the BELB and SEELB.
May 88		School health staff given printed pack and informed of schools in area who had taken advantage of the training and therefore likely to be looking to them as a resource.
		HEOs and education advisers and NICED coordinators provide training for teachers in other boards.

APPENDIX 3

Composition of schools writing group

Senior health education officers × 2
Senior clinical medical officer
Senior registrar in public health medicine
School health visitor
Senior teacher
Senior lecturer in education
Moral philosopher
Northern Ireland coordinator of school health education projects
Chairperson of AIDS Helpline
EHSSB AIDS/HIV education coordinator

APPENDIX 4

Examples of the composition of unit teams

Team A

Assistant director of nursing services
Nursing officer
Assistant group administrator
Consultant bacteriologist
Physician

Team B

Nursing sister
General administrative assistant
Social worker
Senior medical laboratory scientific officer

Team C

Charge nurse
Health visitor
Senior social worker
Domestic supervisor
Dentist
Pharmacist

Team D

Doctor
Staff nurse
Social worker
General administrative assistant
Consultant physician
Domestic services manager
Unit chief chiropodist
Occupational therapist
Ward orderly

Team E

Staff nurse
Senior social worker
Assistant group administrator
Consultant haematologist
Principal microbiologist

Team F

Assistant director of nursing services
Community sister
Ward sister
Charge nurse
Domestic services manager
Laundry manager
Transport officer

Team G

2 health visitors
2 senior administrative assistants
Dental department representative
Area chiropodist
Senior social worker
School medical officer
District nursing sister

Team H

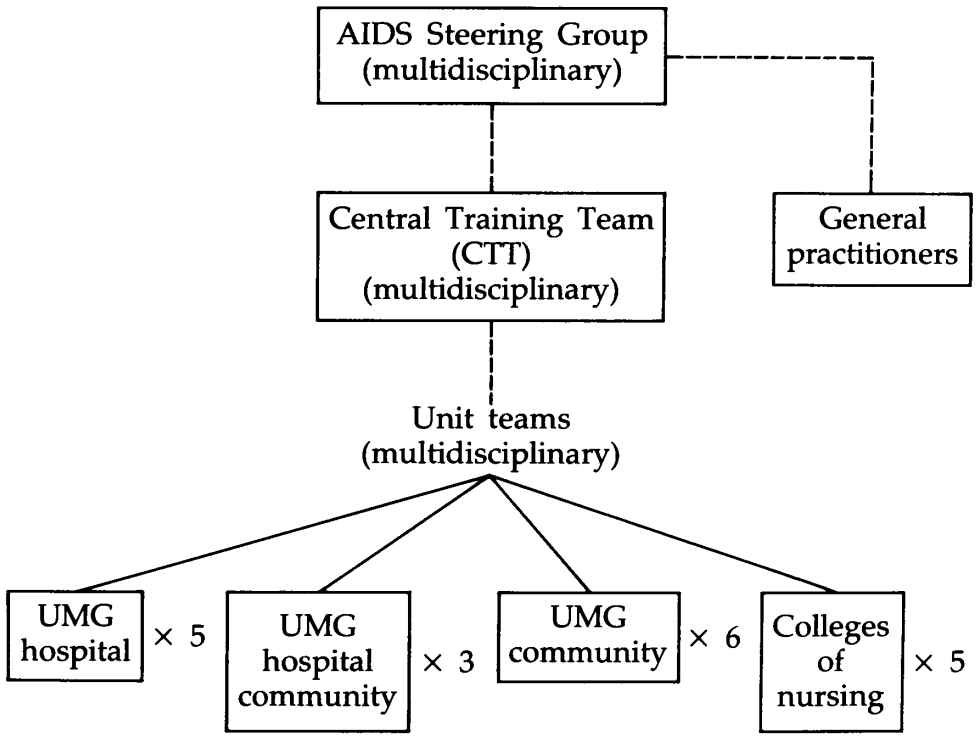
Charge nurse
2 health visitors
2 senior social workers
Domestic supervisor
Dentist
Pharmacist
Assistant director of nursing services
Chief laboratory technician

Colleges of nursing

Northern Ireland College of Midwifery
North Down College of Nursing
Belfast Northern College of Nursing
Belfast Southern College of Nursing
College of Mental Health, Purdysburn
Northern Ireland Hospice
Beaconsfield Marie Curie Home

APPENDIX 5

Organisation of AIDS awareness programme (EHSSB)



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ISBN 1 85551 067 7