

# AIDS Strategy 2000

Report of the National AIDS Strategy Committee

Dublin: Published by the Stationary Office, June 2000  
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Government Publications Sales Office, Sun Alliance House,  
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**DEPARTMENT OF HEALTH  
AND CHILDREN**

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# Introduction

## Foreword by Minister Moffatt

The Report of the National AIDS Strategy Committee (NASC) in 1992 was set against the prediction that Ireland and the rest of the world faced an AIDS epidemic. Indications were that the incidence of HIV would continue to grow. Nations of the developed world have seen a plateauing of incidence of cases and a move to a situation where, for a lot of individuals, AIDS and HIV infection are becoming chronic illnesses.

We are faced with many challenges, however, in relation to HIV/AIDS. There is still no cure for this illness. Highly Active Antiretroviral treatment (HAART) has had a dramatic impact on the overall health and wellbeing of people with HIV, but there is a global pandemic, with millions of people, particularly in the developing world, unable to access any form of treatment. Some people on treatment do not respond to this treatment. Vaccine clinical trials have been ongoing since HIV was first identified, but an effective vaccine has not yet been developed.

In Ireland, as in other parts of the developed world, real progress has been made since 1992. The reports of the four Sub-Committees which have been working to implement the national strategy bear evidence to this and it is encouraging to note that virtually all of the recommendations of those Sub-Committees have been implemented and have been supplemented by further actions.

The overall goal of the Health Strategy, *Shaping a Healthier Future*, is to have a health service which aims to improve people's health and quality of life. In implementing the recommendations of the National AIDS Strategy Committee health services, in partnership with a wide range of voluntary and statutory agencies, have made good progress in achieving this goal.

HIV is a preventable illness. The challenge for the future must be to aim at reducing the number of people who become infected with HIV in the first instance. This can only be done by a concerted effort by everyone. This report sets out recommendations on how we can rise to this challenge and I hope that it will assist those who plan, manage and deliver services in their efforts to prevent people becoming infected with HIV and in providing appropriate care and support to those who need such services.

I want to thank everyone involved in developing and co-ordinating an integrated response to the problem of HIV and AIDS, most especially those who work at voluntary and community levels. I would also like to thank those who made submissions to the Committee and the members of the Committee and Sub-Committees who gave freely of their time in finalising this report. Finally I would like to thank the staff of the Community Health Division of the Department of Health and Children for their vital contribution to the work of the Committee and Sub-Committees.



Dr. Tom Moffatt T.D., Minister of State,  
*Department of Health and Children*

**Introduction**

The First Report of the National AIDS Strategy Committee was published in 1992. The epidemiology of HIV infection and AIDS related illnesses has changed over the years of the pandemic. We have now moved to a situation where, for a lot of individuals, AIDS and HIV infection are becoming chronic illnesses. This is welcome in that it reflects increased survival of those who have been diagnosed with clinical AIDS and a longer incubation period from HIV infection to development of the clinical syndrome. These changes require new surveillance and clinical management techniques. This includes close monitoring and management of treatment, involving laboratory techniques such as viral load testing and resistance testing.

**Contents of this report**

Given the time that has elapsed since 1992 and the changes that have taken place in relation to the epidemiology of HIV/AIDS it was appropriate to conduct a review of the situation and to devise a strategy for future years, taking account of these changes. This Report is the second report of the National AIDS Strategy Committee (NASC). It comprises the reports of the four Sub-Committees of NASC - Surveillance, Education and Prevention, Care and Management and Discrimination. Submissions were invited from the general public through the placing of an advertisement in the main daily newspapers. The agencies that made submissions are listed at Appendix A.

Each of the Sub-Committee reports makes recommendations for future action, which have been endorsed by the National Committee. An important point to emerge from the reports is that HIV/AIDS should now be dealt with in the wider context of sexual health and other sexually transmitted infections.

**Membership of the National AIDS Strategy Committee**

Dr Tom Moffatt, TD	Minister of State at the Department of Health and Children (Chair)
Dr Joe Barry	Specialist in Public Health Medicine, Eastern Regional Health Authority
Mr Gary Broderick	Ana Liffey Drug Project
Dr Karina Butler	Consultant in Infectious Diseases, Our Lady's Children Hospital, Crumlin
Mr Liam Conlon	Assistant Principal, Department of Justice Equality and Law Reform
Mr Paddy Connolly	Director, Cairdre
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Dr John Devlin	Deputy Chief Medical Officer, Department of Health and Children
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Ms Mary Ellen Mc Cann	Ballymun Youth Action Project
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Mr Tom Mooney	Deputy Secretary General, Department of Health and Children
Dr Fiona Mulcahy	Consultant in Genitourinary Medicine, St James's Hospital
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Dr Mary O'Mahony	Public Health Specialist, Southern Health Board

Mr Mick Quinlan	Co-ordinator, Gay Men's Health Project
Ms Linda Reed	Women and HIV Project
Mr Kieran Rose	Gay HIV Strategies
Ms Deirdre Seery	The Alliance Centre for Sexual Health, Cork
Dr Gerard Sheehan	Consultant in Infectious Diseases, Mater Hospital
Ms Mary Jackson	Department of Health and Children
Ms Louise Kenny	Department of Health and Children

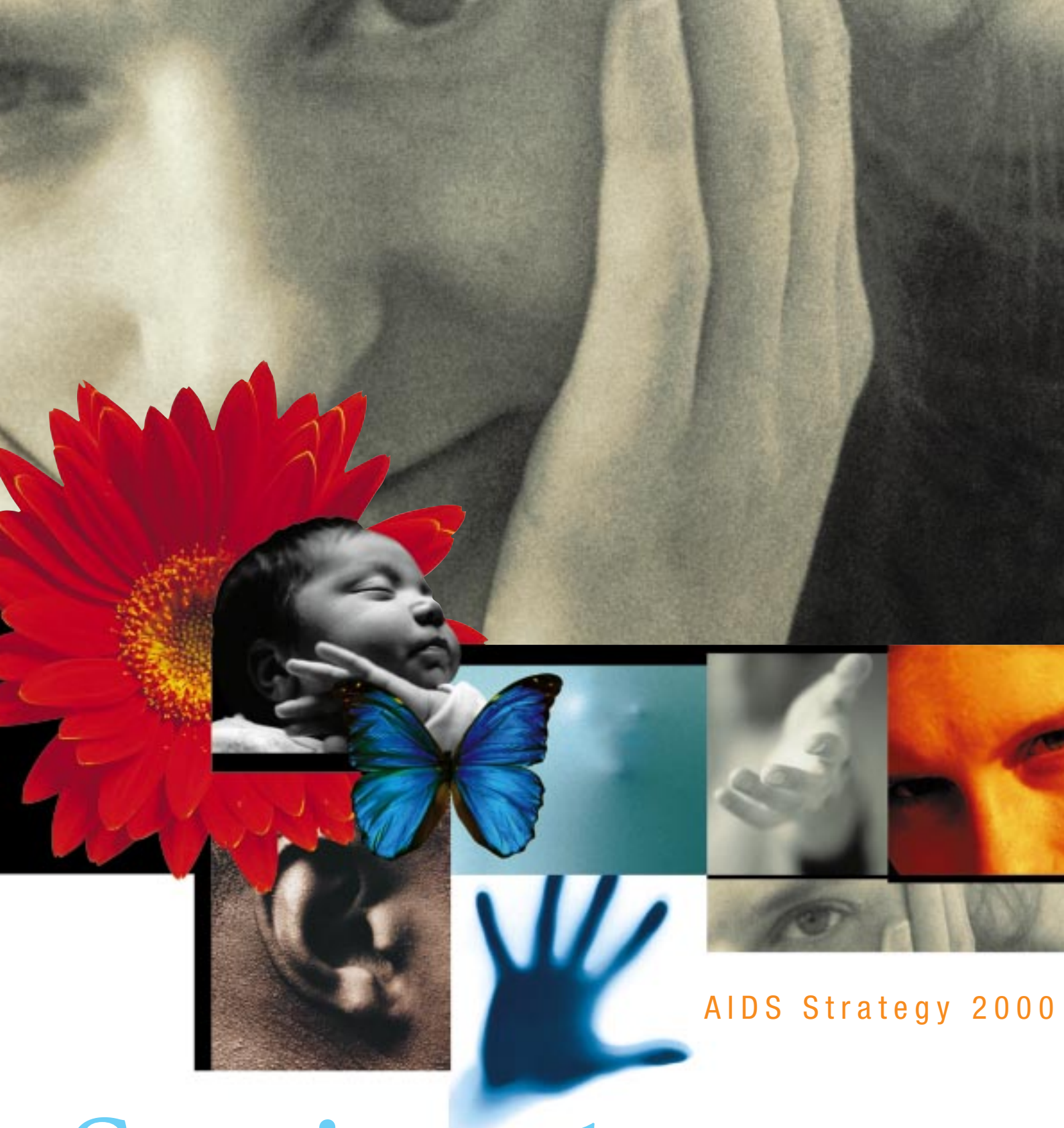
**Context in which the Report has been developed**

ISSUES WHICH HAVE EMERGED SINCE THE PUBLICATION OF THE FIRST REPORT INCLUDE:-

- The need for improved communication mechanisms to impart the message of HIV/AIDS awareness, especially to young people.
- The need for such HIV/AIDS awareness to be delivered in the context of the broader areas of sexual health and sexually transmitted infections.
- The interconnection between drug use, social exclusion and vulnerability to HIV.
- The social exclusion experienced by gay/bisexual men and their vulnerability to HIV.
- The importance of working in partnership with people with HIV and voluntary sector agencies in the development of appropriate responses to HIV/AIDS.
- With the introduction of Highly Active Antiretroviral Treatment (HAART) the need to focus on the promotion of health and wellbeing of people with HIV as opposed to focusing on hospice and terminal care.
- The needs of minorities.
- The needs of children who are HIV positive, as they grow into adolescence.
- The importance of good clinical management of HIV in ensuring maximum effectiveness from drug therapies.

There is a worry that with new effective treatments there may be a risk of complacency in relation to people's exposure to HIV/AIDS. From an Irish perspective it is important to note that although the incidence of AIDS has plateaued in recent years the incidence of HIV continues to rise. This is unacceptable since HIV infection is largely preventable. There must be a concerted effort to promote sexual health and to reduce the incidence of sexually transmitted HIV. Given that good progress has been made in relation to reduction in incidence of HIV among drug users, interventions with drug misusers must continue. This success also shows the value of targeted interventions aimed at specific groups. There must also be a supportive non discriminatory environment where people with HIV/AIDS obtain the treatment and care they require.

As well as taking account of the National Health Strategy, the four Sub-Committees were mindful of other initiatives such as the National Anti-Poverty Strategy, Government policy on social inclusion and the overall aims of the Partnership 2000 and Prosperity and Fairness Programmes.



AIDS Strategy 2000

# Section 1

Report of the

Surveillance Sub-Committee of the National AIDS  
Strategy Committee

# Report of the Surveillance Sub-Committee of the National AIDS Strategy Committee

## Membership of Surveillance Sub-Committee

Dr Joe Barry	Specialist in Public Health Medicine, Eastern Regional Health Authority (Chair)
Dr John Brazil	Virus Reference Laboratory, University College Dublin
Dr Bartley Cryan	Consultant Microbiologist, University College Hospital, Cork
Dr Geraldine Corbett Feeney	Department of Medical Microbiology, University College Hospital, Galway
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Mr Jimmy Duggan	Principal Officer, Department of Health and Children
Dr Derval Igoe	National Disease Surveillance Centre
Mr Hugh Magee	Statistician, Department of Health and Children
Dr Mary O'Mahony	Public Health Specialist, Southern Health Board
Dr Patrick O'Sullivan	Regional AIDS Co-ordinator, Eastern Regional Health Authority
Dr Mary Scully	Public Health Specialist, Northern Area Health Board
Ms Mary Jackson	Department of Health and Children
Ms Louise Kenny	Department of Health and Children

## Introduction

Quality national and international surveillance is essential in order to assess the progress of HIV infection and AIDS. The objectives of surveillance have evolved since the commencement of the HIV epidemic, with a growing emphasis on its use as a tool to define, target and evaluate appropriate interventions for populations most at risk. Given the low incidence of HIV in this country a decline in prevalence or incidence in the short term may not necessarily reflect changes in behaviour or intervention effects, so policy makers and service planners must cautiously interpret short term changes in incidence and prevalence rates.

There are some problems with the present reporting systems, e.g people not coming forward for testing in the first place, others having duplicate tests, which may be anonymous, or delays in reporting. Reported figures must not be seen, therefore, as exact, but as a very good estimate of the incidence and prevalence of HIV and AIDS. The improvement of surveillance systems and the surveillance of HIV must continue as a priority in identifying high risk populations and in assessing the effectiveness of interventions targeted at high risk groups.

## Global HIV Surveillance

The Joint United Nations Programme on HIV/AIDS estimated that in 1998 16,000 individuals were infected each day with HIV and that by year's end over 33 million would be living with HIV/AIDS, nine-tenths of them being unaware of their infection. More than 12 million adults and children have lost their lives to date to the disease. <sup>1</sup>

## HIV/AIDS in Europe - Recent Trends

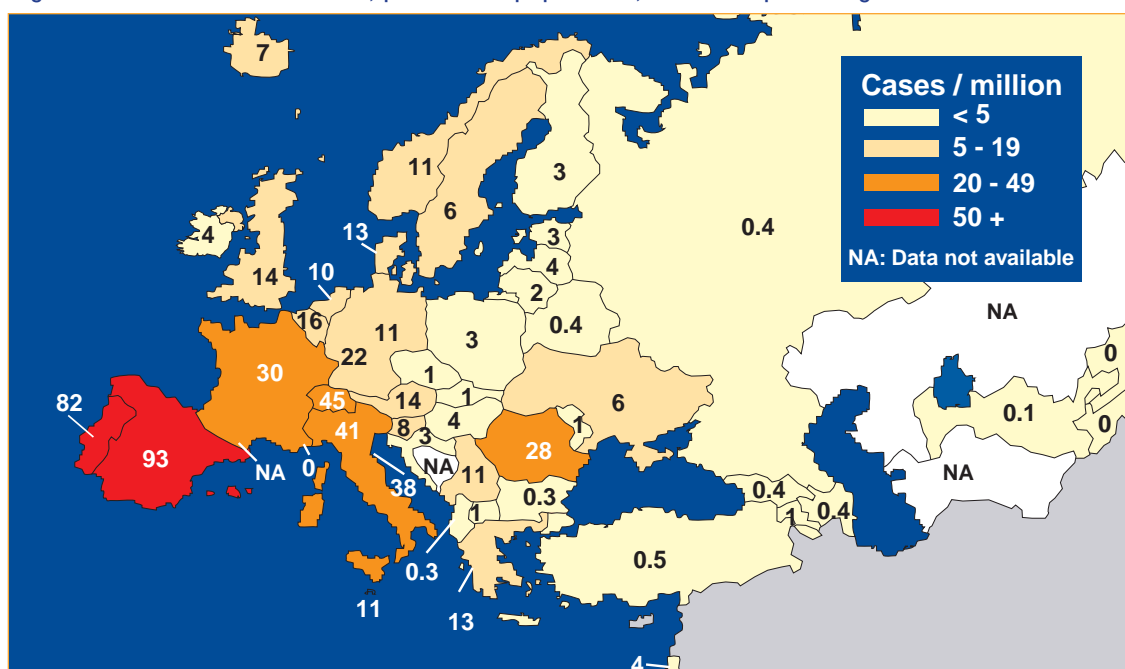
European AIDS surveillance was introduced in 1984. It involves the 48 countries of the WHO European Region. Prior to 1996 western Europe accounted for more than 90% of AIDS cases in Europe.<sup>2</sup> However, with the introduction of new Highly Active Antiretroviral Treatment (HAART) and following major societal changes in Eastern Europe, trends are rapidly changing. In western Europe AIDS incidence declined, for the first time, in 1996 (11%) and is estimated to further decline in the future. Despite this decline, however, a major problem is that many HIV infected persons do not know that they are infected - a prerequisite for being treated. Among AIDS cases diagnosed in 1996 up to 41% of

heterosexual men, 20% of heterosexual women and homosexual/bisexual men and 9% of intravenous drug users were unaware of their infection, prior to AIDS diagnosis. In addition, many HIV infected persons do not present for testing and do not therefore know that they are infected.

#### AIDS CASES

A total of 201,593 AIDS cases were reported in the European Union by 31 December, 1998. Sixty percent (121,840) of these cases are known to have died. The declining trend in AIDS incidence has continued since 1996, with a reduction in incidence between 1997 (13,986 cases) and 1998 (11,071 cases) of 21%. The incidence of AIDS in the World Health Organisation European Region is shown in Figure 1. The highest incidence is in Spain (93.3 cases per million population) with the lowest in Finland (3.2 cases per million population) and Ireland (3.6 cases per million population).

Figure 1: 1998 AIDS Incidence, per million population, WHO European Region



Data reported to 31.12.98, adjusted for reporting delays

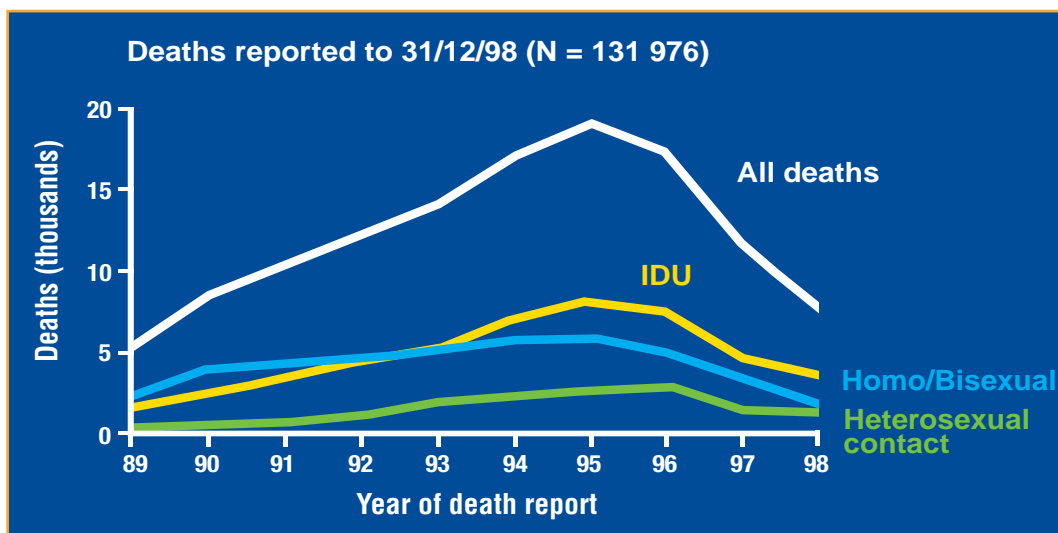
CESES, Saint-Maurice, France

#### AIDS DEATHS

In parallel with trends in AIDS cases, AIDS deaths in the WHO European Region have been declining since 1996, with a 33% decline in deaths between 1997 (11,523 deaths) and 1998 (7,743 deaths).<sup>3</sup> Figure 2 shows the reported deaths among AIDS cases in the 3 main transmission groups in the WHO Region since 1989. At a European level it is recognized that AIDS surveillance and reporting are no longer sufficient to monitor the epidemic, so efforts are being concentrated on reporting of new HIV cases.



Figure 2: Reported deaths among AIDS cases by year of death report for all cases and the 3 main transmission groups, WHO European Region



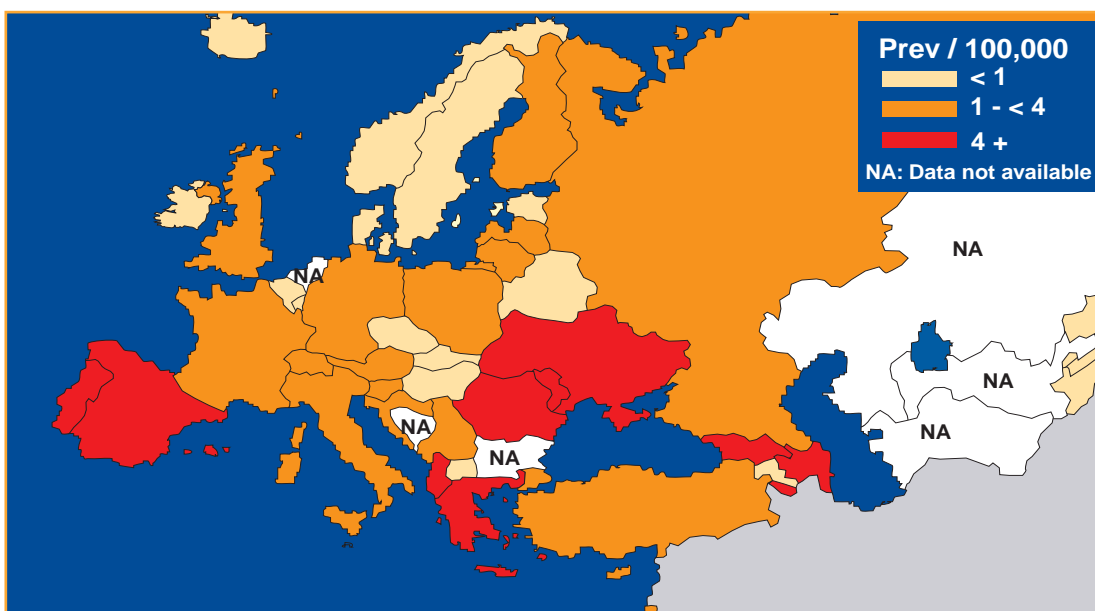
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#### HIV PREVALENCE

The number of persons living with HIV or AIDS at the end of 1998 is estimated at 500,000 in western Europe and 270,000 in eastern Europe and the central Asian Republics of the former Soviet Union. It is also estimated that 30,000 persons become infected with HIV every year in western Europe.

The European HIV prevalence database contains aggregated data on HIV seroprevalence in various populations e.g. pregnant women and blood donors. Both these groups represent a population at low risk for HIV infection and provide some indication of the spread of HIV in the general population. Geographic and time trends in HIV prevalence in blood donations are consistent with the dynamics of the spread of HIV in Europe. Prevalence rates for blood donors in the WHO European region are shown below in Figure 3.

Figure 3: HIV prevalence in blood donations (per 100 000), 1997, WHO European Region



Portugal: Coimbra, Lisbon and Oporto only

CESES, Saint-Maurice, France

## HIV/AIDS in Ireland THE AIDS REPORTING SYSTEM

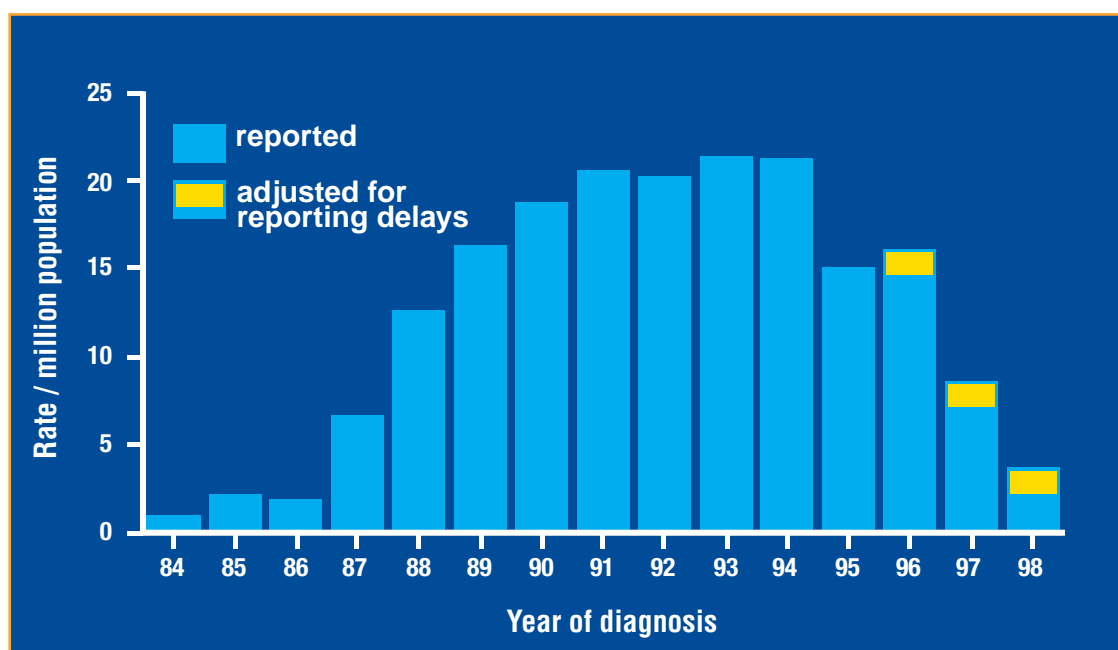
The AIDS reporting system is based on clinical events (i.e. the onset of illnesses which are associated with the Acquired Immune Deficiency Syndrome) which are reported by the Regional AIDS Co-ordinators to the National AIDS Co-ordinator in the Department of Health and Children.

Since reporting commenced in 1982 to the end of 1999 there has been a cumulative total of 691 reported cases of AIDS and 349 reported deaths in Ireland. Figures reported for each year may not reflect actual incidence rates as there may be reporting delays, up to a number of months in some cases, in reported cases and deaths. Cumulative statistics for cases of AIDS and deaths from AIDS (by year of reporting), the most recent statistics for new cases up to the end of October, 1999 and cumulative AIDS cases and deaths by age and gender are set out in Tables 1, 2, 3 and 4 in the Appendix.

### RECOMMENDED CHANGE IN THE IRISH SYSTEM FOR REPORTING AIDS CASES AND DEATHS

The reporting system which has been adopted by the European Centre for the Epidemiological Monitoring of AIDS reports incidence by year of diagnosis rather than by year of reporting. In this system Irish figures are adjusted to take account of reporting delays. The Sub-Committee recommends that the Irish reporting system should, in future, report cases by year of diagnosis rather than by year of report to be consistent with the European system. In addition, the risk categories which have been used in Irish reports for HIV and AIDS should be changed to be consistent with the categories used by the European Monitoring Centre. The categorisations used by the Centre are shown in Table 5 in the Appendix. Irish figures, adjusted for reporting delays, based on the European system are set out in Figure 4.

Figure 4: AIDS incidence rates by year of diagnosis, Ireland, 1984 – 1998

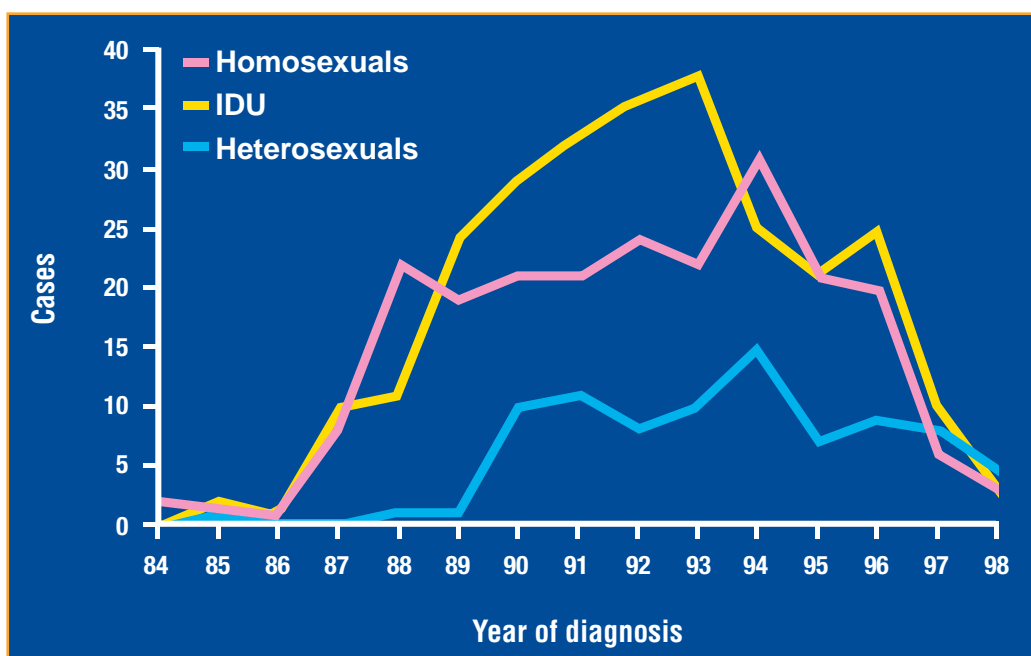


CESES, Saint-Maurice, France

The shaded area represents cases reported to the system in the year or years after first diagnosis.

Irish figures reflect western European trends. AIDS incidence plateaued in the early 90's. Similarly, when the number of AIDS cases by transmission group (for homosexuals, intravenous drug users and heterosexuals) are examined they clearly show a peak figure in the early 90s. (Figure 5).

Figure 5: Number of AIDS cases by transmission group and year of diagnosis, Ireland, 1984 – 1998



#### HIV SURVEILLANCE

A number of laboratories throughout the country carry out HIV testing. Samples which test positive for HIV from nine health boards are sent to the Virus Reference Laboratory, University College Dublin, where a confirmatory test is carried out. Confirmatory tests on samples from one health board are carried out in the Royal Victoria Hospital, Belfast and the results of these tests are also reported to the Virus Reference Laboratory, for inclusion in Irish figures. The HIV surveillance system is based on reports of confirmatory HIV testing and anonymised results provided to the National AIDS Co-ordinator, based in the Department of Health and Children. Reported rates of HIV infection are published twice a year by the Department of Health and Children.

#### HIV ANTIBODY TESTS

In the mid 1990s approximately 200,000 HIV tests were carried out each year in Ireland. It is estimated that at least the same number of tests are undertaken at present. Examining HIV incidence since reporting began gives important information on infection trends. The cumulative statistics for reported Irish cases of HIV since 1985 to the end of 1999 are set out in Table 6 and cumulative cases broken down by risk category to the end of December, 1999 are in Table 7 in the Appendix. The cumulative figures show that 2,195 cases have tested positive. Intravenous drug users represent 41.6% of the total, homosexuals 22.7%, heterosexuals/risk unspecified 18.8% and the balance (16.9%) is made up of haemophiliacs, children and others.

### ANONYMOUS UNLINKED ANTENATAL HIV TESTING

Results of anonymous unlinked antenatal HIV testing are indicative generally of the rate of heterosexual spread of HIV in a population. An anonymous unlinked antenatal HIV testing programme was established in October 1992. Screening was carried out on blood specimens routinely collected for rubella serology from pregnant women who booked into the antenatal clinics. Three laboratories, located in Dublin, Cork and Galway, were already responsible for the rubella testing for these clinics, and it was, therefore, agreed that these would be the laboratories involved in the unlinked anonymous HIV screening.

#### RESULTS:

The data<sup>4</sup> were analysed from the last quarter of 1992 until the last quarter of 1998 inclusively, providing results for 25 consecutive quarters. A total of 354,223 tests had been carried out up to the end of December 1998. 90 of these samples had been confirmed as HIV positive, giving a rate of 25.4/100,000 tests. 55 (61.1%) of these 90 positive results were from women in the Eastern Health Board region (now the Eastern Regional Health Authority) where 124,984 tests (35.3%) were performed.

Table 8 presents the annual figures for blood samples examined, together with positive test results and the percentage of tests which were confirmed positive. For the purpose of presentation data for the last quarter of 1992 have been included in the 1993 figures.

Table 8: Results of Anonymous Unlinked Antenatal HIV Screening in Ireland by Year.

YEAR	Total Tests Undertaken	Total Negative Tests	Total Tests Confirmed Positive	Percentage Confirmed Positive
1993*	53,480	53,467	13	0.024
1994	51,118	51,112	6	0.012
1995	56,081	56,075	6	0.011
1996	62,008	61,996	12	0.019
1997	64,412	64,385	27	0.042
1998	67,124	67,098	26	0.039
<b>Total</b>	<b>354,223</b>	<b>354,133</b>	<b>90</b>	<b>0.025</b>

\* Includes 4th Quarter of 1992.

A significantly higher sero-prevalence was seen amongst women presenting for antenatal care in the Eastern Health Board's antenatal clinics than in women attending the other Health Boards' clinics. In 1998, there were 18 positive tests in the EHB region out of the 24,949 tests undertaken, giving a rate of 72.14 per 100,000 tests, compared to the 8 positive results in all the other health boards taken together out of the 47,175 tests undertaken, a rate of 16.95 per 100,000 tests. Comparisons between overall totals in the East and in other health boards are provided in Table 9.

Table 9: Results of Anonymous Unlinked Antenatal HIV Screening in Ireland by Health Board Region of Residence up to December 1998

Health Board of Residence	Total Tests Undertaken	Total Negative Tests	Total Tests Confirmed Positive	Rate of Positive Results per 100,00 Tests
Eastern Health Board	124,984	124,929	55	44.00
All Other Health Boards	229,239	229,204	35	15.26
<b>Total</b>	<b>354,223</b>	<b>354,133</b>	<b>90</b>	<b>25.40</b>

#### ANALYSIS OF HIV DATA HELD BY VIRUS REFERENCE LABORATORY

In order to examine overall trends in HIV incidence in recent years the Virus Reference Laboratory undertook an analysis of the data held by it over the period 1/7/92 to 31/12/98.<sup>5</sup> The data provide valuable additional information on HIV transmission in Ireland, showing trends by gender, age and geographical location.

*The main findings in the Virus Reference Laboratory's survey were that in the period under review:*

69% of new cases of HIV were male, with 26% female and 5% unspecified. Since 1993 the proportion of female cases has increased from 24% to 31%.

32% of cases were transmitted by injecting drug use, 28% by homosexual activity, 21% by heterosexual activity and 19% by other routes.

The number of HIV cases associated with injecting drug use has fallen continuously since 1993, representing 21.66% of all new cases in 1998.

Two-thirds of all cases associated with drug use are male.

The incidence of HIV associated with homosexual risk activity has remained relatively stable, with an average of 45 cases per year.

There has been a significant increase in both the number and proportion of HIV cases associated with heterosexual risk activity, especially in 1998 (13.4% of all cases in 1993, but 29.4% of all cases in 1998).

50.7% of heterosexual cases are female, with 47.3% male.

The median overall age of adult females in the study was 28 years, compared with a median age of 32 years in adult males.

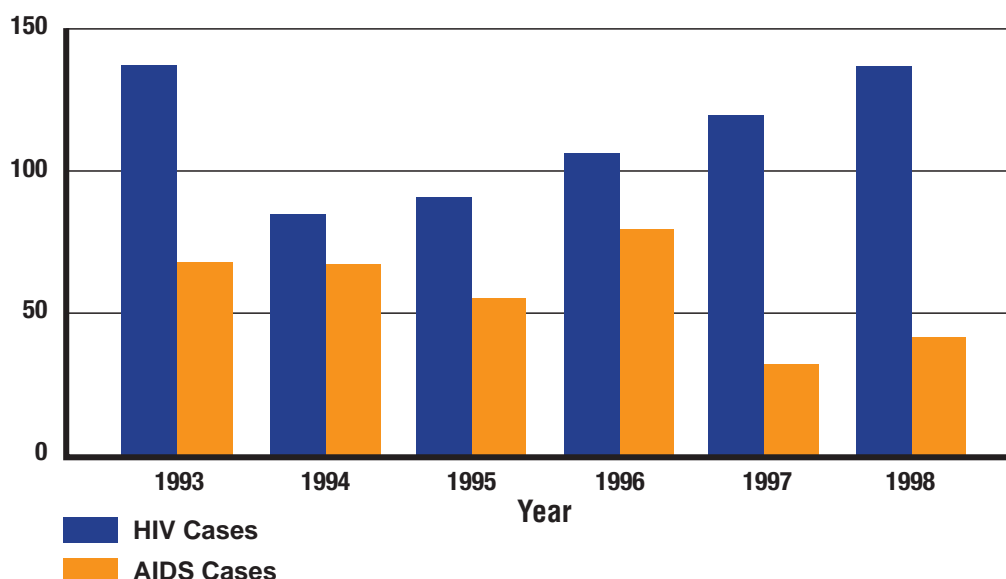
78% of cases originated from within the Eastern Health Board area.

The most common risk associated with infection in the Eastern Health Board area is injecting drug use (36.22%).

The most common risk associated with infection in other health boards is male homosexual activity (48.67%).

While Irish statistics indicate that there is a relatively low incidence of known HIV positivity, with approximately 150 new cases per year in a population of 3.6 million (.04 per 1000), there is still a worry that overall transmission rates have not greatly declined. Only those who have come forward for testing are included in reported figures, so this rate may be an underestimate of the real incidence of HIV. The chart below (Figure 6) shows the comparison of numbers of cases of HIV and AIDS since 1993. It clearly shows that HIV incidence continues to increase but it also shows the decline in the number of cases of AIDS.

Figure 6: Comparison of numbers of HIV and AIDS cases from 1993 – 1998



#### The Surveillance Sub-Committee of the National AIDS Strategy Committee.

In 1992 the National AIDS Strategy Committee, published its report which included the recommendations of the HIV/AIDS Epidemiological Surveillance Sub-Committee. The Report provided an assessment of systems in place and it set out the structures and improvements required to comprehensively address the potential HIV epidemic which was predicted at that time. The terms of reference of the Surveillance Sub-Committee were:

*To consider the development of a sero-surveillance programme to determine as accurately as possible the spread of HIV by category of person by region;*

and

*To consider the provision of information by the Virus Reference Laboratory, U.C.D. with a view to identifying the regional spread of the disease.*

The report was used as the basis for the development of an integrated and co-ordinated strategy to address the issue of epidemiological surveillance of HIV and AIDS.

The Sub-Committee has met on a regular basis over the years and details of progress to date in implementing the recommendations in the 1992 Report (in italics) are set out below.

### Progress made on implementing the recommendations in the 1992 Report

#### Recommendation 3. (i)

*The sub-committee recommends that AIDS cases should continue to be reported centrally as at present, which has been the practice since 1982. However, the reporting form should be amended to indicate the county, or in the case of Dublin the postal code, of the case and that this should be done without prejudice to the confidentiality of the case. Confidentiality must remain the most important aspect of case reporting.*

#### **This has been done.**

#### Recommendation 3. (ii)

*The sub-committee recommends that HIV positive test requests to the National Virus Reference Laboratory indicate the health board area, or in the case of Dublin the postal code, of the case and that the existing request form be amended appropriately. Existing confidentiality of these tests will be maintained.*

#### **This has been done.**

#### Recommendation 3 (iii)

*We recommend therefore that information on the regional spread of infection, both AIDS notifications and HIV positive tests be made available to health boards on a monthly basis.*

The Virus Reference Laboratory, in University College Dublin (VRL) does not provide monthly figures to health boards on new infections. It provides figures to the Department of Health and Children, but these figures are in turn, amalgamated to be reported, for confidentiality reasons, as Eastern Regional Health Authority (ERHA) and other health boards because there are so few reported cases of HIV outside the ERHA area. The Sub-Committee recommends that the Regional AIDS Co-ordinators should obtain anonymous details of figures from the VRL on a regular, confidential basis.

Section 4 of the NASC Report noted that the Sub-Committee was examining the feasibility of establishing surveillance programmes which would monitor the spread of HIV infection in the heterosexual population in various locations.

#### 4 (a) *Anonymous unlinked testing of blood specimens of pregnant women (already being tested for rubella).*

The programme has been running since October 1992. Since then a total of 90 cases of HIV infection were detected in the 354,223 women tested, giving a rate of 25.40 per 100,000 tests.

Unlinked testing of antenatal women has provided useful statistics for comparison purposes between countries in a population that is largely accessible during attendances at antenatal clinics when blood is routinely taken from all women for rubella serology. It is an indicator generally of the rate of heterosexual spread in a population, though women who may have been infected by other routes such as injecting drug use will also be identified as HIV positive. However, this antenatal population cannot be taken to be representative of the whole population.

The increased number of positive antenatal women detected by unlinked testing in 1997 and 1998 supports the impression given by the results of linked testing that heterosexual spread of HIV is becoming increasingly important in Ireland. A logical difficulty with this programme is that because samples are anonymous it is impossible to remove duplicates from the system. It is known, for example, that there were 53,000 births in 1997, while over 58,000 antenatal blood tests were carried out.

- 4 (b) *Anonymous unlinked testing of newborn infants  
(currently being tested for PKU using the Guthrie card).*

Because unlinked antenatal testing got underway it was not considered necessary to undertake this testing.

- (c) *Anonymous unlinked testing of blood from out-patient's departments of General Hospitals.*  
and  
(d) *Anonymous unlinked testing of blood of hospital admissions.*

The Sub-Committee examined the feasibility of commencing an anonymous programme in each of these areas. It decided, however, that because other estimates of the incidence of HIV were being obtained in various population groups e.g. through testing of all blood donors in the Blood Transfusion Service Board (now the Irish Blood Transfusion Service), the benefits of conducting additional studies in hospitals were minimal relative to the resources necessary to implement such studies.

The sub-committee examined *the benefit of unlinked testing of blood from S.T.D clinic attendees*. Several attempts to get such a programme underway were undertaken, but due to ever increasing demands on GUM/STD services and from a cost benefit point of view it was decided not to commence a programme.

Another area which was identified for surveillance of HIV infection in "high risk" groups was *drug treatment clinics*. A survey<sup>6</sup> was carried out among a random sample of 20% of attendees at Eastern Health Board methadone maintenance clinics in 1998. The HIV seroprevalence rate in this cohort was 8.3% based on confirmed laboratory reports.

## HIV Surveillance in Prisons

In order to assess the prevalence of hepatitis B, hepatitis C and HIV in the Irish prison population and to examine the association between the prevalence of these infections and factors such as age, prison history and risk behaviour, the Department of Community Health



and General Practice in Trinity College carried out a cross sectional survey<sup>7</sup> among the prison population in nine prisons between September and November, 1998. Five of the prisons had been classified as high risk and four as medium risk for infection. A total of 1,205 prisoners took part in the survey, representing a response rate of 88%, which consisted of completing a four page questionnaire and collecting a sample of oral fluid for testing for antibodies.

The overall prevalence of HIV was 2% in both male and female prisoners. The HIV infection rate was considerably higher in high risk prisons and especially among drug users, where the prevalence rate was 4%.

Six hundred and thirty respondents (52%) reported opiate use and 514 (43%) reported ever injecting drugs. 60% of women prisoners reported injecting drug use. Twenty one per cent of injectors first started injecting in prisons. Just over one third (37%) had shared drug injecting equipment (needles, syringes, spoons and filters) before committal to prison. Of those who injected in prison, 58% had shared drug injecting equipment (all types). Almost half (45%) of injecting drug users who had been in prison for three months or more said they had injected drugs in the preceding month, and, of these, one third had injected more than 20 times. Individuals who reported ever injecting drugs were 3 times as likely to be HIV positive as non injectors.

One in 40 (28/1116) men reported ever having anal sex with another man and just under 2%, (20/1087) reported having anal sex with men in prison. Men who had anal sex with other men were 8 times more likely to be HIV positive.

Anal sex was the strongest predictor of HIV, although the numbers involved were very small. A history of treatment for sexually transmitted infections was linked to increased risk of both HIV and hepatitis B, with individuals who reported ever having been treated for a sexually transmitted infection being 3 times as likely to be HIV positive. Because the numbers with HIV were small, however, inferences from them are limited.

## HIV infection and babies

The HIV/AIDS statistics, to the end December, 1999 show that to those dates there have been 172 reported cases of HIV in children. 23 children have AIDS and 8 children have died.

Of all babies born with HIV antibodies in their bloodstream a number of these will seroconvert and will test HIV negative. Cumulative HIV figures do not take this into account. So the real number of children with HIV is much lower than 172. At the end of October, 1999 there were 33 HIV infected children with 37 others who were still indeterminate (i.e. they may remain HIV positive or may seroconvert). 7 pregnant women, who were HIV positive, were also in treatment at that date. The Surveillance Sub-Committee will examine how this can be taken into account in future reporting of HIV statistics.

## New Developments

In addition to implementation of the 1992 recommendations the following developments have taken place.

### Routine Antenatal Linked Testing for HIV

The National AIDS Strategy Committee recommended in March, 1998 that routine antenatal linked HIV testing should be introduced nationally at the earliest possible date, giving due attention to providing appropriate information and support to women to allow them to opt for testing.

The establishment of nationwide routine linked antenatal HIV testing was seen as important since it has been clearly shown that perinatal transmission can be reduced or prevented by antenatal treatment of HIV positive women with anti-retroviral drugs and by careful management of the delivery. Mother to child transmission can be further reduced by advising mothers who are known to be HIV positive against breastfeeding, because of the risk of transmission of the virus in their breastmilk.

Drug therapies are available to women who know they are HIV positive, but, prior to the introduction of routine testing for HIV some women may have been unaware that they were HIV positive. It was estimated that in 1997/98 health services had identified less than 50% of HIV positive mothers at an early stage in pregnancy and so the opportunity of early treatment and better health outcomes for both mother and baby may have been missed.

The Rotunda Hospital in Dublin was already carrying out routine HIV testing for some years and its representatives played a key role in the development of practice models for other hospitals. Training was provided for midwives and other relevant staff initially in the Dublin maternity hospitals and Regional AIDS Co-ordinators in other health boards undertook to implement the programme and to organize training for medical personnel throughout the country. The programme has the full support of medical professionals, the National Womens' Council and voluntary agencies with an interest in HIV/AIDS. In areas outside Dublin a number of General Practitioners are involved in antenatal care and it will take time to involve all of them in the programme.

The programme was officially launched in April, 1999. When there is evidence of a high uptake of this antenatal HIV test the anonymous screening system will be discontinued. Until then, however, it will continue in order to give a reasonable estimate of prevalence of HIV in this sample group of the population.

A Committee was established in January, 2000 to draw up the criteria for monitoring and evaluation of the programme and a major part of its work will be monitor uptake rates at various centres and to advise the Surveillance Sub-Committee on how uptake rates can be improved, as an uptake rate of 90% or more is required in order to ensure that the majority of pregnant women who are infected with HIV are detected and offered treatment.

### Workshop on "Should HIV be made a Notifiable Disease"?

This question was raised by public health specialists who proposed that making HIV a notifiable disease would enhance epidemiological data available to service planners and those treating people with HIV/AIDS, which would, in turn, lead to the development of more targeted and effective prevention strategies and better clinical management of people with HIV/AIDS. A workshop<sup>8</sup> was held on 31 March, 1998 and attended by people representing NASC, its sub-committees, voluntary agencies working in the areas of HIV prevention and treatment and social workers and counsellors working in this area.

The group discussed the following:-

1. The benefits of making HIV a notifiable disease.
2. The drawbacks of making HIV a notifiable disease.
3. Improving the present system and who should do this.

The Report of the workshop was examined by the National AIDS Strategy Committee which agreed that making HIV a notifiable disease might lead to people being more reluctant to being tested, so other strategies such as the introduction of HIV Case Based Reporting should be investigated.

### HIV Case Based Reporting

For many years the epidemiological monitoring of HIV infection in Europe has been based on AIDS reporting. In recent years however, there has been a decline in incidence of AIDS in western Europe. This is due, in part, to the new antiretroviral treatment which has delayed the onset of AIDS in treated individuals. The shift in the pattern of disease has implications for surveillance strategies. In Europe at least 33 countries have developed HIV Individual Case Based Reporting (ICR) systems.<sup>9</sup> Some of these reporting systems are voluntary, but most are mandatory. In many countries ICR of HIV infection is linked to AIDS reporting. The European Centre for the Epidemiological Monitoring of AIDS is working towards establishing a standardised HIV ICR system at a European level. This will impact on the nature of Ireland's HIV and AIDS reporting systems over the coming years. At present the HIV surveillance system and the AIDS reporting system operate independently of each other. AIDS reporting is performed by clinicians whereas HIV reporting is laboratory based. The implementation of HIV case reporting will raise a number of issues including;

Confidentiality - there must be assurances that patient confidentiality is preserved. The AIDS reporting system has worked very effectively and, in this respect, it is expected that any new HIV reporting system would operate on the same basis.

Duplicate reporting - the elimination of duplicate samples is essential to obtaining a true picture of actual HIV infection in the population.

Linkage of HIV and AIDS reports - From a clinical perspective it is vital that both HIV and AIDS reporting systems are linked in order to provide additional information on the progression of the diseases, prognosis, management and appropriate prevention strategies.

Incomplete information - At the time of the initial laboratory report many important variables may be missing because of limited contact between the persons tested and the laboratory information system. For follow-up on positive test results there must therefore be good co-ordination between laboratories and clinical information systems to address this issue.

A sub-group of the Sub-Committee is working on the development of this system, examining systems in place in other countries and linking with the European Monitoring Centre on models of best practice. The system will be established in the National Disease Surveillance Centre.

## Conclusions and recommendations

Significant progress has been made in identifying incidence rates and transmission trends in various at risk groups. Recent HIV statistics indicate that interventions with intravenous drug misusers (methadone treatment programmes and needle exchange) are effective in reducing transmission rates in this group. However, short term trends may be misleading, so health service providers must continue providing appropriate treatment and aftercare to this group to minimise transmission.

Relative to other western European countries Ireland has a low prevalence rate of HIV/AIDS, but efforts must continue to reduce incidence in all risk groups.

Transmission among homosexuals has continued to rise at a steady rate, so further work is required among this group. Figures may be influenced by the fact that there is a change in the environment and people can be more open about their sexuality and therefore come forward for testing.

Heterosexual spread is the area where there has been the greatest increase in recent years. Education and prevention programmes need to address this issue, in the context of an overall programme of sexual health.

There is scientific evidence to show that a person with an untreated sexually transmitted infection is up to 6 - 10 times more likely to pass on or acquire HIV during sexual intercourse. According to current hypotheses the risk of becoming infected with HIV from a single exposure is increased 10 - 300 fold in the presence of a genital ulcer.

## The Sub-Committee therefore recommends that:

- 1.** Efforts should be made to normalise HIV within the context of other infectious diseases, especially sexually transmitted infections.
- 2.** At all times confidentiality in relation to individual cases must be maintained. This means that incidence data cannot be broken down by individual health boards, as the numbers are so small their publication may lead to identification of individuals. Giving information by individual health board could act as a deterrent to individuals coming forward for testing.
- 3.** Anonymised details of HIV incidence should be provided by the Virus Reference Laboratory to the Regional AIDS Co-ordinators on a regular basis, in order that they can plan services to meet the needs of clients in their respective health boards.
- 4.** Unlinked anonymous antenatal surveillance should continue until such time as the uptake of routine antenatal testing reaches 90% or more of the target population.
- 5.** Criteria should be set for monitoring and evaluation of the routine antenatal testing programme and a system of monitoring and evaluation should be established as soon as possible.
- 6.** Data from various at risk populations such as attendees at STI clinics and drug treatment clinics should continue to be captured.
- 7.** There should be further surveillance of STIs and an investigation of the links between various risk behaviour, HIV/AIDS and other sexually transmitted infections.
- 8.** HIV case based reporting should be introduced.
- 9.** The quality of HIV/AIDS reporting should continue to be improved. This can be facilitated by making changes to the risk categories under which reporting is made, bearing in mind the categories used at European and international levels, so that international comparisons can be made.
- 10.** Reporting of HIV and AIDS cases should be by year of diagnosis rather than year of report.
- 11.** HIV/AIDS reporting should be incorporated into the range of activities being undertaken by the National Disease Surveillance Centre.
- 12.** The structure of Regional AIDS Co-ordinators has worked well in bringing a co-ordinated approach to all aspects of AIDS management in health boards and should be continued.

13. The relationship between the various laboratories, the health boards, hospitals and the Department of Health and Children needs to be clarified. This will become more important as surveillance and management of hepatitis B and hepatitis C in drug users gains more prominence. Testing protocols and funding for same have to be agreed between the laboratories and the relevant service providers.
14. A process of converting from serum based testing to salivary based testing should be explored.

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Table 1: Cases of AIDS to 31st December 1999

CATEGORY	1982	1983	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	Total
Homo/Bisexual	2	0	1	1	1	6	21	17	22	23	15	13	27	16	34	12	13	13	237
IV Drug Users	0	0	0	1	1	9	10	21	27	31	27	42	21	23	33	9	11	14	280
Homo-Bisexual/ IV Drug Users	0	1	1	1	0	1	1	2	0	0	0	1	0	0	1	0	0	1	10
Haemophiliacs	0	0	1	0	3	3	3	6	1	3	1	1	6	3	0	0	2	0	33
Heterosexuals	0	0	0	0	0	1	1	2	8	11	7	11	7	10	11	7	5	11	92
Babies born to IV Drug Users	0	0	0	1	1	0	2	1	2	1	0	0	1	2	0	1	1	1	14
Other Children	0	0	0	0	0	0	0	0	0	1	0	0	5	0	0	0	3	0	9
Undetermined	0	0	0	1	0	0	0	2	1	1	0	0	0	1	0	2	4	1	12
Transfusion Receipient	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	2	0	3
<b>TOTAL</b>	<b>2</b>	<b>1</b>	<b>3</b>	<b>5</b>	<b>6</b>	<b>20</b>	<b>38</b>	<b>51</b>	<b>61</b>	<b>71</b>	<b>50</b>	<b>68</b>	<b>67</b>	<b>55</b>	<b>79</b>	<b>32</b>	<b>41</b>	<b>41</b>	<b>691</b>

Table 2: Deaths from AIDS to 31st December 1999

CATEGORY	1982	1983	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	Total
Homo/Bisexual	2	0	1	1	1	3	4	7	7	7	12	14	11	11	16	3	9	5	114
IV Drug Users	0	1	0	1	0	3	2	1	11	9	21	21	27	26	17	1	7	7	155
Homo-Bisexual/ IV Drug Users	0	0	1	1	0	2	0	1	1	0	0	0	0	0	0	0	0	0	6
Haemophiliacs	0	0	1	0	3	1	0	1	3	2	1	6	3	3	0	0	1	0	25
Heterosexuals	0	0	0	0	0	0	1	2	2	2	8	3	3	5	1	2	3	5	37
Babies born to IV Drug Users	0	0	0	1	0	0	2	1	1	1	0	0	0	1	0	0	1	0	8
Other Children	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Undetermined	0	0	0	1	0	0	0	2	0	0	0	0	0	0	0	1	0	0	4
<b>TOTAL</b>	<b>2</b>	<b>1</b>	<b>3</b>	<b>5</b>	<b>4</b>	<b>9</b>	<b>9</b>	<b>15</b>	<b>25</b>	<b>21</b>	<b>42</b>	<b>44</b>	<b>44</b>	<b>46</b>	<b>34</b>	<b>7</b>	<b>21</b>	<b>17</b>	<b>349</b>

Table 3: Age Breakdown of AIDS Cases and Deaths by Gender to 31st December 1999

AGE GROUP	AIDS Cases		AIDS Deaths	
	Male	Female	Male	Female
<1 year	2	2	1	1
1-4 years	4	8	2	1
5-9 years	3	4	1	2
10-12 years	1	1	1	0
13-14 years	2	0	2	0
15-19 years	9	0	8	0
20-24 years	30	11	16	3
25-29 years	131	42	72	25
30-34 years	144	42	76	20
35-39 years	107	14	54	7
40-49 years	93	4	41	3
50-59 years	26	5	9	2
60+ years	4	0	0	0
Unknown age	2	0	2	0
<b>Total</b>	<b>558</b>	<b>133</b>	<b>285</b>	<b>64</b>

Table 4: Revised List of AIDS Cases and Deaths up to 31st December 1999

<b>CASES – 691</b>	<b>Male</b>	<b>Female</b>	<b>Total</b>
Homosexuals/Bisexuals	237		237
IV Drug Users	211	69	280
Homo/Bisexual/IVDU	10		10
Haemophiliacs	33		33
Heterosexuals	48	44	92
Children born to IV Drug Users	7	7	14
Other Children	1	8	9
Undetermined	9	4	13
Transfusion Receptient	2	1	3
	<b>558</b>	<b>133</b>	<b>691</b>
<b>DEATHS – 349</b>			
Homosexuals/Bisexuals	114		114
IV Drug Users	114	41	155
Homo/Bisexual/IVDU	6		6
Haemophiliacs	25		25
Heterosexuals	19	18	37
Children born to IV Drug Users	4	4	8
Undetermined	3	1	4
	<b>285</b>	<b>64</b>	<b>349</b>



**Table 5: HIV Transmission Categories used by the European Monitoring Centre for the Epidemiological Monitoring of AIDS.**

<p>Homosexual/bisexual male            Injecting drug user            Homo/bisexual male &amp; injecting drug user            Haemophilia/coagulation disorder            Transfusion recipient            Heterosexual contact            Mother to child            Nosocomial infection            Other/undetermined</p>
<p><b>Sub Categories of heterosexual contact</b></p>
<ol style="list-style-type: none"> <li>1. Originating from a country with a generalised HIV epidemic</li> <li>2. Sex with a bisexual male</li> <li>3. Sex with an injecting drug user</li> <li>4. Sex with a haemophiliac or transfusion recipient</li> <li>5. Sex with a person originating from or living in a country with a generalised HIV epidemic</li> <li>6. Sex with an HIV positive person not known to belong to one of the above</li> <li>7. Strongly believed to have been infected through heterosexual transmission, information on partner(s) not available</li> <li>9. Not applicable.</li> </ol>
<p><b>Sub Categories of transmission category of mother</b></p>
<ol style="list-style-type: none"> <li>1. Injecting drug user</li> <li>2. Originating from a country with a generalised HIV epidemic</li> <li>3. Infected through heterosexual contact and not known to belong to category "2" above</li> <li>4. Transfusion recipient</li> <li>5. Other/undetermined</li> <li>9. Not applicable</li> </ol>

Table 6: HIV Positive Antibody Results from the Virus Reference Laboratory

CATEGORY	1985*	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	Total	% of Total
Intravenous Drug Abusers	221	112	72	58	57	50	34	82	52	20	19	20	21	26	69	913	41.59
Children at Risk	8	11	16	18	10	11	4	7	12	10	4	8	10	20	23	172	7.84
Homosexuals	39	11	21	17	33	25	27	58	48	31	33	41	37	37	40	498	22.69
Haemophiliacs	92	13	7	0	0	0	0	1	1	0	0	0	0	0	0	114	5.19
Haemophiliac Contacts	0	0	0	0	0	0	0	0	0	0	1	1	1	0	1	4	0.18
Hospital Staff/Occupational Hazard/Needlestick	0	0	0	0	0	0	0	0	0	0	1	0	3	0	2	6	0.27
Transfusion	0	0	0	0	0	0	0	0	0	0	0	2	1	1	0	4	0.18
Blood Donors (specimens referred by BTSB)	3	1	3	2	4	1	1	2	1	2	0	5	1	2	1	29	1.32
Organ Donors	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0.05
Visa Requests	0	0	0	0	0	0	0	1	0	0	1	0	0	0	0	2	0.09
Insurance	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	1	0.05
Prisoners	0	0	0	0	12	0	1	0	1	0	2	2	5	3	13	39	1.78
Hetero/Risk unspecified	0	21	26	20	0	24	25	50	21	22	30	27	40	47	59	412	18.77
<b>TOTAL</b>	<b>363</b>	<b>169</b>	<b>145</b>	<b>115</b>	<b>116</b>	<b>111</b>	<b>92</b>	<b>201</b>	<b>137</b>	<b>85</b>	<b>91</b>	<b>106</b>	<b>119</b>	<b>136</b>	<b>209</b>	<b>2195</b>	

\*Cumulative Figures

Table 7: Cumulative HIV Antibody Results to 31st December 1999.

CATEGORY	Positive Individuals
Intravenous Drug Users	
Male	663
Female	236
Unknown	14
Children at Risk	172
Homosexuals	498
Haemophiliacs	114
Haemophiliac Contacts	4
Hospital Staff/Occupational Hazard/Needlestick	6
*Transfusion	4
*Blood Donors (specimens referred by BTSB)	29
*Organ Donors	1
*Visa Requests	2
*Insurance	1
*Prisoners	39
Hetero/Risk unspecified	412
<b>TOTAL</b>	<b>2195</b>

This does not include specimens tested in unlinked anonymous surveillance programme.

**NOTE: The above figures relate to categories of persons as identified either by patients themselves or by their clinicians.**

\*Categorised by site reason rather than risk.



AIDS Strategy 2000

# Section 2

Report of the

Education / Prevention Sub-Committee of  
the National AIDS Strategy Committee



# Report of the Education / Prevention Sub-Committee of the National AIDS Strategy Committee (NASC)

## Membership of the Education and Prevention Sub-Committee

Mr Owen Metcalfe	Department of Health and Children (Chair)
Ms Deirdre Foran	Eastern Regional Health Authority
Ms Mary Ellen McCann	Ballymun Youth Action Programme
Mr Tony O’Gorman	Department of Education and Science
Mr Mick Quinlan	Gay Men’s Health Project, Eastern Regional Health Authority
Mr Kieran Rose	Gay HIV Strategies
Ms Deirdre Seery	The Alliance Centre for Sexual Health
Mr Evan Hackett	Department of Health and Children

## Introduction

The first two cases of AIDS in Ireland were diagnosed in late 1982 and reported in 1983. When Minister Mary O’Rourke set up the NASC in December 1991 there were 257 people with AIDS and 1,156 people with HIV<sup>1</sup>. There was a sense of urgency at the time and the Sub-Committees were asked to make clear recommendations in response to a growing HIV/AIDS problem. The multidisciplinary, multisectoral committee initiated by Minister O’Rourke produced the NASC Report and Recommendations document<sup>2</sup> published in April 1992.

## The Education / Prevention Sub-Committee of the National AIDS Strategy Committee

The Education / Prevention Sub-Committee was comprised of a number of representatives from organisations in the statutory and voluntary sectors who attempted to represent the complexity of the social realities from their varying perspectives. There were certain difficulties in writing the recommendations for the Education / Prevention Sub-Committee at that time.

The issues of safer sex and safer drug use were shrouded in the illegality of some of the risk activities and possible responses to HIV prevention. Condoms were not generally available. Sex between men was illegal. There were difficulties in acknowledging that drug use and sex between some men occurred in prison. Prisoners with HIV were segregated from the rest of the prison population. Possession of controlled drugs, such as heroin, without a proper licence of authority was and still is illegal. Sex education in schools was not yet part of educational policy, although a schools programme on HIV prevention was introduced in 1988<sup>3</sup>.

There have been considerable changes in the political context since the publication of the NASC report and recommendations in 1992. Sex and sexuality are far more openly discussed today. Public policy has altered to accommodate change and provide a more supportive environment for HIV education / prevention work and community participation in strategy development and implementation. There has also been considerable progress in the national health policy with the publication of the National Health Strategy Document, "Shaping A Healthier Future", and the National Health Promotion Strategy, which made recommendations on "making the healthier choice the easier choice".

The Education / Prevention Sub-Committee’s remit as stated in the NASC report document of 13 April 1992 was "to examine the primary role of prevention and education as an integral part of an overall strategy to prevent the transmission of HIV and AIDS". The stated objective was "to limit the spread of HIV infection through public awareness campaigns,

community-based prevention initiatives and improved infection control procedures". The Sub-Committee reviewed the interventions up to 1992 and considered that a combined input from both voluntary and statutory sectors provided the most effective framework for HIV education and prevention.

### Methodology for the Review of NASC Policy

The Department of Health and Children invited submissions for this review in order to include a broad range of perspectives and experiences. In addition, the Education / Prevention Sub-Committee circulated a questionnaire to organisations working in HIV and related fields. Twenty-four organisations, including health boards, government departments, non-governmental organisations (NGOs) and hospitals responded to this questionnaire. This review of the education / prevention strategy therefore reflects the expressed viewpoints of people involved in the issue of HIV.

### Progress made on implementing the recommendations in the 1992 Report.

Since 1992, significant progress has been made in relation to the NASC recommendations for Education / Prevention. The 1992 recommendations are in italics.

### Recommendations(1992)

*The committee feels that the legislation should be amended to allow for sale of condoms from vending machines and also to allow for the distribution of free condoms by statutory and voluntary agencies involved in HIV prevention.*

Condoms were deregulated in The Health (Family Planning) (amendment) Act of 1993 and were available from vending machines shortly after that time. Condoms in Ireland are however amongst the most expensive in Europe and this can prohibit usage amongst the younger population. Consideration also needs to be given to the difficulties in purchasing condoms in rural areas or small towns where outlets might be restricted.

Condoms and lubricant are distributed widely in the Eastern Regional Health Authority (ERHA) area, and are generally available free of charge in other health board clinics. NGOs throughout the country often distribute condoms free of charge, but this activity is restricted, as the condoms must be purchased from existing budgets. It is **recommended** that this issue be addressed by health boards.

*The (1992) committee ... considered that the combination of both voluntary and statutory input constitutes the most effective framework for delivering education and information on HIV and AIDS to particular target groups. The Committee recommends that this should continue and that co-ordination between both sectors will lead to more effective service delivery. In order that this liaison can continue effectively, the committee recommends that funds to the voluntary sector should be increased.*

The voluntary sector (NGOs) continue to play a key role in education / prevention, by providing their target groups and the general public with information about HIV and other STIs and promoting the conversion of knowledge into practice. Increased funding was made

available to facilitate this work. Since 1992, funding has been provided to the health boards, which in turn fund the NGOs. Two submissions from NGOs suggested that there are often barriers to meaningful partnership between health boards and NGOs and suggested the provision of a framework for participation similar to that encouraged by the Department of Health & Children in the physical and sensory disability and mental disability fields. There are also good models of partnership being developed in the social development department of the Eastern Regional Health Authority and the health promotion departments of health boards throughout the country.

NGOs have actively participated as representatives on NASC where their perspective has been instrumental in informing strategies and responses. The National Health Strategy recommends a partnership role for the voluntary sector and their role on NASC has been in keeping with this recommendation. In order to enhance partnership and co-ordination between the sectors, the committee **recommends** that NGO involvement on NASC be viewed as a model for participation in strategy development and implementation at health board levels.

The 1992 NASC report highlighted particular target groups for specific interventions and the recommendations for action will be reviewed under the same headings

## **A** General Public

*It is recommended that the dissemination of the Health Promotion Unit's leaflet "AIDS – The Facts" should be continued.*

An updated and improved "AIDS – The Facts" was produced for World AIDS Day 1996 and disseminated by the Health Promotion Unit (HPU). It provides information on how the virus is spread, methods of avoiding infection and contact places and numbers where people can go for help and information. It has received positive general feedback. It is now envisaged that the health boards will take responsibility for dissemination of this leaflet from the year 2000. The HPU also produced a leaflet "Eating for Health" containing nutritional information for people who are HIV positive.

Other services for the general public are provided by the NGOs and the statutory sector agencies. NGOs provide information and health promotion advice and counselling to the general public at their centres and through their helpline facilities. These services should be continued.

The STI, HIV and drug treatment clinics continue to be important sites for the provision of counselling, health education and prevention messages targeting those most at risk. In recognition of the unique opportunity provided by such clinics, it is **recommended** that consideration be given to developing the prevention role of these clinics in partnership with NGOs.

*It is also recommended that on-going, regular media campaigns be implemented on a national and local level emphasising different aspects of the problem from time to time as appropriate. It is recommended that a series of radio advertisements should be produced in time for Irish AIDS Day in May and a bigger mass-media campaign be developed to coincide with World AIDS Day on December 1st.*

Most of the national initiatives for informing the general public have occurred under the auspices of the HPU of the Department of Health & Children. TV and radio campaigns were initiated; leaflets and videos were produced. There have been three different campaigns since 1992. The first was a multi-media campaign involving radio, television and newspaper advertisements which ran from 1993 to 1995. It involved a selection of well known personalities giving strong messages in relation to HIV prevention, particularly emphasising the use of condoms.

The second campaign which was launched to co-incide with World AIDS Day 1995 showed young people's responses to a vox pop ending with the message: find out about AIDS; use a condom; don't take risks. It was also transmitted on TV during 1996 and 1997. This advertisement won a Golden Apple award for the best TV commercial campaign.

The third campaign was launched in 1998. This consisted of an advertisement entitled "The Brain", which was shown to cinema audiences over 15 years of age. This is an explicit campaign, which focuses on the major transmission routes of homosexual intercourse, heterosexual intercourse and injecting drug use and it gives a clear message regarding safer sex and not sharing needles.

"Convenience Advertising" involves the placing of HIV/AIDS awareness messages in toilet areas where the patrons are guaranteed to view them. These advertisements were first placed in third level colleges and following very positive evaluation, the programme was extended to women's health clinics, health centres, gay venues, selected entertainment venues and the offices of the Department of Health & Children. In 1994, the programme was extended so that the messages were designed to target disadvantaged youth. These messages are reviewed and updated on a regular basis and now include broader sexual health messages. The Committee **recommends** that these advertisements are continued and the venues extended.

In addition to the national campaigns, NGOs and statutory sector organisations, funded by the Department for work on HIV, were effective in gaining media coverage on a regular basis and this practice should be continued. Although media campaigns were produced by the HPU for World AIDS Day each year, the cost of running them on an on-going basis was prohibitive. Campaigns at national level are effective at keeping HIV in the public consciousness. However, the gaps in campaigns between World AIDS Day and Irish AIDS Day could possibly feed a public perception that HIV is no longer a problem.

Analysis of HIV data for Ireland<sup>4</sup> indicates that heterosexual spread has increased from 10.8% of new infections in 1992 to 29.4% of new infections in 1998. While men represent 69% of people with HIV, the proportion of women living with HIV has increased from 24% in 1993 to 31% in 1998. For cases associated with heterosexual transmission, women form 50.7% of the total of cases in 1998. These statistics indicate that HIV prevention strategies targeting the general public need to be sustained and developed.

With increases in the heterosexual spread of HIV there is still a need for national media campaigns. Such campaigns should include other sexually transmitted infections, while at the same time promoting sexual health. It is **recommended** that national media campaigns should be continued in order to promote sexual health and safer drug use amongst the general

public, with a special emphasis on (a) challenging discrimination and stigma and (b) presenting a balanced view between raising awareness of new treatments while promoting the importance of primary prevention.

*Liaison should be built up between the regional health promotion officers where they exist, and the local radio stations.*

Information on whether this happened is not available. In the last ten years there has been a large development of prevention roles in the health boards, whose role is to educate staff and the general population in relation to HIV prevention and sometimes to develop targeted approaches to more high risk audiences.

## **B** Young People

*The Department of Education in conjunction with the Department of Health should be responsible for developing appropriate materials accompanied by associated in-service (training) which would target earlier years.*

The Department of Education & Science and the Department of Health & Children provided for education of young people through the development of AIDS Education Resource materials for schools and in-service training for teachers. The Department of Education & Science conducted an evaluation of the AIDS resources materials for second-level schools and participated in the Education / Prevention Committee until recently. The Department of Education and Science has also developed the Relationships and Sexuality Education (RSE) Programme<sup>5</sup> for national and secondary school levels which will be incorporated into the Social, Personal and Health Education (SPHE) programme. Some progress has been made in terms of providing equal educational opportunities for gay and lesbian youth (see forthcoming report from GAY/HIV Strategies<sup>6</sup>) and in making mainstream youth services accessible to gay and lesbian youth. The Education / Prevention Sub-Committee welcomes the integration of HIV prevention education into a broader RSE programme and **recommends** that support be provided for the full implementation of the programme. It is further **recommended** that co-operation between the Department of Education and Science and the Education / Prevention Committee be continued.

Studies in Cork<sup>7</sup> and Galway<sup>8</sup> indicate the levels of sexual behaviour in those cities require an integrated approach to sexual health promotion for young people. The study in Cork indicated that 71% of young men and 79% of young women did not regard HIV as a concern for them. Agencies involved in HIV prevention work should work within a sexual health context rather than a disease prevention context in order to be relevant and effective.

To date, there is no national study on the knowledge, attitudes and skills of young people in relation to sexual health and diseases. Such a study would provide useful data on young people and a benchmark by which work on HIV and sexual health could be evaluated. It is **recommended** that a national KAB (knowledge, attitudes, and behaviour) survey be undertaken, in line with studies in other European countries.



*It is recommended that early school leavers from post-primary schools should receive particular attention along with those from primary schools who are likely to drop out early. The committee recognises that the voluntary agencies have an important role to play as a resource in the formal and informal education sector.*

The voluntary HIV agencies, through outreach and education programmes and the production of appropriate resource materials, targeted early school leavers in addition to working in the school setting. NGOs usually adopt a multi-sectoral approach, working with other organisations involved with young people in their areas. Voluntary and statutory drugs agencies, particularly in the Eastern Regional Health Authority area, have also played a significant role in working with early school leavers who are using or are at risk of using drugs. Counsellors based in these agencies (including the young persons' treatment programme piloted at some ERHA sites) provide an essential service in engaging young people in risk reduction discussion.

The National Youth Health Programme supports and provides training for health promotion in the non-formal education sector. This programme commissioned The Alliance Centre for Sexual Health in Cork, to develop the education pack "Knowledge is Power", a HIV/AIDS education resource for exploring sexual health issues with young people in this sector. Training to accompany this pack was organised with the Midland Health Board and further training events in other health board areas are scheduled.

The Eastern Regional Health Authority funds the Teenage Health Initiative and has also funded work with lesbian and gay youth groups which included work on HIV awareness and other sexual health initiatives. It is also developing a youth project with treatment and outreach services in the City Clinic in Amiens Street, Dublin

The link between social class and age of first intercourse has been established by a number of studies and the committee recognises the importance of sexual health promotion, outreach work and peer education with this target group. It is **recommended** that funding continues to be provided for this valuable work and a partnership approach between the various voluntary and statutory agencies is fostered, in accordance with the National Health Strategy.

## **C** Young Emigrants

*It is recommended that the Health Promotion Unit should be responsible for developing an information leaflet which would be made available at travel agents, student welfare offices, student medical centres, voluntary agencies, youth information offices, as well as at points of exit from the country.*

There was no leaflet produced specifically aimed at young emigrants. The HPU produced a leaflet entitled "The Sunseeker's Guide to Health" which provides advice for people travelling abroad on how to avoid HIV infection. A European initiative produced an information leaflet for people travelling abroad in the style of a passport with a flying condom. This leaflet was widely distributed in Ireland by the voluntary agencies, co-ordinated by the Red Ribbon Project in Limerick.

Although Ireland now has net migration, a considerable number of young people emigrate and travel abroad for holidays or as volunteers for overseas agencies. There is therefore a need for an information leaflet on HIV, Hepatitis, STIs and other infectious diseases which could be prevented. It is **recommended** that the Health Promotion Unit should be responsible for developing this information leaflet, in consultation with appropriate agencies, and that it is made available at the outlets referred to above.

*There should be on-going links with emigrant groups abroad to monitor and evaluate the situation.*

Funding was provided for Positively Irish Action on AIDS in Britain (the destination of 40% of Irish emigrants) and links were maintained with that agency during its existence. In 1992, it was considered that many people emigrated to avail of better service provision for HIV. As treatment services in Ireland have improved greatly since that time, more people with HIV are believed to be returning to Ireland for treatment than leaving it. Statutory and voluntary sector agencies are in contact with agencies abroad on an individual case basis, particularly when a HIV positive individual wishes to return to Ireland on a short or long-term basis.

## Migrants

At the time of writing the 1992 NASC report, there were no recommendations for migrants. Ireland had traditionally been a country with high emigration. Emigration however has been in decline since 1993. In a reversal of the trend, Ireland now has a growing number of migrants of whom returning emigrants and EU nationals form the majority. Net migration was 15,000 for the year ended April 1997 and 22,800 for the year ended April 1998. In Europe, migrants are perceived to be an 'at risk' group and the Committee acknowledges the work of the Irish AIDS & Mobility Network in highlighting the situation for migrants since 1997.

Ireland also has a growing number of refugees and asylum seekers for whom medical screening is available. Although HIV test results are confidential, the uptake of HIV testing may be low due to fears that a positive test result may impact negatively on applications for refugee status.

The committee acknowledges the special problems which refugees and asylum seekers face. Training should be provided to staff in key sites working with refugees and asylum seekers to provide appropriate culturally specific support services including medical treatment, risk assessment and risk reduction counselling.

## D Drug Users

*The committee considered that whilst HIV preventive services such as methadone maintenance and needle exchange were extremely important strategies, these were more appropriate topics for consideration by the Care and Management Sub-Committee.*

*The (Education / Prevention Sub-Committee) recognises that intervention of an outreach nature based on one-to-one communications is the most effective method of reaching this group*

In 1992, the NASC report noted that IV drug use was one of the primary modes of transmission of HIV at that time, particularly in the Eastern Health Board area. Debates on drug use centred on whether a harm reduction or a drug free policy (abstinence) should be pursued. In 1991, the Government Strategy to Prevent Drug Misuse<sup>9</sup> recognised the importance of a harm reduction approach for HIV prevention. The NASC report in 1992 endorsed this approach and recommended the establishment of satellite clinics outside the hospital setting. As a result, transmission of HIV by IV drug use was considered by the Care and Management Sub-Committee of NASC rather than the Education / Prevention Sub-Committee.

Since 1992, considerable resources have been allocated to the drugs issue. In 1996, the First Report of the Ministerial Task Force on Measures to Reduce the Demand for Drugs<sup>10</sup> established the National Drug Strategy Team and the Local Drugs Task Forces in twelve areas of Dublin and one in Cork City. Strategies to reduce drug use cannot be divorced from strategies to develop community responses, to combat poverty, unemployment, housing shortages and social exclusion. Much of the response to drugs therefore lay beyond the remit of the Education / Prevention Committee which concentrated its efforts in maintaining a focus on HIV within the response to the drugs problem.

The NASC report recognised the importance of outreach work, community drugs teams, satellite clinics, needle exchanges and methadone maintenance programmes. There are approximately 25 outreach workers, 10 education officers, 12 needle exchanges amongst a range of other services in the Eastern Regional Health Authority. While NASC recognised the importance of one-to-one counselling, the sheer numbers of people affected by drug use has sometimes resulted in a high ratio of clients to addiction counsellors in the Eastern Regional Health Authority, despite major investment in services.

Given the large and increasing numbers of drug users attending drug treatment services, the role of counsellors at these clinics needs to be defined and developed. Engaging on a one to one basis with clients can be a highly effective way of addressing the psycho/social factors contributing to on-going drug use, risk taking behaviour and secondary prevention issues such as safer sex / drug use between sero-discordant couples. Guidance for health care workers for the referral of clients to counsellors at these sites is desirable. The prevention role of counsellors at STI clinics and in pre-HIV test counselling needs to be redefined on a multi-disciplinary level to take account of the changing socio-medical environment in which services are provided.

Methadone maintenance programmes have become a major part of the response to HIV and opiate use since 1992. At the end of December 1999, a total of 4,332 people were on the central methadone treatment list.

Transmission of HIV infections through IV drug use has fallen from 41.4% of new infections in 1992 (and 45.2% in 1993) to 21.5% in 1998. This indicates a large measure of success for harm reduction initiatives. However, statistics released by the Department of Health & Children for the period January 1999 to May 1999 indicate an increase in new infections from IV drug use, with 30 (15 men and 15 women) of the total of 76 for the period.

A study undertaken by the Merchants Quay Project<sup>11</sup> indicates that young injectors (under 25 years of age) reported significantly greater lending and borrowing of used injecting equipment than older (over 25 years of age) injectors. Ballymun Youth Action<sup>12</sup> reported a lack of focus on education and awareness raising for all young people. Clearly there is no room for complacency and HIV prevention initiatives need to be maintained and strengthened, particularly in relation to young drug users.

HIV has been replaced by Hepatitis C as a major concern of the IV drug using community. Concern has also been expressed by agencies about the potential for increases in STIs, as drug users (male and female) turn to prostitution to raise money for their drugs. The use of drugs, including alcohol, has been reported to have an impact on sexual risk-taking. HIV therefore needs to be seen in the context of a broader range of problems facing IV drug users. There is continued need for safer sex / safer injecting information (some of which takes literacy problems into account). There is a continued need for targeted approaches, within the context of a more holistic response.

## **E** Homosexuals / Men who have sex with men / Bisexuals

*It is recognised that the criminalisation of homosexuality inhibits promotional work in this field.*

The 1993 Criminal Law Sexual Offences Act which decriminalised homosexual acts provided for equality with heterosexuals and was a fundamental shift in public policy towards the gay community. Research commissioned by The Combat Poverty Agency<sup>13</sup> and The Department of Health and Children<sup>14</sup> have provided essential data on the experiences of gay men which were not available in 1992. The Combat Poverty report illustrated how the gay community is a marginalised or socially excluded community, a fact which impacts on health status. There has been a developing policy response to discrimination, poverty and social exclusion of the gay community. One example of this is the National Anti-Poverty Strategy and its Poverty / Equality Proofing Guidelines. The further integration into mainstream programmes of responses to gay disadvantage, particularly those aimed at gay men experiencing multiple disadvantages, would be of great benefit to HIV prevention programmes. The initiative launched by the Waterford Area Partnership could be viewed as a model of good practice in this regard. The net effect of policy improvements is to create a healthier environment and reduce the sense of marginalisation of gay and bisexual men and women, which in turn should provide a context for healthier choices.

*This committee recommends that information and education should be provided by developing an Outreach programme.*

In 1992, the Eastern Health Board established the Gay Mens' Health Project in Dublin. The service operates a drop-in sexual health clinic with medical screening and counselling, outreach and information services and the distribution of condoms free of charge for gay and bisexual men<sup>15</sup>. The project has shown the benefits of a targeted approach to sexual health promotion. In Dublin, there are now three outreach workers who work exclusively with the gay community. Outreach workers have also been funded in Cork, Limerick and Galway and are involved in education / prevention work in those cities. The Gay Men's Health Network acts as a national network of gay and HIV organisations and includes people with HIV.

Outreach programmes provide a vital service in bringing those gay men most at risk of HIV and STIs into contact with testing and treatment clinics. In the light of developments in policy, the role of counsellors at these clinics needs to be clarified. In addition to the provision of medical treatment, the clinics are in a unique position to engage clients in individual risk reduction strategies (including, for example, motivational interviewing and cognitive behavioural therapy).

Transmission of HIV in the gay community has remained steady, despite the heightened awareness brought about by the campaigns, outreach work and the direct experience which a number of gay men have had of friends and partners dying of AIDS. The median age associated with transmission by homosexual sex is 34. In 1998, transmission by homosexual / bisexual sex was 26.8% of new infections compared to 29% in 1993. There is a need to continue with HIV prevention and sexual health promotion work in the gay community. Young gay men also need to be targeted in order to promote healthy sexual choices.

Gay HIV Strategies, funded by the Department of Health & Children, was formed in 1997 and has played an active role in policy development and capacity building. One of their aims is to gain funding for HIV prevention pilot projects and to build the capacity of the community groups to engage in health promotion and HIV prevention work. They have illustrated the benefits of a partnership approach through the pursuit of another of its aims, which was to improve education and awareness of safer sex in the gay commercial sector. The Sauna Project, as this initiative is called, developed a partnership process between the sauna owners, management and staff, the customers, the various health service providers and the gay community service providers so that effective HIV prevention measures were developed and implemented.

It is **recommended** that since partnership and capacity building is an effective strategy for working with marginalised groups, this approach should continue.

*It is also recommended that funding for appropriate literature should continue to be made available to the relevant agencies.*

The Gay Health Network has produced a host of publications for HIV prevention and sexual health promotion. These include a HIV testing leaflet, Hepatitis B information and the “Play Safe, Play Sexy” booklet and cards. The role of gay organisations should be acknowledged as providers of health information, particularly to those who may be isolated or not actively involved in the gay community.

## **F** Prostitutes

*The committee recognises that the most effective method of reaching this group is through an Outreach programme and recommends the establishment of same. It is recommended that members of this group should be consulted in the development of educational materials. This will necessitate increased expenditure for the voluntary sector.*

There is extensive work undertaken with female prostitutes in the Eastern Regional Health Authority area. It is felt by some workers in the field that criminalisation of prostitution is a

barrier to effective health promotion and HIV prevention work. The Women's Health Project provides medical, counselling and outreach services. The service is linked to Europap which is an EU funded network of people involved in working with prostitutes. Through their involvement in this network, members of the Women's Health Project have been involved in research and organised meetings in collaboration with agencies working on HIV in other health board areas. However, to date, there are few outreach services available for prostitutes outside of Dublin and this should be addressed.

The Gay Men's Health Project has researched into male prostitution and is a member of the European Network of Male Prostitution. GMHP is also developing services with voluntary and statutory agencies for male prostitutes.

## **G** Health Staff

*In-service and pre-service training initiatives are seen as being the most effective way of reaching health staffs.*

Courses provided by St. James's Hospital have been running throughout the decade. These courses provide training on knowledge and attitudes and have been well attended by nurses and others interested in the field.

The Southern Health Board has run a number of HIV training courses for nurses in its area.

The Education / Prevention Sub-Committee organised a series of training days which included updates on medical treatments for health staff.

In 1998, Galway STD clinic staff attended specific training in the UK for Health Advisers and the training of a doctor for 8 weeks in the UK in HIV / STIs for clinic work.

The NGOs in Cork, Dublin, Galway and Limerick provided a range of training courses and inputs into courses for health staff throughout the country.

The Department of Health & Children produced guidelines for the prevention of transmission of blood-borne diseases<sup>16</sup> in health care in 1999. The guidelines aim to protect patients and health care workers from HIV and Hepatitis by providing practical advice and detailed procedures.

More recently, with the availability of antenatal testing in maternity hospitals, training of midwives throughout the country has occurred. With the recent introduction of routine testing in GU Clinics, the emphasis on preventative work, such as health promotion counselling, should be maintained.

## **H** General Training

*The committee recognises that the establishment of a specific HIV/AIDS training unit would constitute the provision of a very important service to meet training needs of many groups working in the HIV/AIDS field. The proposal to establish such a training unit should be structured in conjunction with workers already in the field.*

A specific HIV/AIDS training unit has not been established. The Education / Prevention Sub-Committee organised a series of training days, following assessments of the needs of people working in HIV and related fields. As they were organised in response to the stated needs of the respondents, these training days were very well attended and highly evaluated. It is **recommended** that this work should continue.

St. James's Hospital has provided training on medical treatments and attitudes around HIV. The AIDS and Drugs Unit of the Eastern Regional Health Authority is currently establishing a training unit for staff, which includes training on HIV.

NGOs provide training to a variety of individuals and organisations. The Red Ribbon Project, in partnership with the Health Promotion Unit of the Mid-Western Health Board, organise successful conferences for World AIDS Day and provides specialist training for social workers and youthreach workers in that area. The Alliance Centre for Sexual Health has developed a holistic sexual health programme in response to findings of its research and provides training to young people and to professionals in contact with young people. Dublin AIDS Alliance has provided training in the use of drama as a tool in education / prevention work and is also engaged in broad training initiatives. In addition to its education work with young people, AIDS Help West provides training in self-care for people living with HIV and their significant others. It is **recommended** that funding for the work of the NGOs for the provision of training is continued.

The Education / Prevention Sub-Committee produced *Guidelines for Effective Education*<sup>17</sup>. The Guidelines, which provided a detailed framework for participative education, aimed at promoting a consistent approach and good practice in HIV/STI education.

## Prisoners and Ex-Offenders

The committee recommends:

(a) *The establishment of an organisational structure in the form of a centralised committee that would allow for the dissemination of HIV/AIDS information accompanied by a one-to-one counselling service within the prison context.*

Written and audio-visual information on HIV (risk factors, prevention, treatments etc.) is made available to all prisoners and staff routinely.

(b) *A process of desegregation should be initiated as soon as possible*

Since January 1995 segregation of prisoners with HIV has ceased.

(c) *A policy of confidential testing should be adopted.*

Information is made available to all prisoners and staff. Treatment facilities for prisoners with HIV have been greatly improved which should impact on tertiary prevention. Confidential pre and post-test counselling should continue to be available to prisoners within the prison environment.

*In the longer term the dissemination of information reinforced by counselling is absolutely essential to prevent the spread of the AIDS virus within the prison system.*

Members of statutory and voluntary agencies in Dublin, Cork and Limerick are involved in education and counselling work in prisons on an on-going basis.

A recent study into Irish prisons<sup>18</sup>, which was commissioned by The Department of Justice, Equality and Law Reform provided some interesting data. The report found that 9% of prisoners had hepatitis B, 37% had hepatitis C and 2% had HIV. 52% of respondents reported having used opiates, 43% reported having injected drugs at some time and 37% reported having shared injecting equipment before being imprisoned. Just under 2% reported having had anal sex with men in prison. The report produced detailed recommendations for consideration by the Department of Justice, Equality and Law Reform.

## J Other recommendations

*Continuing research and evaluation should be undertaken in order to assess the effectiveness of interventions.*

Although some programmes and initiatives have been evaluated, there is perhaps less emphasis on evaluation and research than in other European countries. It is **recommended** that The Education / Prevention Sub-Committee organise a training day on evaluation techniques with a view to helping organisations to devise protocols for more extensive evaluation of work so that resources can be utilised in the most efficient and effective manner.

## Impact of new treatments on education / prevention

The availability of HAART has made it possible to provide effective treatment to most people living with HIV. This has shifted emphasis at HIV treatment centres from symptom management and prevention counselling to focussing on planned medical treatment. While new treatments are highly valuable to people with HIV, the role of preventing new infections remains crucial. It is important that HIV negative people who have identified themselves as being at risk of HIV / STIs by presenting for a test continue to have access to health promotion advice and counselling. The Committee recognises the importance of the role of health promotion advice and counselling at clinics and treatment centres in addressing continued risk behaviour among those most at risk, in helping with adherence problems and in helping to prevent secondary infections.

The improvements in treatments have impacted on the lives of people living with HIV. It is **recommended** that The Education / Prevention Sub-Committee organise a consultation day with people with HIV and develop a strategy for secondary prevention. It is also **recommended** that The Sub-Committee co-opt a HIV positive person to the committee to enhance its work.

The Sub-Committee emphasises the need to continue to accommodate to new medical advances by developing a responsive system, to be alert to changing needs and to avoid complacency.



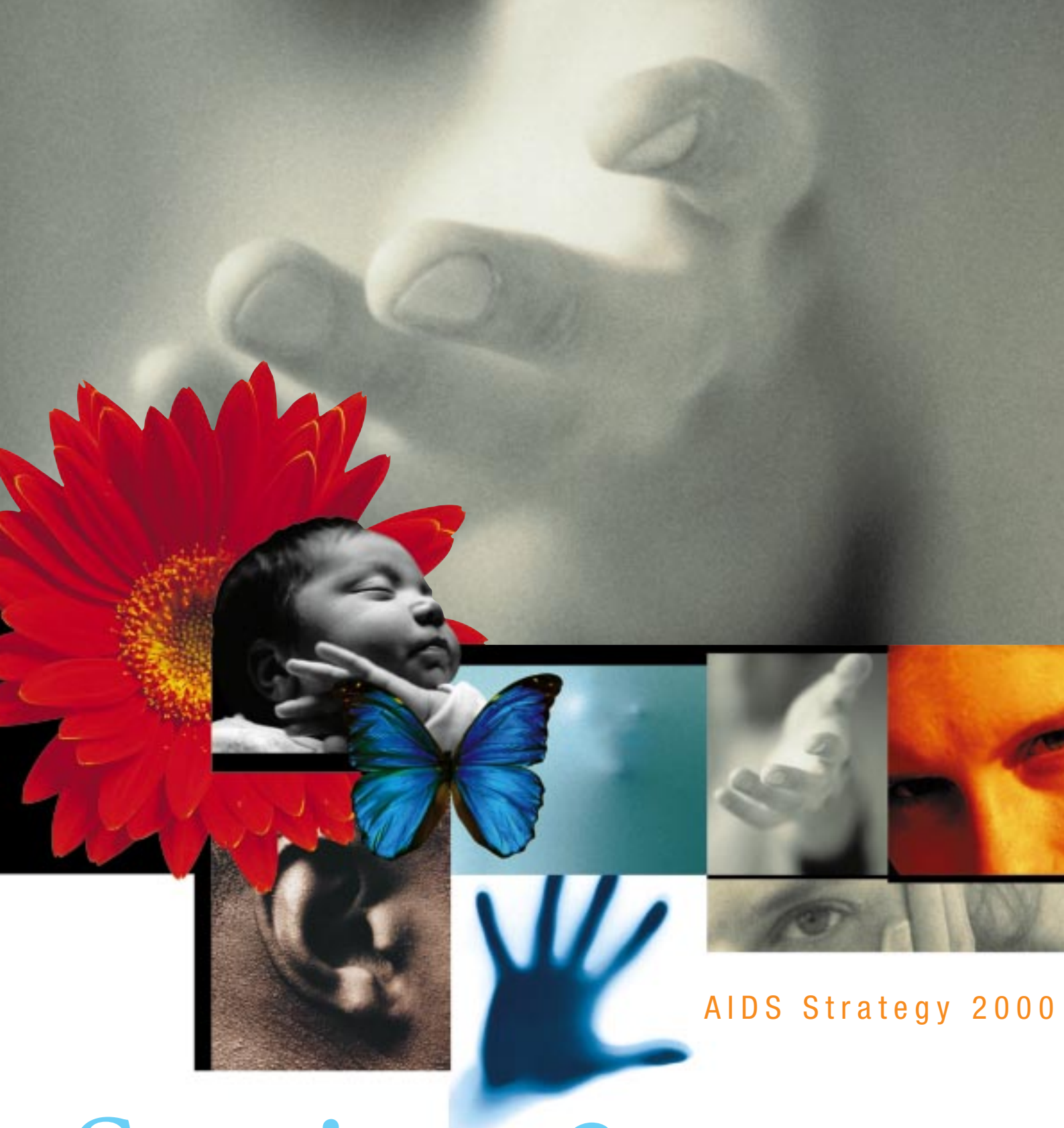
## Recommendations

- 1.** It is recommended that consideration be given to the difficulties in purchasing condoms in rural areas and small towns where outlets might be restricted. It is also recommended that health boards throughout the country address the issue of condom availability to NGOs for distribution free of charge.
- 2.** In order to enhance partnership and co-ordination between the sectors, the committee recommends that NGO involvement on NASC be viewed as a model for participation in strategy development and implementation at health board levels.
- 3.** The Sub-Committee recommends that convenience advertising is continued and the venues extended.
- 4.** It is recommended that national media campaigns should be continued in order to promote sexual health and safer drug use amongst the general public, with a special emphasis on target groups with high or increasing rates of infection from HIV, STIs and Hepatitis. The campaigns should have the twin aims of (a) challenging discrimination and stigma and (b) presenting a balanced view between raising awareness of new treatments while promoting the importance of primary prevention.
- 5.** The Sub-Committee welcomes the integration of HIV prevention education into a broader RSE programme and recommends that support be provided for the full implementation of the programme. It is further recommended that co-operation between the Department of Education and Science and the Education / Prevention Sub-Committee be continued.
- 6.** There is no national study of the knowledge, attitudes and skills of young people in relation to sexual health and diseases. Such a study would provide useful data on young people and a benchmark by which work on HIV/STIs and sexual health could be evaluated. It is recommended that a national KAB (knowledge, attitudes, and behaviour) survey is undertaken, in line with studies in other European countries.
- 7.** The link between social class and age at first intercourse has been established by a number of studies and the Sub-Committee recognises the importance of sexual health promotion, outreach work and peer education with young people. It is recommended that funding continues to be provided for this valuable work and a partnership approach between the various voluntary and statutory agencies is fostered, in accordance with the National Health Strategy.
- 8.** It is recommended that the Health Promotion Unit, in consultation with appropriate agencies, should be responsible for developing an information leaflet on HIV, Hepatitis and STIs and that it be made available at appropriate outlets.
- 9.** The Sub-Committee acknowledges the special problems which refugees and asylum seekers face and it is recommended that training should be provided to staff in key sites working with refugees and asylum seekers to provide appropriate culturally specific support services including medical treatment, risk assessment and risk reduction counselling.

10. The Sub-Committee recommends that HIV/ STI and Hepatitis prevention initiatives need to be maintained and strengthened within the strategy to prevent drug use. There is on-going need for safer sex / safer injecting information (some of which takes literacy problems into account) for drug users. There is also continued need for targeted approaches, within the context of a more holistic response. HIV prevention initiatives need to be maintained and strengthened, particularly in relation to young drug users.
11. The Sub-Committee recommends that the further integration into mainstream programmes of responses to gay disadvantage, particularly those aimed at gay men experiencing multiple disadvantages, would be of great benefit to HIV prevention programmes. There is a need to continue with HIV prevention and sexual health promotion work in the gay community. Young gay men need to be targeted in order to promote healthy sexual choices.
12. The role of gay organisations should be acknowledged as providers of health information, particularly to those who may be isolated or not actively involved in the gay community. Funding for appropriate information materials for the gay community needs to be continued.
13. It is recommended that partnership and capacity building is an effective strategy for working with marginalised groups and that this approach should continue in all health boards.
14. The recommendations of the report on Hepatitis B, Hepatitis C and HIV in Irish prisons should be explored with a view to improving prevention of these diseases in that environment.
15. It is recommended that resources continue to be made available for the provision of training and that the Education / Prevention Sub-Committee's training initiatives be maintained. It is recommended that the Education / Prevention Sub-Committee organise a training day on evaluation techniques with a view to helping organisations to devise protocols for more extensive evaluation of work so that resources can be utilised in the most efficient and effective manner.
16. It is recommended that the Education / Prevention Sub-Committee organise a consultation day with people living with HIV and develop a strategy for secondary prevention. It is also recommended that the Sub-Committee co-opt a person with HIV to the committee.
17. It is recommended that funding continues to be made available to the NGOs to develop and provide innovative training initiatives.
18. It is recommended that the Education / Prevention Sub-Committee include sexual health promotion and other sexually transmitted diseases in its brief.
19. The HIV/STI and drug treatment clinics continue to be important sites for the provision of counselling, health education and prevention messages targeting those most at risk. The role of counsellors at these clinics needs to be clarified. In recognition of the unique opportunity provided by these clinics, it is recommended that consideration be given to developing their prevention role.

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AIDS Strategy 2000

# Section 3

Report of the

Care & Management Sub-Committee of the National  
AIDS Strategy Committee

# Report of the Care & Management Sub-Committee of the National AIDS Strategy Committee (NASC)

## Membership of Care and Management Sub-Committee of the National AIDS Strategy Committee

Mr Donal Devitt	Assistant Secretary, Department of Health and Children (Chair)
Dr Joe Barry	Specialist in Public Health Medicine, Eastern Regional Health Authority
Dr Karina Butler	Consultant in Infectious Diseases, Our Lady's Children Hospital,
Mr Paddy Connolly	Director, Cairde
Dr John Devlin	Deputy Chief Medical Officer, Department of Health and Children
Dr Enda Dooley	Medical Director Prisons, Department of Justice, Equality and Law Reform
Mr Jimmy Duggan	Principal Officer, Department of Health and Children
Ms Maeve Foreman	Senior Medical Social Worker, St James's Hospital
Mr Tony Geoghegan	Director, Merchants Quay Project
Dr Mary Horgan	Consultant in Infectious Diseases, Cork University Hospital, Cork
Dr Emer Mac Hale	Regional AIDS Co-ordinator, Western Health Board
Mr Joe Martin	MALAIDS
Dr John O'Connor	Drug Treatment Centre, Trinity Court
Dr Fiona Mulcahy	Consultant of Genitourinary Medicine, St James's Hospital
Dr Fergus O'Kelly	Irish College of General Practitioners
Ms Deirdre Seery	The Alliance Centre for Sexual Health, Cork
Dr Gerard Sheehan	Consultant in Infectious Diseases, Mater Hospital
Ms Mary Jackson	Department of Health and Children
Ms. Louise Kenny	Department of Health and Children

## 1

### Introduction

When the Report of the National AIDS Strategy Committee (NASC) was published in 1992 HIV was seen as a terminal illness. However, the development and availability of combination Highly Active Antiretroviral Therapy (HAART) in recent years has had a dramatic effect on the natural history of HIV infection. In the early 90's the focus was on acute and terminal care. However, with the development of the new drug treatments HIV can be considered more like a chronic illness, with patients now requiring different levels of medical treatment, housing and social supports at different times over a long period of time.

## 2

### Implementation of NASC recommendations

Since 1992 significant progress has been made in implementing the NASC recommendations in relation to care and management (set out in italics below) and an outline of progress made to date is as follows:-

*It is recommended that proper resource structures should be introduced to allow the general practitioner to care for the HIV/AIDS patients in his own practice setting. [Rec. No. 9(i)]*

and

*The Committee recommends that adequate services be provided at a local level in order to ensure that, having taken due consideration of medical needs individuals can remain outside of hospital care as much as possible. [Rec. no. 9(v)]*

Although GPs were willing to treat patients with HIV it has transpired, of necessity, that patients must access specialist care in outpatient clinics of hospitals, because of the complex nature of the new drug therapy regimens. Combination antiretroviral therapy with three or more agents is offered to those attending HIV treatment clinics where such treatment is

clinically indicated. Monitoring of the effects of drug therapy is done at frequent intervals, using tests such as viral load testing.

Because of the complex nature of the newly developed drug therapies for treating HIV/AIDS this treatment must, of necessity, be provided mainly in specialist facilities in hospitals, on an outpatient basis. A liaison nurse is in place in Cork University Hospital and Our Lady's Hospital, Crumlin. In each case this person greatly improves communication and coordination of services between hospital and community.

Drug treatment services are provided through a network of treatment locations and health board policy is to provide treatment in the person's own local area where possible. For example, at the end of February, 2000 156 general practitioners and 207 community pharmacies were involved in the provision of treatment to opiate misusers in their local areas.

HIV statistics indicate that health board policies of including harm reduction (needle exchange) and substitution treatment (e.g. methadone treatment) interventions are successful in reducing the incidence of HIV among intravenous drug misusers. The average percentage of all newly reported cases of HIV made up by intravenous drug users in 1991, 1992 and 1993 was 39%, while the average for the years 1996, 1997 and 1998 was 20%. However, figures for 1999 show a dramatic increase in new cases (69 compared with 26 in 1998 and 21 in 1997), so health board services must intensify their efforts with this target group.

*The Committee recommends the establishment of satellite clinics outside the hospital setting which would provide primary care for all HIV positive individuals and for all drug users. [Rec. no. 9(ii)]*

*The Committee recommends that satellite clinics be established initially on a pilot basis and that a minimum of two such centres should be established in the Dublin area and consideration should be given to the establishment of a similar clinic in Cork. [Rec. no. 9(iii)]*

To tackle the major health and social problems posed by the opiate problem in Dublin the Eastern Health Board (now the Eastern Regional Health Authority) has developed a comprehensive programme of treatment and care for opiate misusers over recent years. It has established drug treatment services at 52 locations. These services include education and counselling, methadone maintenance, needle exchange, testing for hepatitis B and C and HIV, rehabilitation and aftercare.

A satellite clinic was not set up in Cork as drug misuse there is mainly non-intravenous and the majority of diagnosed cases of HIV are linked with other risk activities. This situation needs to be kept under review, however, in case there is a change in drug misuse trends in the future.

*It is proposed that a strengthening of generic community services provided by the health boards in deprived urban areas would be an important initial step in developing a range of accessible and appropriate services. [Rec. no. 9(iv)]*

Since 1992 health boards have been provided with additional funding to expand and enhance their drugs and HIV/AIDS services. A number of projects have been undertaken to target

social exclusion in deprived urban areas including over 200 projects being undertaken by Local Drugs Task Forces in the 14 areas where the drug problem is most acute in Dublin and Cork.

As part of the Government's initiative on drugs £34.8 million has been allocated to the Young People's Facilities and Services Fund to develop youth facilities and services in disadvantaged areas where a significant drug problem exists or has the potential to develop. The projects being supported by this fund aim to attract young people in those areas who are at risk of becoming involved in drugs into more healthy and productive pursuits. £25 million of this sum was allocated to the Local Drugs Task Force areas.

Recognising that the problem of drug misuse is not confined to the Task Force Areas in Dublin and Cork funding was also allocated to areas outside these priority areas. £2.4 million has been provided each year for 3 years, 1998 to 2000 to set up family support projects aimed at children at risk and families at risk within particular communities and working with voluntary and community groups in a co-ordinated way. Projects have commenced in Cherry Orchard, Naas, Waterford, Mahon in Cork, Thurles, Southill, Athlone, Galway City, Letterkenny, Sligo, Navan and Dundalk.

Future developments will depend on the results of evaluation of the programme.

There is a need for social and health services to develop an integrated service, where providers work in unison to promote the health and wellbeing of individuals while tackling the issues linked to social inclusion. This is particularly relevant to providing optimum services for people with HIV/AIDS. The Taoiseach launched the Integrated Services Process in four areas (Dublin's North East Inner City, The Canal Communities, Jobstown in Tallaght and Togher in Cork) in December, 1998. The Process aims to develop new procedures to ensure a more focused and better co-ordinated response by statutory agencies to the needs of communities with the greatest levels of disadvantage, as a basis for the development of a model of good practice. The Eastern Regional Health Authority and the Southern Health Board are playing a key role in the process being undertaken as part of this two year pilot phase.

*It is recommended that the voluntary agencies should be allocated additional resources to enable them to fulfill the role they are currently undertaking and to allow them to complement the expanded statutory service. [Rec. no. 9(vi)]*

Voluntary organisations play a key role in the delivery of appropriate care and support at regional and local levels to people with HIV and their families. This is in keeping with the recommendations in the National Health Strategy which sees a partnership role for voluntary organisations in the development and delivery of appropriate services. Voluntary organisations are represented on the National AIDS Strategy Committee and its sub-committees where they work in conjunction with statutory agencies in the development of targeted responses to issues which emerge. Since 1992 additional funding has been provided to health boards which in turn fund voluntary organisations whose work complements that of statutory agencies.

*The Committee recommends that welfare entitlements for those who are HIV positive be standardised. [Rec.no 9 (vii)]*

Health Boards are responsible for the payment of Supplementary Welfare Allowance, which allows discretion for claims to be determined on a case by case basis. Welfare entitlements have not been standardised as each case is dealt with on the basis of the needs of that individual. The Drugs/AIDS Teams in the Eastern Regional Health Authority include a Community Welfare Officer. In the Southern Health Board a Community Welfare Officer, based in Cork City deals with HIV/AIDS issues.

*The Committee recommends the availability of free condoms to those who are HIV positive, through health board and other service outlets. [Rec. no. 9(viii)]*

Condoms are available in health board clinics. Voluntary organisations must purchase stocks of condoms from within their own budgets. This is an issue which should be addressed by health boards.

*The Committee recommends that open access to retraining opportunities should be given to individuals who are HIV positive through FÁS and where appropriate, the National Rehabilitation Board. [Rec. no. 9(ix)]*

With the development of new drug treatments the scope for making progress with this recommendation has been expanded. People with HIV are encouraged to access existing education and re-training services for people with a long-term illness such as those run by the National Rehabilitation Board and FÁS.

*The Committee recommends:*

*No individual who is HIV positive should be discharged from institutional care on Friday afternoons without clear prior arrangements being made for housing and medical care (if needed);*

*that attention be paid to the special needs of individuals with HIV, including the fact that ordinary hostel accommodation is often not sufficient;*

*that existing discharge protocols for the homeless already in place in many hospitals should be examined to ensure that they provide for persons with HIV;*

*that hostels receiving funding should not be entitled to continue their practices of refusing to take individuals who are HIV positive. [Rec. no. 9(x)]*

Although some progress has been made, homelessness is still of major concern, especially in the Greater Dublin area. In Dublin chronic drug misusers present particular problems. They require specialised help and support to stabilise their drug using habit and to aim at personal rehabilitation. The chaotic lifestyles of many chronic drug misusers present a particular set of challenges to both statutory and voluntary service providers.

Unstructured release from prisons still takes place.

*The Committee considers that ongoing evaluation and research are necessary to ensure both the widespread dissemination of information on good practice and the development of an integrated approach to the provision of primary care for the HIV/AIDS patient. [Rec. no. 9(xi)]*



The HIV in Primary Care Research Project is a forum for collaborative research with members from three different institutions - Department of General Practice in University College Dublin, Department of Community Health and General Practice in Trinity College Dublin and the HIV / Drugs Service in the Eastern Regional Health Authority, with funding initially provided by the Department of Health and Children and more recently provided by the Eastern Regional Health Authority.

**THE UNITS AIMS ARE TWOFOLD:**

- 1.** to explore the role of the general practitioner in the diagnosis, management and prevention of HIV disease and other bloodborne viruses;
- 2.** to facilitate relevant education programmes in general practice.

Early research by the unit facilitated the increased involvement of general practitioners in caring for HIV positive patients. It explored the medical, psychological and social issues that are important for those involved in caring for this group and included:

- 1993** Attitudes of Irish GPs to HIV infection;  
Irish general practice and the human immunodeficiency virus;  
Clinical aspects of HIV infection, the use of primary care services by drug users attending an HIV prevention unit.
- 1994** HIV / AIDS infection;  
Attitudes towards and experience of general practice among HIV positive patients in the Republic of Ireland;  
Sexual functioning and use of safer sexual practices in an Irish HIV positive cohort.
- 1995** Analysis of care of HIV positive patients – hospital and general practice components;  
Quality of life in a cohort of individuals with HIV / AIDS;  
Community participation in research and planning.
- 1996** An analysis of the effect of HIV infection in a cohort of injecting drug users;  
Application of a new short form quality of life measure in a cohort of individuals with HIV / AIDS.

Subsequently, as opiate substitution with methadone became accepted as an important adjunct in reducing the spread of HIV infection, the unit was involved in evaluating the introduction of this treatment to primary care:

- 1999** Assessment of patients on methadone maintenance considered unsuitable for discharge to general practice;  
The impact of methadone maintenance in general practice on staff attitudes;  
Can research questionnaires trigger learning?  
Randomised controlled trial of methadone maintenance by GPs and drug treatment centres.

More recently, the research interests of the project have diversified to other areas of concern, particularly other causes of morbidity and mortality. It has highlighted heroin overdose and other bloodborne viruses (hepatitis B and C) as areas requiring particular attention in the coming years:

- 1999** Experience of heroin overdose among drug users attending general practice;  
Impact of new methadone prescribing legislation on opiate overdoses;  
Prospective study of opiate overdose in an urban Emergency Department;  
Cross sectional survey of drug users attending general practice in Dublin area;  
Prevalence of hepatitis C among drug users.

Research by the unit has reported a higher prevalence of HIV among young drug users than has been reported in Ireland since the late 1980's. Continued vigilance and research into this area, it seems, are therefore as important as ever. A bibliography of works published by the Research Unit is provided at Appendix 1.

Evaluation and research has been ongoing and account is taken of the results of such research. For example, the outcome evaluation of the clinical management of pregnant women with HIV who had been treated with antiretroviral therapy gave a strong basis to the argument why routine antenatal testing for HIV should commence as soon as possible for all pregnant women. Health Research Board grants are available for fellowships, projects and research on areas such as immunology and pathology, microbiology and pathology and public health. The contribution of psycho-social disciplines are part of this integrated approach and should come under the remit of such research.

The Dublin Dental Hospital, in collaboration with the Moyne Institute of Trinity College, was awarded a grant through the Health Research Board to study opportunistic infections in the AIDS Unit. This research resulted in the isolation (with very important therapeutic implications) from HIV-infected patients of a new species of a yeast called *Candida*, which was named *Candida dubliniensis*, along with many publications in the international scientific literature in this field and on the molecular biology of an essentially HIV specific oral lesion.

*It is recommended that doctors operating from the satellite clinics should be permitted to prescribe methadone. [Rec. no. 9(xii)] and*

*It is recommended that protocols for the treatment of drug misusers be established by a subgroup of this Committee as a matter of urgency. [Rec. no. 9(xiii)]*

Prescribing of methadone is an integral part of the services provided in the 52 treatment locations operating in the Eastern Regional Health Authority area. The Misuse of Drugs (Supervision of Prescription and Supply of Methadone) Regulations 1998 sets out the terms under which methadone can be prescribed by General Practitioners in any part of the country to intravenous drug misusers.

A protocol for prescribing of methadone to drug users was published in 1993, recommending the controls necessary for the effective operation of an opiate misuse treatment service. In February 1998 the Methadone Treatment Services Review Group produced its Report; and in

line with the recommendations in this report the prescribing and dispensing of methadone was placed on a statutory basis in July 1998. At the end of February, 2000 a total of 4420 people were on the Central Methadone Treatment List, with 67 of these from areas outside the Eastern Regional Health Authority area.

*The Committee supports the conclusions and recommendations of the Comhairle na nOspideal Committee on the management of AIDS at consultant level and recommends their implementation at the earliest possible date and in particular:*

*(a) the creation and appointment of an Infectious Diseases Consultant in North Dublin and a similar post in South Dublin*

*(b) the appointment of a Consultant in Genitourinary Medicine to North Dublin.  
[Rec. no. 9(xiv)]*

*(c) the appointment of a Consultant in Infectious Diseases to be based at University College Hospital, Galway. (although this recommendation was made at 5.18 in the 1992 Comhairle report it did not appear as a recommendation in the Sub-Committee's 1992 report).*

*The Committee recommends that additional support be given to the present hospital based services at St James's which are under increasing pressure. [Rec. no. 9(xv)]*

There are now Consultants employed as follows:

- \* 2 St James's Hospital (Genito Urinary Medicine and Infectious Diseases) with some sessions in the the Eastern Regional Health Authority.
- \* 1 Mater/Beaumont (Infectious Diseases)
- \* 1 Our Lady's Hospital for Sick Children, Crumlin (Infectious Diseases)
- \* 1 Cork University Hospital (Infectious Diseases).

Sessional Sexually Transmitted Infection (STI) clinic arrangements have been put in place between the North Western Health Board and the Royal Victoria Hospital, Belfast.

A Palliative Care Consultant, based in Our Lady's Hospice in Harold's Cross, Dublin has overall responsibility for management of HIV/AIDS patients. In September, 1999, 5 of the 145 patients in the hospice had AIDS related illnesses.

3 Consultant Psychiatrists, with responsibility for Drug Misuse oversee the clinical management of treatment services for drug misusers in the Eastern Regional Health Authority area. A fourth Consultant post will be filled in the coming months.

A Consultant-led dedicated unit in the Dublin Dental Hospital provides specialist services for people with HIV/AIDS.

It is clear that significant progress has been made in implementing the recommendations set out in the 1992 Comhairle na nOspidéal Report. As part of this review the Department of Health and Children met representatives of Comhairle na nOspideal, who, in turn met a

number of consultants working in the area and examined service needs in the context of the 1992 Report and this consultation. The Report of Comhairle and its recommendations for future development of consultant based services is attached at Appendix 2.

Another Comhairle Report on Haematology Services<sup>1</sup> recommended that a consultant virologist post be shared between the Blood Transfusion Services Board (BTSB), now renamed the Irish Blood Transfusion Service (IBTS) and the Virus Reference Laboratory (VRL), with a commitment to a Dublin teaching hospital. This recommendation has been approved by the Minister and has been the subject of discussion between the Irish Blood Transfusion Service, the Virus Reference Laboratory and University College Dublin. The 1992 Comhairle Report on “AIDS at Consultant Level” made a specific recommendation that the VRL should be staffed by “a minimum of three microbiologists each of whom would have a hospital commitment”. One of these posts has been filled and a second post was approved by Comhairle na nOspidéal in 1999 and is in the process of being filled.

In the light of the fact that the second consultant post approved by Comhairle na nOspidéal in 1999 will deal exclusively with issues relating to the Irish Blood Transfusion Service the Sub-Committee recommended (and this was endorsed by NASC) that the third consultant post recommended by Comhairle in its 2000 report should be appointed at the earliest opportunity to cater for the increased demands being made on the VRL.

*The Committee recommends that the present services in Cherry Orchard Hospital should be expanded as required to cope with increasing demand. [Rec. no. 9(xvi)]*

Facilities were developed in Ward 3 (The Rowan Ward) Cherry Orchard Hospital in 1990 to provide respite and terminal care to people with HIV/AIDS. The sub-committee understands that this service worked well initially but that a number of problems have developed regarding the role of this unit. In 1998 an Eastern Health Board committee examined the changing needs in Ward 3, taking account of new treatments. The Ward has been operating to full capacity (16 beds) and a waiting list is maintained at ward level. The Eastern Regional Health Authority will further evaluate the situation, particularly in the context of the appointment of an Infectious Diseases Consultant in 2000, with a sessional commitment to the Authority.

*The Committee supports the recommendations of the Comhairle na nOspideal Committee on the management of AIDS at consultant level that the existing services for palliative care of terminally ill patients both home care and in-patient care should be extended to include patients with advanced and terminal AIDS. [Rec. no. 9(xvii)]*

Although the new drug therapies are delaying the onset of advanced and terminal AIDS there will be some people for whom treatment will not be effective. There is a need therefore to ensure that respite care and the care of terminally ill patients be co-ordinated between the acute hospital setting, the hospice and community services. This process should involve the Consultant in Palliative Care, the General Practitioner, community services and voluntary agencies. The AIDS Liaison Nurse has also a key role to play in co-ordinating services and linking with counselling psycho-social practitioners.

Details of the services available for palliative/respite care are set out in Appendix 3.

## 3

## Ethical Guidelines for Professionals working in the area of HIV/AIDS

Neither respite nor palliative care has been an issue for some health boards but the sub-committee recommends that Regional AIDS Co-ordinators consult with health service providers, including the Dublin/Cork hospitals where patients are attending for HIV treatment to project the respite/palliative care needs of patients from their respective boards, so that adequate provision can be made for this through liaison with hospital and community based services. To achieve this there needs to be better communication between hospitals and Regional AIDS Co-ordinators, taking account of the need for confidentiality and for non-identification of individuals.

The aim of those providing medical and support services to people with HIV and AIDS is to provide them with medical, psychological and practical support in a non-judgmental context. Confidentiality has been of paramount importance and respect of the rights of people living with HIV has been seen as central to ensuring that people with the virus are not discriminated against.

Three workshops were held to examine the issues arising for professionals, both in the statutory and voluntary sectors. Speakers from other countries attended these workshops. As a result of this process a report was prepared entitled "*Confidentiality - Ethical Considerations in HIV Transmission: Guidelines for Professionals*".<sup>2</sup> The report explores the concerns expressed by professionals working in the field of HIV/AIDS about, firstly, their responsibilities to people with HIV and, secondly, their responsibility to those who are at risk of contracting HIV without their knowledge.

The guidelines were prepared to help professionals caught between both of these responsibilities and to help them find a suitable response that acknowledges both of these areas of concern. They were circulated to professional bodies, which would have their own ethical codes and the comments from these organisations were absorbed, insofar as was possible into the main document.

The report will give assistance to those working in the area of partner notification and the ethical dilemmas facing health service providers when dealing with this issue.

## 4

## HIV testing policy and practice in Ireland

As part of a review of policy and practice in relation to HIV testing in Europe a survey of HIV testing policy and practice in Member States of the European Community was carried out by the London School of Hygiene and Tropical Medicine and ORSPCA-INSEREM in France<sup>3</sup> on behalf of the European Commission. The following points emerged in relation to Ireland, where practice in relation to testing is in keeping with overall practice in the rest of Europe.

- In Ireland HIV testing is not required by law.
- An HIV test cannot be done without a person's consent.
- HIV positive individuals are encouraged to notify their partners. With the availability of new effective treatments notification may not exclusively be the responsibility of HIV positive individuals. This matter was examined in great detail by the group which drew up the document "*Confidentiality - Ethical Considerations in HIV Transmission: Guidelines for professionals*".

- The HIV test is offered to pregnant women, STD patients, prostitutes, intravenous drug users.
- There is no set policy on home testing kits for HIV. In October, 1998 European Directive 98/79 EC was adopted by Ireland. The Directive provides for the regulation of in vitro diagnostic medical devices, including HIV testing kits, and forms part of an overall drive to complete the single market in Europe, by laying the groundwork for establishing harmonised standards in the manufacturing of in vitro medical devices. The Directive has a defined scope and lays down essential requirements for in vitro diagnostic medical devices and the procedures for checking that all products comply with them. Devices meeting these requirements will be entitled to carry the "CE marking", which is the European wide recognised symbol for the safety, quality and performance of medical devices and may be placed on the Community market without further restrictions. The Department of Health and Children is preparing regulations which will transpose the Directive into Irish law but they will not become mandatory until December 2003, in accordance with the terms of the Directive.
- When a person tests positive antiretroviral treatment is available free of charge when such treatment is clinically indicated.
- Pre-test counselling is no longer automatically provided, but clients can "opt in" to such services. Referral to counsellors should be subject to review to devise a protocol for such referral for counselling therapy and to help standardise best practice.

## 5

### Infection Control and HIV/AIDS

The Advisory Group on the Transmission of Diseases in the Healthcare Setting has produced two reports (in September, 1997 and February, 1999) on "*The Prevention of Transmission of Blood-borne disease in the health-care setting*".<sup>4,5</sup> The Group considered the prevention of transmission of hepatitis B, hepatitis C and HIV. It noted that the major risk for transmission of HIV in the health-care setting is associated with percutaneous exposure to blood or blood-containing fluids contaminated with HIV. Transmission can occur rarely through mucous membranes.

Most contact between healthcare workers and patients carries no risk of transmission of blood-borne pathogens. Exposure-prone procedures are the only procedures associated with a risk of transmission and this risk is extremely low, provided that Standard Precautions for infection control are used. Standard Precautions combine the major features of Universal Precautions, which were designed to reduce the risk of transmission of blood-borne pathogens and Body Substance Isolation, which was designed to reduce the transmission of pathogens from moist body substances. Standard Precautions apply to blood; all body fluids, secretions and excretions except sweat, regardless of whether or not they contain visible blood; non-intact skin; and mucous membranes.

#### The Group recommended that;

1. testing healthcare workers for infection with HIV and HCV should not be instituted
2. any health care worker who suspects that he/she may have been exposed to HIV or HCV be required to seek professional advice and diagnostic HIV or HCV testing.
3. an infected healthcare worker should not perform exposure prone procedures.

The Report sets out essential safety procedures in the health-care setting, which, with Standard Precautions, are effective if applied correctly and consistently. The Sub-Committee supports the recommendations of the Advisory Group. It also recommends that people undergoing testing in relation to occupational exposure risk should be offered therapeutic counselling.

## 5.1

### Body Bags

A number of questions were raised in the 1992 Report in relation to body bags, mainly referring to the medical reasons for the practice of using body bags for people with HIV or AIDS.

There has been ongoing debate on the subject among hospital staff, pathologists, funeral directors and voluntary agencies. It is generally agreed that the policy of using body bags makes no contribution to reducing occupational risks where Universal Precautions are used.

## 6

### Treatment for HIV/AIDS

In Ireland there is universal access to free treatment for anyone who is diagnosed HIV positive or who has AIDS and for whom such treatment is therapeutically indicated.

Two major classes of drugs are currently available - reverse transcriptase inhibitors (RTIs) and protease inhibitors (PIs). A third class integrase inhibitor is under development, as are drugs with other mechanisms of action.

Combination therapy or Highly Active Antiretroviral Treatment (HAART), using a range of drugs is proving to be effective in suppressing the replication of HIV. This is resulting clinically in decreased incidence of opportunistic infections, decreased hospitalisation and the ability to return to a normal lifestyle. Serologically, it is reflected in decreased viral loads, often to undetectable levels and increases in the number of CD4 cells.

Adherence to treatment is a problem for a number of people on antiretroviral therapy. Medication has to be taken many times a day. Some drugs have unpleasant side effects. Incomplete or poor compliance may lead to treatment failure. It is important therefore that there is good communication between healthcare staff and people with HIV and AIDS, helping them to deal with stress and side effects of treatment. Counsellors should be part of care planning to provide support, advice and encouragement in negotiating difficulties regarding HAART.

For some people treatment may not be effective. Counselling and support must be available to help people come to terms with this situation and to address secondary prevention and risk reduction issues.

**The major challenges facing service providers in the future are:-**

- access to appropriate treatment at the earliest stage,
- ensuring that treatments are administered correctly,
- adherence to treatment by patients,
- development of resistance.

## 7

### Laboratory Services/ Viral Load Testing/Resistance Testing

In addition to HIV test analysis, laboratories now play an even greater role in the care and management of patients with HIV. The advances in HIV treatments have focused on antiretroviral therapy, HIV RNA testing and more recently on genotype and phenotype resistant assays as essential components of HIV management. Viral load testing facilities are available at the Virus Reference Laboratory (VRL) and Cork University Hospital.

It is estimated that up to 15% of all new infections involve viruses which display resistance to at least some and, in certain cases, all of currently used medications. The monitoring and detection of resistance has been accepted as essential in optimising drug treatment as it provides a rational basis for drug selection and ensures that the most effective therapy is prescribed. With the introduction of routine antenatal HIV testing vertical transmission of HIV from mother to baby can be prevented, but resistance testing of the virus is essential. The Virus Reference Laboratory commenced provision of national genotype resistance monitoring in December, 1999. It is anticipated that viral resistance will become an increasingly important issue in the next decade and constant monitoring will be essential to reduce the impact of this problem in the management of HIV. In this regard the VRL is part of a European group which is currently making specific recommendations on the indications for, and methods to be employed in, resistance testing.

## 8

### Children and HIV

Paediatric Infectious Diseases services are based at Our Lady's Hospital for Sick Children, Crumlin and the Children's Hospital, Temple Street. The service was established in 1993 and a Consultant in Paediatric Infectious Diseases was appointed in December 1994.

Services provided at Crumlin are listed at Appendix 4a.

Because of the overlap in risk factors between HIV and hepatitis C infection it is now apparent that many HIV infected mothers were dually infected with HIV and hepatitis C. The monitoring of infants born to HCV infected mothers is also necessary as these also form a risk group for HIV, significantly expanding the number of families attending the service.

Services have expanded rapidly in recent years, particularly with the effectiveness of new treatments, which have led to the need to establish a family based service, spanning antenatal care, the neonatal period, childhood and adolescence. This expansion has put increased pressure on both staff and space in the Centre in Crumlin Hospital, to such an extent that additional facilities are required to cope with needs. The need for an expanded range of services arises from a number of factors which include:

- the increased number of HIV positive infants and children presenting for treatment (25 referrals in 1998 compared with 11 in 1997);
- the chronic nature of the illness, which requires long-term care for children into adolescence and adulthood;
- the need to provide appropriate sex education and awareness to adolescents who are HIV positive;
- the impact of HIV on uninfected siblings of children attending the service, many of whom are at increased risk of acquiring HIV in adolescence either through drug use or sexually;



- the advent of complex combination antiretroviral therapy regimens which demand detailed education for families and attention to promoting adherence;
- the increased number of HIV positive women being detected in pregnancy;
- the arrival of people from countries of high prevalence of HIV, with the added difficulties of language and cultural differences;
- incorporation of services to include management of hepatitis B and hepatitis C exposed infants.

Recommendations have been made by the Medical Consultants in Our Lady's Hospital, Crumlin and St James's for the effective management of HIV in children.<sup>6</sup> These recommendations are attached at Appendix 4b.

In Ireland, by adopting a policy of routine antenatal testing for HIV, a major step has been taken to combat paediatric HIV infection. The outcome for an HIV infected woman who is treated with antiretroviral therapy during pregnancy is very good with a reduction of up to 66% in the risk of her baby being infected with the virus. Following on from this, if a comprehensive programme of treatment and support is provided for children diagnosed as HIV positive and their families, this will lead to an overall gain in health and quality of life for those children and their families.

## 9

### Adult HIV/AIDS treatment services

Because of the complex nature of treatment for HIV and AIDS adult treatment services have remained under the clinical supervision of Consultants in Infectious Diseases based in St James's and the Mater/Beaumont Hospitals in Dublin and the Cork University Hospital in Wilton, Cork. HIV/AIDS testing and follow-up support and counselling are carried out at primary healthcare level through GPs and Sexually Transmitted Infections' Clinics. Where more specialist counselling is required an agreed referral protocol is appropriate.

#### St James's Hospital, Dublin

This is the largest teaching hospital in Ireland. The Department of Genito-Urinary Medicine has approximately 20,000 STD attendances per year and provides both inpatient and outpatient care for around 842 HIV seropositive patients. Over the last 3 years the number of new HIV cases presenting for treatment has increased, despite education and prevention measures.

A significant number of patients are less than 23 years of age, with about 50 % of patients being intravenous drug users. There is one full-time Consultant in Genito-Urinary Medicine in St James's Hospital. A second Consultant in Infectious Diseases has just been appointed with 6 sessions in St James's Hospital and 5 sessions in the Eastern Regional Health Authority's clinics. Services need to be expanded to cope with patient needs.

#### Mater/Beaumont Hospitals, Dublin

A consultant post in Infectious Diseases is shared between these hospitals. Around 400 patients are provided with HIV services between both hospitals, with 10-15% of these patients from outside the greater Dublin area.

The Mater Hospital has an 11 bed in-patient facility, divided into small units but the out-patient services are provided from a temporary building. Major upgrading and refurbishment are in the process and it is expected that improvements in Sexually Transmitted Infections' facilities will be part of these developments.

In Beaumont Hospital inpatient facilities are incorporated in a general medical ward, with only one of the beds being in a single room. This does not allow for family consultations or isolation facilities if required. Outpatient facilities are satisfactory. Additional consultant cover is required to cope with patient needs.

#### **Cork University Hospital**

An Infectious Diseases Consultant was appointed in 1997. 2 acute hospital beds are available at present, but around 4 others are required. Combination antiretroviral therapy with 3 or more agents is offered where clinically indicated. A pharmacist, as well as the AIDS Liaison Nurse and the doctor provide education on medications. Monitoring of the effects of drug therapy is done at frequent intervals at the Infectious Diseases Outpatients Clinic in the hospital. Home support is arranged by the AIDS Liaison Nurse.

The Consultant is also the Regional AIDS Co-ordinator and works closely with the Department of Public Health and voluntary and community groups on epidemiological surveillance and prevention and education initiatives.

Initial management of HIV exposed infants is done by the Consultant Neonatologist. The children are referred to the Paediatric Consultant in Infectious Diseases in Our Lady's Hospital, Crumlin. This is done in conjunction with the Consultant in Infectious Diseases and the Liaison Nurse.

#### **Western Health Board**

Although Comhairle na nOspideal recommended that an Infectious Diseases Consultant be appointed in the Connacht region this recommendation was not made in the recommendations of the 1992 Care and Management Sub-Committee.

The Sub-Committee strongly recommends that this post should be established.

#### **North Western Health Board**

Arrangements have been made between the Board and the STI Consultant in the Royal Victoria and Altnagelvin Hospitals for the provision of STI clinic sessions in the Health Board. The Sub-Committee recommends that these arrangements should continue.

#### **Future direction of services**

There has been a steady increase in the incidence of many sexually transmitted infections in recent years (See table at Appendix 5). Hospital consultants on the Sub-Committee wish that the issue of consultant cover to deal with infectious diseases be examined in greater detail in the light of this upward trend. This needs further analysis in the context of the National AIDS Strategy Committee taking on the broader remit of sexually transmitted infections. This issue should be dealt with as a priority whenever the new committee meets, in consultation with Comhairle na nOspideal.

## 10

## Obstetrical Services

There is a multidisciplinary approach to the provision of obstetrical services for women who are HIV positive. In the Eastern Regional Health Authority Liaison midwives are being appointed to work between maternity hospitals and the community in the management of pregnancy, particularly for drug misusers. When someone is diagnosed HIV positive in pregnancy there is close liaison between the Infectious Diseases Consultant, the Obstetrician, the Neonatologist, General Practitioner and the Liaison Nurse. Cork University Hospital and Our Lady's Hospital have a Liaison Nurse post.

## 11

## HIV/AIDS Strategy and the Gay Community

As a result of publication of the Report of the National AIDS Strategy Committee in 1992, under the aegis of this Sub-Committee the following initiatives were undertaken:-

*Outreach services were established for gay men and lesbian women in Dublin, Cork and Galway. These services include counselling and advice on where health services can be obtained. The Eastern Health Board established the Gay Men's Health Project at Baggot Street Clinic which provides an outreach and drop-in sexual health clinic.*

*A research project on "HIV Prevention Strategies in the Gay Community"<sup>7</sup> was conducted on behalf of the Department of Health and Children by the Gay and Lesbian Equality Network (GLEN) and Nexus Research, resulting in the publication of a report in 1996. A number of gay and lesbian associations around the country were involved in the research process.*

In order to pursue the process of implementing the recommendations in this report further support has been given to the Gay HIV Prevention Strategies. A project officer has been assigned to work on implementation of the recommendations. The report identified a number of areas where action was required and work has been undertaken in these areas, including:-

- working with the gay commercial sector to improve education and awareness in relation to safer sex,
- linking with health boards to improve support for the gay community,
- contacting voluntary organisations dealing with the gay community and helping to link them with other similar groups around the country.

The person who was the project officer for the first two years of this project is a member of the National AIDS Strategy Committee and so has an input into the development and monitoring of national policy on HIV/AIDS. The new officer in post since August, 1999 will work in close collaboration with NASC.

An evaluation of the first 2 years of the Gay HIV Prevention Strategies Project has just concluded. Evaluation shows that the Project has been very successful in:

- the development of transferable intervention models within the gay community
- strengthening group development capacities
- forging partnerships with a range of statutory and voluntary agencies.

On the basis of this evaluation it is clear that the work of this Project should be continued.

The Gay Health Network (GHN) is a group of gay men working in HIV/AIDS prevention and support services nationally. This Network provides an opportunity to gay frontline workers to share experiences and to help plan co-ordinated services. It has provided and distributed thousands of safer sex packs/condoms and leaflets addressing such issues as HIV testing, safer sex guidelines and hepatitis B vaccination advice. The GHN and a range of other voluntary organisations provide information and support to gay people who are diagnosed HIV positive.

## 12

### Mobile Populations

Mobility has increased world-wide. A number of mobile population groups lack information on the available health services in the new country. They may not even have access to those services, perhaps due to their uncertain legal status, financial concerns or language problems. The United Nations AIDS programme has referred to the widespread discrimination and disadvantage suffered by migrant groups and ethnic minorities because of their vulnerability to HIV and other infections due to little or no access to appropriate information, education and health care services.<sup>8</sup>

Within the European Union travellers and migrants were seen as groups with varying needs in the area of education and health care. Travellers include leisure travellers and business travellers. Migrants include immigrants and returned emigrants, migrant male and female sex workers, migrant drug users, displaced persons, asylum seekers, refugees, immigrants and European expatriates. A number of these groups are frequently subjected to unjustified and harmful forms of stigmatisation and discrimination.

Health Board staff based in the Baggot Street Clinic in Dublin are part of a European Network on AIDS and Mobility and the information shared through this network has assisted service providers to respond appropriately to the needs of mobile groups.

Medical personnel who travel as part of their training are given advice on how to avoid infection and on post exposure prophylaxis. Some Medical Schools are working on upgrading the skills of personnel travelling abroad and in addition, one School issues a prophylaxis pack, with others considering the matter.

The Sub-Committee recommends that agencies who have responsibility for personnel travelling abroad should provide those individuals with information on prevention and transmission of HIV/AIDS.

In relation to persons migrating to Ireland all persons, including refugees and asylum seekers, have access to healthcare services in line with Ireland's international commitments to provide such services.

## 13

Intravenous Drug Misuse  
and HIV

The heroin problem has been growing, particularly in the Greater Dublin area since the early 1980s. In 1983 there were 1,500 heroin addicts identified. 196 people were in treatment in the only treatment centre at Jervis Street. By 1991, 2,000 people were attending treatment services for heroin addiction in a small number of treatment centres. At the end of February, 2000 a total of 4420 people were on the Central Methadone Treatment List with 4353 of these people being treated in the Eastern Regional Health Authority area in one of 52 treatment locations or through their general practitioners. The average age of those in treatment is the lowest in Europe at 23.6 years.<sup>9</sup> A recent evaluation of the Eastern Health Board's drug services<sup>10</sup> noted that "a programme of service expansion was embarked on that is probably one of the more innovative community drug services programmes in Europe" and that "by international standards of assessment of methadone clinics the rates of both positive and negative opiate tests indicate that they are operating to a very high standard of performance on this particular parameter".

Health Boards have responded to the increasing opiate problem by expanding their services, particularly in the last four years since the publication of two Ministerial Task Force Reports on Measures to Reduce the Demand for Drugs.<sup>11,12</sup> Estimates of the number of opiate misusers in the Greater Dublin Area range from 8,000 to 13,500, but not all of these are intravenous drug users and only a proportion of them will look for treatment.

A National Drugs Strategy Team was mandated to implement the Government's Strategy and this Team is chaired by an official from the Department of Health and Children. Local Drugs Task Forces were established in the 14 areas experiencing the highest levels of problem drug use (13 in the Eastern Regional Health Authority area and 1 in Cork city). These Local Drugs Task Forces prepared action plans, which were aimed at providing a co-ordinated response to the drug problem at local level, with the involvement of local voluntary and community groups. The Department of Health and Children and health boards, with the support of voluntary and community groups, continue to implement the relevant recommendations in the Ministerial Task Force Reports.

The Reports recognised that in order to comprehensively address the problem of drug misuse a number of other areas linked with social inclusion and economic deprivation, especially in inner city areas needed to be tackled.

**The main activities underway at present include:-**

- expansion of treatment services aimed at eliminating drug treatment waiting lists;
- special attention is being paid to the needs of young misusers in the priority areas, and in particular to Community Employment (CE) applications offering integrated services for recovering drug misusers;
- a series of education and prevention steps, including a drug misuse prevention programme have been introduced in primary schools in priority areas, and is being implemented nationally;
- an Estate Improvement Programme is being developed for severely run-down urban housing estates;

- the development of sports and recreation activities by Local Authorities in priority areas;
- the establishment of a Youth Services development Fund, to develop youth services in disadvantaged areas;
- the development of other initiatives aimed at meeting the needs of young people in disadvantaged areas;
- the training and employment of youth leaders from disadvantaged communities.

It is hoped that the multi-agency approach being used, which provides support to health services will result in a lowering of the number of young people turning to drugs in Task Force areas and it will provide not just treatment, but a means of social re-integration and a return to a normal life for people who had turned to drugs as a way of coping with life.

The Eastern Regional Health Authority area is the one worst affected by the drug problem. Treatment services were expanded throughout the Authority during 1999, with an emphasis on providing treatment to people in their own local area. 10 new treatment locations were established. As already stated this brings the number of treatment locations to 52. As services develop in local areas, however, more people come forward to access these services, so it is impossible to say when waiting lists can actually be eliminated. The Authority will continue to expand its services with the objective of providing prevention, treatment, rehabilitation and aftercare services to everyone who needs such services. The Eastern Regional Health Authority's total budget for drugs and AIDS services in 2000 is over £22 million.

Irish Government policy in relation to drug misuse is that a wide range of treatment options should be provided, including methadone treatment, detoxification and other programmes aimed at those addicted to drugs, especially people who are addicted to heroin. Methadone maintenance is internationally recognised as a valid and successful part of an integrated response to the drug problem. It has also been shown that it is possible to reduce the anti-social behaviour of intravenous drug users by taking them into treatment on methadone maintenance programmes.

#### **Methadone Protocol**

The 1998 Report of the EMCDDA<sup>13</sup> on the State of the Drugs Problem in the European Union noted that substitution treatment is the most evaluated field of drug demand reduction, with generally positive results including increases in employment, improvement in emotional status, physical appearance, health, family and social relations, finances and vocational skills, with reduction in criminality, debts and heroin use. Generally also, HIV patients comply with monitoring and treatment. In Member States in 1997 a total of 265,664 people were on substitution treatment, mainly methadone.

The Report of the Review Group on Methadone Treatment Services<sup>14</sup> recommended, inter alia, that strict controls should be introduced on the prescribing and dispensing of methadone. The Misuse of Drugs (Supervision of Prescription and Supply of Methadone) Regulations, 1998,<sup>15</sup> were introduced to give effect to the recommendations of the Review Group. They came into full effect on 1st October, 1998 from which date methadone could

only be prescribed to people who were on a Central Methadone Treatment List and who held a valid treatment card.

Epidemiological surveillance of HIV would indicate that in recent years the overall incidence of HIV among intravenous drug users is reducing. While we must be wary of drawing major conclusions from short term changes in infection patterns service providers are optimistic that this trend is as a result of the intervention through a combination of substitution therapy with methadone and needle exchange services. Although the problem of intravenous drug use is a serious concern in major cities throughout the world it is hoped that, with the availability of treatment and rehabilitation options on demand to those who need them, together with the range of community based programmes aimed at tackling the drug problem in the wider context of social inclusion, there will be a continued reduction in incidence of HIV among intravenous drug users.

Intravenous drug misuse has not become a major problem outside the Greater Dublin area. However, all health boards are involved in the methadone protocol and can provide appropriate treatment to IV drug users who contact their services.

## 14

### HIV/AIDS Care in Prisons

People who require HIV/AIDS treatment in prisons are referred to hospitals for this treatment. A unit in Mountjoy Prison provides triple therapy. Limited methadone maintenance is also available to patients who are HIV positive in the medical unit, but not to other prisoners, who may be intravenous drug misusers. A recent study of hepatitis B, hepatitis C and HIV in the Irish prison population<sup>16</sup> showed that the prevalence of HIV in a cohort representative of the five main prisons in the country was 2%, both in males and females. However, in prisons where there were large numbers of people with a drug misuse history, the prevalence rate was 4%.

There needs to be greater emphasis on education and awareness campaigns among prison populations in order to reduce the risk of sexual transmission of the virus. Drug misuse treatment services need to be on a par with those provided by health boards and should be put in place as a matter of urgency. The Department of Justice Equality and Law Reform and the Eastern Regional Health Authority have agreed on a draft action plan for the provision of appropriate drug treatment services in prisons. This will involve working to provide the same range of services, including counselling and treatment, that are available at community level from health board services.

## 15

### Homelessness and HIV/AIDS

Accommodation for HIV positive people, particularly those with an intravenous drug using history, remains a significant problem. While there has been an increase in the availability of supported accommodation in the voluntary sector, supply has not kept pace with demand. This situation has been exacerbated by the generally poor availability of accommodation in the Dublin area. Homelessness carries with it attendant problems of poverty and lack of a support base. The capacity of those who are homeless to commence or continue with the medication regimens in HAART is severely compromised. Existing health board hostel

accommodation is often inadequate to meet the needs of available suitable accommodation for HIV positive homeless persons. The special housing/placement needs of those suffering from HIV dementia needs to be considered. There is currently no facility which caters for this small group. Those suffering from HIV dementia and not requiring full-time placement will require suitable supported accommodation.

As well as the hospital based statutory services a number of voluntary agencies engage in providing assistance to homeless people with HIV/AIDS.

The AIDS Fund Housing Project has received funding from the Department of Health and Children and the Eastern Regional Health Authority. The Project provides accommodation for homeless people with AIDS. The 15 apartments in the scheme are currently occupied and the majority of the occupants are on combination antiretroviral therapy. At the end of 1999 there was a waiting list of around 80 people in the Dublin area for accommodation in the Project. The majority are drug misusers on methadone maintenance who have AIDS. The Simon Community provides food and shelter to a number of people with HIV/AIDS. Problems have arisen in certain cases, mainly linked with intravenous drug misuse, where anti-social behaviour has occurred.

Cairde's child and family support service and the help and assistance provided by groups such as Dublin AIDS Alliance, Merchants Quay Project, the Alliance in Cork, the Red Ribbon Project in Limerick, AIDS Helpwest in Galway and AIDS Help Northwest play a major part in helping people with HIV who are homeless to access basic services.

The Wethouse model in the U.K. provides chaotic drug misusers with access to basic facilities such as food and shelter with an opportunity for statutory services to provide outreach and counselling services. This model should be examined as an approach to dealing with the problem of homeless chaotic drug misusers, many of whom may be HIV positive.

Local Drugs Task Forces in the Greater Dublin area are developing appropriate responses on a cross-Task Force basis to the problem.

## 16

### Specialist Dental Care for People with HIV

A Consultant-led Unit in the Dublin Dental Hospital provides specialist treatment for people with HIV and AIDS. Another clinic has been set up at St James's Hospital and services are also provided for prisoners in Mountjoy, Arbour Hill and Wheatfield prisons. In May 1999 over 1000 known HIV positive patients were under the care of these clinics. The Unit maintains close links with Infectious Diseases and Genito-Urinary Medicine Consultants in the course of its work. Consultants in the Dental Hospital and School have acted as advisors to the Dental Council and the Irish Dental Association culminating in publications which have been sent to every registered dental practitioner on two important issues: the Pictorial Recognition of Oral Manifestations of HIV Infection<sup>17</sup> and Guidelines on Cross-Infection Control in Dental Practice, including Ethics.<sup>18</sup> UCC School of Dentistry provides specialist services in the Southern Health Board area.



## 17

**Counselling services**

The availability of Highly Active Antiretroviral Treatment (HAART) and the introduction of routine HIV testing in many STI clinics and in antenatal clinics has led to a change in the services being provided by social workers/counsellors, who now concentrate their skills on working with those who are at high risk or have a multitude of problems. These recent changes in practice would suggest that there is a need to devise a protocol around referral criteria on a team level in all sites where HIV testing is carried out. This would help to standardise a "best practice" base.

Ongoing training and information updates are required by those involved in providing counselling services. To address this the Eastern Regional Health Authority is providing training to its drug counsellors in its addiction services to:

- address risk taking activity in a therapeutic context;
- deal with problems of adherence;
- provide support and assistance to people living with HIV/AIDS;
- address secondary prevention issues;
- provide support and assistance to people living with HIV/AIDS.

## 18

**Regional AIDS Co-ordinators**

Regional AIDS Co-ordinators were appointed in each Health Board in 1993. The main objectives of the Co-ordinators are :

1. To maintain an epidemiological information base on HIV/AIDS for the health board area covered;
2. To report new cases and deaths from AIDS within the respective health boards to the National AIDS Co-ordinator (a designated Medical Officer) in the Department of Health and Children at present and when a new reporting system is devised, to the National Disease Surveillance Centre, to be used for National and European surveillance purposes;
3. To be proactive in encouraging an holistic and effective multi-sectoral response to the changing nature of HIV/AIDS in the health board area.

**The duties and functions of AIDS Co-ordinators include:**

1. To collect and collate regional data on HIV positive cases confirmed by the VRL.
2. To collect and collate regional data on new AIDS cases and deaths and to report on these to the National AIDS Co-ordinator.
3. To develop a health board HIV/AIDS strategy for the health board area and review existing services, identify needs and make recommendations based on National AIDS Strategy.
4. To promote the use of appropriate HIV/AIDS diagnostic, therapeutic and prevention policies in the health board area.

5. To promote educational programmes for professional, public and voluntary groups.
6. To co-ordinate HIV/AIDS services in the health board area.
7. To act as a resource person for general practitioners, public health nurses and voluntary bodies in the health board area.
8. To particularly consider the needs of marginalised and minority groups within the region, in terms of HIV/AIDS prevention and care and to ensure that efforts are made to address these needs.

Regional AIDS Co-ordinators have played an important role in co-ordinating appropriate regional responses to HIV/AIDS issues. Most recently they played an active role in the development and implementation of the routine HIV antenatal testing programme. The Sub-Committee recommends that they should continue in their role. Reporting arrangements for AIDS cases will change when the National Disease Surveillance Centre takes over the management of the HIV/AIDS database.

## 19

### AIDS Dementia

There are no accurate statistics on the national prevalence of dementia. It is however estimated that around 8%-16% of people with AIDS will develop dementia. A small percentage of AIDS dementia patients, will, in turn develop psychosis. A good psychiatric service can cope with AIDS dementia patients, as part of an overall care programme for all patients with dementia.

There needs to be good liaison between hospitals and community based workers, as early assessment is the key to good management of this condition. Most people with dementia are looked after by relatives, so support structures are needed in health boards to assist in the care of these patients.

## Care and Management Sub-Committee Recommendations

The Sub-Committee recommends that:-

1. In view of the close links between HIV/AIDS and other infections, particularly sexually transmitted infections the National AIDS Strategy Committee should broaden its remit to deal with such infections also.
2. Because of the increase in sexually transmitted infections, the National AIDS Strategy Committee should, as a priority examine the adequacy of resources provided to deal with this area, in consultation with Comhairle na nOspideal.
3. People with HIV/AIDS should be encouraged and assisted to access re-training services, where appropriate.
4. There needs to be a multi-agency approach to tackling the problem of homelessness and HIV/AIDS, particularly in relation to chaotic drug misusers. Partnerships between statutory and voluntary agencies should be investigated.
5. Evaluation and research into all aspects of HIV/AIDS should continue.
6. Methadone treatment, in accordance with the (Supervision of Prescription and Supply of Methadone) Regulations, 1998 should continue as a central element of a range of treatment options for opiate misusers.
7. Consultant posts should be established in accordance with the recommendations of Comhairle na nOspideal. Because the second consultant post approved by Comhairle to be appointed in the Virus Reference Laboratory will deal exclusively with Irish Blood Transfusion Service issues it is recommended that the third post identified by Comhairle should be filled as soon as possible.
8. The facilities at Cherry Orchard hospital should be re-focused and re-organised, under the supervision of the newly appointed Consultant in Infectious Diseases.
9. The recommendations of the Advisory Group of the Transmission of Diseases in the Healthcare Setting as set out in its reports on "The Prevention of Transmission of Bloodborne Disease in the Healthcare Setting" should be adopted.
10. People undergoing testing in relation to occupational exposure risk should be offered therapeutic counselling.
11. When Standard Precautions are used in dealing with cadavers body bags are not required since they make no contribution to reducing occupational risk of infection.
12. People who are diagnosed with HIV or who have AIDS should continue to have access to treatment where such treatment is therapeutically indicated.
13. There should be enhanced support for people in treatment and their families to help them deal with issues such as adherence to treatment.
14. A liaison nurse should be identified in all health boards where such a liaison nurse is not already in post to act as liaison person between patients and medical service providers.

- 15.** In relation to Our Lady's Hospital Crumlin:-
- the physical space in which services are provided should be expanded and should include the establishment of a family clinic to care for HIV infected mothers and infants;
  - additional staff should be appointed to deal with the growing number of cases presenting for treatment and aftercare.
- 16.** Routine antenatal HIV testing should be introduced countrywide and all staff involved in implementation should be provided with appropriate training to ensure that in the pre-test discussion women are encouraged to opt to be tested.
- 17.** Following the positive evaluation of the first phase of the Gay HIV Prevention Strategies the second phase should continue to build on the developments of the first two years, incorporating an evaluation element into this phase from the outset.
- 18.** The specific needs of mobile populations should be taken into account in relation to service provision. Health boards should examine the nature of HIV/AIDS services being provided and work to accommodate the linguistic and cultural differences of non-national patients.
- 19.** Agencies which have staff travelling overseas should provide those staff with information on prevention and transmission of HIV.
- 20.** Health boards should continue to enhance and expand their intravenous drug treatment services, including heroin substitution and needle exchange, aimed at reducing the incidence of HIV in this population.
- 21.** There must be more education and awareness in relation to HIV/AIDS among the prison population.
- 22.** Intravenous drug misuse services within prisons must provide the same range of treatment options as those provided by health boards, so that there is a continuum of treatment in and outside of the prison environment.
- 23.** Dental services should continue to be provided at community care and/or Dental Hospital levels for patients with HIV/AIDS.
- 24.** Statutory agencies should continue to work in partnership with voluntary organisations who play a key role in the development and delivery of HIV/AIDS services.
- 25.** Regional AIDS Co-ordinators should continue to co-ordinate and integrate HIV/AIDS services in partnership with other agencies, both statutory and voluntary which play an important role.
- 26.** There should be a review of counselling services to;
- devise a protocol for referral criteria,
  - help standardise best practice, and
  - clarify its on-going role in prevention and treatment adherence issues.
- 27.** There must be good liaison and communication between hospitals and community based workers in relation to early diagnosis and management of AIDS dementia.

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*Please note that the above is not a comprehensive listing of references. For clarity, each research project has been represented by one entry only, with publications being listed in preference to conference proceedings or presentations where possible.*

**Appendix 2 - Report of Comhairle na nOspidéal to Secretary of the National AIDS Strategy Committee.**

21st February 2000

I refer to your letter of 20th October 1999 and previous correspondence. The request from the Care and Management Sub-Committee of the National AIDS Strategy Committee to "examine the present situation regarding Consultants in the light of epidemiological trends in relation to HIV / AIDS and taking account of Comhairle's earlier recommendations on consultant appointments" was considered by Comhairle at its October 1999 meeting.

Before responding to the Department, Comhairle considered it appropriate to meet those leading the provision of medical services for people with AIDS/HIV in order to ascertain their views on current and future provision of service, consultant staffing and disease epidemiology.

The following members and officials were nominated to represent Comhairle na nOspidéal and develop a response: Dr. T. Pierce - who chaired the group, Ms C. Carney, Dr. F. Jackson, Mr. T. Martin and Mr. A. Condon. The Comhairle group met with doctors responsible for service provision to patients with HIV / AIDS on 18th November and 8th December 1999. Copies of the minutes of these meetings are attached for background information. The epidemiological trends in Ireland since 1992 and the oral and written views of those consulted including Dr. K. Butler, Consultant in Paediatric Infectious Diseases who was unable to attend either meeting were taken into consideration by the group in formulating the following recommendations:

The 1992 report of Comhairle na nOspidéal entitled "AIDS at Consultant Level" states that "the most appropriate consultant profile to manage HIV and AIDS patients is a combination of infectious diseases consultants and consultants in genito-urinary medicine. Both specialties have complementary roles to play in the care of HIV and AIDS patients".

The majority of those invited attended and those present at both meetings agreed with the broad thrust of the recommendations set out in the Comhairle Report of 1992, particularly in regard to the consultant workforce. The Report's recommendations were still valid. Those recommendations not yet acted upon should be implemented as soon as possible.

Set out below is a table outlining the main recommendations of the 1992 report together with the current position:

Area	Infectious Diseases*		Genito -Urinary Medicine		Psychiatry of Drug Misuse		Palliative Medicine Re: HIV / AIDS	
	Recommended	Now	Recommended	Now	Recommended	Now	Recommended	Now
N. Dublin	2	1	1		1	2	1	1
S. Dublin	2	1	1	1	1	1	2	2
Munster**	1	1						
Connacht	1							
Paediatrics	1 – 2	1						
<b>Total</b>	<b>7 – 8</b>	<b>4</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>3</b>	<b>3</b>

\*The report recommended that the infectious diseases consultants in Dublin would have small sessional commitments to Mountjoy Prison.

\*\*The report also suggested that consideration may need to be given in due course to the appointment of further consultants in Munster.

Set out below are a number of the more salient issues arising from the two meetings and submissions received:

#### **Dublin**

In its 1992 Report, Comhairle na nOspidéal recommended the appointment of four consultants in infectious diseases, two in North Dublin and two in South Dublin. The Report also recommended the appointment of two consultants in genito-urinary medicine. Currently, in North Dublin there is one consultant in infectious diseases who has been in post since 1993. In South Dublin, there is one consultant in genito-urinary medicine since 1987. A consultant in infectious diseases has been appointed this year.

There is a need for the creation of a second post of infectious diseases consultant in South Dublin, together with a new post of consultant in genito-urinary medicine and a second infectious diseases consultant in north Dublin.

#### **Munster**

An infectious disease service is operating in Cork, which is led by an infectious diseases consultant appointed in 1997. She utilises the services of 4 Area Medical Officers in the provision of STD clinics.

#### **Connacht**

Concern was expressed that the recommendation of Comhairle's 1992 Report regarding the creation of a post of Consultant in Infectious Diseases in the Western Health Board area had not been progressed. It is noted that this remains a priority if appropriate services are to be provided nationally.

The major priority is someone at consultant level to deal with S.T.Ds and also cater for the spectrum of infectious diseases. The Comhairle Report of 1992 recommended the appointment of an infectious disease consultant.

The infectious disease service operating in Cork, led by an infectious diseases consultant which utilises the services of 4 Area Medical Officers in the provision of STD clinics, is perceived to be a suitable model for service provision in the Western Health Board area.

#### **Paediatric Infectious Diseases**

In its 1992 Report, Comhairle na nOspidéal "*recommended the creation of a post of consultant paediatrician with a special interest in infectious diseases based at Our Lady's Hospital for Sick Children, Crumlin, with services at The Children's Hospital, Temple Street (and also to Cherry Orchard for as long as Cherry Orchard Hospital continues to admit seriously ill children with infectious diseases). Close liaison with the maternity hospitals will be essential. The need for a second appointment shared between the children's hospitals should be determined in due course when the first has been filled for a reasonable period*"

The first post was approved and filled in 1994. In view of the increased workload the second post is now required. We are advised by the consultant in paediatric infectious diseases that children with serious infectious diseases are not and should not be admitted to Cherry Orchard Hospital. Two posts of consultant in paediatric infectious disease are recommended involving the restructuring of the existing post and the creation of a second post. Both posts should be shared between Our Lady's Hospital Crumlin and The Children's Hospital Temple Street with formal sessional commitments to the maternity hospitals in Dublin.

#### **Virus Reference Laboratory**

The holder of the post of Consultant Microbiologist / Professor of Microbiology at St Vincent's Hospital/University College Dublin is also Director of the Virus Reference Laboratory in UCD. In addition, there is a need for one full time virologist based at the VRL



whose duties would include HIV related workload. This post should be linked to the Blood Transfusion Service Board and also to a large general acute hospital, probably St Vincent's. When this post has been in operation for some time, consideration should be given to the need for a further post.

### **Prisons**

The Medical Director of Prisons has advised that in an ideal situation, appropriate healthcare services including consultant medical and psychiatric services should be provided to prisoners by the local healthboard / voluntary hospital via interagency agreements. Where specialist services such as consultants in infectious diseases and genito-urinary medicine are not available locally, alternative arrangements are required. The committee supports this approach. It is noted that the Minister for Justice, Equality and Law Reform has recently established an expert group to review the structure and organisation of prison healthcare services. In view of this welcome development, the committee has made recommendations only in relation to Mountjoy Prison.

### **Mountjoy Prison:**

There is a concentration of a wide range of infectious diseases in one location - Mountjoy Prison, which is in close proximity to the Mater Hospital. A significant proportion of those prisoners in Mountjoy who suffer from any of the range of infectious diseases - including HIV/AIDs, hepatitis and STDs - are from South-West Dublin. It would be appropriate that sessional inputs to the prison reflect these factors. The 1992 Report stated that the consultants in infectious diseases should have a sessional commitment to Mountjoy Prison and it is recommended that consultants in infectious diseases based at the Mater Hospital and at St.James's Hospital should have formal sessional commitments to Mountjoy Prison. It is also recommended that the post of consultant in genito-urinary medicine to be based at the Mater Hospital should have a sessional commitment to the prison.

### **Sexually transmitted disease services in the rest of the country**

While the issue of the provision of STD services is somewhat separate to the issue under consideration, both the Comhairle group and a number of those doctors involved in service provision recognised the lack of consultant led services outside the major urban conglomerations of Dublin and Cork. It is recommended that the Department of Health & Children and the health boards give early consideration to the matter.

### **Conclusion**

Given the general agreement with the recommendations of the Comhairle Report of 1992 and acknowledgement of their continuing validity, the Comhairle group support the doctors involved in service provision in their expressed desire that those recommendations not yet acted upon would be implemented as soon as possible.

Comhairle na nOspidéal hopes that the recommendations set out in this letter, together with the enclosed background documentation are of assistance to the committee in its review of the National AIDS Strategy.

Yours sincerely,

Tommie Martin  
Chief Officer

### Appendix 3 - Palliative and respite care

In the Eastern Regional Health Authority area a Consultant in Palliative Care has special responsibility for patients with AIDS in Our Lady's Hospice and 4 of the 29 beds have been allocated for the treatment of AIDS patients.

St James's Hospital has a Palliative Care Team comprising of 2 nurses and a doctor. The Team deals with ;

- patients who are in St James's and who are referred to them,
- patients who are in the community,
- day-care patients,
- patients who are at Our Lady's Hospice.

In 1995/1996 the Team was receiving 60-70 referrals per year for palliative home care for people with AIDS. Referrals are mainly people who have failed to respond to treatment. In 1996 -1997 the Palliative Care Team had in total 328 referrals, of which 27(8%) were people with AIDS. In 1997 -1998 it had 432 referrals of which 19 (4%) were people with AIDS.

In the Southern Health Board area it has been agreed with Marymount St Patrick's Hospital that patients who are terminally ill as a result of HIV/AIDS will have access to facilities in the hospice. A Liaison Nurse co-ordinates services between the hospital and community.

In other Health Board areas patients who require either respite or palliative care are accommodated within the hospital/hospice settings.

### Appendix 4a - Paediatric HIV/AIDS Services provided at Crumlin and Temple Street Hospitals

- Antenatal consultation with HIV positive women,
- Management of HIV positive infants,
- Outpatient and inpatient care and management of HIV infected children,
- Management of HIV infection in adolescents, including disclosure programmes and sexual health,
- HIV screening for children at risk,
- Support for families of HIV infected children,
- Education and support to schools, GPs and other community agencies,
- Liaison with Non Governmental Organisations,
- Active research programme including collaboration with European partners,
- Surveillance of paediatric HIV infection

#### Appendix 4b. - Recommendations for development of paediatric services

Urgent expansion of the physical space at Our Ladys' Hospital is required. The facility should be designed to permit the establishment of a family clinic to care for HIV infected mothers and infants. Ideally obstetric/midwifery liaison should also be present.

Two HIV Specialist Registrars with training either in adult or paediatric infectious diseases, Genito-Urinary medicine or obstetrics are needed to link with Infectious Diseases Consultants in other hospitals.

The appointment of an NCHD (paediatric registrar grade) shared between the Children's Hospital, Temple Street and the Rotunda Hospital.

The provision of a medical social worker (based at the Children's Hospital) to cover the North City. At present families attending the Children's Hospital may have no social work/psychological support while dealing with diagnosis and management of HIV infection.

The appointment of a clinical psychologist to deal with issues arising for HIV infected adolescents. This is of particular urgency as disclosure of diagnosis, sexual awakening and issues of antiretroviral adherence all assume major importance.

Regular neurodevelopmental assessment can also provide a sensitive marker of response to treatment.

Expansion of pharmacy services.

Appointment of a service co-ordinator.

#### Appendix 5. Sexually Transmitted Diseases. Cases Notified to the Department 1989 – 1998

SEXUALLY TRANSMITTED DISEASE	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998
Ano-Genital Warts	505	917	1089	1066	1432	1532	1972	2286	2514	2886
Candidiasis	688	1056	1257	1157	1400	1360	1271	1321	1521	1277
Chancroid	2	0	0	2	0	2	3	1	1	0
Chlamydia Trachomatis	174	215	164	192	315	133	245	364	462	646
Genital Herpes Simplex	78	123	109	125	124	173	198	181	211	243
Gonorrhoea	27	90	73	51	24	98	91	83	98	125
Granuloma Inguinale	0	0	0	0	6	0	0	1	1	0
Lymphogranuloma Venereum	0	0	0	0	0	0	0	0	5	1
Molluscum Contagiosum	31	39	43	44	34	56	59	34	74	84
Non-Specific Urethritis	600	738	549	585	756	610	781	823	1034	1083
Pediculosis Pubis	60	70	72	70	77	69	86	79	81	105
Syphilis	12	19	20	20	8	11	11	17	16	15
Trichomoniasis	51	86	163	41	57	29	60	71	94	38
STD's other than those listed	353	458	291	551	425	391	382	505	1138	933
<b>TOTAL</b>	<b>2581</b>	<b>3811</b>	<b>3830</b>	<b>3904</b>	<b>4658</b>	<b>4464</b>	<b>5159</b>	<b>5766</b>	<b>7250</b>	<b>7436</b>

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AIDS Strategy 2000

# Section 4

Report of the

Discrimination Sub-Committee of the National AIDS Strategy Committee

# Report of the Sub-Committee on Discrimination (1999)

## Introduction

At the National Aids Strategy Committee meeting of 16 June 1998 it was agreed that the NASC should review progress made on implementing the targets laid down in its 1992 Report. As part of that request, the Department of Justice, Equality and Law Reform was asked to reconvene the Discrimination Sub-Committee for the purposes of providing an update on matters relating to discrimination in the 1992 Report. The Discrimination Sub-Committee had its first meeting on 13 February 1992 and had ceased having meetings after making its submission to the NASC Report published in 1992. NASC considered that a reconvening of the Sub-Committee was now necessary in order to establish the extent of progress made since the publication of the 1992 Report, to report on the various initiatives that were now in place and to produce a report for inclusion in the strategy document, to be finalised by NASC in December 1999.

The Department of Justice, Equality and Law Reform agreed to reconvene the Discrimination Sub-Committee with the original terms of reference: "*To develop recommendations to avoid discrimination against persons with AIDS/HIV*". The following persons were invited to attend the first meeting of the Sub-Committee on 22 November 1999:

Mr Liam Conlon (Chairperson)	Department of Justice, Equality and Law Reform,
Mr Barry Quinn (Secretary)	Department of Justice, Equality and Law Reform,
Dr Enda Dooley	Director of Prison Medical Services, Department of Justice, Equality and Law Reform,
Mr Tony O Gorman	Department of Education and Science,
Ms Mary Jackson	Department of Health and Children,
Mr Tony Geoghegan	Merchant's Quay Project,
Dr John Williams	Poz Ireland (People with HIV),
Ms Linda Reed	Malais (Women with HIV),
Mr Brian Sheehan	Gay Health Network,
Mr Don Comiskey	AIDS Fund Housing Project,
Mr Mick Quinlan	Eastern Regional Health Authority, Gay Men's Health Project.

## General

In general, since the publication of the Report of the Sub-Committee in 1992, social and legislative developments have led to greatly improved circumstances for persons with HIV / AIDS. The 1992 Report recommended that *consideration of decriminalisation of homosexual acts between male adults should be given priority*. This was achieved by the Criminal Law (Sexual Offences) Act, 1993 which abolished specified sexual offences between persons over 17 years of age.

## Discrimination in Practice

Under the above title, the 1992 Report stated that there was no evidence of direct institutionalised discrimination. In order to get as full a picture of the present day position as possible, the Discrimination Sub-Committee decided to ask people who were infected and people working on a daily basis with persons infected, or at high risk of becoming so, to determine in what respect they perceived themselves as being discriminated against. Based on the information received, it was agreed to proceed under the following headings:

- Segregation in Prisons
- Health Care Guidelines
- General Health Services
- Funeral Arrangements
- Welfare Benefits
- AIDS in the Work-place
- Insurance and Other Commercial Transactions
- Housing/Accommodation
- Schools and Colleges

### Segregation and Medical Care in Prisons

The 1992 Report recommended that *segregation in prisons should cease and that this view should be taken into account when the report of the Advisory Committee on Communicable Diseases in Prisons was being considered by the Minister for Justice, Equality and Law Reform.* The current position is that segregation in all prisons ceased in January 1995 and it is no longer the operational policy of the Prison Service to have a system of segregation of prisoners with HIV/AIDS.

*The Sub-Committee also recommended that all prisoners receive the same standard of medical care as is presently afforded to known HIV positive prisoners. All prisoners have now got access to whatever medical services are required either in prison or in external hospitals. The Sub-Committee acknowledges that while HIV treatment is provided in prisons, there needs to be a focus on the provision of appropriate treatment services for IV drug users. This issue is being dealt with by the Care and Management Sub-Committee.*

### Health Care Guidelines / General Health Services

The 1992 Report contained the following recommendations:

*that all patients presenting for medical or dental treatment, whether they were HIV positive or not, should receive whatever medical or dental care and treatment was appropriate to their needs in a non-discriminatory manner and in accordance with the highest professional and ethical standards.*

*that medical practitioners should not use any provision of the Medical Council's Guidelines to opt out of their responsibility to treat persons with HIV/AIDS.*

*that the Medical Council should reiterate that the same standards of care should be applied to known or suspected HIV positive patients as to other patients. Furthermore, any specific investigation including HIV testing should be medically justifiable and only undertaken with the express informed consent of the patient following appropriate counselling.*

*that the Medical Council in its guidance should emphasise that applying more stringent medical criteria for instance in relation to placing someone on a surgical waiting list in the absence of medical or social risk factors is inappropriate.*

*that the Department of Health issue a revised circular to health agencies pointing out that all hospitals must adhere to official policy on the provision of hospital treatment for persons with HIV/AIDS.*

*that all patients regardless of their illness receive whatever aftercare and treatment is appropriate to their needs from health care staff in a courteous and professional manner. Any health care staff found not to be complying with this provision should be subject to the usual disciplinary procedures.*

The current position is that appropriate medical and dental treatment is provided to all persons, based on clinical need, regardless of their HIV status. Some submissions to the National AIDS Strategy Committee made reference, however, to long waiting times in hospitals and the non-availability of evening clinics for people who are working.

Although GPs are willing to treat patients with HIV, it has transpired, of necessity that such patients must access specialist care in hospitals, where a complicated range of Highly Active Anti-Retroviral Treatment (HAART) is administered.

Special services have developed in the Eastern Regional Health Authority (where the vast majority of opiate misusers reside) in conjunction with voluntary and community groups to provide treatment to injecting drug users. These services are provided at 52 treatment locations. A major focus of the Board in its 2000 Service Plan is the development of rehabilitation services which assist drug misusers to become reintegrated into a normal lifestyle.

In relation to hospital services, a Charter of Rights for Hospital Patients, published by the Department of Health in 1992, aimed to make the health service more responsive to the needs of individual patients. It was intended to be used as a code of practice in hospitals, setting out what patients have a right to expect when they make use of hospital services.

The Charter sets out guidelines for access to hospital in-patient and out-patient services. In accordance with the Charter, patients have the right to be treated in a courteous manner at all times by every member of hospital staff. They have a right to have their privacy respected, especially when the nature of their clinical condition is being discussed with either themselves or their relatives by hospital staff. They have a right to total confidentiality in respect of medical records. Under the Charter, patients also have the right, where a complaint about confidentiality is not resolved to their satisfaction, to have the matter referred to the hospital's Complaints Committee.

The Medical Council exists to protect the interests of the public when dealing with members of the medical profession. In the Council's Guide to Ethical Conduct and Behaviour (1998), the principles which doctors apply in dealing with patients are set out so that the medical profession aspires to the highest possible standard of behaviour and practice. It gives guidance on responsibility to patients and behaviour towards patients.

**The Sub-Committee endorses both the Charter and the Guide and recommends that patients with HIV/AIDS be treated in accordance with the guidelines set out in these documents.**



A report on Ethical Guidelines for Professionals dealing with HIV addresses the issues of confidentiality and disclosure. The report has been prepared by the Care and Management Sub-Committee.

## Funeral Arrangements

In its 1992 Report, the Sub-Committee recommended that *the Department of Health examine the use of body bags and other practices for persons who have died of AIDS with a view to developing realistic guidelines for the handling of bodies of persons who have died from AIDS.* This issue is being dealt with by the Care and Management Sub-Committee.

## Welfare Benefits

The 1992 Report recommended

*that the Department of Social Welfare ask the health boards to bear in mind the very special needs of persons with HIV/AIDS when assessing eligibility for Supplementary Welfare Allowance. This recommendation should also apply to health boards when they are assessing the eligibility of persons with HIV/AIDS for the Disabled Persons Maintenance Allowance.*

*that the availability of such benefits be publicised in such a way as to ensure that all those who may need such benefits and be entitled to them, are aware of their availability.*

*that, in order to safeguard confidentiality, health boards should introduce procedures to reduce the number of people dealing with applications for the Disabled Persons Maintenance Allowance and ensure that such cases receive the utmost confidentiality.*

The position is that Health Boards are responsible for the payment of Supplementary Welfare Allowance, which allows discretion for claims for the Allowance to be determined on a case by case basis. Welfare entitlements have not been standardised as each case is dealt with on the basis of the needs of that individual. The Drugs/AIDS Teams in the Eastern Regional Health Authority include a Community Welfare Officer. In the Southern Health Board, a Community Welfare Officer, based in Cork City, deals with HIV/AIDS issues.

People who are in contact with health and social services are informed by officers such as Community Welfare Officers of the range of supports and benefits which are available.

**The Sub-Committee recommends, however, that information in relation to benefits and supports should be available in printed form from a range of outlets, including health board offices and voluntary agencies, so that people with HIV/AIDS and their families can be assisted to obtain the optimum support to deal with their illness.**

## AIDS in the Work-place / Anti-discrimination Legislation

The 1992 Report recommended that

*so far as it has not been done already, semi-State and other employer organisations should issue similar guidelines to those issued by the Civil Service to prevent discrimination in the workplace and take steps to ensure that the guidelines were followed.*

Discrimination often occurs from a lack of awareness on how HIV is transmitted. To address this issue, in December, 1993 the Dublin Region Private Sector of SIPTU, in conjunction with Dublin AIDS Alliance and the Health Promotion Unit of the Department of Health published an information pack on "AIDS and the Workplace". The pack contained leaflets aimed at Union members, shop stewards and employers. The leaflets explained how HIV was transmitted, gave useful contact addresses and contained the message that "AIDS is no excuse for prejudice and discrimination". The initiative, however, was not extended to other sectors of SIPTU or to other Unions.

**The Sub-Committee recommends that this type of initiative be undertaken by other unions, employer organisations and employment training bodies, in consultation with relevant statutory and voluntary agencies. It also recommends that employees with HIV/AIDS be treated in a non-discriminatory manner.**

Cáirde has recently become the Irish representative on the European network of AIDS in the Workplace and is at present working in conjunction with representatives of similar organisations in other Member States on the development of guidelines for dealing with HIV/AIDS in the workplace.

There have been a number of recent developments in the area of legislation which will significantly advance the elimination of discrimination of persons with HIV / AIDS. The Employment Equality Act, 1998 came into force on 18 October 1999. The Act prohibits discrimination in employment on nine distinct grounds, namely: gender, marital status, family status, sexual orientation, religion, age, disability, race and membership of the Traveller community. The scope of the Act is comprehensive and covers discrimination in relation to access to employment, conditions of employment, equal pay for work of equal value, training, promotion and work experience. These kinds of discrimination are outlawed whether by an employer, an employment agency, a trade union, a professional body, a vocational training body or a newspaper advertising jobs on its careers and appointments pages. All employment contracts have an implied equality clause as a result of this legislation.

The equality infrastructure provided under the Act has been established, namely the Equality Authority and the office of Director of Equality Investigations. These two bodies came into operation at the same time as the Act. The Authority will work towards the elimination of discrimination and the promotion of equality of opportunity in the areas which are the subject of the Act. The office of the Director of Equality Investigations will provide the main locus of redress of first instance for individuals who consider that they may have suffered discrimination.

The Equal Status Act, 2000, prohibits discrimination in the non-employment area. The Act, which complements the Employment Equality Act, 1998, was signed into law on 26 April,

2000 and will come into operation during the course of 2000. It deals with discrimination in education, the provision of goods, services and accommodation and the disposal of property on the same nine grounds as those covered by the Equality Act. All services which are generally available to the public, whether provided by the State or private sector, are covered, including facilities for refreshment and entertainment, credit facilities and transport services. The measure also contains a sanction against registered clubs which are found to be discriminating.

Some provisions of the Employment Equality Act, 1998 and Equal Status Act, 2000 which are relevant to persons with HIV/AIDS are the following: The definition of 'disability' for the purpose of the both the Acts is extremely broad. Specifically, it includes the phrase, in clause (b) of the definition, that "disability means . . . the presence in the body of organisms causing, or likely to cause, chronic disease or illness . . .". The definition of disability is modelled on Australian legislation and is intended to afford protection to the widest possible range of people with disabilities. The clause just quoted would encompass persons with HIV/AIDS but who have not progressed towards showing any discernible symptoms of their condition.

A definition of 'discrimination' is set out in both Acts as also is the definition of each of the nine 'discriminatory grounds'. This provision defining 'discrimination' is broadly drawn and the Equal Status Act covers, for example, the situation of a person discriminated against where the service provider thinks it likely that he or she may get AIDS in the future.

The Equal Status Act prohibits discrimination in the disposing of goods or in the provision of a service to the public or to a section of the public. It is irrelevant whether the disposal of provision is for payment or not. The definition of 'service' in section 2(1) is extremely broad and, by way of example, the following are mentioned:

- access to and the use of any place;
- facilities for banking, insurance, loans, credit or financing- facilities for entertainment, recreation or cultural activities;
- transport or travel facilities;
- professional or trade services; and,
- services or facilities provided by a club (whether registered or not).

The Employment Authority has informed the Sub-Committee that the issue of discrimination against people with HIV/AIDS will be an aspect of the Equality Authority's work in the future. The Authority will provide information, advice and legal representation to people who are discriminated against because they have a disability. The strategic plan of the Authority, which is currently being prepared, will outline the commitment of the Authority to work towards the elimination of discrimination of people with disabilities and will ensure the disability ground is a named dimension in its legal, developmental, communication and policy roles.

**The Sub-Committee accepts that the issue of discrimination against people with HIV/AIDS will be dealt with by the Equality Authority and that, in the circumstances, it recommends that the Discrimination Sub-Committee be wound up. The Sub-Committee suggests, however, that the NASC keep a watching brief on developments in this area with the option of reconvening the Discrimination Sub-Committee in the future, if necessary.**

### Insurance and Other Commercial Transactions

The 1992 Report pointed out that clearly persons with AIDS or who were HIV positive were placed at a disadvantage in not having access to, for example, life insurance or other death benefit cover and recommended that *this factor be taken into account in the application by public authorities of discretionary welfare funds.*

The approach of the Equal Status Act to the insurance/lenders sector is as follows. Because this sector operates on the basis of underwriting risk, an appropriate exemption is made in section 5(2)(d). The subsection states as follows:

(The prohibition on discrimination does not apply in respect of - )

"(d) differences in the treatment of persons in relation to annuities, pensions, insurance policies or any other matters related to the assessment of risk where the treatment -

(i) is effected by reference to -

- (I) actuarial or statistical data obtained from a source on which it is reasonable to rely, or
- (II) other relevant underwriting or commercial factors,

*and*

(ii) is reasonable having regard to the data or other relevant factors."

The subsection will prohibit entirely arbitrary decisions by insurance companies and similar enterprises in providing insurance but, nonetheless, takes account of how the financial services industry operates in writing insurance, extending loans etc. Failure to include such exemption could conceivably have the result that no insurance company could quote different premia for the different levels of risk it is underwriting. The very nature of writing insurance involves the insurance company assessing risk in relation to factors such as likelihood of death at different ages and as between men and women, road accident rates for under 25s male drivers etc.

Difficulties arose in the past in respect of questions relating to testing for HIV appearing on application forms for insurance. The policy of the Irish Insurance Federation was clarified in April 1999 when the Federation informed the Sub-Committee that its policy is that the question which should be posed on insurance application forms is whether an individual has tested positive for HIV and not whether someone has been tested for HIV. The Federation has reminded its member companies of the agreement that all proposal forms should be amended to reflect this change of emphasis. **The Sub-Committee recommends that all insurance companies comply with this policy.**

## Housing and Accommodation

The 1992 Report stated that it was satisfied with the forward-looking policies of Dublin and Dun Laoghaire Corporations and Dublin County Council and recommended that *insofar as these policies may not have countrywide application, steps should be taken to ensure that they are applied by all local authorities*. Concern was expressed by some members of the Discrimination Sub-Committee about discrimination in the provision of local authority housing. It was alleged that that persons with HIV/AIDS experienced disproportionate difficulties when trying to avail of local authority housing. In response, the Department of the Environment and Local Government advises that it is not aware of any discrimination in this area but would be glad to investigate any cases where evidence of discrimination was provided. In the meantime, the Department has circulated the local authorities and requested their comments on the issue.

The 1992 Report also recommended that *discrimination by hostels against persons with AIDS or who are HIV positive must cease*. In this regard, it should be noted that the Equal Status Act contains in sections 6, 7 and 8 provisions prohibiting discrimination in the disposal of land and premises and in the provision of accommodation or any services or amenities related to accommodation. The provision of these services is being dealt with by the Care and Management Sub-Committee.

**The Sub-Committee recognises the inter-relatedness between IV drug users and HIV/AIDS and homelessness. It recommends therefore that the issue may be outside the remit of the NASC and should be addressed by the Inter-departmental Committee on Homelessness chaired by the Department of the Environment and Local Government.**

The Homelessness Committee has stated that there is an urgent need for "wet hostels" which would allow heavy drinkers to drink in a more controlled manner while being accommodated. The Committee is currently examining the feasibility of providing "wet-hostels" for homeless persons on drugs as well as homeless alcoholics. **The Discrimination Sub-Committee fully supports the provision of wet-hostels for use by drug-users with HIV/AIDS and has conveyed this view in writing to the Department of the Environment and Local Government.**

## Schools and Colleges

In the 1992 Report the Sub-Committee stated that it had no evidence of discrimination in schools. However, it felt that there was potential for discrimination in schools and colleges against students who either themselves have AIDS or who are HIV positive, or who have members of their families so diagnosed. It felt that it would be prudent to take practicable steps as are necessary to avoid such discrimination and recommended *that information on HIV should be available to all teachers and that seminars/courses for post primary teachers should be open, to primary teachers as well. It recommended also that guidelines on first-aid and hygiene routines should be issued to all schools*.

AIDS Resource Materials, developed jointly by the Departments of Education and Health and targeted at 14 -18 year olds were disseminated to all second level schools in the early 1990's. Training was provided to teachers delivering the programme and this included

information on infection control. In 1993/1994 Infection Control Guidelines for Schools were developed and circulated to all schools. Information on first-aid was part of these guidelines.

A range of health promotion materials are available free of charge to parents, teachers and the wider community through health board Health Promotion Departments. These materials include leaflets on "AIDS the Facts" and "Sexually Transmitted Infections" and a "First AID Index Chart". The "AIDS the Facts" leaflet emphasises that misinformation about AIDS has resulted in needless discrimination and that it is unjust to victimise persons with HIV or AIDS either socially or at work.

**Conclusion** In conclusion, the Sub-Committee recommends that other public and EU funded bodies should ensure that they have policies on discrimination and that they actively implement those policies. The Sub-Committee recommends that the press, radio and TV should adopt a code of practice which will address issues such as balanced and fair reporting of issues concerning persons with HIV/AIDS. The Sub-Committee wishes to acknowledge, however, that there has been significant progress in alleviating the problem of discrimination against persons with HIV/AIDS since the publication of the 1992 Report.



AIDS Strategy 2000

# Section 5

Other Important Issues in Relation to HIV / AIDS

# Other Important Issues in Relation to HIV / AIDS

## Some areas were not covered by the work of the Sub-Committees but are, however, important to identify in this document.

### Haemophilia and HIV

Haemophilia is a bleeding disorder which results in the blood of the person with haemophilia not clotting in the normal way, because some of the clotting factors normally present in blood are missing. Up to recently the treatment for haemophilia consisted of replacing the missing clotting factors with blood derivatives to allow normal clot formation to occur, thus avoiding haemorrhage. The products used for such treatment were made from pools of many donations and, worldwide, these products have caused infection of the haemophilia population with blood-borne viruses such as HIV.

In Ireland, a Tribunal of Inquiry has been established into (inter alia) the HIV infection of persons with haemophilia. The Tribunal will examine a number of issues relating to the infection, including the source of the infection of products manufactured or imported, the role of the Blood Transfusion Service Board, the Department of Health and Children and other relevant parties in the selection and importation of clotting factor products, and efforts made to secure sufficient supplies of home-produced product.

In 1998, the Department of Health and Children approved the replacement of plasma-derived clotting factor products with recombinant (synthetic) products for the treatment of haemophilia patients, which vastly reduces the chances of transmission of blood-borne viruses.

### European Programme on AIDS and other Communicable Diseases

A five year Programme on AIDS and other Communicable Diseases was adopted in March 1996. The budget for the Programme is 49.6 million ECU over a 5 year period (1996 - 2000). The overall objective of the Programme is to contribute towards stemming the spread of AIDS and other communicable diseases in the Community. This would be achieved by improving knowledge concerning their prevalence and patterns, improving recognition of high-risk situations and practices and improving early detection and social, health and medical support.

Work is on-going in this programme under the headings of;

- Surveillance and monitoring of communicable diseases
- Combating transmission
- Information, education and training
- Support for persons with HIV/AIDS and combating discrimination.

The Department of Health and Children is represented on the Management Committee of this Programme. A number of organisations from the statutory and voluntary sector have participated in European funded projects. A number of these projects deal with surveillance of infectious diseases, including HIV. There is significant added value for Ireland being involved in these projects as they allow Irish experts share experience, knowledge and information on best practice with their European counterparts and their involvement is to be encouraged. Details of the projects funded are available in a report entitled "In From the Margins", produced by the Alliance Centre for Sexual Health in Cork.



An evaluation of the European Programme was carried out in 1999 on behalf of the European Commission. This showed that projects supported by the Programme were usually well managed and resources used cost-effectively. Positive features of the evaluation included:

*Improvement in the co-ordination of communicable disease surveillance systems and in the co-ordination of the European Community response, with initial efforts focused on HIV/AIDS, tuberculosis and drug resistance;*

*Creation and development of a European network for HIV/ STI prevention for prostitutes;*

*Analysis of border issues with regard to HIV/AIDS and STIs;*

*Maintenance and enhancement of the European network on HIV/AIDS and hepatitis prevention in prisons.*

From a negative perspective the evaluation noted that the networks established in European projects often fail to give a convincing picture of actual capacity to gather expertise and experience from all Member States, as well as to disseminate information provided by the networks. This will be addressed in future programmes.

### **The Ireland AID Programme's HIV/AIDS Strategy**

Ireland Aid, the Irish Government's Official Overseas Development Co-operation Programme, launched an HIV/AIDS Strategy in January 2000 to intensify its overseas work in that area in a coherent way across the whole programme. Ireland Aid provides long-term and emergency assistance to developing countries. The programme works in partnership with governments and communities in the developing world, supporting them in their attempts to alleviate poverty by helping them to meet the basic needs by strengthening their capacity to help themselves. It has a special focus on fostering human rights and democracy. The Ireland Aid Programme is administered by the Co-operation Division of the Department of Foreign Affairs and its budget has increased from £40 million in 1992 to £178 million in 1999.

The Ireland Aid Advisory Committee (IAAC) advises the Minister of Foreign Affairs and the Minister for State with responsibility for Development Assistance on policies for the effective delivery of development aid and on future strategies. In 1999, IAAC completed an analysis of the impact of the HIV/AIDS pandemic in the sub-Saharan African countries, which Ireland Aid supports. This review was undertaken in recognition of the fact that, while in the developed world HIV/AIDS has in many respects become just another chronic disease, in developing countries it continues to have a devastating impact, which in many of these countries is now reversing the progress achieved by development programmes in the last decade or so. On the basis of this review, Ireland Aid developed the HIV/AIDS strategy with the dual purpose of supporting prevention of the further spread of HIV/AIDS and of reducing the impacts of this disease on developing countries.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated that by the end of 1999 there would be a total of 33.6 million people in the world living with Human Immunodeficiency Virus (HIV) infection, including those who had gone on to develop AIDS. An estimated 5.6 million people were newly infected with HIV in that year and there were 2.6 million AIDS related deaths in 1999, bringing the total deaths to 16.3 million since the pandemic began in the early 80s. A cumulative total of 11.2 million children have been orphaned by AIDS. It is clear, therefore, that globally the threat posed by the HIV/AIDS pandemic is far from over and, indeed, in many countries the disease still appears to be out of control.

The countries where HIV infection and AIDS are most clearly out of control are all in the developing regions of the world. Over 95% of all HIV infected individuals live in developing countries and sub-Saharan Africa is the worst affected region of the world. While only around 10% of the world's population live in sub-Saharan Africa, almost 70% of all of the people who became infected with the virus in 1999 live there and 84% of the 16.3 million AIDS related deaths so far have been in that region.

These specific effects of the HIV/AIDS pandemic, combined with rapid population growth and the resultant increasing population pressure, worsening environmental degradation, increasing food insecurity and the persistent and worsening poverty, mean that any progress in development in the region is already being neutralised or reversed. However, many agencies including large, multi-national organisations, bilateral aid programmes and international Non-Governmental Organisations are already active in the area of HIV/AIDS prevention and control. In developing the strategy, Ireland Aid tried to build on the experience of these other agencies to identify strategies through which it could bring its own particular expertise to bear on the situation and by which it was most likely to significantly impact on the control or management of the disease in the developing country situation. The first step in this process was to develop, from the existing information, an AIDS Profile for the current situation regarding the disease and its impact in each of the countries of interest to Ireland Aid. This was followed by the development of a strategic plan for mainstreaming HIV/AIDS in the Ireland Aid Overseas Development Assistance Programme.

The six priority countries for Ireland's overseas development assistance are Ethiopia, Lesotho, Mozambique, Tanzania, Uganda and Zambia. However, on the basis of a brief preliminary overview of the HIV/AIDS situation in all sub-Saharan countries, taking account of the needs and the potential for developing a successful intervention, it was decided to also include South Africa and Zimbabwe in the study. Therefore, AIDS Profiles were developed for a total of eight countries.

The overall aim of the strategy that was subsequently developed was to mainstream the issue in all aspects of Ireland's Overseas Aid Programme. Three strategic goals were set out:

**To improve the awareness, responsiveness and effectiveness of the Ireland Aid programme to HIV/AIDS as a development issue (The Institutional Response);**

**To protect existing social and economic development gains from the adverse effects of HIV/AIDS and to promote further development in these areas (The Broad Based Response);**

**To support sectoral policies, programmes and activities in partner countries which address HIV/AIDS at the national, community and individual level (The Specific Response).**

Work is already underway to achieve these goals. The short-term priorities for Ireland Aid in the next two years include:

*to significantly increase the level of support for HIV/AIDS activities in the Ireland Aid Programme;*

*to contribute to the consciousness raising and capacity development of Ireland Aid personnel in the Development Co-operation Division and overseas in the Development Co-operation Offices;*

*to nominate focal persons at HQ, regional and country level to co-ordinate the implementation of the strategy;*

*to increase support for HIV/AIDS activities at a multi-lateral level, especially in the EU and the UN;*

*to look at how HIV/AIDS activities can be integrated into other aspects of the Ireland Aid Programme, including its support for indigenous and international NGOs.*

## Appendix A Submissions received on the Review of National AIDS Strategy

1. Gay Switchboard Dublin
2. Open Heart House
3. Gay Community News
4. USI-Lesbian, Gay and Bisexual Rights Officer (LGBRO)
5. D Brennan
6. D Clancy
7. Southern Gay Health Project
8. Positive Voice Ireland
9. Youth Initiative Partnership
10. Paul Burns
11. GPI Publications
12. Noel Walsh
13. Lisa O'Rourke
14. Gay HIV Strategies
15. Cairde/Dublin AIDS Alliance (Joint submission)
16. Grainne O'Hara
17. Bill Foley, HIV Counsellors Group
18. Infection Control Sisters, Cork University Hospital
19. Michael Hevey
20. Dr Patrick O'Sullivan, EHB
21. Dublin Dental Hospital
22. Seamus Mannion, WHB
23. Gay Men's Health Project
24. GUM Consultant in St James's and Infectious Diseases Consultant, Crumlin.
25. Gay Men's Network
26. The Alliance Centre for Sexual Health, Cork

In addition members of NASC and its sub-committees made submissions, both written and oral, which have been taken into consideration in drawing up this report.