



HIV Prevention Policies And Practices In Ireland 1999

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CHAPTER 1

SHORT HISTORY OF HIV PREVENTION IN IRELAND

The first two cases of AIDS in Ireland were diagnosed in late 1982 and reported in 1983. Both cases were diagnosed in gay men with Kaposi's Sarcoma. By 1984 there were six cases of AIDS with 126 cases by the end of 1989. The first case of HIV was diagnosed in 1985.

HIV first became an issue in the public awareness in Ireland during 1984 / 1985. The media became interested in the disease at this time and helped to bring the issue into the public domain. Two communities which were most affected at that time took steps to highlight the disease. The Irish Haemophilia Society was aware of the risks to haemophiliacs from blood products. Gay Health Action, (GHA) founded in January 1985, was the first non-governmental organisation (NGO) to campaign specifically on AIDS in Ireland and produced information on AIDS (and other health issues) for gay men, the media and health workers.

In 1985 GHA produced the first leaflet on AIDS, partly funded by the Department of Health. In 1986, the Department of Health produced an information leaflet "AIDS the Facts" for broad circulation amongst the general public. The first information campaign organised by the Department in the mass media was launched in 1987. The message was that casual sex spreads AIDS and the target population was the general public. It was difficult for a government department to target specific groups as both homosexual acts and possession of illicit drugs were illegal at that time (homosexual acts were decriminalised in 1993).

There is no legal framework specifically governing HIV in Ireland. Blood screening was introduced in 1985. HIV is not a notifiable disease. AIDS cases and deaths are reported to the regional AIDS Co-ordinators and passed to the National AIDS Co-ordinator in the Department of Health and Children. The Virus Reference Laboratory in University College Dublin provides anonymous reports of all confirmatory tests for HIV to the National AIDS Co-ordinator. The Department of Health and Children produces statistical reports on HIV/AIDS twice a year.

The first Genito-Urinary specialist consultant (the term used to describe the doctor responsible for the medical care within a particular field) in Ireland was employed in 1987 and management of HIV was part of that brief. In December 1991, the new Minister for Health, Mary O'Rourke, formed the multisectoral National AIDS Strategy Committee aimed at providing a framework for national policy on HIV. The National AIDS Strategy Committee Report and Recommendations document was adopted on 13th April 1992¹ and formed the basis for priority action. The Committee still meets regularly and reports on needs as they arise. The Committee has four sub-committees: Care and Management of persons with HIV/AIDS; HIV/AIDS surveillance; Education and Prevention strategies; Anti-Discrimination. With the exception of the latter, all sub-committees meet on a regular basis.

In the 1980s, in the absence of a response from the statutory sector, NGOs began to develop and to concentrate their efforts on HIV/AIDS. As mentioned above, Gay Health Action was the first group to specifically respond to AIDS in 1985. They invited members of the Shanty Project from San Francisco to Ireland, as a result of which Cáirde, a befriending organisation, was formed in 1985. Dublin AIDS Alliance and Helpline (1986), Cork AIDS Alliance (1987) (now The Alliance Centre for Sexual Health), Western AIDS Alliance (1987) (now AIDS Help West) and Limerick AIDS Alliance (1987) (now the Red Ribbon Project) followed suit in the various regions under the umbrella of AIDS Action Alliance. Their aims were primarily to provide services which were not provided by the statutory sector; support for people with HIV and their families / friends, education / prevention programmes and lobbying for better services. Body Positive was also founded around this time and some of its members appeared on TV and radio representing the views of positive people.

Other NGOs, such as drug agencies, found that HIV became an issue for their work when individuals using their services became HIV positive. In addition to the Irish Haemophilia Society referred to previously, the Anna Liffey Project, which was formed in 1982 to provide a service to drug users, also became involved with the issue of HIV. In 1989, the Merchants Quay Project was founded with a specific focus on drug use and HIV. Community responses to drugs had also developed, such as Ballymun Youth Action Project, which sought to respond to the issues through community development and a systems approach. The Eastern Health Board's AIDS Resource Centre opened in Dublin in 1989. It became the first official needle exchange and provided methadone maintenance programmes and outreach workers.

Members of NGOs and statutory organisations faced with the problem of HIV met once a month in an AIDS Liaison Forum in order to share information and problems. In 1989, the Government provided lottery funding to the AIDS Fund which in turn provided small amounts of funding to NGOs and people with HIV.

The first people with AIDS were treated by hospital consultants with specialities in other fields, such as oncology and respiratory diseases. Some GPs with a particular interest in HIV (or STIs) became involved in treatment from 1985. The first Genito-Urinary Consultant was appointed in Dublin in 1987 with responsibility for HIV. The GU Consultant was linked to the MRC Unit in England and therefore had access to all treatments to which they had access. Initially, AZT was available on a named patient basis only. Access to treatment drugs has always been quite good in Ireland.

There are now five specialist hospital consultants with responsibility for HIV in Ireland: the GU Consultant referred to above, three Infectious Diseases Consultants (two in Dublin and one in Cork) and a Paediatric Consultant. Concerns are often expressed by people outside of the two

main cities at the lack of access to specialist consultant care throughout the rest of the country which results in people having to travel to Dublin or Cork for their treatment. However, other commentators suggest that the numbers of people with the virus does not justify a specialist in these areas with the possible exception of the Western health board area.

At present the National AIDS Strategy Committee is reviewing its 1992 recommendations in the light of the current treatments and availability of services with a view to establishing an updated strategy for the millennium. Due to the advances in the treatments there has been some effort to normalise the disease. However, some commentators would use the phrase "medicalise" rather than "normalise", stating that although the stigma attached to HIV is not so great as it was, there is still a great deal of work to be done on the socio-economic fronts before HIV might be considered normalised. The current review of NASC which is due to be completed in December 1999, will be the first official reference to this debate.

CHAPTER 2

GENERAL POLICY ON HIV/AIDS IN IRELAND

Policy developments, which affect HIV/AIDS in Ireland, can be explored by examining HIV/AIDS specific policies and broader initiatives aimed at effecting change in society which in turn has had an impact on HIV/AIDS.

The National AIDS Strategy Document is the primary policy document on HIV. The NASC adopted the recommendations of the report at its meeting on 13th April 1992. The NASC is chaired by the Minister of State for Health and Children. The issue of HIV/AIDS continues to be a priority in the Department of Health and Children. Since the publication of the NASC report in 1992, there has been a concerted effort on the part of the Department, in consultation with a wide range of opinions, to work towards reducing the overall number of people who become infected with HIV and in providing the best possible treatment and care for those who are HIV positive or who have AIDS.

The NASC committee continues to meet on a regular basis and addresses issues of policy raised by the sub-committees or members of NASC. Members of the NASC and the Sub-committees (which includes additional members co-opted for their expertise in areas of relevance to that particular committee) are drawn from the statutory sector, non-governmental organisations, medical profession (including four specialist hospital consultants and a representative of the Irish College of GPs), people living with HIV and senior civil servants. Decisions at national level are reached by consensus. While recommendations can be made to government from NASC, the committee can only "advise" on areas which are outside its remit such as other government departments and the Irish Medical Council.

The 1992 policy is currently under review and in addition to the contributions from NASC members to this review, submissions have also been requested in a national newspaper advertisement so as to allow as broad a response as possible.

The National AIDS Strategy Committee Sub-committees on Education and Prevention, Care and Management and Surveillance Sub-committees have also met regularly since 1992. These sub-committees primarily discuss and make recommendations on areas which are identified as problematic or not having been envisaged at the time of the 1992 recommendations. In this way policy is made and evolves.

Education and Prevention's remit in 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, and to make recommendations on future strategies in this area. The objective of

preventive measures is to limit the spread of HIV infection through public awareness campaigns, community-based prevention initiatives and improved infection control procedures². Policy which impacts on HIV is also developed in relation to sections of Irish society which have been most affected by HIV. These can be summarised as follows.

Policy affecting drug users.

The NASC report recognised that intravenous drug use was a main source of transmission of HIV at that time, particularly in the Eastern Health Board area (the largest area which includes Dublin, the capital). In 1992, almost 60% of HIV positive tests and almost 40% of full AIDS cases were drug related.³ Throughout the 1980s, when HIV was first appearing and growing, there was no national policy or strategy on drug use. The debate on treatment was polarised between abstinence on the one hand and the free availability of methadone and clean needles in response to the AIDS crisis on the other hand. The Government Strategy to Prevent Drug Misuse⁴ recognised the importance of a harm reduction approach for HIV prevention and recommended the setting up of Community Drug Teams in the most vulnerable areas. It also recommended the involvement of GPs and other generic agencies in the response. The NASC report in 1992 endorsed the formal adoption of a harm reduction approach and recommended the establishment of satellite clinics outside the hospital setting. NASC envisaged that Community Drug Teams would work closely with and complement the satellite clinic service in order to provide a comprehensive and integrated approach. Methadone prescribing was considered an appropriate response to prevent the transmission of HIV.

Deaths from AIDS and growing drug use presented major problems for some communities. Dissatisfaction with official response led people to take to the streets in protest. A prevalence study conducted in 1996⁵ has estimated that there were over 13,000 opiate users in Dublin at that time.

Current policy was set in 1996, in the First Report of the Ministerial Task Force on Measures to Reduce the Demand for Drugs.⁶ The report established the Cabinet Sub-Committee on Drugs, (subsequently the Cabinet Sub-Committee on Inclusion and Drugs), the National Drug Strategy Team and the Local Drugs Task Forces in twelve areas of Dublin and one in Cork City. The Task Forces have the involvement of the local community as a central plank of their strategy. Funding was provided to support the actions in the plan. Two years into their existence, evaluation supported the work of the Task Forces and currently they are working on developing a strategic plan for the future. Funded actions are currently undergoing evaluation.

At the end of September 1999, 4094 people were on the central methadone treatment list; the majority of them being in the greater Dublin area.⁷ Analysis of national statistics between 1992 - 1998 indicates a significant reduction in HIV infection associated with injecting drug use.⁸ The most recent statistics however support anecdotal evidence from workers in the drug's field that

there is again a dramatic increase in HIV amongst young drug using people attending new satellite clinics in areas which have not had clinics before. The national drugs policy appears to have had some impact on the transmission of HIV. There are however on-going problems which will be addressed below.

Policy affecting gay and bisexual men and men who have sex with men.

While gay men were the first to be affected by HIV in Ireland, this occurred in a context where homosexual acts were illegal and many gay and bisexual men (and women) living in a society of prejudice and discrimination could not be open about their sexuality. The Catholic Church in Ireland through its teachings and management of institutions such as schools and hospitals enhanced this atmosphere. It could be argued that AIDS has helped bring homosexuality into the open in Irish society.

When NASC was originally set up, the gay community was not directly represented on the committee. This has since changed. As a result of pressure from organised gay men and based on the recommendations of the NASC report, the Department of Health and Children funded 'HIV Prevention Strategies and the Gay Community'⁹ which aimed to develop effective HIV prevention strategies for gay men based on a partnership between the statutory sector, gay men and other agencies. This in turn led to the funding of Gay HIV Strategies (see below for further details) which targets gay men in terms of HIV prevention.

Considerable progress has been made in relation to the policy and other contexts for HIV prevention for gay men since the 1992 strategy was formulated. The 1993 Criminal Law Sexual Offences Act¹⁰ decriminalised homosexual acts. This Act provided for equality with heterosexuals and was a fundamental shift in public policy towards the gay community. The Department of Health (now Health and Children) produced policy documents 'Shaping a Healthier Future' in 1994¹¹ and 'A Health Promotion Strategy' in 1995.¹² Their emphasis on issues of equity, multi-sectoral co-operation, the creation of supportive environments and the strengthening of community action, provided a positive context for developing HIV prevention programmes targeting gay men. The Combat Poverty Agency commissioned a study 'Poverty, Lesbians and Gay Men: The Economic and Social Effects of Discrimination in 1995'¹³ which provides essential data on the experiences of gay men and which makes recommendations for action for a wide range of agencies. This report has contributed to significant mainstreaming developments including the National Anti-Poverty Strategy Poverty / Equality Proofing Guidelines¹⁴ which explicitly include sexual orientation.

The net result of these policy developments has been to create a healthier context or environment which results in potentially less marginalisation of gay and bisexual men and women, which in turn should impact on HIV prevention (and other health) strategies.

Policy affecting prisoners

In 1992, there was very little scope for HIV prevention measures in prisons as drug use and sex between men was illegal. Prisoners with HIV were segregated from other prisoners. Since then, homosexual acts have been decriminalised and in January 1995 segregation of prisoners with HIV ceased. Treatment facilities have also improved greatly which will impact on tertiary prevention.

Responding to drug use within prisons remains problematic. A recent report prepared for the Department of Justice, Equality and Law Reform "Hepatitis B, Hepatitis C and HIV in Irish Prisoners; Prevalence and Risk"¹⁵ found that 9% of prisoners had hepatitis B, 37% had hepatitis C and 2% had HIV. 52% of respondents reported opiate use and 43% reported ever injecting drugs, with 37% having shared injecting equipment before entering prison. Just under 2% of prisoners reported having anal sex with men in prison. The fact that this report has been commissioned by the Department may be an indication that hepatitis and HIV in prisons may be addressed in the near future.

Contraception

Contraception has been legal in Ireland since 1985. Since that time, and arguably even before, the church has had less influence on sexual attitudes and practices, although this varies from area to area. After The Health (Family Planning) (amendment) Act of 1993¹⁶ condoms became widely available. Although they can be purchased from shops, pharmacies and vending machines in pubs and nightclubs, we must also recognise that it can still be difficult to purchase condoms in small or rural areas. Condoms in Ireland are amongst the most expensive in Europe, a fact which may impact on the numbers purchased, particularly by the younger population.

Health Promotion /Education

In 1988 a schools programme on HIV was introduced by co-operation between the then Departments of Health and Education.¹⁷ This programme was reasonably successful at the time, although it was up to each individual school as to whether they used the programme.

In recognition of the changes in Irish society over the last ten to fifteen years in particular, the Department of Education and Science has introduced relationships and sexuality education into the Social and Personal Health Education Programme.¹⁸ This initiative was implemented during 1998/99 and enables schools to develop policies on the provision of sex education. Within the school setting, HIV can now be part of this programme.

In the past, HIV was often dealt with as a specific issue at first, then located within a broader

sexual health context and then sometimes broadened again into health programmes such as the youth health programme. Some NGOs now approach HIV and STIs within a sexual health promotion context which would also address prevention of unwanted pregnancies, but also work with a sex positive approach - i.e. not just look at disease and risks. Gay Health Network would also emphasise the importance of addressing other areas of gay and bisexual peoples' health needs in addition to HIV in education programmes.

Evaluation of national prevention measures

As can be seen from the above, the primary influence on HIV/AIDS policy has been the multi-sectoral committee which is NASC. However, the other influences on policy have also made an important impact on the social environment within which HIV prevention operates. There is an eclectic approach to HIV prevention policy, which believes that health status is affected by a person's social and economic circumstance and that discrimination and social exclusion have an impact on life style and life chances. So, a community developmental, socially inclusive and partnership approach is what is aspired to by many participants.

Evaluation of some of the national prevention measures has been undertaken. Independent bodies were commissioned for that purpose. These include evaluation of radio and TV campaigns and Convenience Advertisements (see below). The AIDS programme in schools was also evaluated. Gay HIV Strategies is currently being evaluated. Community developmental approaches have not specifically been evaluated but there is on-going analysis of impact and effectiveness undertaken by the projects themselves.

Links with other communicable diseases

The specialist hospital consultants with responsibility for HIV also have responsibility for STIs. In areas where there is no specialist consultant, the STI and GU clinics have been involved in HIV testing. Increasingly, education and prevention messages refer to STIs as well as HIV. Many people at risk of HIV are also at risk of Hepatitis, such as IV drug users and haemophiliacs, so again there is overlap of personnel and policies.

International Policy Influences

HIV/AIDS policy development also occurs within an international context. Irish policy makers are members of the EU Management Committee on AIDS and Other Communicable Diseases and participate in a multiplicity of EU and other international networks. Policy makers remain informed of developments from the WHO, the UNAIDS and also observe developments in Europe, the US, Australia and the African countries. One example of how international sources informed policy development was in 1998 when NASC was presented with the ethical considerations regarding confidentiality if a known positive person is putting others at risk of

infection. Two day long events were organised to which all relevant people from Ireland were invited. Speakers from the UK and Sweden presented details of how the issue was addressed in their countries. After much discussion, the resulting policy document was an Irish response, informed by procedures in other countries.¹⁹

CHAPTER 3

INSTITUTIONAL STRUCTURES OF POLICY IMPLEMENTATION

Whereas NASC has been instrumental in policy development, it is not responsible for its implementation, which some may regard as a shortcoming.

Each government department is responsible for policy implementation within its own remit. The Department of Health and Children is responsible for funding HIV treatments and prevention programmes and their funding is channelled through regional health boards and hospitals. Therefore the responsibility for implementation of policies in this instance lies with programme managers and AIDS Co-ordinators within the health boards. Some health boards have internal audits in place. Some have contracts with NGOs to provide particular services. NGOs are responsible for policy implementation within their own organisations and must relate to their regional health board for funding. Therefore NGO services have to be regarded by the funders as beneficial and fit with the general health policies outlined above in order to maintain funding.

Each health board has an AIDS Co-ordinator, who is usually a public health doctor; one is the Infectious Diseases Consultant with responsibility for HIV. These AIDS Co-ordinators meet regularly in the Department of Health and Children. Reports of their meetings are presented to NASC and NASC reports are presented to their meetings. This method improves communication and may or may not impact on policy implementation.

The Department of Justice, Equality and Law Reform has responsibility for prisons and prisoners. The NASC may make recommendations to that Department on HIV treatments and prevention but its implementation is their responsibility. Similarly, other government departments are responsible for the areas which are part of their remit.

In general, hospitals and GPs provide most of the medical services, with some medical personnel employed in some of the drug service agencies. NGOs tend to be responsible for much of the education / prevention work, particularly outside of the Dublin area. They provide personal support and counselling for people with HIV and significant others. People with HIV/AIDS may be involved in NGOs.

According to most of the people interviewed for the compilation of this report, co-ordination of services varies from region to region, depends upon individuals and structures and can be erratic. Individual AIDS Co-ordinators may or may not be completely informed about everything which is happening in their area. It may or may not be their responsibility to liaise with everyone working in the HIV field in their area. NGOs may perform different roles in different areas depending on the historical development and the gaps in services which exist in each region. Some people are assigned responsibility and others take responsibility for service provision when it is not provided elsewhere.

The main structural deficiency is outlined above. The NASC report is the blueprint but this is not necessarily adhered to on a systematic basis throughout the country. One commentator suggests that there is institutional inertia to new responses, which results in some individuals or organisations blocking initiatives which may result in progress in their area. Others suggest that there is an imbalance of power and resources between the NGOs and the health boards and NGOs require greater resources and formal structures to tackle this imbalance effectively.

CHAPTER 4 LEGAL ASPECTS

DRUG USE

Drug use in Ireland is controlled under several acts outlined in 'Facts About Drug Abuse in Ireland.'²⁰

The Poisons Act of 1961

The sale of poisons is restricted to authorised pharmacists. This act refers most of the street drugs.

Misuse of Drugs Acts 1977 & 1984

"Intended to prevent the non-medical use of drugs... such as heroin, other substances such as sedatives, stimulants and hallucinogenic drugs which are liable to abuse." The Act also prohibits the unlawful possession, supply, intention to supply, importation or exportation or unlawful production of controlled drugs. The act distinguishes between possession for personal use and for supply to another person.

Non-Fatal Offences Against the Person Act of 1997

The Act made it an offence to injure a third person with a syringe, to spray blood, or any fluid resembling blood on a third person resulting in that person believing they may have become infected with HIV. Persons convicted may be fined or face a prison term of not exceeding 10 years.

HOMOSEXUAL BEHAVIOUR

Since the Criminal Law Sexual Offences Act 1993, the age of consent for homosexuals and heterosexuals is 17 years of age. There is no legal recognition of gay marriages. There is equality legislation as outlined above which pertain to employment and non-employment areas.

Sex Workers

Sex working / prostitution is illegal. The Criminal Law (Sexual Offences) Act 1993 made it is an offence to solicit for the purposes of prostitution (maximum fine £1,000) or to be suspected of loitering in order to solicit.

Youth

The Intoxicating Liquor Act of 1988 prohibits the sale of alcohol to people under 18 and also makes it an offence for people under 18 to buy alcohol or to drink it in public places. The age of consent for sexual intercourse is 17. Sex education is available throughout the school system in the form of Relationships Sexuality Education as part of the Personal and Social

Health Education programme. However, parents can withdraw their children from the classes should they choose to do so. "The RSE provides children with structured opportunities to develop the knowledge, attitudes, values, beliefs and practical skills necessary to establish and sustain healthy personal relationships as children and, subsequently, as adults".²¹

Migrants

Ireland has traditionally been a country with net emigration. However, recent prosperity has resulted in net inward migration, with returning emigrants, migrants from EU and non-EU countries and refugees. EU nationals form the majority of migrants and are entitled to enter and remain in Ireland under the Treaty of Rome (amended by the Maastricht Treaty). Other nationals must seek permission to legalise their status. Ireland now has a growing number of refugees and asylum seekers whose status is governed by the Refugee Act of 1996. Programme refugees are invited by the government and are therefore legalised. Medical screening for HIV and Hepatitis is offered on a voluntary basis to refugees and asylum seekers.

Prisons

There is no mandatory screening for HIV of people in prison in Ireland. Syringes, needles or condoms are not available to prisoners. The Hepatitis B, Hepatitis C and HIV in Irish Prisons Report commissioned by the Department of Justice, Equality and Law Reform recommends "a strictly controlled supply of clean needles and syringes" coupled with provision for their disposal.²² The report also recommends the provision of free condoms to all prisoners. It is not known at this stage whether the government will implement the recommendations of this report.

People living with HIV/AIDS

People living with HIV/AIDS have the same allowances as any other person with a long-term illness. If they are ill they can access additional allowances. The equality legislation referred to above outlines policies which could be used to protect people with HIV/AIDS from discrimination.

Health Care Professionals

*The Prevention of Transmission of Blood-Borne Diseases in the Health-Care Setting*²³ February 1999, sets out the current guidelines for protecting patients and health care workers from HIV and Hepatitis. The guidelines provide practical advice and detailed procedures (page 32) for preventing the spread of blood-borne diseases for workers in the private and public sectors. Standard precautions, involving the wearing of protective barriers (gloves, gowns, aprons, masks or protective eyewear) are recommended to protect against blood and bodily secretions.

Testing health care workers for HIV infection is not recommended by the guidelines. Should health care workers suspect that they have been exposed to HIV (or Hepatitis C (HCV)), they are "required to seek professional advice and diagnostic HIV and HCV testing". While the

report recommends that workers with Hepatitis C should not be involved in exposure-prone procedures, it does not make the same recommendation for workers with HIV. The guidelines support voluntary disclosure of risk infection and sets out a protocol for health care workers with blood-borne infections.

Other vulnerable groups

Most commentators stress that poverty, discrimination, unemployment, abuse, educational opportunities, homelessness and other factors which result in marginalisation and disadvantage all impinge on HIV. For this reason, community developmental approaches and outreach work have been an essential part of the prevention strategies. For many people with HIV, the virus is not their major or most immediate problem and working with people with HIV often requires a range of responses to an even broader range of problems.

CHAPTER 5 EPIDEMIOLOGY

Until recently, epidemiological data on HIV/AIDS was primarily focussed on AIDS data rather than HIV. (Ireland follows the CDC definition of AIDS.) The NASC report of 1992 targeted for specific interventions the general public, young people, young emigrants, drug users, homosexuals /men who have sex with men / bisexuals, prostitutes, prisoners and ex-offenders and health staffs.²⁴ This broad range of target groups does not fully reflect the epidemiological data at the time, when drug users and gay men were the primary groups of people with HIV/AIDS. Over the years responses to HIV/AIDS became more focussed on strategies to prevent increased transmission among gay and bisexual men and drug users as a result of the decriminalisation of homosexual acts, in response to pressure and research from gay activists and with the sheer enormity of the scale of the drug problem in Dublin.

The introduction of a computerised laboratory information system in the national Virus Reference Laboratory has improved the data available for monitoring of epidemiological trends in HIV infections. From 1993 to date, there has been a significant change in trends. At the end of December 1998, there were 1,986 people who had tested HIV positive, 650 people who had been diagnosed with AIDS and 332 deaths. Infections through IV drug use have dropped considerably since 1993 from 45% to 22% of new HIV transmissions (42% of the total HIV transmissions since 1985). There has been a steady increase in heterosexual infections from 13% in 1993 to 21% in 1998 (18% of the total HIV transmissions since 1985). Women make up 26% of the total HIV transmissions from 1992 to 1998. During the period January 1999 to May 1999 however, 34 out of the total of 76 new HIV positive cases were women. Of the HIV cases associated with heterosexual risk, 51% are women, 47% are men and 2% are unknown. Transmission amongst gay and bisexual men remained steady over this period, an average of 45 new cases per year, comprising 27% of new infections in 1993 and 25% in 1998 (23% of the total HIV transmissions since 1985).²⁵ One commentator suggested that it was easier to change drug using behaviour than sexual behaviour as if an IV drug user has access to clean needles they are likely to use it, whereas access to condoms does not necessarily result in their use. These statistics indicate that the strategy to reduce HIV transmission by IV drug use has been somewhat successful, (with some reservations given the recent evidence of increases in new infections among young drug users in some parts of Dublin).

Decision-making has been influenced by the epidemiological data which is available, but not determined by it. Details of some of the interventions are outlined below. Services for drug users have continued to expand since 1992. Services for gay men have also been provided on the basis of epidemiological evidence and research conducted by Gay HIV Strategies (see

below).

The increase in transmission amongst heterosexuals indicates the need for continuing strategies aimed at the general population. Details of national information campaigns are provided in chapter 7 below. In addition, since 1992 various NGOs have been funded to provide HIV prevention and support services in their areas based on local and regional needs.

It is unclear at present whether the advances in anti-viral treatments have had an impact on HIV prevention. The fact is that fewer people are dying, terminal care and home support services are less in demand. With the increasing medicalisation of the problem, people living with HIV increasingly attend hospitals on an outpatient basis for their medication and medical monitoring on a regular basis. Evidence from one of the main hospitals in Dublin suggests that some seropositive women now appear to plan pregnancies and the hospital has produced a leaflet to enable this to happen as safely as possible. There are also more obvious problems surfacing among sero-discordant couples, according to social work sources in the hospitals.

It is not yet known whether the advances in treatments have resulted in complacency amongst target populations. There are certainly fears of complacency being voiced by outreach workers and some support workers, but the evidence for this is not available.

CHAPTER 6

SURVEILLANCE SYSTEM

There are three major HIV testing laboratories in the country; the Virus Reference Laboratory Merlin Park Hospital and Cork University Hospital. All positive tests are sent to the VRL for confirmation. The VRL then forwards the (anonymous) results to the AIDS Co-ordinator of the Department of Health and Children who is then responsible for circulation to the community health division in the Department which releases the figures to NASC and the media, at present on a twice yearly basis.

AIDS and AIDS death statistics are reported on a special form by the treating hospital to the Regional AIDS Co-ordinator who in turn notifies the National AIDS Co-ordinator.

Statistics are collated by risk category. The "risk categories" used at present are: IV drug users (male and female), children at risk, homosexuals, haemophiliacs, haemophiliac contacts, hospital staff / occupational hazard / needle stick, transfusion, blood donors, organ donors, visa requests, insurance, prisoners, heterosexual / risk unspecified. These categories are currently under review as there are anomalies in the present system. For example, "prisoners" refers to the number of positive HIV tests in prisoners rather than a specific risk. Donation of blood and organs and visa and insurance requests are not risk categories for HIV but refer to occasions

which give rise to discovery of HIV status. Categorisation by age and gender has only recently been made available, but only for data dating from 1st July 1992. Members of the Education / Prevention Committee have also requested changes in categorisation of risks as it is difficult to monitor trends under the current headings.

Another problem with the current surveillance and monitoring system, which is soon to be addressed, is that the national statistics are collated on the basis of the year they are reported, whereas European CESES statistics are collated on the basis of the year of diagnosis. This can lead to some confusion when attempting to analyse data from different sources. One advantage of moving to the year of diagnosis system is that the current problem caused by reporting delays could be overcome, as statistics could be altered retrospectively.

A further anomaly is caused by the fact that babies have appeared in HIV statistics when they were born positive, but have not been removed from the totals once they lose their HIV status. Another issue, which has been addressed, is whether HIV should be a notifiable disease and the Department of Health and Children organised a series of discussions to look at monitoring of people with HIV.

The introduction of anti-viral treatments has resulted in greater consensus towards moving from AIDS surveillance towards HIV surveillance, as reliance on the former no longer provides adequate information to determine the need for care and prevention services. There are possibilities for recommendations for change in the surveillance system in the current review of NASC policy and it has already been decided that the new National Disease Surveillance Centre will be involved in future HIV surveillance.

Screening

Anonymous unlinked HIV screening of ante-natal bloods in the major maternity hospitals in the country resulted in 64 cases being confirmed HIV positive out of 287,099 tests carried out during the five year period from October 1992 to December 1997. Screening of bloods taken at STD clinics on an unlinked anonymous basis has recently commenced in some clinics.²⁶ Routine linked antenatal HIV testing was introduced in April 1999 and maternity hospitals throughout the country have been receiving training for its implementation in order to reduce perinatal transmission. The success of screening management in this field is exemplified by the fact that there have been no new HIV infections of babies born to known HIV positive women since 1994 in Ireland.

CHAPTER 7 PRIMARY PREVENTION

POLICY PRIORITIES

The written policy priorities date back to 1992 and as stated above, are currently under review. The NASC policy document states that “the objective of prevention measures is to limit the spread of HIV infection through public awareness campaigns, community-based initiatives and improved infection control procedures. All these initiatives should raise awareness about the disease, how the infection is spread and how the risk of infection can be eliminated and reduced”.²⁷

The committee acknowledged the importance of “knowledge of and instruction in safer sex”²⁸ and the availability of condoms. The committee also recommended that the most effective framework of service delivery was a co-ordinated voluntary and statutory sector approach. Particular initiatives were highlighted for each of the target groups.

Since 1992, the NASC and the sub-committees have initiated policies on a number of areas, as needs arose. The main developments and gaps in policy will be referred to below under target group headings.

General Public

The major initiatives for informing the general public have occurred under the auspices of the Health Promotion Unit of the Department of Health and Children. Since 1995, the positively evaluated “Convenience Advertisements” have been placed on the back of toilet doors in public houses and colleges. These advertisements reach the general public in a discreet, yet direct way. The messages change according to what is perceived to be relevant at the time and are very accessible. The recall rate in evaluation was very high and this initiative is being expanded to more health board areas.²⁹

Between 1995 and 1997, a series of advertisements entitled “Straight Talking” were released on TV and radio. This series won a Golden Apple award for best TV commercial. From 1997-1999 an advertisement aimed at young cinema going audiences called “The Brain” was the first government sponsored advertisement to show physical intimacy between two men. “AIDS The Facts” leaflets, some written by the Department of Health and Children and others written by an NGO were distributed nationally. Two videos were produced, one of which “Don’t Turn Away” dealt with drug use and won a European Award.

Information campaigns on a national level have the advantage of keeping HIV in the public eye. However, they consume a large proportion of the Health Promotion Unit's budget and are therefore only used at particular times, such as World AIDS Day. The absence of national campaigns can then result in the general public perception that HIV is no longer a problem.

Intra-venous Drug Users

The NASC report recognised the importance of outreach work, counselling, community drug teams, satellite clinics, needle exchanges and methadone maintenance programmes.

Provision of additional satellite clinics in the Dublin area to provide primary care and risk-reduction services including methadone maintenance programmes, needle exchange facilities and access to free condoms has been a policy priority due to the large numbers of IV drug users.

There have been many changes within the drug's field since the NASC report of 1992. Methadone has become a major part of the response to controlling opiate use during this time. Some commentators argued that its use has been to stop the spread of HIV from the drug using population to the non-drug using population.

The NASC report recognised the importance of one-to-one communication with drug users. Yet the sheer numbers (and as one commentator argued, the strength of the medical lobby which keeps HIV and drug use as a medical problem requiring medical intervention) have resulted in psychological interventions not being given the political weight required in order to be effective. The ratio of clients to addiction counsellors in the Eastern Health Board methadone clinics can be as high as 100-1 in some areas. Despite major investment of resources in this model, waiting lists continue. One commentator suggested that outcome studies are necessary to ascertain the affect of these programmes on individuals, families and communities. It is my view that strategies to reduce HIV among IV drug users cannot be divorced from strategies to reduce the demand for drugs and to combat poverty, unemployment, housing shortages, homelessness and social exclusion. Another commentator also highlighted the connection with other public health messages suggesting that as HIV is still seen as the virus which kills, this seems to undermine the understanding of the impact of other viruses, particularly Hepatitis C.

A study conducted by the Merchants Quay Project³⁰ found that young injectors (under 25 years of age) were significantly more likely to report recently borrowing and lending used injecting equipment than older (over 25 years old) injectors. The authors also noted the presence of a large proportion of young female injectors in the younger group, and the lack of awareness among the younger respondents of their HIV and Hepatitis B or C status given their level of risk behaviours. Anecdotal evidence from other drug agencies working with young people supports

these findings. Drugs workers at community level describe high levels of risk behaviour both in terms of injecting and in terms of sexual practices and are now reporting significantly more young people testing positive for HIV and Hepatitis C.

Ballymun Youth Action Project (YAP) suggests that the harm minimisation message has been somewhat de-emphasised in policy and practice and is not reaching young people. In addition, YAP has noticed a lack of focus on education and awareness raising for all young people. Safer sex is still a message not getting through to many clients, according to YAP. However, the Merchant's Quay study reported higher condom use among younger users.

In 1992, the HIV problem was to some extent a stimulus to provide much needed resources to agencies and communities working on drug use. The social problems, which are often associated with such extensive drug use, may now add impetus to the momentum for resourcing policy implementation in this area.

Gay and Bisexual Men and men who have sex with men.

The 1992 NASC report recognised the problems associated with the criminalisation of homosexual behaviour and also recommended the importance of outreach programmes to provide information and education. Since 1993, the legal situation has altered and outreach programmes exist in the major cities.

A Gay Men's Health Network acts as a national liaison body of the various outreach services for gay men in the major cities. However, outside of Dublin, there has been little evaluation of the success of this work. A Gay Men's Health Project established in Dublin in 1992 operates a drop-in health clinic for gay and bisexual men and extensive outreach and information services. The clinic provides medical and counselling services. In 1997 full screening for sexually transmitted infections was (re)introduced which resulted in increased clinic attendances. The project distributes information packs and free condoms.

Gay HIV Strategies (see below) has been operating in the field of policy development, capacity building and special initiatives since the findings of a research project³¹ on HIV in the gay community. Gay HIV Strategies have argued that there ought to be a response from all health boards and other agencies to the needs of gay men. They say that many health boards and other agencies have done nothing or very little and refuse to develop a programme in partnership with the gay community. They suggest that the reasons for this are somewhat explained by the historical legacy of criminalisation and the still prevalent prejudice and discrimination against gay people. Also, the often hidden nature of the gay community means that needs are not immediately apparent to service providers. Under-resourcing of gay activist groups can thus result in what they term "a negative cycle of underdevelopment".³² The way in which this group has responded to these structural problems will be addressed briefly in chapter

7.

Sex workers

The NASC report in 1992 recommended an outreach work strategy for working with sex workers (I am told by outreach workers in Ireland that they prefer to be called prostitutes here). The report also recommended that prostitutes be consulted on the development of educational materials.

Outside of Dublin, there are no outreach programmes working with prostitutes. Due to the problem of drug use in Dublin, many women and men engage in prostitution to finance their addiction, which causes visible problems for service providers and policy makers. The Mid Western Regional Health Board carried out a research study on prostitution in its area in 1998 and recommended a multi-agency approach and a safe environment for drop-in services which they have since established with the Red Ribbon Project in Limerick. In Dublin the Eastern Health Board funds a comprehensive women's health clinic and outreach work aimed specifically at prostitution. The Women's Health Project and the Ruhama Women's Project have succeeded in building trust and on-going relationships with female prostitutes in Dublin.

In 1997, an outreach worker and a counsellor in the Eastern Health Board produced a report on men in prostitution³³ which detailed many of the issues for men in prostitution and the agencies in contact with them. The Eastern Health Board is currently reviewing its strategy for working with men in prostitution.³⁴ Clearly, there is a need for other health boards to address this issue.

Adolescents

The NASC report recommended that the Departments of Health and Education should be responsible for developing materials for young people in school. This has been completed (although the stimulus for doing so was not necessarily from the NASC recommendation) with the development of the Relationships and Sexuality Education Programme. One possible problem with this otherwise welcome initiative is that each school is left to devise its own policy on implementing the programme, which could result in more conservative schools providing quite a narrowly based programme.

The NASC report also highlighted the need for "particular attention" for early school leavers and recognised the role of the voluntary sector in the formal and informal education system. NGOs are involved in innovative education and prevention work with young people in the Eastern (Dublin AIDS Alliance), Southern (Alliance Centre for Sexual Health), Western (AIDS Help West) and Mid-Western (Red Ribbon Project) Health Board areas. These areas include all the major cities. AIDS Help Northwest operates in the North Western Health Board area but much of the centre of the country and the north and south-eastern areas have no NGOs specifically working on the issues. The reason for this is perhaps the proactive way in which NGOs have

developed, so that if there are no people attempting to set up an NGO then it is not seen as a priority by the health board. Also, recognition of the work done in this field is not consistent from health board to health board and this has implications for policy implementation and resource allocation.

The NGOs listed above tend to adopt a multi-sectoral approach, working with other organisations involved with young people in their areas. While all the NGOs provide education, outreach and training services for young people and people in contact with young people, strategies and programmes vary according to local needs and situations. Dublin AIDS Alliance has greater involvement of drug users in its services and a greater emphasis on HIV in its education work. The Alliance Centre for Sexual Health in Cork has a sexual health promotion orientation born out of its research into the sexual attitudes and behaviour of young people (see chapter 7) and places special emphasis on peer education and creative means of interesting young people in sexual health. The Red Ribbon Project provides skills training for young women in order to improve their life chances and opportunities. All of the above NGOs provide counselling and support services for people with HIV and some provide health promotion counselling for young people.

Migrants

Ireland has traditionally had high emigration. The NASC committee recognised the importance of reaching young emigrants and recommended the production of a leaflet to be made available at travel centres and points of departure from the country. This leaflet has not been produced and the organisation working on HIV issues in Britain (the destination of 40% of Irish emigrants) no longer exists. Some HIV positive emigrants have returned to Ireland for treatment. Emigration has been in decline since 1993. Between 1997 and 1998 it was an estimated 21,200 people. In recent years Ireland has seen a reversal of this trend with net migration of 15,000 for the year ended April 1997 and 22,800 for the year ended April 1998. As migrancy into Ireland was not very significant in 1992, there are no recommendations in the NASC report on migrants.

Ireland, the land of a hundred thousand welcomes, does not necessarily extend this welcome to refugees and asylum seekers and often refugees face hostility from the general public. At present there is a one-stop shop for applicants seeking asylum and refugee status housed in the Department of Justice Equality and Law Reform. As medical screening is offered in the centre for applications, it may mitigate against people volunteering for HIV tests for fear that a positive result may interfere with a successful outcome to their application. Although results would be confidential within the medical centre, given language problems and the hostile environment faced by applicants, it can be appreciated that they may be reluctant to take a HIV test, thus being deprived of medical treatment should they prove positive. Although treatments are available free of charge to all people with HIV, there may be ethical dilemmas associated

with treating an asylum seeker who may be returned to a country where it would not be continued. Another concern expressed by the medical centre dealing with refugees and asylum seekers was about how positive tests may be categorised in public statistics. However, one benefit of the procedures in Ireland is that this can be referred to the appropriate committee of NASC.

Prisoners

The 1992 NASC recommendations spoke of the difficulties in making recommendations for prisons as it came under the remit of a different committee. It did however note the importance of information and counselling in order to reduce transmission in the prison.

The policy developments and gaps in implementation have been discussed in earlier sections and are elaborated in the report on Hepatitis B, Hepatitis C and HIV in Irish Prisoners: Prevalence and Risk.³⁵ Problems arising from lack of clean injecting equipment and condoms were referred to by one of the drugs agencies, suggesting that people who have practised safer sex and safer injecting outside of prison tend not to be able to do this as easily, if at all, inside. This is of concern if people present negative before prison and HIV or Hepatitis C positive afterwards. However, this agency also states that recognition also needs to be given to the fact that some drug users respond positively to the drug free programme available in Mountjoy prison in Dublin, the impact of which could be greatly improved with staff training programmes and planned aftercare. In addition, the improvements in treatment facilities in Mountjoy provide for greater care of those who are HIV positive.

A number of agencies are involved in work with prisoners, including the major hospitals, medical services, NGOs (almost all NGOs have some involvement in prisons) and statutory services. On reflection, perhaps there is a need for a more co-ordinated strategy amongst all the agencies.

People living with HIV/AIDS

The NASC has come in for some criticism from one of the agencies for people living with HIV for providing only one place on the committee for a representative of positive people. There are also very few people living with HIV/AIDS participating fully in agencies which work with HIV as an issue. Perhaps this is as a result of the fear and stigma which still exists, so that positive people are concerned about their status being known to family and friends. Perhaps it is as a result of agencies not trying sufficiently or not providing an appropriate environment for their participation on a larger scale. There is concern amongst agencies that these issues are addressed.

There are a number of positive people involved in a group in Dublin which is concerned with lobbying and education and in Poz Ireland, which publicises a regular medical information

pamphlet. Outside of Dublin there is a support group in Cork. The hospitals and NGOs provide counselling and support services throughout the country at different stages. Hospice care and home support for people at end stage is provided in Dublin, Cork and Limerick. As people are living longer with the virus, the social supports for people living with HIV need to be re-examined in the light of new and effective treatments.

Healthcare professionals

The current policies and recommended practices for healthcare workers have been discussed in chapter 4 above.

Campaigns

Campaigns have been on-going for all the target groups listed above on an on-going basis. The main aim of most campaigns has been to limit transmission of HIV through safer sex and safer drug use. Changes in emphasis have occurred over the years. Information campaigns in the early days emphasised correct and incorrect modes of transmission. Today information on safer practices is provided and measures to improve self esteem and assertiveness skills are regarded by most people working in the field as essential to effective HIV prevention programmes. There is now also increased emphasis on routine testing so that people may avail of treatments should they be HIV positive.

Examples of best practice:

Example 1: Alliance Centre For Sexual Health

The Alliance Centre for Sexual Health shifted its educational orientation from HIV disease prevention to sexual health promotion. The Alliance felt that its HIV prevention programme was popular in schools because it provided an opportunity for participants to discuss the topic of sex, even though the main messages in the programme were emphasising risk behaviours. The Alliance undertook research into the sexual attitudes and behaviour of 800 young people in Cork City entitled "What on Earth Are They Doing" ³⁶ and found that over 70% of them were not concerned about HIV. The study provided detailed information on the attitudes and sexual behaviour of young people. It particularly noted that those who were not sexually active felt that disease prevention programmes were not addressing their needs and concerns. Subsequently, The Alliance devised an educational programme for young people aimed at improving knowledge, exploring attitudes and providing skills for negotiation of healthier choices. The programme aims to acknowledge and affirm the diversity of attitudes and experiences of young people. The programme has been very well received in schools and is particularly successful in some of the rural schools, which in the past would have had nothing of this type of initiative.

The Alliance has also developed two other initiatives as a result of the research. An arts based initiative aims to reach young people in a more creative and non-verbal way. One example of

this is the Quilt of Hope which encouraged young people from a variety of backgrounds to produce small quilts of what AIDS meant to them and which were then exhibited around World AIDS Day. Another initiative is peer education as a result of which young people have been involved in producing a pilot sexual health promotion video. Funding has recently been secured for a peer helpline for and by young people on issues relating to sex and drug use.

Participants evaluate the education programme at the end of each session and the success of the programme is gauged partly by the numbers of requests for return visits. The impact on behaviour has not been evaluated. The reasons for success are associated with the relevance of the programme to the needs of the participants, based on sound research, rather than programmes based on the needs of the organisation to deliver a particular message. Young people can now be involved in education with a real expertise based on their own experience and training provided by the Alliance. The organisation has benefited from the new energies stimulated by the young people themselves and by the new project possibilities. The policy implications of this initiative indicate that education work which is based on sound research into the perspectives and needs of the target group, coupled with an imaginative response and skilled personnel provide an effective base for good practice.

Example 2: Gay HIV Strategies

Gay HIV Strategies was formed in June 1997 to develop a partnership approach to target gay men for HIV prevention. The project has worked on a number of initiatives, which emphasised this approach to developing its work.

The Sauna Project's aim was to build 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 HIV prevention measures would be consensus-based and part of the everyday management of the saunas. The project was very successful in building this collaborative approach and also in the significantly improved provision of safer sex materials such as condoms and lubricants.

The Waterford area partnership project aimed to engage with the local development structures and programmes which had not particularly addressed gay issues, to document the process and to provide a model of good practice for the other 37 local area partnerships in the country. The particular local objectives were to build the capacity of the gay community in Waterford and to engage with the various local service providers such as the Health Board, youth services and others in order to promote joint practical actions which could be undertaken.

The Eastern Health Board was approached with the aim of building a partnership process between the gay community service providers and the Health Board. The aim was to gain funding for HIV prevention pilot projects developed by the community groups and to build the

capacity of the community groups to engage in HIV prevention and health promotion work. This was the first health board funding which most of these groups received and indeed the first time that most of the groups met the health board.

The reasons for the success of the initiative are based on having a clear, overall, consensus-based strategy which resulted from research which obtained a picture of needs and which provided the opportunity to learn from best practice in more developed sectors. Identifying practical actions, which could significantly improve the situation in the short term, provided encouragement and energy for continuing the process. The project also had the services, funded by the Department of Health and Children of a skilled and committed project director.

Gay HIV Strategies is currently being evaluated and the Department of Health and Children has agreed to continue its funding. The project has made considerable progress in building bridges between the gay community and statutory agencies (capacity building) to encourage gay groups to engage proactively and effectively in HIV prevention work. The impact on policy implications has been to highlight to state agencies that their gay client group have particular needs and that they can work in partnership with and resource the gay community to improve state and community service responses.

Example 3: Ballymun Youth Action Project

Ballymun Youth Action Project (YAP) was founded in 1981, by local people in response to three teenage deaths in the area from drug related incidents. The project seeks to utilise the strengths of the whole community in developing appropriate strategies and actions. The project has three main beliefs: that drug addicts can and do recover, that families do not have to cope on their own and that the community is the most effective place for recovery.³⁷ The project aims to develop a community response to drug use in an area of high unemployment, negative media images, an early school leaving population which suffered discrimination and official neglect through a community development approach. This approach emphasises equity, participation and intersectoral collaboration. The group has moved from a service provision to a community action organisation focussed on both individual needs and the alleviation of difficulties and the development of community work as a means of achieving social change.

Through its education and training activities, YAP has developed the capacity of the community to participate in needs assessment, planning and implementation. YAP was the first group in the area to organise public awareness on HIV/AIDS and to encourage a caring approach to people with AIDS. Their approach humanises the issues of drug use and related illnesses such as AIDS and explores effective ways of responding. It has also helped other communities to do the same and the project is recognised as having contributed significantly to building inclusive measures to those in need, within their own communities.

The lessons learnt from this project show that a community approach is complex and open to various interpretations. The role of the community in responding to drug related problems (such as HIV) involves interventions which help with the specific problems and at the same time contribute in a far broader capacity to the underlying social problems.

The policy implications of actions such as YAP indicate that community participation is feasible, with the presence of enabling structures, professional clarity, training and commitment to developing innovative responses. At national level mechanisms need to be established through which community and service users can continue to be involved as active partners at local and national level.

CHAPTER 8

SOCIAL AND ECONOMIC SUPPORTS FOR PEOPLE WITH HIV

Supports for people with HIV are the same in Ireland as for anyone with a long-term illness. These include free treatment, travel concessions, food and fuel allowances, and help with rents for housing. In addition, people with HIV have access to NGOs, drop in services, housing projects and help with holidays, much of which is not available to people with other diseases.

The policy priorities are currently being reviewed. However, one important priority is to provide good quality treatment and care to everyone who is HIV positive. Implementation of policy varies from health board to health board, as discussed above. Most NGOs also emphasise the central involvement of individuals in their own health care as a policy priority.

Support is provided by the hospitals through medical and social work / counselling services; by NGOs providing information, support, counselling, housing support, referral advice; by statutory services providing counselling and addiction services. The Irish Haemophilia Society has been centrally involved in compensation cases against the government on behalf of its members. The government funds the majority of support services, either directly or indirectly. Some fundraising organisations specifically for HIV have also provided funds for particular projects. These include the AIDS Fund and Comfort AID in the past and Friends for Friends at present. NGOs also raise monies for service provision through their own fundraising efforts.

CHAPTER 9

HIV/AIDS TREATMENT AND CARE

The national policy is that all people with HIV should have access to treatments free of charge. All people living with HIV can access specialist hospital consultant services in Dublin or Cork for treatment, counselling and social work services. Consultants are available in St. James (GU), Mater / Beaumont and Cork University Hospital (Infectious Diseases) and Our Lady's Hospital for Sick Children. Those who do not live in Dublin or Cork have to travel for their treatments. Each hospital has a full team of doctors, nurses, dieticians and pharmacists. Consultant led services in palliative care in Dublin and Cork provides care for people who are dying. Access to hospice care is also available in Limerick.

The specialist hospital consultants determine the treatment and care policy. Hospitals staff liaise with general practitioners for co-ordination of patient care, although this is not always easy. Treatments are available for all people and each consultant has to make a judgement as to when and whether a person is ready for treatment, both medically and in terms of promoting adherence to medication. There are no financial obstacles to providing treatment and they are available for all groups and individuals that satisfy the medical criteria. Issues of stigma and fears around issues of confidentiality are perpetually a problem with HIV in Ireland, and can often mitigate against people with HIV accessing the full range of community services available from NGOs, such as home support, counselling, help with retraining and social supports. As a result, some people may feel very isolated.

Examples of HIV/AIDS programmes dealing with prevention:

Example 1: St James' Hospital Social Work Services

All patients at St. James are allocated a social worker or counsellor who will discuss secondary prevention with the positive person on a one-to-one basis. The onus is on the person as to whether s/he attends for counselling. Pre-test counselling is seen as an important means of contact with people who are vulnerable or at risk of future infection (if HIV negative). Attendance at the STI Clinic means that people have already identified themselves as being vulnerable to infection, so there is a proven target audience for the counselling interventions. The counselling aims to encourage the person to look at their behaviour and discuss ways of changing it if necessary. The intervention is just one cog in a wheel of prevention measures, and its effectiveness is judged by responses from participants who have found it useful, supportive, accessible and non-judgemental.

The intervention is currently being evaluated by one of the social workers to assess the extent to which it has an impact on behaviour change. With the increases in test sites and reasons for promoting HIV testing as a result of improved treatments, there is now less emphasis on pre-

test counselling. In antenatal and STI clinics, those identified as vulnerable people are targeted for pre-test counselling, while others are offered pre-test discussion. The St. James' counselling initiative shows that there is still a place for pre-test counselling in promoting primary and secondary prevention of HIV.

Example 2: Open Heart House

Open Heart House identified a need for day care services for people with HIV in Dublin. The centre provides support to people in taking control of their lives and challenges the isolation which many people living with HIV feel. The success of the project is gauged by the involvement of people with HIV at all levels of the project and the sense of responding to key needs.

The project has not yet been formally evaluated, but the number of members (ninety) bears witness to its success. The policy implications for Ireland are that we can involve people with HIV in decisions affecting their lives, which enables us to meet their needs and in turn challenge social stigma by raising awareness of the disease.

CHAPTER 10 EXPENDITURE

The level of expenditure on HIV/AIDS is not known in Ireland, as services are funded from different budget headings and from different government departments. The current review of NASC policy may see a shift in expenditure. Certainly, the new treatments are very expensive, so the medical costs will be increased. We will have to wait and see whether the current expenditure will be maintained, increased or decreased after the review in December of this year.

CHAPTER 11 RESEARCH PROJECTS ON RISK AND BEHAVIOURAL CHANGE

There has been no countrywide research undertaken to study knowledge, attitudes, behaviours and practice. There are no indicators on behavioural change documented on a national basis for sexual behaviour. The Department of Education and Science evaluated its AIDS programme in second level schools. The Eastern Health Board has records of needles used in needle exchanges. Anonymous unlinked testing provides evidence of the extent of HIV in the heterosexual population, but does not necessarily supply information on behaviour change.

Research into prisoners has recently provided information on the level of HIV in prison and sexual and drug using behaviours of the prisoners.³⁸ Changes in behaviour resulting from prevention strategies could be ascertained by further studies.

The Alliance Centre for Sexual Health undertook such research in Cork city on 800 young people between the ages of 16 and 24 the findings of which are summarised in Appendix 2. In Galway, Dr Emer Mac Hale also conducted a KARP study with fairly similar findings.³⁹

CHAPTER 12

PERCEPTION OF THE SYSTEM

CURRENT DEBATES ON HIV PREVENTION

A number of viewpoints were sought as background for this sector. Interviews were held and written submissions were received from key government personnel (2), the statutory sector (5 individual and 3 group responses), NGOs (10) and people with HIV (3). There was a large degree of consensus in perceptions of the current system, which is perhaps not surprising given the manner in which broad ranging views and experiences have been sought for representation on the National AIDS Strategy Committee. Some differences emerged however in perceptions of the main challenges and possible obstacles facing future prevention policy.

All commentators agreed that the general perception of HIV/AIDS has changed over the last few years. The main reason for this is the effectiveness of new treatments so that HIV is now seen as a chronic illness. The media no longer tends to focus on HIV prevention, preferring to concentrate on treatments in its now reduced coverage. One social worker suggested that there is less fear of contagion now that HIV is no longer a terminal illness. Whether this impacts on risk behaviour is still unknown.

Current debates in prevention by sexual spread tend to focus on whether to adopt a disease prevention or a sexual health promotions approach. While most commentators (statutory and non-statutory) agree that a sexual health promotion orientation is more effective and relevant when working with some target communities, there are fears about the impact of such a move on funding for education / prevention work. Another on-going debate centres on whether HIV prevention should be integrated into other areas of work, such as drugs work, community development work, or maintained as a separate interest. The fear here is that HIV could become lost amongst other issues.

MAIN CHALLENGES FOR FUTURE HIV PREVENTION POLICIES

The most common responses from commentators from the statutory and non-statutory sectors was to keep the issue alive, to avoid complacency, to be relevant and effective and to target people at risk of infection.

Complacency was highlighted as a particular problem by almost all commentators. One worker in a drug's agency said that HIV was hardly mentioned these days, as they are so busy dealing with problems of addiction and poverty. A number of others mentioned the increasing medicalisation of the problem and the (medical) perception that there is no longer such a need

for psychological support services.

One commentator from an NGO suggested that the presentation of safer sex messages should be reassessed, as they are no longer appropriate. Another person suggested that there was too much re-inventing the wheel and there should be greater collaboration between organisations in the sector and between sectors.

Members of the gay community stressed that the challenge still exists to access people who are not part of identified communities. They referred to men who have sex with men who do not identify as gay and who are not part of the community, or men who may be married or who live in rural areas.

There is also a growing awareness, mainly among NGOs, that social, economic and discrimination barriers to effective HIV prevention programmes must be addressed. Some drugs workers have reported on the significant increases in teenage girls becoming infected with HIV through drug use in areas of Dublin which would have seen a large number of people die of AIDS, some of them related to those who are newly infected. These young people, often disaffected and alienated, are sometimes from families facing the third generation of unemployment, and what one commentator described as poor people in every sense of the word.

Two NGOs and one statutory sector worker referred to the impact of anti-natal testing which one person described as “not a positive experience” as procedures were poor and staff were “not properly trained”. While the introduction of widely available anti-natal testing is to be welcomed, there is a need for monitoring of its implementation from the users’ perspective as well as the epidemiological outcomes. A social worker, while welcoming routine testing stressed the need to redefine practice on a multidisciplinary level. An NGO highlighted the need to develop guidelines and protocols for safe and good practice in this area.

Gaps / obstacles regarding HIV prevention policy and support for PLWAs

With the effectiveness of treatments, the social supports for people need to be improved as people are living longer. Those with responsibility for caring for children also pointed to the increasing need for social support for positive children as they are reaching adolescence and the age when they may be thinking of forming sexual relationships. As peoples’ health has improved, positive people are now looking to improving their skills in order to re-enter or improve their situation in the labour market.

A number of commentators highlighted the need to address the issues of homelessness as a means of supporting positive people and reducing opportunities for infection. One commentator said that drug use tends to become a problem for people who are homeless and

risky behaviour is regularly reported. People are not allowed to bring needles into hostels and therefore tend to use drugs in more unsafe environments.

Gaps / obstacles regarding quality of counselling and access to treatments

One positive person said that while the medical services looked after her treatment, the NGOs helped with her dignity. She feared that members of the medical profession were becoming complacent because the treatments were so effective and that they may lose sight of the fact that they are dealing with whole people rather than just their bodies. Another positive person said that her appearance mattered to her a great deal and she did not feel that the medical profession was taking into consideration the impact of the treatments on her body. A national HIV organisation expressed the need for the establishment of a standard of care and treatment for people with HIV/AIDS to ensure equal access to state of the art treatment.

One medical person expressed the view that people living in the two main cities have better access to treatment than those who live elsewhere. A social worker also stated that those living in rural areas may travel to Dublin or Cork regularly for their medical treatment but have very little opportunities for on-going counselling near their homes. A worker in Dublin suggested that there was a need to tailor available information for people with literacy problems. Some people living with HIV have also expressed reservations about using services in their locality as they fear the outcome should confidentiality be breached. There are often difficulties in addressing some of these issues due to the small numbers of people affected in any one geographical area.

On the prisons issue, apart from broad welcome for the report on hepatitis and HIV in prisons, one organisation called for an expansion of the methadone programmes, improved detoxification facilities, greater involvement of counsellors and targeted information dissemination. A counsellor in a GU clinic emphasised the language barriers which some migrants face when accessing services.

HIV/AIDS prevention policies for the future

One government official stressed the importance of systematic education as the number one priority, with a systematic strategy and education policy and targeted interventions for various groups.

Others agreed the need for more systematic approaches, greater collaboration between the statutory agencies and NGOs. A number of people wish to see improved work with vulnerable young people and improved educational materials aimed at young people at risk. One NGO wished to see more focus on youth, involving mainstream youth services and educational agencies.

Gay HIV Strategies wish to see the establishment of a Task Force on Discrimination against gay men and lesbian women to challenge prejudices and tackle social exclusion. They would also wish for greater support for gay men who experience multiple disadvantages including poverty, unemployment, homelessness and mental health issues. They advocate advertising directed at gay men as part of the Health Promotion Units ongoing programme. They stress that partnership and capacity building are the keys to success.

Two NGOs wish to see NASC having more of a co-ordinating and monitoring role. As Ireland is still relatively new to the age of sexual freedom there are many issues which need to be addressed. These issues will effect the ways in which programmes are delivered, what is acceptable in its content, the age groups and sexualities of the people targeted, the impact on behaviour and ultimately the sexual health and wellbeing of the nation.

Outstanding HIV prevention measures in Ireland

There have been many inspirational programmes and measures in HIV prevention in Ireland. However, the National AIDS Strategy Committee as a model for policy development and as a forum for developing consensus on priorities has proven itself to be a most effective mechanism. The Committee benefits from the large measure of commitment from civil servants, a succession of Ministers for Health, the medical profession, people living with HIV, social workers, counsellors, outreach workers and members of NGOs. It should be acknowledged that there are some people who think the committee is not representative enough. However, the fact that so many people wish to participate on the committee may also be an indicator of its success in addressing issues of importance.

The Education / Prevention Sub-committee has been one of the most active of the sub-committees. It has produced education guidelines for people working on HIV, organised training for people in the sector in order to improve information and skills and has been active in developing policies on and discusses many of the issues represented above.

The Irish response to HIV prevention and practices has been one of consensus building, with involvement of highly committed individuals and organisations from amongst the governmental and non-governmental sectors. The challenge facing us today is to maintain this momentum, to respond to the new gaps and obstacles which are appearing before us in order to proceed to a higher level of wellbeing for Irish people at risk of and living with HIV.

HIV/AIDS FACT SHEET: IRELAND (1998)

Total population: (1)	3,704,887
(1) Demographic information by age 0-14, 15-64, and 65+ proportions	24%, 65%, 11%
(2) Total migrant population and proportion (2)	Not available
(3) Estimated number of adults living with HIV/AIDS end of 1997	1,500
(4) Estimated number of women living with HIV/AIDS end of 1997 (3)	Not available
(5) Estimated number of children living with HIV/AIDS end of 1997	129
(6) Estimated number of I.V. Drug Users with HIV	816
Estimated number of drug users	13,500
HIV infections:	
Number of new infections per year:	120 - 180
Total number of persons infected since the start of the epidemic (estimated):	1986
Breakdown by gender of total infections from 1st July 1992 to end 1998	970
Men:	673
Unknown	46
Women:	251
Children under 13:	149
Infection routes of importance today	
Homosexual contacts among men:	approx. 23%
Intravenous drug abuse:	approx. 43%
Heterosexual contacts:	approx. 18%
Persons from Pattern II countries:	N/A
Vertical transmission (mother - child):	approx. 7.5%
Blood transfusion and products:	7%
AIDS cases:	
Total number of reports since 1982 (not corrected for under-reporting):	650
Those of which reported as dead (not corrected for under-reporting):	332
Cumulated Incidence in 1998 per 100,000 inhabitants:	18
New cases per year:	Average 55
Completeness of recording:	N/A

BREAKDOWN BY GENDER

Men:	81%
Women:	19%
Children under 13:	3%
Infection routes (cases diagnosed in year January 1998 - December 1998) AIDS cases	
Homosexual contacts among men:	32%
Intravenous drug abuse:	27%
Heterosexual contacts:	12%
Patients from endemic regions (Pattern II):	N/A
Haemophiliacs:	5%
Blood transfusion and products:	5%
Vertical transmission (mother - child):	9%
No data:	10%

Source: National statistics: Central Statistics Office, Ireland, 1999. HIV/AIDS Statistics: Department of Health & Children, Ireland, 1999.

Notes:

1. National census in Ireland was held in 1996. 1998 statistics are arrived at by adding net population change to the total population at the April 1996 census.
2. Migrants: There are no national statistics available for the total migrant population. Net

migration for the year ending April 1998 was 22,800.

3. Women: Total number of women infected with HIV from 1st July 1992 to the end of 1997 is 203.

4. Total new AIDS diagnosis in 1998 was 41 people

APPENDIX 2

ALLIANCE CENTRE FOR SEXUAL HEALTH IN FROM THE MARGINS

SUMMARY RESEARCH FINDINGS

1. SEXUAL VALUES:

- 1.1 AIDS is a relatively small concern for young people. 71% of men and 79% of women did not perceive themselves to be at risk from HIV. Young people have a range of interests and concerns with regard to relationships and sexuality, the most pertinent concern being pregnancy.

While most young people are informed about the main forms of HIV transmission and prevention, there were some gaps in information, particularly among 15 - 17 year olds. The majority of young people wanted more information on AIDS. There was a tendency to associate HIV with people who engage in casual sex and people with multiple partners. As a consequence, 'steady' 'monogamous' relationships decreased the sense of vulnerability to AIDS.

- 1.2 Meanings of sex are complex and variable and there was largely a cautionary attitude to sex. Positive factors mentioned were love, trust, and intimacy. There was little emphasis on pleasure. Negative factors included fear and trepidation, doubt and uncertainty. There was a preoccupation with risks - especially pregnancy.

The research concluded therefore that AIDS specific or disease prevention programmes do not reflect young peoples concerns. The Alliance therefore initiated a sexual health promotion programme in order to create a meaningful response to these concerns.

1.3 Gender specific differences:

80% of women, compared to 50% of men saw sexual activity in the context of a steady relationship. Male respondents felt constrained by stereotypes of male sexuality. Respondents also exhibited negative images of female sexuality: 47% of men and 61% of women thought that sexual activity gives women a bad reputation.

1.4 Perception of risk:

Respondents tended to focus on general rather than personal risks.

2. **SEXUAL ACTIVITY:**

- 2.1 The findings showed that many young people in Cork City were sexually active. 61% of men and 45% of women between the ages of 15 and 24 report having had sexual intercourse. 32% of men and 22% of women had their first sexual experience by the age of 16. 70% of women and 55% of men in the 15 - 17 age group had no sexual intercourse experience. However, half the young men from disadvantaged backgrounds had their first sexual intercourse experience at 15 years.

Men had more sexual partners than women. 55% of sexually active men reported three or more partners compared to 32% of women. 31% of men and 46% of women reported having had one partner. So, lifetime monogamy was not an option for many.

3. Young people who were not sexually active were concerned about safe sex.
4. Contraception: 41% of men and 45% of women did not use a condom at last intercourse. Choice of contraception was influenced by the type of relationship and by age. The pill was the main choice in a "steady" relationship. The findings showed that as age increases, condom use decreases and pill use increases.

The survey also highlighted the obstacles young people face in using contraceptives. These include maintaining contraceptive use over time, buying, using and negotiating condoms and communicating on sexual matters. Availability and accessibility of contraceptives and alcohol use also impacted on contraceptive use.

SOURCE: What On Earth Are They Doing (1997), available from The Alliance Centre for Sexual Health, 16 Peters Street Cork, Ireland. Email: alliance@tinet.ie

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