

NO ROOM FOR COMPLACENCY

Families, Communities and HIV

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FOREWORD

It is apparent through Cairde's work with families that the presence of HIV in their lives exacerbates what for many are already difficult living conditions. This report lays stark testimony to the isolating impact HIV has on individuals and families. Individuals within their own families and families within their own communities.

The stories the families tell of facing prejudice, of losing loved ones, of helping their children fight a terminal illness, of not being heard and most of all, of doing it with little or no support, challenges those of us working in the area to question why more is not being done.

Since the first cases of HIV were registered in 1982, HIV/AIDS policy has largely emanated from a medical model and has come under the auspices of the Department of Health.

There have been enormous advances in the treatment of HIV and lives have been saved but those living with HIV are still living with a terminal illness and the resulting uncertainty.

This report, through the testimony of those most affected, “gives voice” to the social and emotional consequences for families of a HIV diagnosis.

It gives a clear account of the isolation families experience, the financial strain that HIV brings, the support children need, and incredibly almost twenty years into the presence of HIV in Ireland, the stigma still associated with HIV/AIDS.

When Cairde first spoke to families about this project many expressed a desire that they would get to tell their stories and our desire to honour that is reflected in this report.

Recording the families’ stories will not on its own address the many issues raised in this research, however, this report presents us with an opportunity to affect the necessary policy changes. It identifies the issues that need to be addressed and the sites of responsibility where that can happen. The Department of Social, Community and Family Affairs through its family affairs unit and its community and voluntary section has a significant role to play. The Department of Health too has much more it can do.

Responsibility too lies with other sectors, the non-government and community organisations need to be more cohesive and pro-active in their actions. This report clearly highlights the issues families face and shows that while HIV/AIDS may have slipped off the public and policy agenda, there is “no room for complacency”.

Cairde would like to thank all those who supported this project, in particular the families and individuals who told their stories, the Eastern Health Board and The Combat Poverty Agency for financial support, the members of the Research Advisory Committee and a very special thank you to Aileen O’German for the sensitive and respectful way in which she conducted her research.

Paddy Connolly

Director
Cairde

RESEARCH SUMMARY

SECTION 1: THE RESEARCH STUDY

This research study was commissioned by Cairde, who, during the course of its work providing emotional and practical support to HIV positive individuals and their families, had become increasingly aware of the difficulties families experience in relation to issues of exclusion, emotional stress, and financial strain.

The study is based on the premise that in addition to the people directly *infected* by the HIV virus, there are also those people whose lives have been *affected*, by the virus i.e. the parents, partners, children and siblings of the people who are HIV positive.

In addition, the study focuses on HIV rather than AIDS, for it is at the point of a positive HIV

diagnosis that individuals and families become affected by HIV/AIDS.

The aims of this study were:

- i) to assess the circumstances and needs of the HIV positive individuals and their families;
- ii) to examine their responses and coping mechanisms;
- iii) to use the experiences of those affected to inform policy making and practice.

A qualitative research methodology was chosen as the most appropriate means for assessing the circumstances and needs of individuals and families affected by HIV/AIDS. This approach focused on the use of semi-structured in-depth interviews to 'give voice' to the individuals and families concerned and relate their experience from the initial positive diagnosis, to life, and in some cases death, with HIV/AIDS.

Supplementary data was collected through a series of 'information interviews' with personnel from the statutory and voluntary sectors providing services in the HIV/AIDS field. Secondary data, on the epidemiology of HIV/AIDS, HIV risk behaviour, social exclusion, and policy issues, were collected to contextualise the interview data. In addition, members of the families affected and personnel from the HIV/AIDS services, participated in a policy seminar to discuss the emerging themes from the research: issues arising from these discussions were used to inform the study.

Members of nineteen families participated in the research study. In the nineteen families represented, 26 adults and seven children had been diagnosed HIV positive, a further 29 adults and 54 children were affected by HIV/AIDS.

Additional research needs were identified which were outside the framework of this study. These related to the experiences of gay men, their partners, friendship networks and families; and children's experience of HIV/AIDS from their own perspective.

SECTION 2 - THE EPIDEMIOLOGY OF HIV/AIDS

In Ireland, our understanding of the epidemiology of HIV/AIDS (that is its prevalence and distribution in the population) and our awareness of the numbers of people who have been affected by HIV/AIDS, is restricted by the lack of appropriate research data.

Given the deficiency of HIV data, it is difficult to make a grounded appraisal of current and future trends in HIV transmission. Advances in the treatment of HIV/AIDS and the decrease in the number of new AIDS cases recorded, have contributed to the declined prominence of HIV/AIDS on the public health agenda. Yet, this reduced prominence seems misplaced when the number of new HIV cases continues to rise and the full extent of HIV in the population remains unknown.

TRENDS IN HIV TRANSMISSION

In recent years the epidemiology of the known HIV population has begun to change. While intravenous (IV) drug users still account for the highest proportion of all HIV cases (42%), their numbers, as a proportion of the new HIV cases recorded, have decreased. Currently, the highest rates of HIV transmission are homosexual sex for men and heterosexual sex for women.

A new pattern in the geographic diffusion of HIV has also been noted, and which reflects the trend towards the sexual transmission of the virus. 14% of current new diagnoses and 42% of the women who tested positive in antenatal screening programmes live outside the Eastern Health Board area.

HIV RISK BEHAVIOUR

Despite increasing rates in the sexual transmission of the HIV virus, there is little recognition of heterosexual sex as an HIV risk behaviour at either policy or personal levels. Studies of sexual behaviour and levels of sexually transmitted infections, indicate high levels of sexual risk behaviour and low perceptions of HIV risk in the general population.

With respect to the decrease in the numbers of IV drug users (IVDUs) testing HIV positive, a number of cautionary points were identified. Research findings have shown that IVDUs not in treatment are more likely to engage in HIV risk behaviours and consequently have a higher prevalence of HIV. In Ireland, the high proportion of drug users who are out of treatment and who are likely to be engaging in HIV risk behaviour has serious implications for future trends in HIV transmission.

In addition, the HIV risk posed to drug injectors and their partners through sexual transmission tends to be overlooked even though their sexual behaviour has been seen to reflect the sexual risk behaviour of the rest of the population.

While the size of the HIV positive population anticipated in the 1980s has not materialised, trends in HIV epidemiology and indicators of HIV risk behaviour illustrate that there is little room for complacency with regards to the future prevalence of HIV.

ESTIMATION OF THE NUMBERS OF ADULTS AND CHILDREN AFFECTED BY HIV/AIDS

Attempts to estimate the number of people affected by HIV are hampered by the lack of relevant data. Nonetheless, an estimation of the numbers affected was calculated.

The estimated total HIV positive population was 2,875, almost 1,000 more than the number officially recorded. A further 3,220 adults and between 1,000 and 3,000 children are estimated to have been affected by HIV/AIDS.

While these figures most likely underestimate the full extent of the phenomenon, the point of this exercise is to highlight that for each HIV positive individual there are additional numbers of people who have been affected by HIV/AIDS.

SECTION 3 - ISSUES FOR FAMILIES

THE SOCIAL ASPECTS OF HIV/AIDS

Since HIV/AIDS was first identified in the 1980s it has developed a curiously demonic mythology quite unlike any other life threatening illness. Fears of contracting what was initially an untreatable disease, and the association of HIV with perceived 'deviant behaviour' (such as homosexual sex and intravenous drug use) provided a ripe breeding ground for the multitude of moral panics and urban myths that developed around HIV/AIDS.

In the absence of adequate public information campaigns to counteract misinformation and promote a grounded awareness of HIV risk behaviour, HIV and AIDS continues to be widely viewed with prejudice, fear and ignorance. As a result, HIV positive people and their families live with the stigma and secrecy that surrounds this disease. Children from such families were identified as being particularly vulnerable.

THE DIAGNOSIS

Receiving a positive HIV diagnosis is a traumatic event for the person who has been infected and their family. Not only must they come to terms with an illness which, until recently, resulted in inevitable death, but an illness which is deeply stigmatised and which fundamentally alters social relationships both within the family and between the family and the outside world:

I went for the results with him and when he found out that he was HTV positive, well he ran amuck ... panicking he was, he cried all the way home and cried, I think he cried for a week after, "I'm going to die, I'm going to die"

Given the nature of HIV transmission, when one family member has been diagnosed, there is the possibility that their sexual partners and children are also positive:

I remember just sitting there frozen solid. You know I hadn't got the power to get off the chair. And even at that time I didn't know the full consequences of it you know.

I was left here thinking what if I have it. That was my biggest fear, I must have it as well. If he has it, I must have it.

DISCLOSURE OR SECRECY

Disclosing an HIV positive status tends to be a protracted affair. In addition to telling a partner, there are children, parents, brothers, sisters, the whole extended family and friendship networks to consider.

Deciding who to tell involves making a judgement call as to how that person is likely to react. Many people found this prospect too overwhelming, deciding instead to keep 'the secret' within the family. As a result, many HIV positive people and their families are isolated from their extended families and their communities. In such circumstances, HIV is truly a lonely disease:

Nobody else actually knows and I find that hard ... it would be nice to have a pal that you could talk with... [but] if you tell one you have to be ready to tell the world. It's a big burden to tell someone.

The stress of keeping 'the secret' and the double-life it forces people to lead was magnified when there were different levels of awareness about the illness within the family. For example, where older teenage and adult children knew the true nature of the illness, while younger ones remained unaware.

Disclosing to children who are themselves HIV positive was seen to present a particularly difficult problem for parents and carers. Parents felt pressurised to tell their children about their status

and to inform their child's school of the situation. **But**, most parents are reluctant to do this fearing their child will be ostracised:

I mean if the neighbours here found out about it I might as well throw my hat at it, \ the kids wouldn't be able to go outside the door and you 'd finish with having to move. I have no doubts about that. I mean people may try and be understanding but when it comes to their kids playing there's no way.

LIVING WITH HIV/AIDS

The uncertainty and life-threatening potential of HIV places a heavy toll on relationships within families, and in particular on a couple's relationship. Maintaining a sexual relationship was a problematic issue, and with the ongoing concern of transmission many sexual relationships altered radically after HIV was diagnosed.

Relationships within families are further affected by the stress of keeping 'the secret' from some family members, often necessitating the construction of elaborate stories to explain illness and medication.

On a daily basis, the ongoing stress of living with a chronic illness, confronting possible death and being in constant anxiety about their health, gives rise to bouts of depression:

It's just this constant/ear of getting sick and dying and spreading the disease to someone I love. That's the main sort of dread and depressing thing about it. Sometimes I do be thinking of the child growing up and me not being there ...so it's mainly/ear and depression.

For many families, the defining aspect of living with HIV, was having to cope with the accompanying prejudice and harassment:

Branding, I mean that's totally what it's like. You're branded for life.

Even children do not escape harassment:

A girl two doors up - came out and started giving out to Rosie and then she turned round and said "you know, your mother is dying from AIDS". So Rosie came in and she was roaring crying and I had to explain that people can be very hurtful, don't mind them.

SUPPORTING FAMILIES

Keeping a HIV positive diagnosis a secret within the family affects people's ability to develop support networks. However, families were also concerned with maintaining the confidentiality of their status. In approaching services in the relatively small city of Dublin, families considered themselves to be at risk of being identified, outside the city this concern was even greater. Others found counselling support services too intrusive and advocated the need for more practical

support:

I nearly run a mile when I see the counsellor coming... I think you're far better off sort of aiming for practical help and, rather than sort of indirect help. I think that's the best way forward because you're taking a certain amount of the pressure off then and once you have some pressure lifted you can sort of sit back and concentrate on doing other things.

Peer support was particularly favoured by parents, partners and carers of positive people, who found meeting others an opportunity to pool experiences and coping strategies, as well as accessing emotional support.

The focus of most support services on the positive person, unwittingly left many' negative partners feeling isolated and alone. For families living in rural areas, their distance from services made their isolation even more pronounced. A shortage of child care also resulted in parents experiencing difficulties in attending support services.

Not only do families internal lives come to revolve around the virus, but externally the families are perceived and identified, first and foremost, as families with HIV. Despite this, the families themselves had found little opportunity to define their own needs in terms of the support structures they required. In addition, their loss of identity is also accompanied by an erosion of the power and control they have over their own lives.

COPING WITH TREATMENT

Within the last few years, the availability of anti-retroviral drugs has radically altered the prognosis of HIV, and led to a greatly improved health and life expectancy for those diagnosed positive. Nonetheless, the treatment regime proves a hugely difficult and emotive issue for HIV positive people and their families.

Among the difficult aspects of the treatment, there is the highly intrusive nature of the medication routine which involves taking large quantities of different drugs at regular intervals throughout the day. Adhering to this regime involves continuous self-discipline to maintain a healthily lifestyle, avoid alcohol and once started to persist with the medication for life. In addition, many people experience a range of upsetting and debilitating side-effects such as nausea, vomiting, rashes, diarrhoea, stomach upsets, weight gain etc. Added to this, the range of treatment options available can result in the patient receiving conflicting advice from different sources, and/or advice which is too complex to fully understand.

The complexity of the treatment presents problems for health professionals to provide the necessary information in an accessible form. However, failure to do so was seen to have far reaching repercussions, particularly when this was accompanied by a patient's difficulty in adhering to the treatment regime: in such cases the likelihood of the patient taking a 'drug holiday' was increased.

In addition to accessible information, the need for information specifically geared towards the needs of homosexual men, women, and ethnic minorities, was identified.

Patients from rural areas, and those who are working and/or caring for young children had particular difficulties attending the clinic. In addition to these practical difficulties, patients found

the clinical setting and its hierarchical structure extremely alienating. Families were frustrated that their efforts to inform themselves and their concerns over treatment were often dismissed, despite as a patient remarked:

They just dispense the drugs, we've got to live with them.

The vulnerability experienced by people in treatment was further amplified by their concerns over the long term effects of the medication and its possible failure.

Overall, the issues relating to treatment were extremely emotive ones for patients and their families. This may be explained in part, by the continuing adjustments both patients and their health carers are having to make as a result of the transition in HIV/AIDS treatment. That is, the transition from a situation where HIV/AIDS was a terminal illness with little treatment available, to the current situation where HIV/AIDS is a chronic illness requiring ongoing, indefinite medical care.

Managing Positive Children's Treatment

The difficulties adults experience in adhering to the treatment regime are acutely magnified for children who also have to follow detailed medication routines.

Children experience difficulties in taking part in activities which would impact on this routine. Parents and carers are seen to have developed innovative responses to deal with such situations. However, even some very ordinary activities, are less manageable and have to be ruled out. Parents and carers experienced great anxiety when their children had adverse reactions to the medication. An anxiety that was further exacerbated by their need to keep the child's status private from other family members and even the child him/herself. As one mother remarked:

We'll never have the little old ladies prayers, you know the way there's always little old ones in the parish who are saying oh I'll say a prayer/or you and that like but never, there's nobody that would ever say one for us.

The constant supervision of a positive child's routine places many restrictions on the lifestyles of parents and carers. In such families, working outside the home, attending clinics and support services, even nights out are problematic, as child care is almost impossible to access and even more so if medication needs to be given or a child is ill. The lack of appropriate child care is a major concern for families affected by HIV/AIDS, particularly as the support of the extended family is often unavailable because of the families' wish to keep their child(ren)'s status private.

COPING WITH LOSS

Since 1982, three hundred and thirty two deaths from AIDS have been recorded in Ireland. An additional unknown number of positive people have died from other causes. Families affected by HIV/AIDS can have several family members, often involving different generations, who have been infected - e.g. father, mother, and child (ren). Consequently, families may experience multiple bereavements.

Coming to terms with the death of a young partner and having to cope alone with a young family is difficult to bear, particularly when the bereavement process is exacerbated by the stigma surrounding the illness. Yet, for many of the families support soon disappeared even though the grief and isolation continue:

I do say to myself what could have been, what we could have had. He was only thirty eight years of age when he died. He should have been around for at least another thirty years you know. I get very angry now over that, I do. You know he could have been there for his kids. Sometimes it just gets totally, you know you can't cope and then the way I look at it, I have to go on, no matter what life throws at me, I have to take it and try and handle it.

Even many years after the death of a partner from AIDS, the stigma remains. Many of the women who had lost a partner to HIV/AIDS were young, yet they felt it was unlikely that they would ever form new relationships. Telling a potential new partner about 'the family secret' was viewed as a daunting prospect, and one that only seemed to invite rejection.

THE IMPACT ON CHILDREN

In addition to coping with their own grief, parents have to deal with their children's feelings, from telling them of a parent's death, to supporting them through the funeral and helping them to cope with the aftermath. One mother, with five young children, recalled:

I had to take them in one by one and sit them on me lap now I think, looking back on it, I think that was the hardest part of the lot. Like I remember sitting down there and saying now I've something very sad to tell you, you know your Da went to heaven last night and like I was more concerned about holding them, watching them and making sure like that they were okay ...I remember saying to myself, they 're going to be alright you know, I'll make sure they 're alright.

However, parents found a whole series of difficulties developing after the other parent's death, problems which they found difficult to cope with alone.

Things just steadily got worse after he died and like my eldest son ...he was so angry, angry with him for dying you know what I mean. Not being there for him when he needed him. I was under this illusion that my kids would be like me, they 'd be strong, they'd be able to cope with it, but I was totally wrong you know. I feel if my kids, my older kids, could sort of be able to talk about it, it would be a lot better for them. There's a lot of things they haven't dealt with, concerning his death and leading up to his death and afterwards. Like they'd mention him in passing... but nothing concerning the sickness or the death afterwards. They've sort of just buried it.

Children's difficulty in coping with their parent's death often resulted in problems at school, especially when children were being taunted about their parent's death, yet, little support is available.

SECTION 4 - HIV/SIDS MUD SOCIAL EXCLUSION

In Ireland, the association between HIV/AIDS and social exclusion is two-fold. In the first instance, HIV/AIDS is seen to disproportionately affect people from marginalised, socially excluded communities.

In the second instance, many individuals and families affected by HIV/AIDS are forced into positions of marginality by their experience of isolation and discrimination, and in particular, by their long-term dependence on social welfare payments as a result of ill-health or caring duties. For the vast majority (81%) of the individuals and families included in this study, welfare payments are the main source of income. For such families the normal weekly payment for two adults and two children is £138.10. The income inadequacy experienced by people dependent on welfare payments, particularly in the long-term, has been noted. Indeed long-term welfare dependants have been identified as being at an exceptionally high risk of poverty and social exclusion.

Children from such households are at a particularly high risk of poverty. Current average weekly Child Support Payments amount to £20.47 per week, falling far short of even the minimal costs associated with the upbringing of children. In addition, children from poor households also experience social exclusion in that they are unable to participate in the extra-curricular activities regarded as essential for their healthy development.

While additional Supplementary Welfare Allowances are available for those with inadequate funds, these payments are not entitlements but subject to the discretion of the Health Boards and Community Welfare Officers. The psychological distress caused by illness and poverty is amplified by the need to hustle for diet allowances, rent allowances, clothing allowances, back to school money etc., and by the unpredictability of the response. In addition to the financial implications if these negotiations are unsuccessful, there are further difficulties for families who wish to keep their HIV status private.

Ironically, the improved health of many HIV positive people due to the new treatments available, hinders their ability to claim some allowances, such as the diet allowance, and also has implications for their continued eligibility for disability payments. Yet, most positive people, and those providing HIV/AIDS services, remain apprehensive as to the long term outcome of the new medication, as one positive woman described:

It's the psychological implications you know, am I back in the land of the living or am I going to get sick again? Should I take up a job? Should I not? You know there's a whole lot of people who are very confused at the moment, wondering is it just a reprieve or what.

The reliance on supplementary allowances and charities to make ends meet, is brought home most forcibly in the families' experiences of coping with the cost of past and/or future funerals. Many families experienced huge financial difficulties over the cost of funerals, and despite keeping expenses to a minimum, it took a number of years to pay off the bills. Families who had taken out life insurance, found the insurance companies unwilling to pay when the death was AIDS related. Difficulties in accessing insurance and mortgages also impacted on the more financially secure families.

HOUSING

In addition to financial difficulties, accessing housing was a major issue for a number of the individuals/families interviewed. The current shortage of public housing and high rents for private accommodation impact especially on the economically vulnerable, and places much of this type of housing outside the reach of those dependent on Rent Allowances.

Members from four of the nineteen families participating in this research study had experienced homelessness since their HIV positive diagnosis. Some had experienced periods living in hostels and Bed and Breakfasts, others were in unsuitable often overcrowded accommodation:

I'm living with my mother and she has my sister's three children that she left behind when she died. And there's my brother that has the virus as well in the house. Like there's a couple of us, in the house and it's only a two bedroom. And it's a small two bedroom.

Accessing public housing required a struggle similar to that encountered in accessing other welfare benefits. Additional complications have arisen for HIV positive individuals and families since the introduction of the Housing Act (1997) which allows for the eviction from, or refusal of, local authority housing to persons engaging in 'anti-social behaviour'. For HIV positive people the provisions in the Housing Act are a cause of concern in that their positive status is perceived by many to imply a history of anti-social behaviour and could discriminate against their accessing local authority housing.

SECTION 5 - RESEARCH FINDINGS: IMPLICATIONS FOR PRACTICE AND POLICY

While the size of the HIV positive population anticipated in the 1980s has not materialised, trends in HIV epidemiology and indicators of HP/ risk behaviour illustrate that there is little room for complacency with regards to the future prevalence of HIV. Consequently, there is an urgent need to reinstate HIV/AIDS on the public health agenda and conduct empirical research to provide a grounded basis for health promotion and harm reduction campaigns, and to assist in the assessment of future trends in HIV/AIDS.

For those people who have been, and continue to be, affected by HP/, combating the stigma associated with HP/ is of the utmost priority. Both statutory and voluntary agencies need to adopt a more proactive approach towards de-sensationalising HP//AIDS and combating the prejudices and misinformation that are associated with this illness.

Once diagnosed, individuals and their families, should have access to an ongoing continuum of care with regards to emotional and practical support. For example, with regard to issues concerning disclosure, transmission risks, testing of family members, child care, health and welfare entitlements etc. A key aspect of such support should be the role peers (that is persons affected by HIV/AIDS) play in its provision.

As demonstrated by the research study, children affected by HP//AIDS, both those who are positive themselves and those with a positive family member, are in particular need of ongoing support. With many of the HP/ positive children now reaching their teenage years they will require particular support in coming to terms with their positive status and its implications for their health and sexual behaviour. Children also need support to cope with the stigma and prejudice they experience, with behavioural issues that may arise, and in coming to terms with a bereavement in a family.

Treatment clinics need to consider how patients, parents and carers can become more involved in their care management. The introduction of a patient's charter and/or a patient-staff forum would assist in clarifying issues in clarifying issues for both patients and clinicians alike.

Information regarding treatment updates and options should be made available in a manner which is accessible to clients and which addresses the concerns of different groups e.g. women, homosexual men. Patients, for whom English is not their first language, require translated material and an approach which is culturally sensitive.

The association between HIV/AIDS and many aspects of social exclusion - isolation, discrimination, income inadequacy and housing need - highlights how the social aspects of HIV/AIDS need to be tackled in a more holistic way by both the statutory and voluntary sectors if the situation of families affected by HIV/AIDS is to improve.

Voluntary organisations providing support to families and individuals affected by HIV/AIDS could play a key advocacy role in campaigning for such policy changes.

Tackling the needs of such families affected by HIV/AIDS requires an integrated approach by a range of statutory and voluntary services and government departments. Existing policy mechanisms such as the National Anti-Poverty Strategy (NAPS), the Cabinet Sub-Committee on Social Exclusion, the Family and Community Resource Centres advocated by the Report of the Commission on the Family, the National AIDS Strategy Committee, and the local Drug Task

Forces provide suitable sites for implementing co-ordinated strategies that address the broader needs of families affected by HIV/AIDS.



SECTION 1 THE RESEARCH STUDY

This research study was initiated by Cairde, who, during the course of its work providing emotional and practical support to HIV positive individuals and their families, had become increasingly aware of the difficulties families experience in relation to issues of exclusion, emotional stress, and Financial strain. Consequently, in June 1998, Cairde commissioned a research study to focus on the impact of HIV/AIDS on positive people and their families.

The overall aims of this research study were:

- i) to assess the circumstances and needs of families affected by HIV and AIDS in relation to their social, emotional and financial needs;
- ii) to examine the responses and coping mechanisms that individuals and families have developed;
- iii) to use these experiences to inform policy making and practice.

More specifically, the Terms of Reference for the study were to:

- consider the situation and circumstances of families affected by HIV and AIDS in the Dublin area;
- quantify the number of families and family members who have been affected by HIV and AIDS in the Dublin area;
- assess the current approaches and responses to families affected by HIV and AIDS (statutory agencies, drug task forces, voluntary organisations etc.);
- analyse national and international research which has been carried out in relation to families affected by HIV and AIDS;
- consider the linkages between families affected by HIV and AIDS, and poverty and social exclusion;
- make policy recommendations in relation to the ways in which relevant organisations and agencies (statutory and voluntary) might make their most appropriate responses to the needs of families affected by HIV and AIDS.

RESEARCH METHODS

A qualitative research methodology was chosen as the most appropriate means for examining the experience of individuals and families affected by HIV/AIDS. This approach focused on the use of semi-structured in-depth interviews to 'give voice' to the individuals and families concerned. The in-depth interviews were guided by a topic schedule which covered issues such as diagnosis, disclosure, treatment, -support networks, child welfare, finances and coping strategies. However, the participants were encouraged to focus on the issues that were of particular concern to them and in this way their lived experience was given precedence.

Initial contact with the research participants was made through Cairde; the Aisling Clinic, Ballyfermot; Dublin AIDS Alliance, Parnell Square; The Women's Health Project, Haddington Road; and through flyers placed in Poz Ireland and the Gay Community News. Introductory sessions with the families were followed by one or two longer meetings which gave different family members the opportunity to contribute to the interviews.

The interviews were recorded and subsequently transcribed and the scripts analysed for patterns and trends. These transcripts also enabled the experiences of the participants, as

expressed in their own words, to be used in the report.

The research study's focus on qualitative methods allowed for an in-depth insight into the experience of those affected by HIV/AIDS. However, doing so required making a trade-off over the number of people that could be included in the study in favour of the quality of the data that could be collected using these methods. Consequently, a target number of twenty families was set as a sufficiently large enough sample to meet the study's needs. While this report does not claim that the experiences of the research participants represent the totality of experiences of those affected by HIV/AIDS, there was nonetheless, a remarkable degree of consistency in the interview data.

In addition to the in-depth interviews with the individuals and families affected by HIV/AIDS, a series of 'information interviews' were held with personnel from the statutory and voluntary sectors providing services in this field [see Appendix 2]. These interviews provided background data on the current approaches and responses to families affected by HIV/AIDS and an overview of the issues and needs of clients attending services.

Secondary data on the epidemiology of HIV/AIDS, HIV risk behaviour, social exclusion and policy issues, were collected through literature reviews and documentary research, and were used to contextualise the interview data.

Finally, in order to maximise the development of appropriate policy recommendations, members of families affected by HIV/AIDS and personnel working in the provision of HIV/AIDS services participated in a policy seminar, held in October 1998, to discuss the emerging themes from the research. Issues for discussion in the workshops [see Appendix 3] were grouped into three categories:

- i) The Emotional Impact of HIV/AIDS;
- ii) Social Needs;
- iii) Health/Treatment Issues.

These issues were then prioritised and the subsequent discussions used to inform the recommendations of this report.

Throughout the research study the ethical implications of researching a sensitive issue, as is HIV/AIDS, were kept to the forefront and sociological research guidelines for good practice were followed. As a result, the rights of the research participants were protected with regard to the sensitivity and the confidentiality of their data, and their informed consent. No identifying data on participants was recorded and the names and situations used in this report were changed in order to preserve their anonymity.

RESEARCH ISSUES

During the research process a number of issues arose which impacted on the focus of this research study.

The study's aims and objectives had identified the family as the appropriate site of investigation for examining the experiences of people affected by HIV and AIDS.

Subsequently, much consideration was given as to what constituted 'the family'. Initially, a

broad definition covering a range of family systems - such as the nuclear family (parent(s) and children living together), homosexual couples, and the extended family (grandparents, uncles, aunts and cousins) —was taken. However, as the research study progressed, it became apparent that the experiences of gay men, their partners, friendship networks and families, were not being adequately covered by the framework of the study. Consequently, their experiences remain to be researched.

A further research issue related to the inclusion of children's experience of HIV/AIDS. Most of the children from the families who participated in the research study were unaware that they, or a member of their family, were HIV positive. Some of the children who were aware, participated in the general discussions held with the family. However, given the sensitivity of the issue, it was decided that an in-depth exploration of the children's experience could not be appropriately conducted within the structure of the research study.

Finally, while the research study's Terms of Reference focused on the experience of families affected by HIV/AIDS in the Dublin area, as the research progressed the growing number of families affected by HIV who live outside the Dublin area, and the particular difficulties faced by them, became more apparent. Consequently, the remit of the study was broadened to include these families. Unfortunately, time and resource constraints, as well as problems accessing rural families, prevented their substantial inclusion in the research. Nonetheless, where possible their particular experiences have been highlighted.

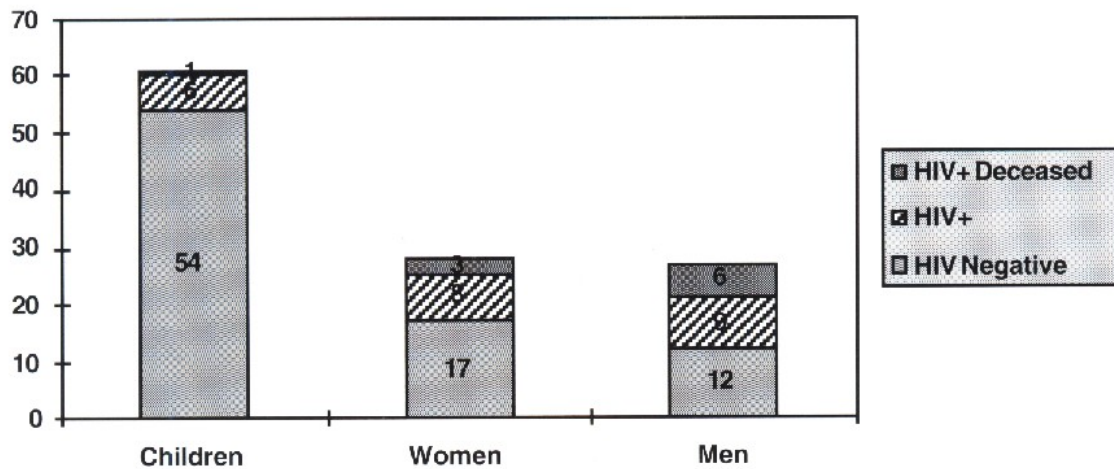
PROFILE OF THE RESEARCH PARTICIPANTS

Nineteen families, comprising of 116 immediate family members, participated in the research study. In all, 25 people were interviewed.

In the nineteen families represented:

- 33 people have been diagnosed HIV positive - 15 men, 11 women and 7 children;
- 7 couples have been diagnosed HIV positive;
- 12 men and 13 women had partners who had been diagnosed HIV positive;
- 8 adults have experienced the death of their partner from AIDS;
- 29 children have experienced the death of a parent from AIDS;
- 1 family has experienced the death of a child from AIDS;
- 8 adults have partners living with HIV;
- 31 children have parents currently living with HIV;
- 5 families have children currently living with HIV;
- a further 29 adults and 54 children were immediately affected by HIV/AIDS.

Figure 1: Family members by HIV status



SECTION 2 THE EPIDEMIOLOGY OF HIV/AIDS

In Ireland, the epidemiology of HIV and AIDS, that is its prevalence and distribution in the population, is difficult to ascertain due to the lack of research conducted in this field. The main source of data available are the quarterly statistics¹ published by the Department of Health and Children (DoH&C). However, these published figures only represent the known HIV/AIDS population, that is the number of people who have had an HIV test and subsequently tested positive. An additional, but unknown number of people are also HIV positive. This hidden population of HIV positive people includes those who have become positive since their last HIV test; those who have not been tested either because they do not perceive themselves to have been at risk of infection, or for a variety of reasons have not come forward for testing; and those who have been tested abroad and as a result are not recorded in the Irish statistics.

Our understanding of the epidemiology of HIV/AIDS is further restricted by the lack of socio-demographic details on those who have tested HIV positive. For example, a breakdown of the HIV data by gender and Health Board region² has been made available only recently, and then only for new cases recorded since 1998. No data on the parental or family status of the HIV positive person is available.

Given the deficiency of HIV data, it is difficult to make a grounded appraisal of current and future trends in HIV transmission. Advances in the treatment of HIV/AIDS and the decrease in the number of new AIDS cases recorded, have contributed to the declined prominence of HIV/AIDS on the public health agenda. Yet, this reduced prominence seems misplaced when the number of new HIV cases continues to rise (Figs 1 and 2), and the full extent of HIV in the population remains unknown.

This section of the report examines the available data on HIV prevalence and HIV risk behaviour, for indicators of current and future trends in HIV transmission.

For the purposes of this report, the focus is on HIV rather than AIDS data, for it is at the point of a positive diagnosis for HIV antibodies that individuals and families become affected by HIV/AIDS.

TRENDS IN HIV TRANSMISSION

Given the lack of HIV data available in Ireland, it is tempting to consider trends from other countries as a basis for discussing patterns and trends in HIV transmission. However, one of the peculiarities of the HIV virus is its adaptation to local cultures. For example, very different HIV epidemiologies have evolved in the geographically close cities of Glasgow and Edinburgh, with very high levels of HIV among intravenous (IV) drug users in Edinburgh and very low levels in this population in Glasgow.

-
- 1 These statistics give the number of AIDS cases, AIDS deaths and HIV positive cases notified in the previous three months as well as the cumulative figures for each of these categories. The figures are further broken down by the perceived route of HIV transmission - mainly Intravenous Drug Use, Homosexual sex, and Heterosexual sex.**
 - 2 This regional breakdown is only available for the 'Eastern Health Board' and 'All Other Health Boards Combined'.**

Thus, while the epidemiology of HIV in Dublin bears *some* resemblance to that of Edinburgh, in relation to the high prevalence of IV drug users in the recorded HIV positive population, the Irish data needs to be placed in the context of local cultural phenomenon.

The most recent HIV statistics available (i.e. to the end of December 1998) indicate that 1,986 people have tested HIV positive in Ireland³.

On a cumulative basis, the risk behaviours⁴ associated with these positive cases (Figure 2, p13) are:

- IV drug use 42%
- Homosexual sex 23%
- Heterosexual sex 18%

The high number of IV drug users in the known HIV positive population may be explained by two main factors. Firstly, the culture of intravenous drug use in the 1980s, when both information on injecting hygiene and access to needle supplies were limited, which resulted in the rapid transmission of the HIV virus among this population. Secondly, the IV drug using population has been more available for testing, through their contact with drug treatment services, than people engaging in other HIV risk behaviours, such as heterosexual and homosexual sex.

In recent years the epidemiology of the known HIV population has begun to change. The proportion of IV drug users among the new HIV cases recorded has decreased to just under one fifth (19%) of all new cases (Figure 4, p15). The highest proportion of new cases, over one third (35%), are now in the heterosexual risk category.

The need for socio-demographic breakdowns of HIV data becomes apparent when the gender breakdown of these figures is examined⁵ (Table 1) for doing so illustrates a very significant gender difference in HIV transmission. For men, the

Table 1: Number and Percentage of New HIV Diagnoses by Gender A: Adult Males				
	Homosexual	IV Drug Use	Heterosexual	Other
1997	37 (47%)	18 (23%)	16 (20%)	7 (10%)
1998	37 (44%)	16 (19%)	23 (27%)	9 (10%)
B: Adult Females				
		IV Drug Use	Heterosexual Sex	Other
1997		3 (10%)	24 (77%)	4 (13%)
1998		10 (32%)	18 (58%)	3 (10%)
<i>Source: DoH&C</i>				

- 3** *It is important to note that the total number of tests recorded (152,679) refers to the number of tests carried out not the number of individuals tested; some individuals will have been tested a number of times.*
- 4** *The risk categories used in the HIV/AIDS statistics may distort the nature of the transmission of the virus in that IV drug users may have become infected through sexual transmission rather than through unsafe injecting behaviour.*
- 5** *Unfortunately a gender breakdown for these figures has only been made available for the last two years, so it is difficult to assess the full significance of the figures.*

figures indicate that the highest risk of HIV transmission is through homosexual sex, while for women the risk is predominantly through heterosexual sex.

On an overall basis, the gender breakdown of the HIV data shows that men represented almost three quarters (73%) of the new cases recorded in 1998 (Table 2). However, as almost one third (32%) of the overall figures relate to homosexual risk behaviour, which are all male, a different gender pattern again emerges when individual risk behaviours are examined. Doing so shows that women account for nearly half (44%) of heterosexual transmissions and over a third (38%) of IV drug use transmissions (DoH&C 1999).

Table 2: Number and Percentage of Adult HIV Diagnoses, 1998			
Risk Category	Male	Female	Total
IV Drug Use	16 (62%)	10 (38%)	26 (22%)
Homosexual Sex	37 (100%)	0 (0%)	37 (32%)
Heterosexual Sex	23 (56%)	18 (44%)	41 (35%)
Other	9 (82%)	3 (28%)	12 (10%)
Total	85 (73%)	31 (27%)	116 (100%)
<i>Source: DoH&C</i>			

Furthermore, the results of the anonymous unlinked antenatal HIV screening (Table 3) show that while few positive cases have been recorded, each year since

Table 3: Antenatal HIV Screening		
Year	No. Tested	No. HIV positive
1992-3	53480	13
1994	51 118	6

1995	56081	6
1996	62008	12
1997	64412	27
Total antenatal tests conducted		
1992-1997	287 099	64
<i>Source: DoH&C</i>		

1995, the number of women testing positive has doubled. (In assessing epidemiological trends, the length of time for numbers to double is regarded as statistically significant.)

A new trend in the geographic diffusion of HIV has also been noted. As a result of the initial relationship between IV drug use and HIV in Ireland, the spatial distribution of HIV was presumed to mirror the spatial distribution of heroin use i.e. that it was a Dublin based phenomenon. However, the broader geographical distribution of new HIV cases may very well reflect the trend towards the sexual transmission of the virus. In 1998, 14% of the new diagnoses recorded have been of people living outside the Eastern Health Board area. In addition, 42% of all women who tested positive in the antenatal screening programme live outside the Eastern Health Board area.

INDICATORS OF HIV RISK BEHAVIOUR

Despite increasing rates in the sexual transmission of the HIV virus, there is little recognition, at either policy or personal levels, of heterosexual sex as a HIV risk behaviour. A recent study of sexual behaviour (Durex 1998) found almost one-fifth (19%) of respondents had unprotected sex with a new partner in the last 12 months. Only half of the respondents claimed to have changed sexual behaviour as a result of AIDS - 11% reported having fewer partners, 10% reported using condoms, while 20% were more selective of their partners. However, while half of the respondents (49%) were concerned about contracting AIDS, a quarter (26%) were not; this latter figure had almost doubled since the previous year's study. Results from a similar study conducted by Alliance (1997) on the sexual behaviour of young people in Cork city, showed three-quarters (75%) of the respondents felt they were not at risk of getting AIDS.

Further indicators of unsafe sexual behaviour may be seen in the number of attendances at clinics for the treatment of sexually transmitted diseases (STD). In 1997, 1,558 people attended the STD clinic in Waterford, 3,000 attended the Limerick clinic, and 1,700 the Galway/Mayo clinics (Boland 1998). In the same year, there were just under 16,500 attendances at the GUM clinic at St. James' Hospital, Dublin.

The decrease in the numbers of IV drug users (IVDUs) testing HIV positive has been attributed to the provision of harm reduction programmes such as methadone maintenance and needle exchanges (Keating *et al* 1997) and the trend for 'chasing' (smoking) rather than injecting heroin. However, a number of cautionary points need to be made with respect to this decrease.

Findings from research studies on the prevalence of HIV among the IV drug using I population have shown a wide range of rates, from 0.6% (Smyth *et al*, 1998), 6.5% \ (Smyth *et al*, 1998), 14.8% (Johnson *et al* 1994), 17% (O'Mahony 1997), to 24% (Comiskey 1992). These variable rates reflect factors such as the recruitment site of \ j the research participants

(e.g. in treatment⁶, attending a needle exchange, /[^]community-based), and the duration of their drug injecting career.

The significance of these factors is that IVDUs not in treatment have been shown to be more likely to engage in HIV risk behaviours (Power 1988, Donoghoe 1993, Frischer *et al* 1993) and consequently have a higher prevalence of HIV. Therefore, community based studies will show much higher HIV prevalence rates than those based in treatment sites. For example, in the UK, Donoghoe (1993) and Rhodes *et al* (1993a) found that HIV prevalence in IV drug users who had never experienced treatment was over twice the level (21%) of those currently in treatment (10%).

6 'In treatment' in this instance refers to IV drug users participating in methadone maintenance/detoxification programmes.

In Ireland, prevalence studies of HIV in the drug using population have invariably been conducted on IVDUs in treatment. While studies such as Smyth *et al* (1998) show low rates in HIV prevalence among IVDUs presenting for treatment (from .6% to 6.5% depending on the duration of their drug injecting career), there is no current information as to the prevalence among those who do not present for treatment.

In addition, despite the increasing number of drug users in treatment (over 3,511 were registered on the Central Methadone Treatment List in November 1998) this only represents a fraction of the drug using population which Comiskey (1998) estimates to be between 10,500 - 12,500. Further indicators of the proportion of drug users in treatment can be found in Comiskey's (1998) data which shows that almost three-quarters (72% of the opiate users known to the Dublin police had not been treated that year, while O'Mahony's (1997) study of Mountjoy prisoners found that two-thirds (66%) of heroin users had never been on a methadone maintenance programme. Moreover, young IV drug users are less likely to be receiving treatment, yet they are far more likely to engage in HIV risk behaviour (Rhodes *et al* 1996). Thus the high proportion of drug users who are out of treatment and who are likely to be engaging in HIV risk behaviour has serious implications for future trends in HIV transmission.

The significance of HIV risk posed to drug injectors and their sexual partners through sexual transmission is often overlooked (Rhodes *et al* 1993b) even though their sexual behaviour has been seen to reflect the sexual risk behaviour of the rest of the population. Johnson *et al*'s (1994) study of IVDUs attending a needle exchange, noted that while almost all (92%) of the research participants were sexually active, a third (33%) never used condoms. Over three-quarters (77%) of the IVDUs surveyed by Comiskey (1992) were sexually active, yet less than a quarter (23%) of the male respondents and only 6% of the women respondents always used condoms. Considering that women are 50% more vulnerable than men to HIV transmission through sexual intercourse (Comiskey 1992, Bourke 1997) and are far more likely to have an IVDU partner (Comiskey 1992, Rhodes *et al* 1993), these rates are a further cause for concern.

Individuals who are HIV positive also engage in sexual risk behaviour. A study conducted by Hickey *et al* (1994) on the sexual behaviour of a sample of HIV positive individuals reported that almost half of the respondents (43%) were not practising safe sex. Among the sample of positive respondents, the group most likely to report practising safer sex were homosexual men (almost 70%) while the women respondents were the least likely to adopt safer sex practices (70% never/not always).

While the size of the HIV positive population anticipated in the 1980s (Kelly 1984) has not materialised, trends in HIV epidemiology and indicators of HIV risk behaviour illustrate that there is little room for complacency with regards to the future prevalence of HIV.

Estimation of the Numbers of Adults and Children affected by HIV/AIDS

Attempts to estimate the number of people affected by HIV are hampered by the lack of relevant data, such as the total number of HIV positive individuals in the population (rather than those who have tested positive) and socio-demographic details of those who have tested positive. Nonetheless, by using the data available on the IV drug using population (in Ireland, most HIV positive research has focused on this population) an estimation of the numbers affected can be calculated on the basis of the following assumptions.

TOTAL HIV POSITIVE POPULATION (TABLE 4)

- 1) There are an estimated 11,500 opiate users — average of Comiskey's (1998) range of between 10,500 - 12,500.
- 2) Approximately 12% of these opiate users are HIV positive - based on the average rate of the proportions found in Smyth et al 1998, Johnson et al 1994, O'Mahony 1997, Comiskey 1992.
- 3) As IV drug users account for approximately 40% of the total known HIV positive population (DoH&C), this 12% is taken to represent 40% of the total HIV positive population. Consequently, the remaining 60% of the total HIV positive population can be calculated.
- 4) By totalling figures (2) and (3) the estimated total HIV positive population is found to be 2,875 which is almost 1,000 more than the number officially recorded.

Table 4: Basis for Estimating Total HIV positive Population			
(1) <i>Opiate Population</i> <i>(OP)</i>	(2) <i>HIV+OP</i> <i>(12%)</i>	(3) <i>Rest HIV+ Pop</i> <i>(60%)</i>	(4) <i>Total HIV+Pop.</i>
11.500	1,150	1,725	2,875

Number of Adults Affected by HIV/AIDS

From the 26 HIV positive adults represented in this research study, twenty nine non HIV positive adults (parents/partners) were affected by HIV/AIDS - an average of 1.12 people per HIV positive person. (This low figure is due to the number of HIV positive partners and siblings in the same families)

By applying this figure to the estimated HIV positive population, a further **3,220 adults are estimated to be affected by HIV/AIDS.**

Number of Children Affected by HIV/AIDS

In order to calculate the number of children that may be affected, it is necessary to control for the proportion of homosexual men without children who are included in the HIV figures. Consequently, this first estimate is based on the number of HIV positive women with children (Table 5):

- 1) Murphy, D. *et al* (1993) located 130 HIV positive women with a total of 206 children = 1.58 children per HIV positive woman.
This research study, found 11 HIV positive women with a total of 28 children = 2.55 children per HIV positive woman.
 - overall average of 2.07 children per HIV positive woman.
- 2) As 202 HIV positive IDUs are women and an estimated 44% (155) of HIV positive heterosexuals are women (DoH&C), then a total of 357 i.e. 18% of the known HIV positive population are estimated to be women.
- 3) Calculating 18% of the estimated total HIV positive population (2,875) gives a figure of 517 HIV positive women.
- 4) And, if these 517 HIV positive women have an average of 2.07 children each then **at a very minimum** (given that this does not include children by HIV+ men) **1,000 children have been affected by HIV/AIDS.**

Table 5: Basis for Estimating the Number of Children Affected by HIV/AIDS (1)			
(1)	(2)	(3)	(4)
<i>Average No. of Children per HIV+</i>	<i>No. of HIV+ Women</i>	<i>18% of Total HIV+ Pop.</i>	<i>No. of Children Affected (1) x (3)</i>
2.07	357	517	1,070

In order to account for the number of children by HIV positive men, a second estimate of the number of children affected is calculated from the following studies (Table 6).

- 1) Murphy Lawless and Redmond (1993) located 83 HIV positive people with a total of 83 children = 1 child per HIV positive person.
This research study, located 26 positive adults with 61 children = 2.35 children per HIV positive person.
 - overall average of 1.68 children per HIV positive person.
- 2) If we take 60% of the known HIV population to be heterosexuals, possibly with children (i.e. controlling for the proportion of homosexual men without children who are included as well as the number of children themselves).
- 3) And, if these 1,725 HIV positive people have an average of 1.68 children each then **almost 3,000 children have been affected by HIV/AIDS.**

Table 6: Basis for Estimating the Number of Children Affected by HIV/AIDS (2)		
(1)	(2)	(3)
<i>Average No. of Children per HIV+ person</i>	<i>60% of Total HIV* Pop.</i>	<i>No. of Children Affected</i>

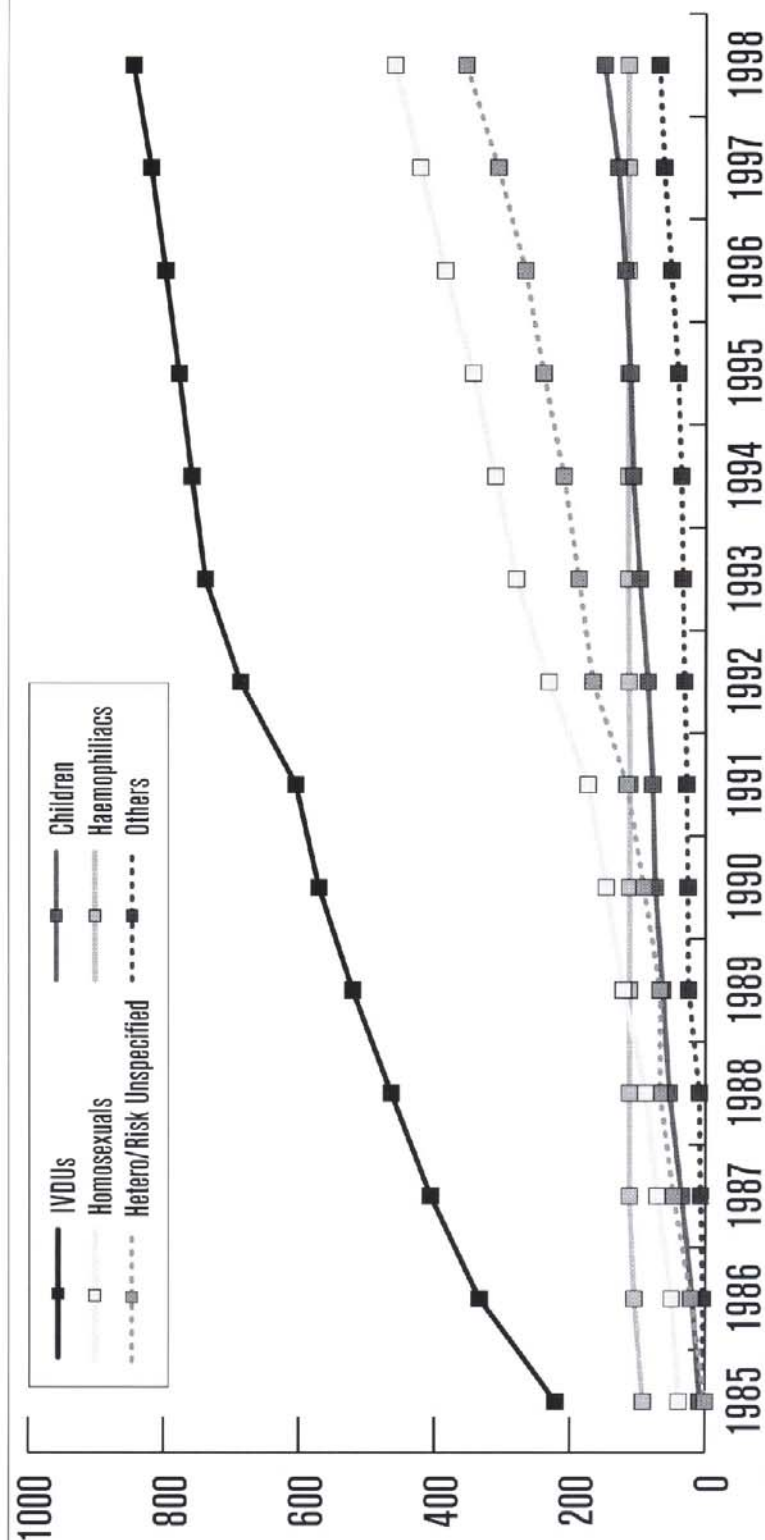
1.68	1,725	2,898
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While the estimate of 3,200 adults and between 1,000 and 3,000 children who are affected by HIV/AIDS is most likely to be an underestimate, the point of this exercise is to highlight that for each HIV positive individual there are additional numbers of people who have been affected by HIV/AIDS. However, estimating the numbers affected does not capture the difficulties encountered by HIV positive individuals and their families. The following sections in this report deal with the impact HIV/AIDS has had on those who have been affected.



Figure 2: Cumulative HIV Antibody Results

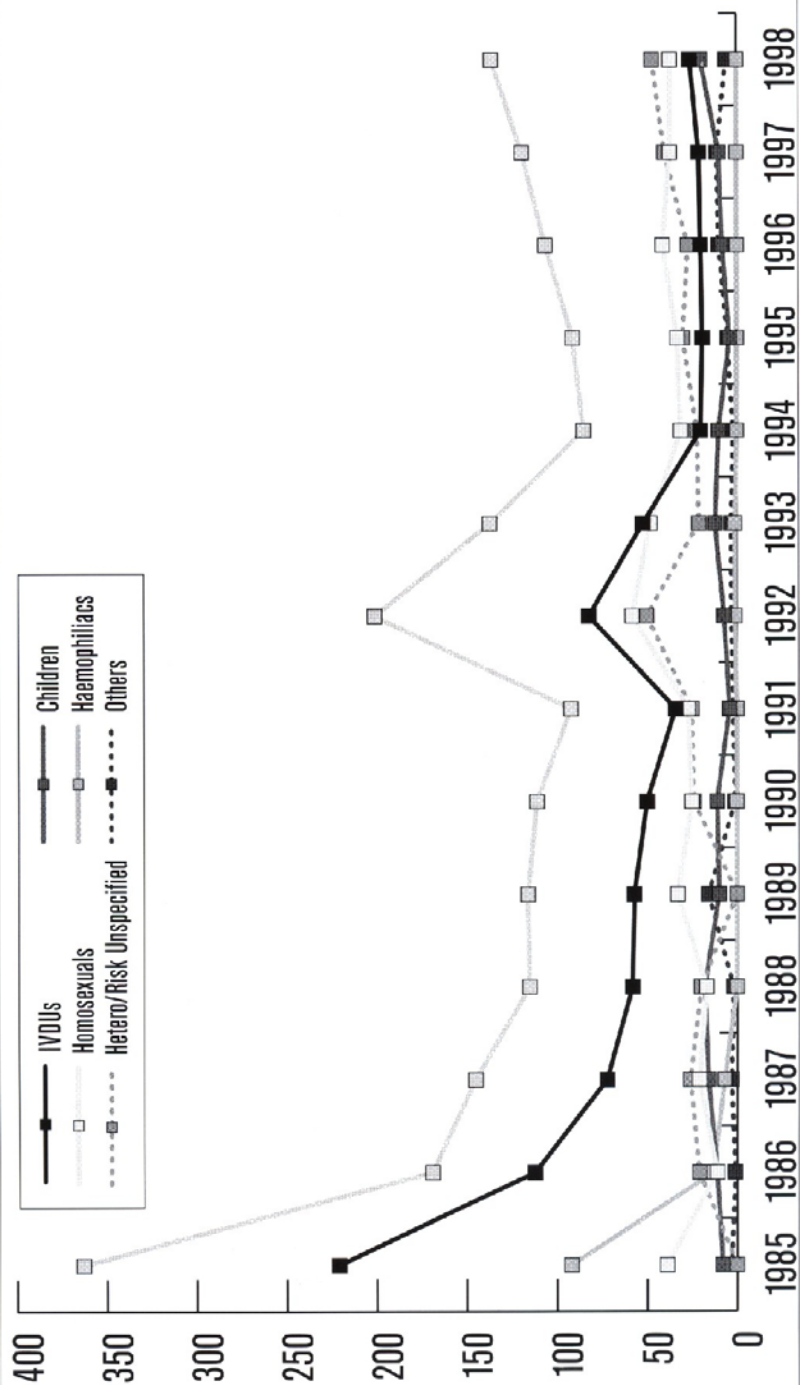
Number	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998
IVDUs	221	333	405	463	520	570	604	686	738	758	777	797	818	844
Homosexuals	39	50	71	88	121	146	173	231	279	310	343	384	421	458
Hetero/Risk Unspecified	0	21	47	67	67	91	116	166	187	209	239	266	306	353
Children	8	19	35	53	63	74	78	85	97	107	111	119	129	149
Haemophiliacs	92	105	112	112	112	112	112	113	114	114	114	114	114	114
Others	3	4	7	9	25	26	28	31	34	36	41	51	62	68
Total	363	532	677	792	908	1019	1111	1312	1449	1534	1625	1731	1850	1986



Source: Virus Reference Laboratory/DH&C

Figure 3: Annual HIV Antibody Results - Number

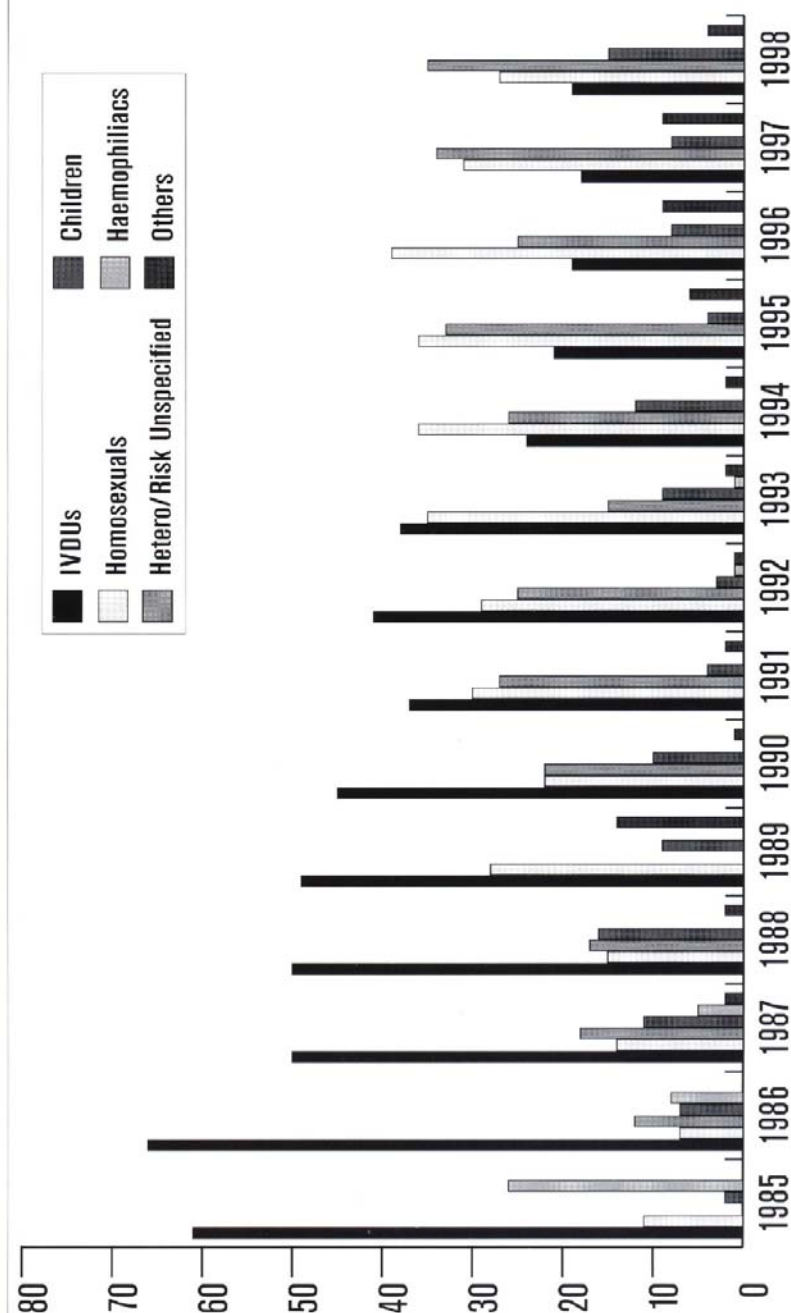
Number	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998
IVDUs	221	112	72	58	57	50	34	82	52	20	19	20	21	26
Homosexuals	39	11	21	17	33	25	27	58	48	31	33	41	37	37
Hetero/Risk Unspecified	0	21	26	20	0	24	25	50	21	22	30	27	40	47
Children	8	11	16	18	10	11	4	7	12	10	4	8	10	20
Haemophiliacs	92	13	7	0	0	0	0	1	1	0	0	0	0	0
Others	3	1	3	2	16	1	2	3	3	2	5	10	11	6
Total	363	169	145	115	116	111	92	201	137	85	91	106	119	136



Source: Virus Reference Laboratory/Doh&C

Figure 4: Annual HIV Antibody Results – Percentage

Percentage	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998
IVDCs	61	66	50	50	49	45	37	41	38	24	21	19	18	19
Homosexuals	11	7	14	15	28	22	30	29	35	36	36	39	31	27
Hetero/Risk Unspecified	0	12	18	17	0	22	27	25	15	26	33	25	34	35
Children	2	7	11	16	9	10	4	3	9	12	4	8	8	15
Haemophiliacs	26	8	5	0	0	0	0	1	1	0	0	0	0	0
Others	0	0	2	2	14	1	2	1	2	2	6	9	9	4
Total	100	100	100	100	100	100	100	100	100	100	100	100	100	100



Source: Virus Reference Laboratory/DaH&C

SECTION 3 ISSUES FOR FAMILIES

THE SOCIAL ASPECTS OF HIV/AIDS

Since HIV/AIDS was first identified in the 1980s it has developed a curiously demonic mythology quite unlike any other life threatening illness. Fears of contracting what was initially an untreatable disease, and the association of HIV with perceived 'deviant behaviour' (such as homosexual sex and intravenous drug use) provided a ripe breeding ground for the

multitude of moral panics and urban myths that developed around HIV/AIDS: as evident in the many transmission scares about 'folk devils' deliberately spreading infection from the 'deviant' to the 'innocent' population.⁷

In the absence of adequate public information campaigns to counteract such misinformation and promote a grounded awareness of HIV risk behaviour, HIV and AIDS continues to be widely viewed with prejudice, fear and ignorance. Indeed, MacGreil's (1996) study of social prejudices in Ireland found "appallingly negative" attitudes towards people with AIDS.

Such prejudiced reactions to HIV/AIDS highlight how the social aspects of this disease have compounded with the health and medical aspects to produce situations whereby "people are having to deal not just with HIV infection but with society's views of HIV infection" (Murphy Lawless and Redmond 1993:13).

In addition to the people directly *infected*, by the HIV virus, there are also those people whose lives have been *affected* by the virus i.e. the families, partners and friends of the people who are HIV positive. This research study estimates that between 4,000 and 6,000⁸ adults and children are affected by HIV/AIDS in Ireland, predominantly in Dublin. They also live with the stigma, fear and secrecy that surrounds this disease and as a result are often isolated from their extended families and their communities. Children from such families have been identified as being in a particularly vulnerable situation:

"The vast majority of these children will not be infected with HIV and are physically healthy, but their lives, mental health, educational, social and behavioural development will almost certainly be affected by their experience of their parent's health condition, chronic illness and eventual death. On the other hand, children may also be affected by the stigmatising and prejudiced responses of families, friends, communities, schools and social networks and the wider society to their home situation... implications which can be long term and far reaching." (Imrie and Coombes 1995:13)

The following sections of this report focus on the experiences of HIV positive individuals and their families, from the initial positive diagnosis, to life, and in some cases death, with HIV/AIDS.

7 Most notably the moral panic in Dungarvan in 1995 when a woman was identified as deliberately infecting men in the locality.

8 See section on "Estimation of the Numbers of Adults and Children Affected by HIV/AIDS" p. 10-12.

THE DIAGNOSIS

"The subsequent individual and social adjustments required [after diagnosis] often have implications for family life, sexual and social relations, work, education, spiritual needs, legal status and civil rights. Adjustment to HIV infection involves constant stress management and adaptation. It is a dynamic, evolutionary and lifelong process that makes new and changing demands on infected individuals, their families and their communities." (WHO 1990:12)

Receiving a positive HIV diagnosis is a traumatic event for the person who has been infected and their family. Not only must they come to terms with an illness which, until recently, resulted in inevitable death, but an illness which is deeply stigmatised and which fundamentally alters social relationships both within the family and between the family and the 'outside world'.

Unlike other medical conditions, HIV is often diagnosed before symptoms have developed. Sometimes, tests for HIV antibodies are carried out as part of an ongoing medical

intervention, at other times they are conducted on the basis of a person's history of HIV risk behaviour. Either way, people have found themselves unprepared for the outcome. While undertaking a test for HIV antibodies tends to be presented as a process whereby individuals receive counselling beforehand and, if found positive, medical and social support afterwards. The reality is often quite different and results can be given without adequate preparation or support. Those, like Joe⁹, who were diagnosed in the early 1980s found no support procedures in place:

They asked me [at the drug clinic] did I want to be tested and I was just in a bit of a - oh might as well - sort of mood. There wasn't any real counselling like but even after, I had to ask them for my result. And I was sort of flippantly told you know, then they asked me "Have you any questions?" There wasn't any counselling afterwards either.

Nowadays, the extent of pre-test counselling conducted is seen to be dependent on the perceived level of risk for the individual concerned. However, given how erroneous such perceptions can be, 'unprepared' diagnoses can occur. For example, Tom and his partner Kate found her diagnosis to be insensitively and badly handled:

I went into the hospital that morning, I remember it well and I went into her room and she wasn't there so I went down and said "where's Kate?" and I mean they just stopped and looked at me and nearly dropped what they had in their hands and I knew straight away at that stage ... it was the reaction I mean. I knew straight away from their reaction to me. Like she had been in there a number of weeks - she'd done the test and like and normally if you walk down they are busy, they'd be running around, you could be there for up to ten minutes and they 're running around avoiding you. But this time about three of them just stopped and the little droplets of sweat started appearing there on their foreheads ... and by that evening Kate knew something was up - they started putting a drip into her and she

⁹ Names have been changed to avoid identification.

asked the nurse what it was and it was the medication for it and she said "but that's for AIDS" and the nurse said "ah yeah" and the next thing Kate was in bits. So I mean I had found out by accident and she had found out by accident.

Even for those people anticipating a positive diagnosis, the impact is devastating. Brid recalled how her husband reacted to his diagnosis in sheer terror and panic:

I went for the results with him and when he found out that he was HP/positive, well he ran amuck. Started hammering the table in the little office you know - the counsellor, she got a fright as well, she wanted him to sit down like and talk it through and he just wanted to get out of that office as quick as

he could you know, panicking he was, he cried all the way home and cried, I think he cried for a week after, "I'm going to die, I'm going to die"

IMPLICATIONS FOR THE FAMILY

After a positive diagnosis has been made, the main issue of concern for families is whether sexual partners and children are also positive. Mary's reaction to her partner's diagnosis was partly one of fear for her own status:

I remember just sitting there frozen solid. You know I hadn't got the power to get off the chair. And even at that time I didn't know the full consequences of it you know. I was left here thinking what if I have it. That was my biggest fear, I must have it as well. If he has it, I must have it. So I went and got a test done and thank God I was clear.

For mothers, the shock of their own diagnosis is exacerbated by the fear that their children could also have contracted the virus. After her husband had been diagnosed HIV positive, Rita had undergone an HIV test only to find she too was positive, at which stage her main concern was for her children:

When they told me, I wasn't really taking it in, you know that way. I was saying to myself "God my kids "... So with that I was concerned about the last two kids, so then I'd to get them tested, my nerves were actually gone. If the kids have it I said I'll kill him dead. I'll kill him myself ... they went for the test and we waited again. I think it was a week, it was years going in that week it was... but the kids were grand.

For pregnant women who are HIV positive, there are many anxious months to wait before they know whether their child has avoided contracting the virus. While the children of positive women may test positive at birth they may lose the HIV antibodies as their own immune system develops, a process which takes a year or more. Coping with a child's diagnosis in addition to her own, as Sonia had, was profoundly traumatic:

I fell pregnant and that's when all the tests started and I had it. And they were able to test Tim when he was born and I found out when he was only four weeks old that he had it and he wasn't going to lose it. So we found out about very close together, in the space of three months. So it was very hard, I didn't take it too well... the way I seen it was, it was death.

POST-DIAGNOSIS NEEDS

A positive HIV diagnosis raises a series of questions regarding the nature and progression of the illness, the treatment available etc. Few families had much knowledge of HIV before the diagnosis was made, as Tony related:

At that stage, well certainly in our case anyway, HIV was something that I didn't really know about. It was something that affected drug users and gays. It wasn't our problem here. We're in the safe haven of middle class suburbia and it wasn't something that happened to nice people like us.

One of the initial concerns of the families affected was regarding the prevention of the virus within the family. However, these concerns were often based on erroneous information about the transmission of the virus. As a result many HIV positive people experienced periods of quarantine within their families when they were first diagnosed, as Sally recalled:

The paranoia in the beginning, like she used to wash my plate separately and my clothes ... and for a long time Mum would never let me near the knives, she was afraid of blood.

However, as Pat explained, when her son was diagnosed positive they wanted practical information and reassurance about sharing cups, cutlery, toilets etc:

Initially, It was mostly information we wanted it, like we knew generally that it was passed by blood and it wasn't physically dangerous to anybody else. We generally knew that but we just needed to know exactly what, how you could pass it. And like they turned round and said you 'd have to have a great big gushing cut, that it wasn't an easy thing to pass on ... it was that kind of thing that we needed to find out, practical information, what precautions you might or might not have to take, that's all.

Families also identified the need for peer support at the time of diagnosis. Given the whole uncertainty as to how HIV would develop and impact on their lives, families wanted to hear about other people's experience of coping with the disease. Indeed for John, whose wife and son had been diagnosed positive, this was the one time he would have appreciated such support:

When a person is first being told their diagnosis for their child or themselves, to have somebody there who's done well for a number of years to say "well listen it isn't great at times but you 're going to be okay most of the time and who knows, five or six years down the line what the story with medication is going to be". Instead you get your diagnosis from the doctor who is only dealing with the patients and the clinical symptoms and I think it would be very helpful to have a - I don't even think the social worker is the right person, I think to have somebody there who is capable of saying what it's like and don't be afraid. This is the way I deal with it... I think you can get all the counselling in the world and it won't do you any good. I mean that's the only stage that I felt like talking to somebody with it.

DISCLOSURE OR SECRECY

Disclosing an HIV positive status tends to be a protracted affair. In addition to telling a partner, there are children, parents, brothers, sisters, the whole extended family and friendship networks to consider. In the families interviewed for this research all partners were aware of the other's diagnosis from an early stage. However, other evidence indicates that this is not always the case. Foreman and Mulcahy (1997:73) noted:

"Some people who are HIV positive have difficulty disclosing their status because of fear of rejection or discrimination. This can raise issues about the individual's right to privacy versus the other's right to be informed or protected and clients may need help and support from social workers in disclosing their HIV status to sexual partners".

One aspect of the difficulty in disclosing a positive status is that it often involves a "double disclosure" (Adam and Sears, 1996:59) i.e. revealing a lifestyle, such as drug use or homosexuality, that may not have been known previously. Consequently, deciding who to tell involves making a judgement call as to how that person is likely to react. One couple, anticipating a negative reaction from some members of their families, were selective about who they told:

My mother and my brothers and sister know, but none of his, his parents are both dead and he has a collection of brothers and sisters that I would say would run a mile.

Just as individuals may have hidden their lifestyle from their families, families in turn may have hidden their child's/partner's sexuality and/or drug use from others, in this way the process of 'double disclosure' is often replicated when families decide to disclose outside their immediate family members. Many found this prospect too overwhelming, deciding instead to keep 'the secret' within the family even though they were severely isolated as a result. In such circumstances, HIV is truly a lonely disease as Eileen found:

Nobody else actually knows and I find that hard because I'd love a friend you know to be able to go out for a pint at night and say I'm wrecked today ... it would be nice to have a pal that you could talk with apart from Sean [husband]. But... if you tell one you have to be ready to tell the world. It's a big burden to tell someone. If I told one friend and said look don't tell the others, do you know, that's not fair ...I mean if it gets to the stage where I can't cope or I crack and then we have to tell or whatever, then maybe but not at the moment.

The stress of keeping 'the secret' and the double-life it forces people to lead was magnified when there were different levels of awareness about the illness within the family. For example, where older teenage and adult children knew the true nature of the illness, while younger ones were unaware. Such situations tended to arise when parents were concerned about their children's psychological ability to cope with the information and their ability to maintain the secret. Brid hadn't wanted her children told that their father was positive, but he went ahead and told them with disastrous results:

I was saying don't tell the kids you know, and I don't know what was going on in his head but he told every one of them there and then, "Your Da's going to die", "I'm HIV", like he had them in bits.

In contrast, Sally's approach of telling her children over time that she was positive, was seen to lessen the impact of the disclosure:

The way I did it... I brought up HIV and AIDS at every opportunity from when they were small. And I used to tell them at the beginning that it was a new illness and people were very scared of it as such. And answered questions as they came up but only answered what they asked, like if they asked what were the tablets for I wouldn't go into the whole thing. So about a year and a half ago, maybe two years ago anyway my daughter asked me outright one day and I told her and there were tears and then I told my other daughter and both of them felt that they should have guessed.

However, the disclosure to some negative children that others in the family are positive can leave them feeling inadequate, as Richie experienced with his daughter:

She has a bit of a hassle with dealing with that like she finds it hard to adjust to the fact that like there's nothing wrong with her. She thinks there's something wrong with her that she didn't get it like and wants to know what's wrong with her and why didn't she get it. I just keep saying to her you 're lucky you didn't you know but she still thinks that there's something wrong with her that she didn't get it.

For children who are aware that their family is affected by HIV/AIDS, there is the issue as to whether or not they could tell friends. Mary recounted how she had advised her children in this respect:

They asked me who they could tell. And I had to be very careful to explain to them that not everybody is okay about it you know. I said you can tell who you like certainly and everybody does need somebody to tell... so my daughter's told most of her friends, my son has only told one or two but he's getting much more comfortable with it now.

However, other children, like Rita's, didn't want their friends to know:

No one else knows. They wouldn't tell their friends, only mine and his family knows... It's a thing you don't go round, saying. I'd say they 'd be embarrassed you know.

DISCLOSING TO POSITIVE CHILDREN

Disclosing to children that are themselves HIV positive was seen to present a particularly difficult problem for parents and carers. In Ireland, very few children (5%) have been told of their diagnosis (Travers 1996). Parents and carers expressed a desire to protect their positive

child, particularly if they had lost a parent from the illness - almost 50% of HIV positive children in Ireland have had one or both parents die of AIDS (Hayes 1996). Nonetheless, a number of parents felt they were being pressurised into telling their children about their status. Seanie whose eight year old son is positive, finds himself under pressure to disclose:

They say for example it's making their job very difficult that he doesn't know and they say well you 're going to have to tell him sooner rather than later so tell him sooner. And I said I mean my point is, if I told him two years ago I'd a very bleak outlook for him especially say last year when his mother died, he'd be asking well have I got the same thing I mean what's he supposed to think then. But I mean at least even if I tell him now I can tell him that it's an illness that if you take these [tablets] you're probably more or less going to be fine but my idea would be to hold off for as long as possible and then maybe in another couple of years time there'd be something better ... they send me these books and pamphlets on a regular basis about this is the way to explain to children about red blood cells and white blood cells and T-cells and your army of T-cells is a bit smaller than the other boys. But I mean it isn't fair burdening kids with stuff that you don't have to.

Sonia, whose son aged four is positive, is similarly unconvinced of the need to disclose to him:

They're trying to get children from the age of eight upwards to be told about their diagnosis. They 're trying to work with their mothers so as to get the child to know why they 're taking medicines and not trying to make them afraid of anything but just to kind of face up to it so they don't have any anxiety or fear because they 're being told the truth. I don't know ... they kind of think that telling them when they 're young they can adapt to it and then they can understand and learn to kind of accept it, but I don't know.

However, as children in the family grow older it becomes more difficult to provide an explanation for the positive child's illness, their visits to the clinic, and their medication routine. One parent's explanation to his young child was:

I said to myself how am I going to explain this to him but I was lucky because he's one of the smallest in the class so I said to him these are vitamins. The nurse is going to give you vitamins

and they're going to help you to grow so he's still buying that. But there will come a day sooner or later ...he asks nearly every time "Do I have to take these?" "Why am I taking them?"

Some parents have started a gradual process of disclosing. Maureen describes how she and her husband have begun preparing their son for the information:

We've started to use the initials H.I.V. around him. Not very often but within the context of the hospital I'm using the words, not the word AIDS, just the HIV initials and that book dam's story, I would have kind of skipped over that. It's only mentioned once in the book but like that's included now if he's ever reading it, so that at least it will be part of the vocabulary, so it's step by step. Every year we'll take it another bit but I mean by eleven or twelve he's going to have to know.

DISCLOSING A CHILD'S POSITIVE STATUS TO OTHERS

In addition to feeling under pressure to disclose to their positive children, parents also reported being exhorted to inform their child's school of the situation. While schools that have been informed of a pupil's diagnosis were seen to respond positively (Hayes 1996), parents are most reluctant to do this. Eileen, who's son is positive, lives outside of Dublin and like other parents feared her child would be ostracised:

I know there's a case where they told the school and the school were quite open about it and very supportive and all the rest of it and fair play to them, but I mean I don't want to tell them if I don't have to. I mean I'd imagine the teachers would be fine but then you see, it's like you tell one you have to tell everybody. If the teachers know then you have to tell the parents committee. And if the parents committee know then the parents know and if the parents know then the child is ostracised at the best. At the worst they're all asked to leave. I could see it, because the school that they're in, even though it's such a small lovely little school, one of the teachers was pregnant and she's not married and the parents wanted her to leave, there was ructions over it. "How dare she be pregnant and single in our school" I mean you couldn't have that. Can you imagine now what it would be like with HIV? I wouldn't want to draw it on ourselves at all.

While parents acknowledged that schools may have a need to know on health grounds, they believe that a standardised policy in all schools regarding the implementation of appropriate procedures would remove this necessity. As Seanie explained:

I just want them to have a procedure. If any kid falls in the school, they put on a pair of rubber gloves, they get cotton wool, they get bleach and all they need you know what I mean and I was trying to say to them that's what you should be doing. You should have a standardised approach or practice and then it doesn't matter.

When a child's HIV status is involved, disclosing outside the family takes on additional complications. For example, Tony and Deirdre were particularly concerned that their neighbours would not find out that their daughter was HIV positive for fear that she would be isolated within their community:

We felt we couldn't tell people. We told brothers and sisters. I mean that's the way it still stands. A couple of friends know ... no I don't believe that you can tell anybody because it's something that won't stay confidential because it's so sensationalised and so I think you have to be careful in who you tell because I mean once you tell somebody you can't take it back and there is a danger especially in a sort of middle class area where people would be less likely to have any previous experience of it. I mean if the neighbours here found out about it I might as well throw my hat at it. The kids wouldn't be able to go outside the door and you 'd finish with having to move. I have no doubts about that. I mean people may try and be understanding but when it comes to their kids playing there's no way. Which is something that I could probably understand. I mean if I was put in this situation five or six years ago, I'd certainly think twice about letting Vicky [positive daughter] play with somebody like this or even having contact with them so I mean I don't really pass judgement on people's reaction to it.

However, keeping a HIV positive diagnosis a secret within the family and/or the community not only affects peoples ability to develop support networks (Travers 1996; Hayes 1996), but can have unanticipated repercussions as one mother discovered:

You know, you have to be careful too because we call it just our family business. But then they go into school and if they do the 'Stay Safe' programme, they're taught secrets are bad. If grown ups tell you to keep a secret, you don't, you tell your teacher, you tell someone. Don't ever keep secrets, any grown up who tells you "this is a secret" has to be mistrusted. So you're there with your AZT and it's like "it's not a secret dear it's just us, it's family business".

THE IMPACT ON RELATIONSHIPS

The uncertainty and life-threatening potential of HIV places a heavy toll on relationships within families, and in particular on a couple's relationship. Partners spoke about their difficulties in talking about HIV with one another, fearing to do so would cause distress. For couples where one partner is HIV positive, maintaining a sexual relationship was a problematic issue. Adams and Sears (1996:74) have noted that:

"The continuation of sexual relationships after testing HIV-positive involves a variety of issues. Among other things, those affected must work through fears of transmission, the complexities of negotiating safer sex... and changes in sexual desire linked to health status."

Many couples, like Brid and Jimmy, found their sexual relationship altered radically after HIV was diagnosed:

From the time he was diagnosed, that was it, if there was any sexual contact there was protection used and then he totally went off sex. I think it was a fear of passing it on to me even though we used protection.

For HIV positive people not in existing relationships, the possibility of forming new relationships in the future seemed remote, as Julie described:

One of the things with most positive people I know is that when you find out you 're positive you think that you're never going to have, be able to have a relationship with anyone again. And I know a lot of, particularly women who choose to remain celibate because they 're just too afraid to and you feel I mean I know I felt certainly that like who's going to want me or want to make love with me you know I'm positive. AIDS, AIDS, kind of thing. Cos again that's what you pick up.

However, for those who did maintain or commence a sexual relationship there was an ongoing concern over the risk of transmission. Consequently, repeat HIV testing, with all the stress this involved, had to be undertaken:

I got tested in hospital and I was negative and I went back then I'd say another year later I think it was and I was negative again and then I got tested there two years ago ... and like it took me a year and a half to get the courage up to get a test done after Johnny died because like I was saying well now all them years is gone by. If it's there it's going to show up now.

The risk involved in having unprotected sex often resulted in couples making the decision to have no more children, an issue Lisa found difficulty in coping with:

One of the things I find very hard is that people always ask you are you going to have more kids and all that sort of stuff and that can be very hard sometimes cos I suppose before I had a child that was one of the big issues, the decision not to have any kids. Like it got to the point of looking at little babies and I'd be getting very upset about it that I wasn't going to have any kids.

However, for positive women, developments in treatment and procedures at birth have minimised the risk of maternal transmission and having a healthy child is now a feasible option.

Some couples who had been separated before the HIV diagnosis found themselves 'reunited' in the aftermath. This was particularly the case where the male partner had been diagnosed positive and their female partner offered to care for them. In such situations the isolation experienced by the women could be acute, as was the case with Mary who had been estranged from her husband prior to his diagnosis:

Everything centres on the person that has this illness and there's nothing for the partner that isn't sick ...my husband used to do that he'd be well you're supposed to be here for me and them kids nothing else ... like he was paranoid. Like I couldn't have went to anything like that when he was alive you know what I mean. That was the type of person he was. You know everything doesn't have to centre around them. Although they're sick, it doesn't have to. I mean you're a person in your own right as well. It's just, everything was sort of centred on the sickness you know. Maybe it's a lot to deal with I don't

know. I suppose you 'd have to be in that position to understand how they're feeling.

In contrast, a number of HIV positive men left their marital home to return to their parental home while they were ill, causing much distress to their wives and children, as Annie described:

Like he didn't even want to know us, all he wanted was his family. And I went mad now over it, cos like the person he was living with was me and the kids. We were looking after him, he was my husband... that got to me you know, it really got to me.

Cathy, whose husband was HIV positive, faced a similar situation but was able to enlist help to sort out the situation:

When Barry was down in his parents house I had to kind of fight little battles with them you know like trying to, like not saying it to them [his parents] because I knew there'd be a big major row, but I'd get the social worker or the health worker or the counsellor to go and have a little chat with them and say "listen you know Cathy is his wife and you should kind of let her help out more, I know you want to do everything for him because you are his mother and father but at the end of the day Cathy is his wife and you know you have to let her help out as well. " So it worked out well I mean, I was upset, but I can understand now because he was born in his mother's house so since his house was still there and his mother and father was still alive he just wanted to you know, so I wasn't going to stop him.

Relationships within families are further affected by the stress of keeping 'the secret' from some family members, often necessitating the construction of elaborate stories to 'explain' illness and medication. In addition, relationships between children and their parents can deteriorate after a diagnosis has been made known. Lilly remarked how her granddaughter had withdrawn from her father after she had been told he was positive:

She doesn't talk very much about him, I think she's afraid to get close to him.

Relationships within the extended family were also seen to worsen where an HIV diagnosis revealed a parent's drug use and there were concerns regarding children's welfare. In such cases grandparents, aunts etc. became actively involved in caring for the children concerned.

LIVING WITH HIV/AIDS

On a daily basis, coping with HIV often involved forgetting about the illness and getting on with life. While many care professionals consider this strategy a form of denial, for those like Pete, who were living with the virus, it allowed them to plan for the future:

Now I'm looking forward to the year 2000 to see my young fella make his communion and after that I'll get to the year 2001 to see the other young fella and if I can get to them I'll be happy ... they can't understand that people can just live with it.

Others like Tom, whose young daughter was HIV positive, preferred not to look to the future but coped on a day-by-day basis:

I mean I think in these situations you don't try to analyse it too much. You just put your head down and get on with it. You don't try to deal with it. If you try to deal with it, you'd just crack up. You can't look four years down the line, you just have to deal with the day or the week and if she's not sick that's a bonus and if she's sick you have to work through that and get a doctor, get the medication.

However, for many, the ongoing stress of living with a chronic illness, confronting possible death and being in constant anxiety about their health gives rise to bouts of depression, as Joe described:

It's just this constant fear of getting sick and dying and spreading the disease to someone I love. That's the main sort of dread and depressing thing about it.

Sometimes I do be thinking of the child growing up and me not being there ...so it's mainly fear and depression.

Such depression sometimes results in positive people contemplating and even attempting suicide. David recalled how close he came to this:

There was a couple of times when I thought what's the point, you know, end it all. I came close to it once. College Green, I was crossing over from the Bank of Ireland, heading for Grafton Street and I was in the centre island and there was a big truck coming down the side, a big juggernaut and I was going to, I was literally thinking about doing it only for this girl who decided she wanted to be first across the road pushed her way in on front of me - then I got over that, it was just one little moment of madness.

Another aspect of living with HIV was that although it may be many years before the positive person becomes symptomatic, as Seanie related, every time he felt ill he presumed the worst:

I thought the HIV was starting to kick in and I was like "Oh God I'm starting to die " you know what I mean... any sickness

I used to get in the late eighties and early nineties I used to put it down to that, like it's sore under me arm at the moment and I'm thinking God what's this, what's this, like really uptight about it.

EXPERIENCING THE STIGMA

For many families, the defining aspect of living with HIV, was having to cope with the accompanying prejudice and harassment, as Tom remarked:

Branding, I mean that's totally what it's like. You're branded for life.

In this respect HIV is unlike other medical conditions. Lisa, whose partner is HIV positive, noted:

My Dad died of cancer and the one thing about cancer is that you can talk about it and accept it for people to have cancer but with HIV like a lot of people think it's the person's own fault that they have it. It's just something that's not talked about as easily as cancer is talked about. It's like the way when you 're out selling red ribbons it's very hard to get money out of some people but when they 're doing daffodils for cancer, people literally hand you lots of money.

The perception that it is a person's own fault for contracting the virus, that their illness represents 'the wages of sin' for their deviant behaviour, is widespread. Pete who contracted HIV through intravenous (IV) drug use, described the reaction of others as being:

If you 're an ex [drug user] you get this "he brought it on himself' do you know what I mean. We asked for it, the majority of people would look at it, I went out and asked for it so I got it.

Homosexual men are particularly prone to experiencing prejudice and even homophobic violence because of their sexuality (GLEN/Nexus, 1995), an experience aggravated if the person is known to be HIV positive. Families themselves can be the site of some such prejudice as illustrated by David's relationship with his family:

I wouldn't go out socialising with them but like that stems from the fact that I'm gay, they never really had that much time for me anyway and I got sick of trying to explain my lifestyle to them - but being HIV really put the nail in the coffin with them you know.

Even children do not escape harassment. Sarah, who cares for her deceased daughter's children, recounted how:

Sometimes, people would say something to the kids you know and it's very hurtful, but they can cope with it now because

before their mother died I had to sit down and explain to them about why their Mammy was sick and that she was going die. That they 'd only have her for a certain time and then a girl two doors up - came out and started giving out to Rosie and then she turned round and said "you know, your mother is dying from AIDS". So Rosie came in and she was roaring crying and I had to explain that people can be very hurtful, don't mind them.

While Margaret's son, whose father had died of AIDS, also experienced harassment from a neighbour:

There was an argument with the eldest young fella ...in the heat of the argument the mother turned round and said "as for that riddled AIDS bastard off the Main road". Well that was the first time I ever heard it and I hope it's the last because it really did hurt. Jesus it really hurt ...to hear it back, knowing that you 're doing your best like to move on and cope.

However, neighbours were not the only source of prejudice, some care professionals were also perceived as being culpable in this respect, leading one partner of a positive woman to remark:

It's bad enough being terminally ill without being treated like dirt.

This was seen to be especially the case in relation to pregnant women, both those who were positive themselves and those whose partner was positive. For positive mothers giving birth, particularly when less was known about the transmission of the virus, the reaction of staff was hugely distressing for both them and their partner. Jean, who is HIV positive, recalled how:

The person that was delivering the baby right, had, well she had two coats on her, then she'd plastic, she had these big gloves, and I was in a room on me own outside the labour ward.

While Eddie, whose partner and child were positive, described how:

They were isolated in a ward and even the lady who came to give them their tea was like preparing to go in a fuckin' moon rocket.

For families affected by HIV, their experience of prejudice was an intolerable addition to an already difficult situation. One by-product of this experience was an intense concern that their HIV status remain private and confidential.

SUPPORTING FAMILIES

While most HIV/AIDS services are directed towards the needs of the positive person, families affected by HIV can avail of support, mainly in the form of counselling. Most of the families who participated in this research study received such support, but this is more a reflection of where they were recruited for the research rather than representative of families in general. A

more accurate reflection of the situation may be that found by the Murphy Lawless and Redmond (1993:33) survey where:

"only a small percentage (26%) of respondents' partners and families belong to a HIV group or receive counselling or other forms of support"

Families interviewed in this study, highlighted a number of difficulties in relation to counselling which may account for the low take-up of services. Their main concern was with maintaining the confidentiality of their status. In approaching services in the relatively small city of Dublin families considered themselves to be at risk of being identified, outside the city this concern was even greater.

Others, like Pete and Sandra, found the counselling process too intrusive:

Our counsellor... he wasn't kind of listening. He kept going into other avenues that we could handle ourselves, we didn't need him on them... it was coming to terms with your illness and whatever but like the way he was going about it was completely, wasn't what we needed you know.

Families also found it difficult to deal with the changing personnel in support services which necessitated disclosing and discussing intimate details to each new person. Seanie related how he had stopped attending counselling as a result of this:

There's no way I could start all over again you know what I mean ... You don't want to keep going over and telling people over and over again your story do you know what I mean. You get pissed off with it.

Others, like Ritchie, were frustrated that non-positive professionals were telling positive people how to cope:

I mean nobody can sit there and tell you what it feels like having the virus. They read all about it, that's all it is. They don't know.

As noted earlier, the secrecy within families as to the nature of the illness, places limitations on the support children affected by HIV can access. However, where the illness is known counselling was not always wanted by the children. Lilly, who cares for her grandchildren, as both their parents are positive and unwell, recounted her granddaughter's view:

She said it to me "I don't want any counsellors, I know what it's all about now. " She said "I don't need anyone to explain anything to me. "Like she's going on twelve but she's going on twenty you know what I mean. She's very sensible. Too cute half the times, you know ... Like I don't hide nothing from her. She's told everything. But she doesn't want anything, nothing to do with counsellors.

Some families advocated the need for more practical support than counselling. Tony's attitude towards counselling was:

I've never really felt like talking it through was the right approach. To be honest with you, I nearly run a mile when I see the counsellor coming because I mean and I know it's her job, but I mean she's there counselling me and I'm not sure if it's the right approach ...I don't know maybe it's just a personality thing but I did obviously think about it but you have to physically cut yourself off and just deal with the here and now. I mean that's, like there was good days and bad days and as I say a good day was a bonus but I didn't really feel I needed to be counselled. Then again having said that maybe if I tried it maybe it would have been a help but I think you're far better of f sort of aiming for practical help and, rather than sort of indirect help. I think that's the best way forward because you're taking a certain amount of the pressure off then and once you have some pressure lifted you can sort of sit back and concentrate on doing other things.

The focus of support services on the positive person, unwittingly left many negative partners feeling isolated and alone. Lisa, whose husband is HIV positive found that her volunteer support worker the main source of support:

I suppose one of the things about the virus is that I feel very isolated sometimes. Say when Joe's [partner] viral load went up, he had people, his Mam and stuff and people that he knows from meetings that he could talk to but I found that I have to wait until my befriender is up but that's the first person I could talk to I haven't got anybody that I can, say anybody on a personal level that I can really talk to cos although me sister knows I don't feel like I could ring her up and talk. and my befriender on average is about once every week and a half, but we do a lot over the phone when the kids are gone asleep.

For families living in rural areas, their distance from services made their isolation even more pronounced. Maureen was able to access her husband's counsellor when she went with him to the clinic, which helped her cope with the isolation:

You couldn't trust -you felt you couldn't confide in people. You had to sort of carry it all on your own. It was very hard it was. Very, very hard. And the only support I had then was the counsellor at the Hospital - I always went to the hospital with him because that was the only way I'd find out anything about the illness. And when he'd go into the doctor, like I'd go into the doctor as well and say somebody would call him for blood

and then I'd get the opportunity to go into the counsellor. You know, in a sense he was sort of counselling me as well, you know what I mean, but where you live, there was no sort of support you know and then everything sort of centered around Dave [partner] because he was the person that was sick.

A shortage of child care also resulted in parents difficulties in attending support services. As Cathy described:

If I wanted some counselling my problem is that I haven't got anybody to mind the two children ... now there's a support group that's in the morning times but I mean I'm in a situation that my youngest son is only in play-school so the support group starts from eleven until one o'clock and the play-school is on from ten until half twelve. Sure I'd be only going into town and I'd have to leave to be back for half twelve. So it's just a little bit awkward for me to get to these support groups because of childcare, I mean I'm very kind of limited to where I can go you know.

Peer support was particularly favoured by parents, partners and carers of positive people, who found meeting others an opportunity to pool experiences and coping strategies, as well as accessing emotional support. Eileen, whose son is positive, recalled how:

This year for the first time we got to go on the family camp to Barretstown and it was just absolutely brilliant because like the kids were all doing their thing and there was five families and that was the first time ever that I had been sitting with the other parents. And it was great, it was great for Sedn [partner] to meet men cos he wouldn't really have anybody, and to have other negative men parenting positive children, like that was a great thing for him to be able to sit down and have a few pints and actually talk to them about it.

However, in contrast many positive people admitted to finding their experience of peer support a bit strange. Joe's view of these groups was that:

It's a bit surreal in that I wouldn't like I have nothing really in common with these people. Maybe I took drugs, they took drugs, loads of people have taken drugs. It's not really a common heritage to talk about and some of them could be still on methadone, some of them still probably taking drugs and then there's gay people. Like I don't know, it's not as if we're part of the same club and we all go doing something together. It's like they're bringing these people together for HIV and they've nothing else in common and I find it hard to sort of click with people. Now I haven't gone up there a lot like you

know what I mean but I find that just because I've HIV like, how do you form a sort of camaraderie with them just because of that fact. I know that the basis of it is a support system and you get these information networks and things like that but I just don't know.

Joe's comment also reflects the loss of identity positive people and their families experience once HIV has been diagnosed. Not only do families internal lives come to revolve around the virus, but externally the families are perceived and identified, first and foremost, as families with HIV. Despite this, the families themselves had found little opportunity to define their own needs in terms of the support structures they required. In addition, their loss of identity is also accompanied by what Melvin (1993 :229) terms "the chronic erosion of power and control people have over their own lives". Nowhere is this more apparent than in the families account of their medical treatment.

COPING WITH TREATMENT

In contrast to the usual fatalistic portrayal of people with HIV, a number of positive people, in the families interviewed, had lived with the virus since the mid 1980s without any notable ill health and with little contact with the HIV clinics save for occasional monitoring. However, this unpredictable progression of the virus is found to be very stressful, particularly with regard to deciding the optimum time to commence treatment. Joe had experienced this situation when his viral load suddenly increased:

Like my T cell count has always been sort of around five hundred for the past six years, but my viral load is, last year it was sort of negligible and then about five months ago it went up to twenty one thousand so they said well maybe that was something wrong with that. And then they took another one there about six weeks ago and it went up to eighty thousand. So my T cell count is still around five hundred or five fifty or whatever. Like they ask me "what do you want to do", like they're advising me to go on them sort of... they gave me information on the side effects and you can ask all the questions you like, but what do I know really to ask... Well I don't know really, I could have been going from A to B forever asking and probably if you asked twenty people, ten of them would say go on them and ten of them say don't. Like who do you believe.

Within the last few years the availability of anti-retroviral drugs has radically altered the prognosis of the illness, and led to a greatly improved health and life expectancy for those diagnosed positive. Nonetheless, the treatment regime has proved a hugely difficult and emotive issue for positive people and their families.

Among the difficult aspects of the treatment, there is the highly intrusive nature of the medication routine which involves taking large quantities of different drugs at regular intervals throughout the day. Adhering to this regime involves continuous self-discipline to maintain a healthy lifestyle, avoid alcohol, and once started to persist with the medication

for life. In addition, many people experience a range of upsetting and debilitating side-effects such as nausea, vomiting, rashes, diarrhoea, stomach upsets, weight gain etc. Co-infection with Hepatitis C causes additional health problems. And, as the progression of HIV is an uncertain process, so too is its treatment in that each patient needs to work through a trial and error process of different drug combinations to find the most suitable, a process which may have to be repeated intermittently. Added to all this, the range of treatment options available can result in the patient receiving conflicting advice from different sources, and/or advice which is too complex to fully understand.

Rita, for example, found the information she was given about her treatment just too difficult to grasp:

I'm not a one that can understand things. Like it's hard to understand it, it's hard. Like they'd have these charts and everything and I'd be thinking, like I'd be just sitting there looking ... the first time I went I was sitting there and I hadn't got a clue what they were talking about.

The complexity of the treatment presents problems for health professionals to provide the necessary information in a form accessible to the patient concerned. However, failure to do so was seen to have far reaching repercussions, particularly when this is accompanied by a patient's difficulty in adhering to the treatment regime. For example, Rita's experience of not understanding the information given at the clinic was followed by her experience of side-effects to the drugs, consequently, she took a 'drug holiday':

They put me on the viral tablets. Oh my stomach was in a knots, in bits on them. I wasn't even eating. I was as sick all the time, the whole time. I was trying to keep them down as long as I could. It was only after one load went down it was time for me to take another load you know that way. I was taking them, five times a day and then they were only down me about an hour and I was vomiting and everything. I wasn't even able to do anything in the home. I just wanted to sleep the sickness off me and that and I said ah no. I said I'm worse on these tablets so I'll just stop them... I was afraid now telling them, I was but then there was no point in going up and taking the tablets and just leaving them lying there. I was better off just leaving them.

In addition to accessible information, the need for information specifically geared towards the needs of homosexual men, ethnic minorities, women etc. was identified. For example, Sally had found that:

There's very little women specific information, you know what I mean. With women a lot of the information that you receive

would be very general AIDS information whereas... only recently they put down certain gynae things, like you know the way lots of women have abnormal smears ... thrush is very common and stuff like that and it wasn't being picked up on for a long time ... but the whole point is that even a very basic thing like drugs affect women differently to men, we've a different bodily make up, different fat levels etc.

ATTENDING THE HIV CLINICS

Attending the HIV clinics was much disliked by all concerned, not only because of the queuing and waiting around for tests, but because the visits invoked constant reminders of their illness and mortality and, for many, of deceased peers. In this respect, Sarah noted that while her adult son:

Can go down any day if there's anything wrong with him. You know what I mean if he's not feeling well or that he can go down. He doesn't go down though, he hates going down there, like nearly all the fellas that went on the drugs the time he went on them is all dead he's the only one still alive out of it and it keeps bringing back memories to him.

Patients from rural areas, those who are working and/or caring for young children, such as Sonia, had particular difficulties attending the clinic:

For the first three months I had to go every month, they had to monitor you. And now, I just go back every three months so it's not too bad... Oh you could be waiting two or three hours. It depends on how many people are in the clinic and it depends on how many doctors are working in the clinic that particular day. So you could be in within an hour and a half then again you could be there within three hours... they have no creche no. So what I normally have to do is arrange for somebody to mind the kids, it got to the stage that it was too stressful bringing kids to hospitals because you have to watch them all the time.

As Foreman and Mulcahy (1997:75) have noted:

"Services are not specifically directed at women with family responsibilities and services for children with HIV are located in hospitals separate from those with adult services. A HIV positive drug using woman with a HIV positive child could attend up to four separate hospitals or treatment centres to receive proper care for herself and her child including a HIV clinic for her outpatient care, a children's hospital for her child's care, a

separate drug treatment centre for methadone maintenance and a gynaecology clinic for colposcopy to check on cervical changes.”

In addition to the practical difficulties encountered in attending the clinics, patients found the clinical setting and its hierarchical structure extremely alienating. Consequently, patients found it difficult to establish relationships with many of the staff. As Tom related:

The hospital structure is so formalised, even the white coats. Why do these guys need white coats ? It's just to distance themselves, I think it's crazy in this day and age, doctors wearing white coats ... Take off your white coat, sit down and talk to the person and then they would learn so much. I mean it's funny because compared to the GP, they have so much time and I think for most of the people it would mean so much like. I mean if somebody doesn't want to talk, well then fine, but a lot of the people do you know.

Similarly, Sally had found:

Some doctors are okay and some doctors are not. Some doctors I think feel a bit threatened, some still have this image of themselves as like I'm the doctor. I make the decisions but there's a lot of doctors sit down, go through the options, talk about the possibilities, listen to what the patient has to say you know. It should be on an equal footing you know. I respect their superior medical knowledge but they have to listen to me about how I feel, I know my body. I know how I'm feeling.

In living with HIV many positive people and their families keep themselves informed of new developments through magazines such as POZ Ireland, Positive Nation as well as the Internet, in order that they can take a more active part in their own care management. However, families were frustrated by the feeling that their efforts to inform themselves and their concerns were often dismissed, despite as Richie remarked:

They just dispense the drugs, we've got to live with them.

The frustration at not being listened to about the difficulties experienced in taking the medication, was explained by Julie:

A big problem there is that up until these new drugs came out, there wasn't much hope and the hospital staff, doctors and nurses didn't have much to offer and they're now so delighted with these new drugs that you know, they're handing people a carrier bag full of pills not realising all the implications of trying to manage that on a practical level taking tablets every

few hours, they 're so delighted and like unless you're absolutely nearly dying on the floor in agony they play down the side effects. Things like hair loss, skin rashes, they may be minor but they 're huge if you 're going through them and particularly with the new drugs, the different changes in body shape and that.

Many of the patients perceived staff as being quick to jump to assumptions about their lifestyles - that they were "branded". This was particularly felt by patients who had a history of drug use, as Carol related:

Because they 're drug using women and they 're perceived to be very fucked up you know, decisions are made for them. Do you know what I mean, without them being included.

Part of these feelings of exclusion from treatment decisions and of being branded were seen to be related to the difficulty in building up rapport with the medical staff when the personnel rotate every few months. Cathy found that:

If you did get a decent doctor you were just building up a relationship and then six months later you'd walk in and they'd have changed over and there'd be a new student sitting there "and tell me what happened to you?" and like you 'd have to go through the same crap all over again and maybe about six months later it was the same thing again.

With ever changing personnel, there was also the concern that details would be missed. Tom recalled his wife's anxiety over this:

It used to bother Kate especially where there's a nice one and the nice doctor leaves and you've to start from scratch again ... the big difficulty was that like Kate's file dated back about five or six years say and it was so big it had gone into two, that size. But like they would read the last three pages of the file and they wouldn't know anything about the rest of the history and there was always a big gap there in knowledge... I've a certain amount of sympathy if you 're coming into that and you 're in therefor six months, why should you read a file and I'm sure most of the files would have been that size ...I mean, there was a couple of things that she might have had that

mightn't even have been relevant to the illness but which might still have been important like but no I felt that there was always a gap there which was never bridged.

The vulnerability experienced by people in treatment was further amplified by their concerns over the long term effects of the medication and its possible failure, adding to their apprehension as to what the future would bring, as Sally described:

It's the psychological implications you know, am I back in the land of the living again or am I going to get sick should I take up a job, should I not. You know there's a whole lot of people who are very confused at the moment, wondering is it just a reprieve or what.

Overall, the issues relating to treatment were extremely emotive ones for patients and their families. This may be explained in part, by the continuing adjustments both patients and their health carers are having to make as a result of the transition in treating HIV/AIDS. That is, the transition from a situation where HIV/AIDS was a terminal illness with little treatment available to the current situation where HIV/AIDS is a chronic illness requiring ongoing, indefinite medical care.

INVOLVING GPs IN TREATMENT

The centralisation of treatment for HIV/AIDS was queried by some families who wondered why their GPs couldn't take on the day-to-day management of their illness. This was particularly the case for rural families who had difficulty attending the Dublin based clinics, especially when not feeling well and who were anxious about being far from the clinic if an emergency arose. However, while some families, like Eddie's, found their local GP invaluable at times:

A typical example would be if you went into the hospital with a cough, you 'd finish up getting three x-rays done from four different angles. You 'd be there all day and you 'd come out with a hugely potent antibiotic. Whereas this guy, you go in, you sit in front of him and you 're out in five minutes with your normal antibiotic and it works and if you want to talk to him, he talks.

Other families perceived their GP as being reluctant to treat HIV positive patients, or of not having sufficient experience of HIV. Sonia's policy was to:

Go to my own GP really only for practical things. If I had a cold or a cough you know, while anything like a stomach bug or anything like that I go straight to the hospital because there's nothing really that your own GP would have the knowledge of you know. Like they 're still learning.

Families often made a distinction between the family doctor and the clinic, and/or keeping one GP for the positive person and one for the rest of the family. As Annie, whose husband is HIV positive, explained:

My doctor doesn't know anything about him, I'm not telling him, none of his business, I mean it doesn't affect me, my health as such, I haven't got it, I know I haven't got it, I got tested for it.

Rita, however, found she had no choice in whether to tell her GP as he had been informed, she presumed by the hospital. As a result, she worried how confidential her positive status really was:

My own doctor knows I have the virus. I didn't tell him, they sent it in the post. Well they must have, because I didn't tell him.

MANAGING POSITIVE CHILDREN'S TREATMENT

To date, one hundred and forty nine children have been diagnosed positive in Ireland. However, many of these children lose their HIV antibodies in the year after birth, and while data on the number who do so is not available, approximately a quarter of this figure are currently attending treatment.

Initially, children with HIV were not expected to live long. However, with advances in medication, some of the HIV positive children have survived and are now in their mid teens. Consequently, families have had to adjust and start planning for living, rather than death.

The difficulties adults experience in adhering to the treatment regime are acutely magnified for children. As illustrated by Tony's account of his four year old daughter's routine:

The medication was in syrup form and tasted like petrol. It was awful and she had to take ten mls three times a day and it's very harsh in the morning on your stomach but like unfortunately it wasn't even one gulp. If you could get it down in one gulp you'd be grand, it's a bit of a bad taste and I'd give her a sweet but when she has to come back for another gulp, actually giving it to her was quite difficult but she was good enough and took it.

Children also have to follow detailed medication routines, as described by one mother who's four year old son was positive:

He has to take the medication, the 'AZT', '3TC' 8mls in the mornings, 8mls in the afternoon and 8mls in the evening so it's three times a day. Like the 'ddI' is twice a day, it's 7.5 mls in the morning and 7.5mls at night. You can give them together once he gets them before food and then wait at least twenty minutes and then give him something to wash it down with, something to let it work into his system.

While an eight year old boy's routine was described as:

He has two liquids and one tablet at half seven in the morning, a liquid and a tablet at half three, liquid at half seven and liquid and a tablet at half eleven at night.

The difficulties parents and carers have with regard to disclosure and the secrecy maintained with other family members and friends, have been outlined earlier in this report. Further implications of this situation are evident in the families' daily management of the medication routine. Despite many children having no name for their illness, they are aware of the need to keep 'it' a secret, as Eileen relates other eight year old son:

When we had to give him the injections and I used to have to inject him three times a week. He never told anybody in school or to this day and he was only like five and a half or something but he just knows somewhere that it's serious stuff and that you know. Just the family business... they were here one day recently and some little fella that was in the house was saying something, I had to take medicine in a syringe once and I could see Tim looking over at me as if to say - I've to take that four times a day and big deal - but like he didn't open his mouth, he just noticed it but said nothing... he's very good and it's our business. Like he'd be out there playing on the green with his pals and I can see him and he'll come in, go up the stairs and take it and go down the stairs again and he won't say a word to anybody. Like he's keeping the secret so well.

For older, school attending children, some degree of flexibility is allowed in the intervals between tablets, but for children whose status is kept secret there are difficulties in taking part in activities which would impact too heavily on their routine. Parents and carers are seen to have developed innovative responses to deal with such situations, as one mother described:

Saturday afternoon he wanted to go out. The child next door is one of his good buddies and they 'd be going down to Dunnes Stores shopping centre. He needed new runners, the lad and they were going to get chips and they were going to go and get this and they were going to go looking at toys and looking at the toy shop and all the rest of it. And it would break your heart because he has to get his medicine at half three, and rather than say no you can't go, you've to tailor your whole life. Now I no more wanted to go to Dunnes Stores on a Saturday

afternoon in the run up to Christmas than the man in the moon but I was saying to my neighbour then actually I have to go myself. She was like have you to do your shopping yourself and I said no, no I just have to get one or two little things. So she was maybe I'll meet you for coffee somewhere so I said that would be lovely. So we actually organised that we'd meet at a quarter past three for coffee because I had to give him his stuff at half three and then I'd say oh I have to go to the butcher, you sit and stay there cos I need to get it and Brian you come with me because you know I need to have a little chat with you about whatever. And people don't actually pay attention they let you do that kind of thing and we just ran around the corner and back again. Same thing, the great unwashed don't care if you're putting a syringe to your child's mouth, it's only somebody who knows that might look at you but I don't care if somebody looks at me you know. And he's so good he just kind of puts his head down and takes his tablet and back again and that's it then. Goodbye and see you later and don't come back till six o'clock if you don't want to. But that's, you have to tailor your whole life to the child's life and that's just the way it is.

However, some activities are less manageable and just have to be ruled out:

He's in the cubs and last Friday, he came home with a letter that the cubs are going off to this forest and they 're sleeping the night. They bring their sleeping bags and their this and their that and he just loves the whole idea of scouting and that's over now. Like he can't go ... and if it was any other disease, anything else, you could say you know this child has cancer, will you give him this at eleven o'clock at night. But you see there's four times a day that he takes the medicine and the day time ones are okay but there's a half eleven at night and really he does it nearly in his sleep for myself and Sean [partner] but anybody else would kind of wake him up and it would be strange so that even if you did have somebody who would do it, it probably wouldn't work anyway, you know in a room full of twenty cub scouts all asleep on the floor in their

sleeping bags. You know, to wake one up — no. So that's a shame.

ATTENDING THE CHILDREN'S CLINICS

In addition to the day-to-day medication routine, children attend clinics in Dublin every three months for monitoring and to replenish their medication supplies. Eddie described the procedure for his son's visits:

Sometimes you'd see the registrar or whatever, the six monthly junior doctors on their rotations and some of them are wonderful and some of them are not so. You've to start the same old story. You just go in and it's like they would take him off for a weight and height check, that kind of thing and then it would be in and just chat and if you've any problems, anything going on at the moment, writing all that down and checking the tests and like the blood test - they used to always do that in the clinic but now they 're moving that along to a phlebotomist and you need to go up to her office now and she does the blood test. That's fine as well. She's used to doing that, well I mean she's used to doing the blood. It was a dramatic failure the first time because Barren hates anything new, it bugs him altogether and he wouldn't go near her and he was screaming and roaring, but the last time now he went in he let her do it so, it was just a matter of getting used to it.

Organising the children's attendance at the clinic is difficult when parents and carers have kept the child's condition a secret. For rural children this entails organising the visits around school holidays. Maureen related how this works out for her and her son:

We go up on a Monday after school, about five o'clock on the Monday. Go to the clinic on Tuesday and come back then on the half three train so you're back in school for Wednesday and there's no other way round it really. You couldn't go up and down in the day. I suppose you could if you went early on Wednesday and came back very late on a Wednesday night but that doesn't work with a child either. They need to be in bed but if you were to do it up on the Monday and then had to get a bus from the train station to a bed and breakfast in Crumlin or somewhere and then back to hospital again the next morning,

a bus back to the train station or a taxi back to the train station and back again ... the last visit, was the last week of the summer holidays, the last week of August and that will swing me until December. The first of December, would have been three months but I changed it to the eighth of December because they're off school the Monday and the Tuesday. So that will swing me until February and I'll probably have a mid-term somewhere around about then you know like you go with the school thing and Crumlin will either let you have a week extra that way or whatever.

CONCERNS OF PARENTS AND CARERS

As adults had expressed their difficulty with the side-effects of the medication and the frustrations regarding their lack of involvement in their treatment decisions.

Parents and carers were caused great anxiety by their children's adverse reactions to the medication. Tom recalled how his seven year old daughter reacted to her medication:

She was never really sick in her life until she started taking them. Oh she was sick for about two months -pure reaction to the tablets I mean she hardly ate anything for two or three months I'd say. She was sick every day. She was sick four or five times a day and I mean she was just listless, she'd a high temperature. It was just unbelievable. I mean I knew there was going to be side effects but I didn't know at this level and I mean the advice I was given was don't ask her if she's sick. Let her tell you. But I mean it was obvious after day two that she was going to be very sick. I was even thinking of stopping it at one point but we soldiered through. It lasted about six or eight weeks. She wouldn't have the energy to go out. I had to take her out of school ...I mean she used to have to be lifted out of the bed in the morning, bring her down to the couch, bring a blanket and she'd just sit there watching telly all day long. This is a girl who does not watch telly but I mean there's weeks there she was just looking at it listlessly.

For a few parents, the distress caused to their child by the medication was so great that they curtailed the medication. One parent described how this came about:

I felt at the time when he started taking it first that I got very little support from the hospital and I mean "you just have to see it through" and that was the reaction. And it wasn't until I actually forced their hand and I actually stopped him taking them for about three or four days which I know is a risky thing to have done but he was so sick that had it gone on for another

few weeks, he 'd have finished up in hospital seriously ill. So I took it upon myself. I stopped them on a Friday evening and I rang them up then on the Monday morning and said listen this is killing him and only then did they react. But I had been ringing them twice a week telling them how sick he was and it wasn't until I had actually done something that they brought him in on the Monday and they practically halved the amount of tablets he was taking and I mean I couldn't believe it, he had been unnecessarily sick for about two months.

Others, like Eddie, also felt totally frustrated by the medical staff's attitude and treatment of his four year old son:

There was no communication because they just took me for granted as common and their attitude was we'll take care of this, we know what we were doing, we'll look after it, we'll put this into him, we'll put that into him and we don't know where it starts but Jesus we know more than you. Total exclusion - until I started asking, I had to ask and say look I want an input. I want a physical input, I want an intellectual input. I want to do what I can and I was put down as some neurotic father.

However other parents found the medication transformed the life of their children. As one mother described of her son, then aged five:

He got very sick very quick. And we were up and down [to the clinic] and he went onto AZT. His bone marrow went and we had to give him injections three times a week and he'd to have a blood test once a week and have to go up every week... that was his once ever big sickness and he was grey and skeletal and everything like a little Aids patient looks like and oh just gone, like behind his eyes he wasn't there at all. But then all the medical drugs came, first of all he was on dual therapy then triple and he literally hasn't been sick. He hasn't overnighted in the hospital since Christmas '95 so it's great and he's as big as any fella and he's healthy.

ISSUES FOR FAMILIES WITH POSITIVE CHILDREN

The constant supervision of a positive child's routine places many restrictions on the lifestyles of parents and carers. In such families, working outside the home, attending clinics and support services, even nights out are problematic, as child care is almost impossible to access and even more so if medication needs to be given or a child is ill. The lack of appropriate child care is a major concern for families affected by HIV/AIDS, particularly as the support of the extended family is often unavailable because of the families' wish to keep their children's status private. Some parents, like Sonia, have to devise elaborate schemes in order to have a night out:

It's very hard if I want to go out, my sister baby-sits on a Saturday night so I have to hide the medications. Like I'd normally keep medications in me press over there or the DDI in the fridge so I do kind of have to peep out and when I see her car coming up the road I bring the medications up to my room and put them in the back of my wardrobe you know, so she won't see them. And then I do have to kind of slide in and give him his medication then.

Others like, Eileen and Sean weren't even unable to manage one night out together:

One of the things we'd love is a baby sitter. I would like to pay somebody to come in and stay here just for one night. If there was somebody who had gone through the system like with Cdirde and had maybe a befriender or whatever that you could say right would you come and work with me for just this one night or two nights or whatever, because you see you can't, nobody wants to babysit and mind a child that has drugs at all weird and wonderful times of the day. You know, it's a big responsibility ... so we get out for the night alright, but we're latter day Cinderellas because with Tim [positive child] and the half eleven dose you could swing it like till midnight if you were being really bold... like we have a babysitter and she's lovely or whatever but you can't tell a seventeen year old girl all that, so you just don't go.

In order to alleviate the isolation experienced by the parents and carers of HIV positive children, a newsletter and support group meetings have been organised by the clinic at Crumlin hospital. Parents and carers found these meetings helpful in terms of talking about how they're coping and discussing medications etc. But, again, those living in rural areas are unable to avail of this latter form of support, as one parent described:

There are parents who have faced this in Dublin who could teach me an awful lot if I could only get to them or get to a meeting or get hold of them for a couple of hours and like they've been through all this that I've been through or am going to be going through but I can't get to them or find out. There's nobody that I can ask that will say well in our experience, this was the way to cope with this, or this is how you deal with it or this might help or this might work or try this you know. So it's just going blindly ahead, I mean it would be

nice, there must be so much information out there that the other parents have, and yet we're going to have to go and do it all alone again, and it's just a waste of energy you know.

However, for some parents there was the concern that participation in support groups would compromise their anonymity. As Richie explained:

A lot of the parents are very paranoid and they won't go to these groups because they're more afraid in case they bump into someone they'd know or people are very on edge about is it confidential you know is it confidential like. You know is this all going to be sent back, you know there is a lot of parents that are very afraid to open up to people you know. Well I was like, I can understand that I was like that at the start when I was first diagnosed.

While others, like Eddie, favoured the support group meeting away from the hospital environment:

Now I've recommended that we all go out into town some night and get to know each other, where there's no pressure, there's no restrictions, there's no authority figures and like nobody pointing sit down and there's no table in between us and there's no pen and there's nobody taking notes.

Parents and carers of HIV positive children were seen to live in constant anxiety about their children's health. An anxiety that was further exacerbated by their wish to keep the child's status private from other family members and even the child him/herself. As one mother remarked:

We'll never have the little old ladies prayers, you know the way there's always little old ones in the parish who are saying oh I'll say a prayer for you and that like but never, there's nobody that would ever say one for us.

COPING WITH LOSS

Since 1982, three hundred and thirty two deaths from AIDS have been recorded in Ireland. An additional unknown number of positive people have died from other causes. Families affected by HIV/AIDS can have several family members, often involving different generations, who have been infected - e.g. father, mother, and child(ren). Consequently, families may experience multiple bereavements.

The ailments associated with the latter stages of AIDS - diarrhoea, digestive disorders,

extreme weight loss, respiratory problems, skin lesions, memory loss, and dementia - are particularly distressing. For the ill person and their families, the support available to assist them through this time helped make the situation more bearable as Mary recalled of the later stages of her husband's illness:

I think it was the end or the middle of November he sort of didn't go anywhere - that's when the hospice started coming out just to make sure that he was pain free and he was comfortable but it got that he couldn't put his feet on the ground. Now he used to try and get out of the bed and at one time I remember he thought I was a nurse. The things he used to come out with when he was rambling you know ... He had this fear of the body bag at the time. Now I don't know if they still do but at that time if you died from AIDS they put you into this body bag. It was a fear he had. But I have to say he died upstairs and it was lovely. All his family were here. His mammy, his brothers, his sisters, the kids.

Cathy, whose husband died in 1996, recalled the support they received to help them through his death:

He said "I'm going home to die", so as soon as he was discharged/row. St. James', the Hospice team got in contact with us and between the hospice and the team and the public health nurse coming out every day and getting us all the equipment he needed like a commode, padding for the bed, the mattress, padding for his hands and his legs you know. Like they did everything you could possibly do. They were fantastic. Anything we needed, they had it within a half an hour and we had a night nurse and a day nurse. They were very good and they were able to tell us exactly "well it's going to happen this week" and when it came to the day and they were very accurate, "it's going to happen sometime today". They were very precise. Which was sad but great as well that at least we knew well we won't leave the house today you know and when the time came we were all there. His mother and father were on one side of him and I was on the other side and we were basically all there when he died.

However, coming to terms with the death of a young partner and having to cope alone with a young family was difficult to bear, as Mary related:

I do say to myself what could have been, what we could have had, you know what I mean. He was only thirty eight years of age when he died. He should have been around for at least another thirty years you know. I get very angry now over that, I do. You know he could have been there for his kids. Sometimes it just gets totally, you know you can't cope and then the way I look at it, I have to go on, no matter what life throws at me, I have to take it and try and handle it.

Even partners who had experienced difficult times with the deceased person found that:

I mean it's amazing like we'd so many, I felt like we'd so many bad times but I can't even remember the bad times you know what I mean. And there was so few good times yet they're the ones I keep coming up with you know when you 're thinking of it. I feel like sort of a hypocrite, I really do, do you know what I mean. It's very confusing sometimes, your own feelings, it's very confusing.

The bereavement process for those coming to terms with an AIDS death is exacerbated by the stigma surrounding the death. Yet, for many of the families support soon disappeared afterwards, even though the grief and isolation continued. For Brid, the help of a support group was invaluable even some time after the death:

I would not have known who to talk to, where to go you know. At least when you go up there [to the support group] you go up and you meet someone else that is living the same life, something similar like - and you sit down and talk, it's a great help you know. It really is, so that got me through it and that's why I still go once a month now because if I can help somebody else coming along you know. Like I used to look up to Mary when I started the meeting up there because she more or less had the exact same life as myself you know and I'd say well she's still okay, she's surviving. I can do it... if someone had come along to me and said you're not on your own now we can help you through this. It would have been a great help you know but no one knocked at the door. Like you were lost because your head is so messed up that you don't know who to go to, you lose track with the outside world as well you know.

You don't know who to trust, who to talk to, should you speak about it you know.

Even many years after the death of a partner from AIDS, the stigma remains. Many of the women who had lost a partner to HIV/AIDS were young, yet they felt it was unlikely that they would ever form new relationships. Telling a potential new partner about 'the family secret' was viewed as a daunting prospect, and one that only seemed to invite rejection.

THE IMPACT ON CHILDREN

In addition to coping with their own grief, parents have to deal with their children's feelings, from telling them of a parent's death, to supporting them through the funeral and helping them to cope with the aftermath. One mother, with five young children, recalled:

I had to take them in one by one and sit them on me lap now I think, looking back on it, I think that was the hardest part of the lot. Like I remember sitting down there and saying now I've something very sad to tell you, you know your Da went to heaven last night and like I was more concerned about holding them, watching them and making sure like that they were okay, forgetting about myself like you know.

A few days later, you know the way you're like a lump of jelly, it's all finished with, the neighbours are starting to die away you know ... so I remember thinking to myself, I going to have to get out and walk you know. So I said there's only one place I can go, that was shopping. It was Sunday and I remember thinking if I get mass I'll feel a bit better. I got around to the church and me legs were like jelly and this is a few days after and I'm standing wobbling in the church and at the back of me mind I was saying to myself I have to get the kids, give them a little treat. So I said after mass I'll bring you to McDonalds. Where I was getting the strength from I don't know - and I remember sitting in McDonalds looking at them all with their little cokes and burgers and me, my stomach was closed I couldn't touch a thing. But I remember saying to myself, they're going to be alright you know, I'll make sure they're alright.

However, parents found a whole series of difficulties developing after the other parent's death, problems which they found difficult to cope with alone. One mother related how:

Things just steadily got worse after he died and certainly the kids, like although he was a drug abuser he had a certain

amount of control over them, they done what they were told. Now I've one son that's doing time, he's a drug abuser but he'll never admit it, my daughter has a problem as well and she won't admit it, and my eldest son, he sort of blames me. Like one time when we were having an argument he said, "You never cared about my father" ... He was so angry, angry with him for dying you know what I mean. Not being there for him when he needed him. Like, there's nothing there for families afterwards, maybe it is out there but I don't know where to go for it, and I sort of thought to myself, I was under this illusion that my kids would be like me, they 'd be strong, they 'd be able to cope with it, but I was totally wrong you know. I feel if my kids, my older kids, could sort of be able to talk about it, it would be a lot better for themselves. There's a lot of things they haven't dealt with, concerning his death and leading up to his death and afterwards. Like they'd mention him in passing, "Daddy used to like that" or "me Daddy used to do that" or "Do you remember the way he used to go on?" or whatever. But nothing concerning the sickness or the death afterwards. They've sort of just buried it.

Mary also found difficulty in coping with the effect her husband's death had on their children:

Like they 're lost, they 're genuinely lost because no matter if they had AIDS or they were drug abusers, the kids idolise them. I know Jesus mine did, especially the smallest fella. He thought there was no one like his Da even though he put me through hell you know. He was his hero. Bad enough when a parent dies but like with the drug abuse and the HTV and the all the sadness that comes with it you know the one that's left behind to cope with it needs all the help they could do with.

Children's difficulty in coping with their parent's death often resulted in problems at school, especially when children were being taunted about their parent's death. Yet, as Brid experienced with her younger son, there was no support available:

Back to school, that was another big step you had to take you know, are they strong enough now? ... the elder two settled down grand. But Brian had a problem from day one ...so me, the teacher and the principal ended up in the office and none of us had a clue what was going on with Brian. You know I was so caught up in the grieving myself I couldn't see what was going on. "You're better off taking him home" she said. They couldn't handle him. So I remember crying coming out of the school and I think it was the first decent cry I had, Brian was crying, I was crying. There was no one there again. No back up system at all... there was no support in the school for him, nothing you know to deal with the grieving ... he'd think he was dying, he

was choking, he was going to die, if he kicked a can he was going to die, with the germs on it you know - he's only ten, its an awful pity there wasn't any back up system in the school.

Support services have noted the difficulty in conducting effective bereavement counselling with children coping with the loss of a parent from AIDS because of the secrecy which surrounds the nature of their death. Nonetheless, support such as the outings organised for children, were regarded as a great help by parents, even though these were only available for younger children:

The kids were brought away three times for days out and even that in itself, it gives them a break away from me and it gives me a break away from them and then they 're meeting kids that have the same problem as them. You know it's either a mammy or daddy or something that's gone you know. So it kind of gets them out of themselves and they 're meeting different people as well.

For children who have been orphaned, or whose parents can no longer care for them as a result of HIV, arrangements need to be made so that they can be looked after either by their extended family or in care, although if the child is also HIV positive foster placements are difficult to access. However, carers can experience a number of legal complications, particularly when one parent is still living, and in situations where a caring status is not legally defined problems arise regarding financial support. In addition, in some families there may be dissension as to who should care for the children. One grandmother recalled the struggle she encountered trying to keep her daughter's young children together:

There was a bit of hassle with his family, they were trying to get the eldest young one and I said look if you take Rosie, you take the others. I said there's no way them three kids are going to break up. Now this was before my daughter [Susan] died and his sister wanted Rosie ... then Susan was with a social worker up in the hospital and she told her, she got a solicitor down and made the will just in case anything happens. You know, it was just as well. Although they wouldn't have got the kids because I had them all along and she was my daughter, I'd have probably got them but I was afraid like if my young one, Susan, died and her husband was alive, he might have had a claim on the kids, but he died the year before her. But now I'm glad the way things worked out, that I got the will done, like I had proof of them being mine.

CONCLUSION

This section of the report focused on the experience of families, from the initial positive diagnosis, to life, and in some cases death, with HIV/AIDS. Their experiences illustrate the overwhelming impact HIV has had on the lives of the adults and children affected. The fear, frustration and stress of coping with an unpredictable, chronic illness is augmented by the

stigma and secrecy that surrounds this disease and isolates those affected from their extended families and their communities.



SECTION 4 HIV/AIDS AND SOCIAL EXCLUSION

In Ireland, the association between HIV/AIDS and social exclusion is two-fold. In the first instance, HIV/AIDS is seen to have disproportionately affected people from marginalised, socially excluded communities. And, in the second instance, many individuals and families have become socially excluded through their experience of HIV/AIDS.

In contrast to the traditional pandemic view of HIV/AIDS (i.e. that it cuts across geographical, social and political boundaries), evidence to date, in Ireland, points to the uneven development of HIV/AIDS in the population. Given that 42% of those who have tested positive for HIV antibodies are IV drug users, and that the incidence of IV drug use is disproportionately concentrated in areas where unemployment, poverty and marginalisation are the norm (Dean *et al* 1983, O'Kelly *et al* 1988, O'Higgins, 1996, O'Gorman 1998), then the epidemiology of HIV/AIDS must show a similar geographical and socio-economic clustering.

In addition, within the communities who have been disproportionately affected by HIV/AIDS, live families who have been disproportionately affected, in that more than one family member (sibling, partner and/or child) is often infected. Of the nineteen families represented in this research study, two families had four HIV positive members; one family had three HIV positive members and three families had two HIV positive members. One participant in the research study, whose own daughter and son-in-law are HIV positive, related how drugs and AIDS had affected families in her neighbourhood:

Now there's a woman around here she's after burying three with AIDS and she's another daughter 'Mary' dying in a hospital in London. Everyone of her family was on drugs except one. She'd a son twenty-six who died, she'd a daughter she died, another daughter who died, and now 'Mary' and two of her other sons is on it.

However, not only does "AIDS thrive [s] in the cracks of society's inequalities" (Hopkins Tanne 1992:209) but individuals and families affected by HIV/AIDS are forced into positions of marginality by their experience of isolation and discrimination and, in particular, by their long-term dependence on social welfare payments as a result of ill-health or caring duties.

In addition to the social and emotional impact of HIV/AIDS on their lives, their life chances

are also restricted by their financial inability to participate in even the most ordinary of activities. This experience of social exclusion has further implications in that:

“Families stand to lose the dignity that comes with self-determination as they find their best efforts are continually thwarted and their coping strategies are pushed beyond the acceptable, perhaps to such an extent that the locus of control shifts from the family to external social agencies.” (Walker 1995:125)

This section of the report examines the issues of poverty, housing and the lack of employment and training opportunities which, for the majority of individuals and families, exacerbates the health and social aspects of HIV/AIDS.

THE FINANCIAL IMPACT OF HIV/AIDS

For the vast majority (81%) of the households included in this study, welfare payments are the main source of income. Consequently, a key issue is the lack of financial resources to meet their needs. For the families dependent on either disability, lone parent or unemployment assistance, the normal weekly payment is £70.50 per adult, £41.20 per ‘qualified adult’ and £13.20 per dependent child. Annie, whose husband is HIV positive and seriously ill, and who has two young sons, described her weekly income (£138.10) and outgoings:

I collected our money now this morning a hundred and eleven pounds and twenty six pounds for the kids. But I left the kids one in and I put thirty pound out of this into the post office. Have to do it for Christmas, so forty pound I have left for the shopping and a couple of smokes you know. I have to do it. It's only a few weeks till Christmas and if I don't do it now I won't have anything you know ... I'll give fifteen rent, ten to the light bill, and I got clothes out of the catalogue for the kids, I got runners and jeans for the kids for the summer - that's another fifteen. Then me insurance and that - six pounds for myself and the two kids. Then a bit of shopping, you won't get much shopping out of forty pound you know what I mean. Then I've to give the girl up there a few bob she was after buying carpet - so she was asking me to buy it off her, so I have it for the kitchen, we're saving up for the paint and the wallpaper. So I've to give that to her this week as well, so I won't even have forty.

The income inadequacy experienced by people dependent on welfare payments, particularly in the long-term, has been noted elsewhere (Murphy Lawless 1992). Indeed long-term welfare dependants have been identified as being at an exceptionally high risk of poverty and social exclusion (Combat Poverty Agency 1999, 1998, Walker 1995). For such families like Annie's, every week involves a constant struggle to make ends meet. Bills and debts accumulate, and approaches must be made to the Community Welfare Officer, money

lenders, or charities to make up the shortfall.

Children from such households, i.e. reliant on Social Welfare, are also at a particularly high risk of poverty (CPA 1998). The 'Cost of a Child' study conducted by Carney *et al* (1994) calculated that the average weekly cost of rearing a child on a 'Basic Minimum Budget' to be £28.50, and on a 'Modest-but-Adequate' budget to cost roughly £10 per week more i.e. £39.90. Despite this study having been conducted a number of years ago, current average weekly Child Support Payments only amount to £20.47 per week (i.e. Child Benefit of £7.27 and Child Dependent Allowance of £13.20) falling far short of even the minimal costs associated with the upbringing of children.

In addition, children from poor households also experience social exclusion in that they are unable to participate in extra-curricular activities such as outings and holidays which Carney *et al* (1995:18) note "constitutes an essential element of a child's healthy development." One mother, whose husband had died from AIDS, related how support in this respect would help the children affected:

Like with small kids, it 'd be nice to think that someone would step in and take them out. Just even to help with the grieving thing you know. See if the kids are happy the mothers are happy. You know and what makes it worse is when the mother can't do anything for the kids and she's as I said to you like it took me three years to get all the bills down you know. Just on me lone parent book. But I suppose if they had something like for people, especially for when one of the parents die, little trips here and there. It does boost up their confidence you know.

While additional Supplementary Welfare Allowances are available for those with inadequate funds, these payments are not entitlements but subject to the discretion of the Health Boards and Community Welfare Officers. As a result, families in different areas were seen to have different experiences so that the outcome was often seen to be more due to good luck than a measured response to a person's needs. In such situations, the psychological distress caused by illness and poverty (Whelan, 1994) is amplified by the need to hustle for diet allowances, rent allowances, clothing allowances, back to school money etc., and by the unpredictability of the response. In addition to the financial implications if these negotiations are unsuccessful, there are further difficulties for families who wish to keep their status private.

In their study of people living with HIV/AIDS, Murphy Lawless and Redmond (1993) identified the need for a package of entitlements to come on stream once HIV was diagnosed rather than having to seek them on a piecemeal basis. In the intervening years since that study was completed this has still not happened and HIV positive people like Sally continue to experience difficulties in claiming allowances:

There's no streamlining so that once you test positive or you get to a certain stage right you're told okay, you're entitled to x, y and z. You do this, this and this. You have to literally you've to find out somewhere else and then go and ask them. They don't, your community welfare officer doesn't sit down and tell you. If you go in and disclose you're positive and you do have to for these allowances they don't say right okay you're entitled to x, y, z. Like I mean it was a good few months before I knew about the diet allowance. I found out so many things by chance and you really do need your extra stuff but the stress you have to go through finding out what you're entitled to and then back in to get them. There's so much that you've to go through that it's really bad for you.

The frustration of dealing with such an unpredictable system was noted again and again by the interview respondents:

The community welfare has an awful lot of power and particularly when it's supplementary welfare benefits and it's wrong. I was refused by one welfare officer my clothing allowance, initially you got a clothing allowance every year regardless of whether you were positive and you're unemployed. Sixty pounds for the year -because you're on the dole and you can't afford to buy clothes right but I mean particularly again being HIV positive it would be doubly important not to get cold and have holes in your shoes and stuff. But they tightened up on that and you now have to, when you apply, it's not automatic, it used to be you just used to get it once a year. You need to bring a letter stating why so I got a letter from the hospital saying I'm HIV positive, Stage IV, and because of my health you know whatever and that. I was turned down... they've too much power. All the decisions are at their discretion and that's their answer. It's at their discretion so in some places, people can have a good community welfare officer.

Going to the relieving officer, he'd give me clothes and that every Christmas but I don't think I'll get it this Christmas because he's not there. The fella that's supposed to be over

there now is very, and why do you need this, and why do you need that so I won't get that this Christmas. I used to get sixty and I think it was another sixty then for the kids and thirty pound each for the kids which is not very much but I know it's something that will help you know, at the same time.

Ironically, the improved health of many HIV positive people due to the new treatments available, hinders their ability to claim some allowances such as the diet allowance of £27 fortnightly. As Julie described:

For a long time I didn't feel I could work and I was just on the dole and I got my diet allowance straight away. Now they've tightened up very much on the diet allowance, their argument is well unless you're Stage IV or your T Cells are under 200 you don't get a diet allowance. The point is that it's really important for people with HIV to stay healthy and stay well and have a good diet. So I mean you need your diet allowance when you're well as well as when you get sick to stop you getting sick ... you have to get a letter from your hospital you've to bring a letter from the dietician right. So you go to the hospital and say my welfare officer wants a letter saying that I need the diet allowance and most of the time if you're symptomatic what they put down is high protein, high carbohydrate although again and you bring that back to the welfare officer and they make a decision then on the amount. Like that's another thing that puzzles me, I would have thought there's a standard amount. The amount seems to vary hugely from area to area as to what that amount actually is.

People's improved health had also implications for continuing on the disability allowance. There was a concern that if people tried to return to work, they would lose their disability allowance, yet they were unsure if, healthwise, they would be able to hold down a job in the long-term, in which case it may not be possible to access the disability allowance again. This quandary was described by one HIV positive person as:

The disability allowance is permanent unless, if I go back into full time employment I have to come off it. Now that's a thing I'm a bit scared about because I don't know how difficult it's going to be to get back on it and I know that's an issue for a lot of people. Like I'm well now I'd like to work again full time or whatever but I may get sick again you don't know.

However, while unemployment rates continue to fall, it is unlikely that people who are HIV positive will be able to take advantage of the new job opportunities, even if their health allows. Many HIV positive people have been out of the jobs market for a number of years, but because of their positive status are unable to access many of the employment training schemes. In the event of securing a job, there is a concern over the need to disclose one's status to an employer in order to have time off to attend clinics etc. Therefore, people who are HIV positive appear destined to remain excluded from the labour market as long as the current situation remains.

In circumstances of long-term exclusion from the labour market and in the absence of sufficient state support, charities, such as the St Vincent de Paul, were relied on for assistance as some of the families described:

Vincent's would call around to have a chat every week and they would bring around vouchers, bottled gas, bag of potatoes, vegetables and all and a tenner off your rent.

When Jimmys [husband] died, there was phone numbers all over the walls, wall paper torn off, horrible you know, no lino on the floor or anything and the Social Worker wrote to Gay Byrne and got me a hundred pound and I bought a load of paint out of it. It's marvellous what a bit of paint can do, the kids were delighted, the little bit of painting in the house cheered them up - it cheered me up too.

The reliance on supplementary allowances and charities to make ends meet, not to mention for additional expenses, is brought home most forcibly in the families' experiences of coping with the cost of past and/or future funerals, a particular difficulty when there's more than one positive person in the family. For Annie, whose husband was very ill, the cost of a funeral was one of many concerns:

We even priced a grave there last week - it was four hundred and seventy five pound. That's cheap now, it's heavy though. You can't even put a deposit on, you know what I mean you have to buy the whole lot... if I had the money I'd go up and give it do you know what I mean and I'd have that off my mind.

Both Brid and Mary had encountered huge financial difficulties over the cost of their husbands' funerals, even though they had kept the expenses to a minimum. Mary related her experience in this respect:

His funeral only cost me nine hundred and fifty pound. Now his family bought the grave. They made a collection because there's a lot of them and they knew I hadn't got any money. I went to X [funeral directors] he's the cheapest of the cheapest and he'll go through everything with you. Like you could say

well I don't want this but I want that. My husband got a fairly, good enough funeral, you know what I mean. I only had one car because his family had cars, there's no point in being left in debt.

Brid, similarly, had kept the funeral costs to a minimum, yet it took a number of years to pay off the bills:

I was saying to the social worker "what am I going to do?" and fair play to him now he told me each step to take, the funeral parlour, the arrangements, the whole lot. Keep it as low as possible you know, and that's the way I done it. It cost a thousand four hundred. Like Jesus that was another hard one, every allowance day throwing in fifty pound a month you know and then the Vincent de Paul paid two hundred pound for me - the community welfare, five hundred pounds. And it's terrible hard because I had two for confirmation and one for communion all in the one year. it took three years I think, was it two and a half years, to get rent and all that down, funeral bills and everything you know.

Families who had taken out life insurance, found the insurance companies unwilling to pay when the death was AIDS related. Cathy experienced such a situation, and even though she is HIV negative, she encountered difficulty with her own insurance because of her family circumstances:

Now I had my husband insured but after eighteen months after he died. I had to fight it but I still got nothing because they went back on his records and found out that he had attended Jervis Street Hospital in 1981 so I got nothing ... I went to the Ombudsman and all about the insurance. No you see when my husband signed the form there's a question on it, did you ever take illegal drugs or I may not have the exact wording and he said no and they went back on his records. So, I'm very wary of insurance now and that. I got out of that insurance company and went to another insurance company about two years ago, three years ago and I had to go for a full medical, for myself and I'm only insured for five thousand pound because I'm seen to be at risk.

The difficulty of accessing insurance and mortgages also impacted on more financially secure families, as Joe and Tony described:

I had about five grand in the bank. You know, about twelve years ago ... and I spent it all and I gave it away ... if I hadn't got HIV I would have been thinking about investing it for a house or something around that time ... but the insurance wouldn't give me a mortgage so I never really pushed myself in that direction ...I should have lied. I should have gone for the mortgage and lied you know about it, but then if I'd, say if I died, they'd probably take the house off my wife.

There's the other things like the economic things about buying a house and insurance. Like I never took out a pension, you know I should have fucking taken out a pension twelve years ago in the job. I would have had twelve years of it now but I never took out things like that. I never sort of planned for the future at all. You never think, plan for next year or you know it'd be always just fruitless.

HOUSING

In addition to financial difficulties, accessing housing was a major issue for a number of the individuals/families interviewed. The current shortage of public housing and high rents for private accommodation impact especially on the economically vulnerable. As David described:

Housing is the greatest concern/or a lot of people you know. There have been a lot of people who have been, not so much dumped out on the street but you know the lease had come to an end and it hadn't been renewed you know. Or people who had just moved back home again you know. Their independence then was like completely taken away you know and they wanted to get back out, get their own flat, do whatever.

Members from four of the nineteen families participating in this research study had experienced homelessness since their HIV positive diagnosis. Some had experienced periods living in hostels and Bed and Breakfasts, where regulation regarding having to leave the accommodation during the day and the lack of cooking facilities had adverse effects on their health. Many others experience living in unsuitable accommodation, such as Carol who is sharing her mothers house while trying to secure a house from the local authority for her own family:

I'm living with my mother and she has my sister's three children that she left behind, you know, she died. And there's

my brother that has the virus as well in the house. Like there's a couple of us, in the house you know what I mean and it's only a two bedroom. And it's a small two bedroom.

And Sally, who recalled:

I'd lived in a horrible bedsit for a whole year. It was just tiny and damp and so it was really awful... like so much of how well you are has to do with your psychological well being and if you're inadequately housed it's such a big issue and it does affect your life.

However, the escalating costs of private rented accommodation places most of this type of housing outside the reach of those dependent on Rent Allowances, as Jean found:

I've been looking around for to rent somewhere, it's just too expensive and again to get a proper rent allowance ...if you're on the dole or on disability you're getting seventy two pounds a week. If you've to put twenty five of that towards your rent on top of you know everything else, I mean really that could be just for something grotty you know and you need like somewhere halfway decent.

Nonetheless, accessing public housing required a struggle similar to that encountered in accessing other welfare benefits, as Julie related:

There's really a shortage of housing and I mean I know people who were positive and they were, okay maybe they 're still using but they 're staying in hostels and that and how can you look after yourself. It's very inadequate. I'd to go through an awful lot of harassing and phoning and hassling and literally that's what people who have got housed said to me 'to get it you have to hassle, hassle, hassle'. But what that takes out of you as a person you know. So I was very, very lucky as I say. I got that housing and that's given me a feeling of security as well... Now I was very lucky but... it's got one open fire place in the sitting room. Now I'm putting in an application form for, there are a bit, there's no special grant for heating. I asked them about this, there's a loan facility thing you can take out but I don't want to take out a loan. I found out by hassling and hassling that there is a disabled person's home improvement grant. They never told me about that but even though I'm saying I'm not well, I need the heating. So what I've basically tried to do now is see will they put heating in for me or give me an allowance/or that. But like they housed me but they put me in a house with no heating you know what I mean. But like that sounds dreadful I'm delighted to get it but even on that score, like it's not adequate housing. It's not adequately heated you know.

Additional complications have arisen for HIV positive individuals and families since the introduction of the Housing Act (1997) which allows for the eviction from, or refusal of, local authority housing to persons engaging in 'anti-social behaviour'. While primarily aimed at curtailing the activities of drug dealers, Kelly (1997) notes that the loose definition of the term 'anti-social behaviour' includes a wide range of behaviour that may or may not be related to drug dealing. For HIV positive people the provisions in the Housing Act are a cause of concern in that it provides potential for further discrimination in that their positive status, which implies a history of behaviour that is perceived as anti-social (e.g. drug use and/or a homosexuality), could hinder them accessing local authority housing.

Carol, who is a HIV positive drug user, experienced numerous refusals from tenant selection committees, as she explained:

I have seventy odd points and that's for over crowding you know what I mean and I still can't get anything... and there's nothing but flats empty around me you know and houses ...I was thinking that it was because of my drug use that I'm not getting anything and that's being out straight because when I did go for a few, tried a few places and they said what drug unit are you attending you know and how long are you on it and that and they said I wasn't on it long enough and I was misusing and that.

And even for those who are not, or are no longer, drug users, being HIV positive leads selection committees to presume that they are:

You have to disclose you're positive and again that's a risky thing to do as well. Cos I thought it would go in my favour. It only occurred to me, in fact it was pointed out to me that possibly because of people's attitudes to HIV "ah you're positive, you must be a drug user" and they don't want drug users in their community.

CONCLUSION

The association between HIV/AIDS and many aspects of social exclusion - isolation, discrimination, income inadequacy and housing need - highlights how the social aspects of HIV/AIDS need to be tackled in a more holistic way by both the statutory and voluntary sectors. The final section of this report, focuses on the issues identified by this research study which must be tackled if the situation of families affected by HIV/AIDS is to improve.



SECTION 5

RESEARCH FINDINGS: IMPLICATIONS FOR PRACTICE AND POLICY

THE EPIDEMIOLOGY OF HIV/AIDS

In Ireland, our understanding of the epidemiology of HIV/AIDS (that is its prevalence and distribution in the population), as well as the numbers of people who have been affected by HIV/AIDS, is restricted by the lack of appropriate research data.

Given the deficiency of HIV data, it is difficult to make a grounded appraisal of current and future trends in HIV transmission. Advances in the treatment of HIV/AIDS and the decrease in the number of new AIDS cases recorded, have contributed to the declined prominence of HIV/AIDS on the public health agenda. Yet, this reduced prominence seems misplaced when the number of new HIV cases continues to rise and the full extent of HIV in the population remains unknown.

While the size of the HIV positive population anticipated in the 1980s has not materialised, trends in HIV epidemiology and indicators of HIV risk behaviour illustrate that there is little room for complacency with regards to the future prevalence of HIV. Consequently, there is an urgent need to reinstate HIV/AIDS on the public health agenda.

The practice of designating a particular risk behaviour as responsible for transmitting the virus in cases where a person engages in a number of risk behaviours, for example, both sharing injecting apparatus and engaging in unsafe sex, needs to be reviewed so as the risk relating to unsafe sexual behaviour is not underestimated.

Extensive empirical research of HIV risk behaviour, particularly sexual risk behaviour, needs to be conducted in order to provide a grounded basis for health promotion and harm reduction campaigns and to assist in the assessment of future trends in HIV/AIDS.

ISSUES FOR FAMILIES

In the absence of adequate public information campaigns to counteract misinformation and promote a grounded awareness of HIV risk behaviour, HIV and AIDS continues to be widely viewed with prejudice, fear and ignorance. As a result, HIV positive people and their families live with the stigma and secrecy that surrounds this disease. Children from such families were identified as being in particularly vulnerable situations.

For families affected by HIV, their experience of prejudice was an intolerable addition to an already difficult situation. One by-product of this experience was an intense concern that their HIV status remain private and confidential.

Disclosing a HIV positive status involves making a judgement call as to how that person is likely to react. Many people found this prospect too overwhelming, deciding instead to keep 'the secret' within the family. As a result many HIV positive people and their families are isolated from their extended families and their J communities. In such circumstances, HIV is truly a lonely disease.

Disclosing to children who are themselves HIV positive was seen to present a particularly difficult problem for parents and carers. Parents felt pressurised to tell their children about their status and to inform their child's school of the situation. But, most parents are reluctant to do this, fearing their child will be ostracised

The focus of support services on the positive person, unwittingly left many negative partners feeling isolated and alone. For families living in rural areas, their distance from services made their isolation even more pronounced. A shortage of child care also resulted in parents difficulties in attending support services.

Peer support was particularly favoured by parents, partners and carers of positive people, who found meeting others an opportunity to pool experiences and coping strategies, as well as accessing emotional support.

The constant supervision of a positive child's routine places many restrictions on the lifestyles of parents and carers. In such families, working outside the home, attending clinics and support services, even nights out are problematic, as child care is almost impossible to access and even more so if medication needs to be given or a child is ill. The lack of appropriate child care is a major concern for families affected by HIV/AIDS, particularly as the support of the extended family is often unavailable because of the families' wish to keep their children's status private.

Coming to terms with the death of a young partner and having to cope alone with a young

family is difficult to bear, particularly when the bereavement process is exacerbated by the stigma surrounding the illness. Yet, for many of the families support soon disappeared afterwards, even though the grief and isolation continue.

In addition to coping with their own grief, parents have to deal with their children's feelings, from telling them of a parent's death, to supporting them through the funeral and helping them to cope with the aftermath.

For those people who have been, and continue to be, affected by HIV, combating the stigma associated with HIV is of the utmost priority. Both statutory and voluntary agencies need to adopt a more proactive approach towards de-sensationalising HIV/AIDS and combating the prejudices and misinformation that are associated with this illness.

An ongoing public information campaign focusing on the provision of factual information about the nature and transmission of HIV would help in alleviating the stigma associated with this illness, as well as assist in preventing future transmissions.

Once diagnosed, individuals and their families, should have access to an ongoing continuum of care with regards to emotional and practical support. For example, with regard to issues concerning disclosure, transmission risks, testing of family members, child care, health and welfare entitlements etc. A key aspect of such support should be the role peers (that is persons affected by HIV/AIDS) play in its provision.

A pool of mobile support workers, trained in dealing with HIV/AIDS issues and available to work with families in their homes providing home help, child care, respite care and counselling would be appropriate. This form of support would be particularly beneficial for isolated rural families and families from ethnic minority groups.

As demonstrated by the research study, children affected by HIV/AIDS, both those who are positive themselves and those with a positive family member, are in particular need of ongoing support. With many of the HIV positive children now reaching their teenage years they will require particular support in coming to terms with their positive status and its implications for their health and sexual behaviour. Children also need support to cope with the stigma and prejudice they experience, with behavioural issues that may arise, and in coming to terms with a bereavement in a family.

The adoption of standardised policies with regard to HIV in all schools, youth clubs and services to young people and the implementation of appropriate health and safety procedures would help alleviate some of the concerns of parents and carers of positive children.

One of the key issues in supporting families affected by HIV/AIDS is their concern that their anonymity will be preserved. Consequently, HIV/AIDS services need to create safe places where people can meet and support each other. Technological innovations regarding the establishment of protected Internet sites should be explored as a possible space for families to network while preserving their anonymity and linking geographically isolated families.

Within the last few years, the availability of anti-retroviral drugs has radically altered the

prognosis of HIV, and led to a greatly improved health and life expectancy for those diagnosed positive. Nonetheless, complying with the treatment regime proves a hugely difficult and emotive issue for positive adults and children and their families. The adverse side-effects of the medication and the frustrations experienced regarding their lack of involvement in treatment decisions were extremely difficult issues for patients, parents and carers.

The complexity of the treatment presents problems for health professionals to provide the necessary information in an accessible form. However, failure to do so was seen to have far reaching repercussions, particularly when this was accompanied by a patient's difficulty in adhering to the treatment regime, in such cases the likelihood of the patient taking a 'drug holiday' was increased.

In addition to accessible information, the need for information specifically geared towards the needs of homosexual men, women, and ethnic minorities, was identified.

Patients from rural areas, those who are working and/or caring for young children had particular difficulties attending the clinic. In addition to the practical difficulties encountered in attending the clinics, patients found the clinical setting and its hierarchical structure extremely alienating. Families were frustrated that their efforts to inform themselves and their concerns over treatment were often dismissed. The vulnerability experienced by people in treatment was further amplified by their concerns over the long term effects of the medication and its possible failure.

With regards to the clinical treatment of HIV/AIDS, patients expressed a frustration with the didactic approach taken by clinics, and anxiety about the difficulties in complying with onerous treatment regimes. Consequently, clinics need to consider how patients, parents and carers can become more involved in their care management. The introduction of a patient's charter and/or a patient-staff forum would assist in clarifying issues for both patients and clinicians alike. Information regarding treatment updates and options should be made available in a manner which is accessible to clients and which addresses the concerns of different groups e.g. women, homosexual men. Patients, for whom English is not their first language, require translated material and an approach which is culturally sensitive.

HIV/AIDS AND SOCIAL EXCLUSION

In Ireland, the association between HIV/AIDS and social exclusion is two-fold. In the first instance, HIV/AIDS is seen to have disproportionately affected people from marginalised, socially excluded communities. And, in the second instance, many individuals and families have become socially excluded through their experience of HIV/AIDS.

For the vast majority (81%) of the individuals and families included in this study, welfare payments are the main source of income. The income inadequacy experienced by people dependent on welfare payments, particularly in the long-term, has been noted. Indeed long-term welfare dependants have been identified as being at an exceptionally high risk of poverty

and social exclusion.

Children from such households are at a particularly high risk of poverty. In addition, these children also experience social exclusion in that they are unable to participate in the extra-curricular activities regarded as essential for their healthy development.

While additional Supplementary Welfare Allowances are available for those with inadequate funds, these payments are not entitlements but subject to the discretion of the Health Boards and Community Welfare Officers. The psychological distress caused by illness and poverty is amplified by the need to hustle for diet allowances, rent allowances, clothing allowances, back to school money etc., and by the unpredictability of the response. In addition to the financial implications if these negotiations are unsuccessful, there are further difficulties for families who wish to keep their HIV status private.

Ironically, the improved health of many HIV positive people due to the new treatments available, hinders their ability to claim some allowances, such as the diet allowance, and also has implications for their continued eligibility for disability payments. Yet, most positive people, and those providing HIV/AIDS services, remain apprehensive as to the long term outcome of the new medication.

In addition to financial difficulties, accessing housing was a major issue for a number of the individuals/families interviewed. The current shortage of public housing and high rents for private accommodation impact especially on the economically vulnerable, and places much of this type of housing outside the reach of those dependent on Rent Allowances.

Members from four of the nineteen families participating in this research study had experienced homelessness since their HIV positive diagnosis. Some had experienced periods living in hostels and Bed and Breakfasts, others were in unsuitable often overcrowded accommodation. Accessing public housing required a struggle similar to that encountered in accessing other welfare benefits. Additional complications have arisen for HIV positive individuals and families since the introduction of the Housing Act (1997). For HIV positive people the provisions in the Act are a cause of concern in that their positive status is perceived by many to imply a history of anti-social behaviour and could discriminate against their accessing local authority housing.

The association between HIV/AIDS and many aspects of social exclusion - isolation, discrimination, income inadequacy and housing need - highlights how the social aspects of HIV/AIDS need to be tackled in a more holistic way by both the statutory and voluntary sectors if the situation of families affected by HIV/AIDS is to improve.

Voluntary organisations providing support to families and individuals affected by HIV/AIDS should play a more active role in campaigning for such policy changes

To date, HIV/AIDS policy and service provision has been regulated by the Department of Health, and the Drugs Service of the Eastern Health Board. Notwithstanding the

health and medical implications of HIV/AIDS, and its relationship to intravenous drug use, there is a compelling need for a broader and more integrated response to tackle the social aspects of HIV/AIDS.

Tackling the needs of such families affected by HIV/AIDS requires a co-ordinated approach by a range of statutory and voluntary services and government departments such as Health (especially Health Promotion regarding safe sex campaigns); Social, Community and Family Affairs; Local Authorities (regarding the provision of housing); Health Boards (regarding Supplementary Welfare Allowances); Education and Employment (regarding Health and Safety regulations, and training and work opportunities) etc. The relevant departments should at a minimum be represented on the National AIDS Strategy Committee.

Existing policy mechanisms such as the National Anti-Poverty Strategy (NAPS), the Cabinet Sub-Committee on Social Exclusion, the Family and Community Resource Centres advocated by the Report of the Commission on the Family, and the local Drug Task Forces provide suitable sites for implementing strategies that address the broader needs of families affected by HIV/AIDS.

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Appendix 1

MEMBERS OF THE RESEARCH ADVISORY COMMITTEE

Paddy Connolly	Cairde
Mary O'Neill	The Women's Health Project
Linda Reid	Women & HIV Project, Dublin AIDS Alliance
Stephen Rourke	Research Consultant;
David Silke	Combat Poverty Agency

Appendix 2

VOLUNTARY AND STATUTORY PERSONNEL INTERVIEWED

Bill Foley & Marie Kilty	Infectious Diseases Clinic, Mater Hospital
Brogan Whittle	Aisling Clinic, Cherry Orchard
David Wyse	City Clinic, Amiens St.
Dr Catherine Comiskey	Maynooth University
Dr Patrick O'Sullivan	EHB HIV/AIDS Co-ordinator
Dr. Jo Barry	EHB Drugs, HIV and AIDS Programme
Dr. John Williams	Poz Ireland
Eileen Smith,	
Rachel Roche, Jazz Brack	Cairde
Erin Nugent	Dublin AIDS Alliance
Fr Paddy McGrath,	
Michael Dredge	AIDS Fund Housing Project
Jacinta McGrath	Open Heart House
Kieran Rose	Gay HIV Strategies
Linda Reid	Women & HIV Project, DAA
Maeve Foreman	Haemophiliac Unit, St. James' Hospital
Mary O'Neill	Women's Health Project
Mick Quinlan	Gay Men's Health Project
Rita Travers	Our Lady's Hospital for Sick Children,
Crumlin	

Social Work Team

Dr Karina Butler

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Dr Fiona Mulcahy

GUM Clinic, St James' Hospital

Our Lady's Hospital for Sick Children,

St James' Hospital

Appendix 3

POLICY SEMINAR WORKSHOPS AND THEMES

The Emotional Impact of HIV/AIDS

- Coming to terms with a positive diagnosis
- Fear of positive status being known
- Coping with reactions to positive status (from friends, family, workplace, and community)
- Coping with discrimination and homophobia
- Learning to live with an unpredictable and chronic illness
- Families isolated from their community by their need to keep their status secret
- Families divided by secrecy
- The isolation of rural and ethnic minority families affected by HIV/AIDS
- Coping with partner's/child's sexuality and/or drug taking behaviour
- Coping with long-term illness and possible death within the family
- Relationship difficulties when a partner is positive
- Fear of transmitting/contracting the virus

SUPPORT NEEDS

- Accessible HIV/AIDS information
- Opportunity to talk with other positive families
- Advice about social services and benefits entitlements
- Sufficient money to meet needs
- Adequate and appropriate housing
- Disclosing to positive children
- Disclosing to children of family member's positive status
- On-going support for children living in families affected by HIV/AIDS
- Practical help e.g. home help & child minding by carers familiar with HIV issues to relieve families under stress
- Long-term and short-term child care arrangements when needed
- On-going bereavement counselling for parents; partners and children
- Advice and financial assistance with making funeral arrangements.
- Support for pregnant women being routinely tested for HIV
- Information on safe sexual behaviour

Health/Treatment Issues

- Insufficient information regarding treatment
- Inaccessible information regarding treatment
- Little opportunity for involvement in decision-making regarding treatment
- Anxiety about starting triple therapy treatment
- Anxiety about adhering to the treatment
- Anxiety about the (long-term) effects of treatment
- Anxiety about treatment failure
- The lack of HIV/AIDS awareness by health professionals outside the HIV/AIDS field
- More accessible opening hours for clinics

- Respite care with facilities for children
- Health impact of Hepatitis C on people who are positive
- Maternal Transmission