

The Experiences of Families Seeking Support in Coping with Heroin Use



NACD

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The Experiences of Families Seeking Support in Coping with Heroin Use

Dr Carmel Duggan

April 2007



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Foreword Minister of State

I welcome this latest report, "The Experiences of Families Seeking Support in Coping with Heroin Use", from the National Advisory Committee on Drugs.

I have long been of the opinion that families of problem drug users need and deserve support in dealing with the problems that they encounter. This issue is reflected in Action 108 of the National Drugs Strategy, which was an addition to the Strategy arising from the Mid-term Review in 2005.

At the same time, as stressed in the recent deliberations of the Working Group on Drugs Rehabilitation, families of problem drug users can have the potential to be key to the rehabilitative effort. However, they are not always adequately involved in the treatment/rehabilitation of family members. In particular, as many problem drug users live in the family home, I feel that families should be seen as partners in the majority of situations and be centrally involved in the recovery process.

The study examined the experiences of families seeking support to cope with heroin use and I broadly welcome the recommendations arising. I have frequently indicated an openness to examining proposals regarding support for families of problem drug users and this remains the case.

I would like to thank the families who participated in the research and the family support groups who played a central part in facilitating their involvement. I also acknowledge the work of the author, Dr. Carmel Duggan of WRC Social & Economic Consultants, the Research and Advisory Group who supported her work, and the National Advisory Committee on Drugs who commissioned the research.

Noel Ahern T.D.

Minister of State with Responsibility for the National Drugs Strategy

Foreword Chairperson NACD

In fulfilling the NACD's remit to advise Government about the consequences of problem drug taking, the Committee commissioned Dr Carmel Duggan to explore the experiences of families trying to cope with heroin use by a family member. In this way we hoped to develop an understanding of the consequences of drug use on the family in the same way that our recent "Community Study" report provided an insight into the impact of drugs on communities.

The research conducted so ably by Dr Duggan in 2005 and 2006 among families from inner city, suburban and provincial settings clearly demonstrates the role of the family in the treatment and rehabilitation of heroin users.

This report is essential reading for all those working with drug users in Ireland. It is a moving, indeed at times distressing account of the experiences of families from different backgrounds, rural/urban neighbourhoods and economic circumstances. Despite those differences, the seven stages through which families go when they are confronted by a family member using drugs is remarkably identical. What is also striking is the fact that once families receive information, education and support, their role changes from being that of a victim to one of being a carer, an advocate and agent of recovery. This is the most important lesson to be learned from this report.

The NACD is indebted to all the families who took part in the study, who gave of their time so freely and who willingly talked about what had happened to them, in order that Government might learn from their experiences.

As a result of the findings in this research, the NACD has made a number of recommendations to Government; that the role of the family be recognised and valued in the delivery of drug services; that interventions by a specialist worker for families be provided irrespective of how the drug using member is doing; that information on where to go for help, what to expect and how to cope with addiction be made available and as part of this, that key workers also be assigned to families to assist with the interface across fragmented services and finally, that a national body be established to which family support groups could affiliate and from which best practice guidelines would emerge.

On behalf of the NACD I would like to praise Dr Carmel Duggan for her work and thank the Research Advisory Group comprising Sadie Grace, Phillip Keegan both from the Family Support Network, Aileen Mooney from the Family Support Agency, Mary Ellen McCann and Mairéad Lyons from the NACD for the support and guidance they provided during the research. I wish to thank Barbara Connolly and Catherine Darmody for their work in proof reading the report and preparing it for publication.

Dr Des Corrigan

Chairperson

Acknowledgements

I am indebted to a great many people for their assistance and support in carrying out this research. Mairéad Lyons, Director of the NACD and the members of the Research Advisory Group (Sadie Grace, Phillip Keegan, Mary Ellen McCann, Aideen Mooney) provided valuable assistance at all stages of the research. Across the three study areas, personnel in community organisations, the Local Drugs Task Forces and the HSE were helpful and supportive. I am particularly indebted to the Family Support groups in the three areas who arranged access to families and facilitated the interviews. I am thankful also to Mick O’Broin who provided research assistance.

Above all, I am indebted to the mothers, fathers, wives and sisters who participated in this research. Through their honesty and integrity in sharing their very difficult and sad experiences, they have highlighted the problems facing families coping with heroin use. They deserve an adequate response.

Research Advisory Group

Ms Sadie Grace, Family Support Network

Mr Phillip Keegan, Family Support Network

Ms Mairead Lyons, NACD

Dr Mary Ellen McCann, NACD

Ms Aideen Mooney, Family Support Agency

Glossary

CDT	Community Drug Team
CJS	Criminal Justice System
DMRD	Drug Misuse Research Division of the Health Research Board
DTCB	Drug Treatment Centre Board
EMCDDA	European Monitoring Centre for Drugs and Drug Addiction
HRB	Health Research Board
HSE	Health Service Executive
LDTF	Local Drugs Task Force
MQI	Merchants Quay Ireland
NACD	National Advisory Committee on Drugs
NDS	National Drugs Strategy
NDST	National Drugs Strategy Team
RDTF	Regional Drugs Task Force

Executive Summary

Introduction to the Research

This study examined the experiences of families seeking support to cope with problem opiate use, and specifically heroin use, on the part of one or more family members. The overall objective of the study was to develop a greater understanding of the ways in which these families, and in particular the person in the family with the primary caring role, sought support, their expectations in doing so and their perception of the adequacy or effectiveness of the responses they received. The concept of support was broadly defined and included provision from the statutory, private or community sector that was accessed by families as they sought to respond to heroin use. It also included informal supports such as those provided by family, friends and neighbours.

The primary component of the methodology was in-depth interviews with the principal carer in thirty families, in three different locations, who were coping with problem heroin use, augmented by interviews with another family member in the case of seven families. The vast majority of those interviewed were parents (and mostly mothers), while a small number were siblings or partners of the drug user. Consequently the main focus of this study is on the experiences of the parents of the drug users in seeking support. For many of the families involved in the study, the problem of heroin use had emerged over fifteen years ago: for some of these families, the problem had been resolved, usually through the user abandoning heroin use: for others, the problem was ongoing at the time of the study. For the rest of the families, the problem was more recent, having emerged in the past eight years or less and all these families were still coping with the problem at the time of the study. This study, therefore, benefits from both a retrospective view of families using support services throughout the last decade and a half, together with a more contemporaneous perspective. From this it is clear that despite the developments in policy and provision over the last number of years, the contemporary experiences of families seeking support in coping with heroin use are not fundamentally different from those of families in the past.

Research Questions

The specific questions that the research sought to address were:

- What support (and where) has been sought by the family/family member?
- What were their expectations in seeking this support?
- What support has been the most/least helpful?
- What are the barriers to seeking support?
- What would help family members to cope?

In answering these questions, it is clear from the data that over the lengthy period in which they seek help, parents and other carers have extensive interaction with a wide range of supports, including support from their own informal networks, support from non-specialist or generic services and support from specialist drug services. It is also clear that the geography of coping with heroin use is both varied and extensive: informal supports tend to be local, generic or non-specialist supports also tend to be local, albeit somewhat less so, but the specialist supports were widely dispersed regionally and nationally. The study has also developed insights into issues such as the expectations of families in seeking support, the barriers they encountered in doing so and their assessment of the helpfulness or otherwise of different sources of support.

Families' Engagement with Heroin Use

In understanding the data reported here, it is necessary to situate it within the reality of the families' experiences, as articulated in their accounts of help seeking. From these accounts, it is clear firstly that coping with heroin use is a long-term problem, for the most part extending over fifteen years or more, and secondly, over this time period, families deployed different ways of engaging with the problem of heroin use on the part of a family member. These different ways of engagement have implications for how they respond internally to the problem of heroin use within the home and for how they interact externally with the support services.

This study identified seven different ways of engaging with heroin use on the part of family members. These were:

Unknowing (Ignorance, confusion and denial)

In the first instance, families were unable to recognise the existence of a heroin problem in their homes, either ignoring early telltale signs or attributing them to the problems of adolescence. This way of engaging (or really, non-engaging) lasted for many months until being brought to an end by the discovery of the problem, by which time it had taken a firm hold.

Coping alone

Once they discovered the problem, the predominant reaction on the part of parents was to attempt to cope with the issue themselves and not to seek external support. While this way of engaging was inevitably doomed to failure, it took parents many months to realise this during which time the negative impact of drug use on the user and on the family had intensified.

Desperately seeking help

Upon finally realising that they could not 'fix' the problem themselves, families embarked on a long and often desperate process of seeking support from both generic and specialist agencies. However, their lack of understanding of the problem they were dealing with, the manipulative behaviour of the user and the fragmented nature of the interface with the support agencies made it extremely difficult for the families to identify the type of help they needed or to seek out sources of support. Consequently, this experience of seeking help added to, rather than ameliorated, their burden of care.

Supported learning

Most of the families included in this study had eventually come to learn about the problem of heroin use – about the physical and psychological impact of the drug, about what to expect in terms of the drug users' behaviour and about how to engage more effectively with managing that behaviour. Once they had acquired this information, this tended to be a pivotal point for families in that they were able (with adequate support) to disengage from their previous ways of coping and move on to more effective and strategic ways of engaging with the problem of heroin use.

Reclaiming the family

Once they were equipped with information and personal support, families were able to develop new strategies of engaging with heroin use, within which separating the needs of the family and their own needs from those of the drug user featured largely. Families or parents began to disarticulate the family dynamic from the heroin dynamic and to address the wider family needs.

Supporting recovery

Subsequent to interrupting the dynamic of heroin use, families were better able to facilitate the drug user to make effective choices and to support them in implementing those choices. In this way of engaging, families were able, potentially, to reinforce the work of treatment centres and other agencies and to play a strategic role in supporting the process of recovery.

Contributing

Finally, a number of families who had progressed through the various stages of engaging had acquired sufficient expertise and experience to be in a position to give something back – to contribute to the response to problem drug use in their own communities.

Families' Engagement with Services

Many families recounted their experiences of these different ways of engaging in terms of a 'journey': from the early stages where they had insufficient information to recognise the existence of a problem to later stages where they could begin to engage more effectively and strategically with the drug user and even to contribute to supporting other families in their communities. While not an accurate metaphor, this 'journey' through the different ways of engagement also had implications for how families interacted with the support services: just as their way of engaging with the problem of heroin use became more strategic over time, so too (and directly linked to the former) their way of interacting with the support services also became more strategic. Three specific ways of interacting with the services were identified, reflecting three different roles of the family vis-a-vis the problem of heroin: victims, carers and agents of recovery.

- The retention of drug users in the family home means that the negative effects of drugs misuse is experienced not just by the users, but by the members of their families and by the family itself as it comes under stress and relationships become distorted. In effect, the family and the family-members of the drug user become co-victims, exposed to traumas that are at least equally problematic to those experienced by drug users themselves. Consequently, one aspect of the interaction of families with support services, is their involvement in seeking help for the difficulties they themselves experience.
- Secondly, the family, and particularly the primary carer, plays a significant role in caring for (or trying to care for) the drug user. This has a positive dimension for the drug user, in that basic needs for food and shelter are met and some of the extreme negative impacts of heroin use are ameliorated. The caring role also extends to finding help for the drug user and this is the second dimension of families' interaction with support services. However, this study clearly shows that in seeking support for the user, the family is often trapped between a lack of information on what help is available and how to access it, the manipulative and controlling behaviour of the user, and the complexity of current provision wherein a multiplicity of stand-alone agencies present a complex interface to families. The result is that help-seeking strategies tend to be both ineffective and inefficient.
- Finally, and in contrast to the above, the family can potentially play a positive role in facilitating the user into recovery and in supporting them through this and beyond. For this to happen, however, it is necessary for the family to be helped to help: helped to deal with their own problems, helped to understand the nature of the problem they are dealing with and helped to develop a strategy of

coping and caring that can at a minimum protect the family from the negative impact of heroin use and potentially support the user into recovery. In this respect, the family occupies a very specific position in relation to services for drug users – being, in effect an agent of recovery. This enables the family to work strategically alongside the treatment agencies and other specialist services and to reinforce the work of these agencies. However it appears that few opportunities are provided for families to actually play this role.

From the perspective of the health of users, the well-being of their families and the effectiveness of services, the most desirable situation is that families would be facilitated to engage strategically with the problem of heroin use in the home and interact strategically with support services as quickly as is possible. Currently, however, this is not the situation. Instead, it takes many years for families to reach a position where they can engage with the problem in a way that is effective both for themselves and for the user. While the passage of time itself can be a factor in helping families reach this stage it is not the only one. Of critical importance in enabling families to reach this stage, is the availability of relevant and accurate information on the problem of drug use and treatment options and the provision of ongoing support. Families cannot cure the problem of heroin addiction on the part of their loved one. But they can be helped to respond to the problem in a way that minimises damage to the family and facilitates supporting the user into recovery.

Recommendations

1 The needs of families coping with problem drug use should be addressed by recognising, valuing and resourcing the role of peer-led Family Support groups in assisting families in coping with heroin use.

- 1.1 Throughout the country, peer-led Family Support groups should be sufficiently well-resourced to provide families with the level and nature of support which they require. Resourcing of family support groups should include provision for the employment of **peer** support workers (who could be drawn from support group members) as well as provision for support, education, information and respite activities.
- 1.2 Family Support groups should be further resourced through funding networks and networking activities at local, regional and national levels, to reinforce, add value and facilitate shared learning and to promote common standards of good practice.
- 1.3 The value of Family Support in assisting families to cope with problem drug use and in facilitating them to support the user into recovery should be explicitly acknowledged within the continuum of care, and service providers in both generic and specialist services should, as part of their own good practice in responding to drug use, recommend family members to Family Support groups.
- 1.4 The value of Family Support should be recognised within the structures of the National Drugs Strategy (NDS), through the formal representation of local and regional Family Support networks in the Local and Regional Drugs Task Forces (L/RDTFs) and at national level through involvement in the National Drugs Strategy Team (NDST).

2 The burden of care on families arising from the lack of constancy of support to drug users should be addressed through the deployment of specialist personnel at local level to provide ongoing support to drug users and ongoing liaison with families.

2.1 Throughout the country, specialist personnel should be established at local level to work primarily with drug users but also, as appropriate, with their families. These locally-based specialist personnel would:

- (a) act as supports to, and advocates for, drug users in dealing with all medical, social and economic dimensions of their lives
- (b) liaise with the families of drug users on an ongoing basis.

2.2 Such specialist personnel should be a central dimension of responding to drug use at community level. They would work with the drug user, and as appropriate, in conjunction with the family, in developing personal maps to guide the transition into a heroin-free lifestyle, incorporating links into education, training and employment opportunities.

2.3 These personnel should be independent of any service provider within the treatment system and should be available to provide assistance and advice to the drug user and to liaise with their families on an ongoing basis, regardless of the treatment status of the drug user.

3 The problems encountered by families as a result of the fragmentation of provision and the problematic interface with the treatment system should be addressed by establishing formal links between family support groups and specialist personnel.

3.1 Formal links at local level should be established between the specialist personnel referred to in Recommendation 2 and Family Support groups/workers referred to in Recommendation 1. These links would ensure a comprehensive continuum of provision within which the needs of the user and those of the families are addressed.

3.2 Specialist personnel and family support groups/workers should also be active in promoting greater consultation, on an ongoing basis, between families and the treatment system in order to improve the interface between families and the range of service providers within the treatment system and to facilitate more effective involvement of families in supporting recovery.

3.3 There should be active consultation, on an ongoing basis, between these specialist personnel and Family Support groups/workers at local level and the structures of the NDS, RDTFs and the LDTFs regarding the development of community-based responses to heroin use, including greater exploration of drug-free responses.

4 The difficulties encountered by families arising from the inadequacy of support to families from the generic services should be addressed by developing codes of practice in relation to information provision.

4.1 All non-specialist providers – including GPs, counsellors, hospitals, youth services, schools etc – who come into contact with heroin users or their families should be provided with up-to-date and accurate information on the services available within the treatment system.

4.2 All service providers, both within the generic and specialist sectors, should, without compromise or prejudice to the delivery of their own services to drug users, inform drug users of the availability and role of the specialist personnel referred to in Recommendation 2.

4.3 All service providers, both within the generic and specialist sectors, should, without compromise or prejudice to the delivery of their own service to the family members of heroin users, inform families of the availability and role of family support groups.

5 In the ongoing development of responses to problem drug use, the spatial and social diversity that now exists in relation to patterns of heroin use should be acknowledged both within policy discourse and provisions.

5.1 Measures to create greater awareness of the prevalence of the threat of heroin use and the growing social diversity amongst those affected, should be implemented, with the specific objective of challenging existing stereotypes of heroin users, of families with heroin problems and of communities with heroin problems.

5.2 The provision of information and services to local communities throughout the country should anticipate rather than react to the emergence of problem drug use, with a particular focus on the transfer of identified best practice in relation to support for users and families.

5.3 It is also important to recognise and respond to the deep and complex problems that beset families and communities where a heroin problem has been endemic for generations. Adequate supports should be put in place for such families and communities to cope with the long-term consequences of heroin use: these include support for grandparents looking after their grandchildren and support for families caring for those with HIV or Hepatitis C.

Chapter 1

An Overview of the Issue

1.0 Introduction

This study examined the experiences of families seeking support to cope with problem opiate use, and specifically heroin use, on the part of one or more family members. The overall objective of the study was to develop greater understanding of the ways in which these families, and in particular the person in the family with the primary caring role, sought support, their expectations in doing so and their perception of the adequacy or effectiveness of the responses they received. The concept of support was broadly defined and included provision from the statutory, private or community sector that was accessed by families as they sought to respond to heroin use. It also included informal supports such as those provided by family, friends and neighbours.

It was estimated that in 2001, there were just under 14,500 heroin users in Ireland (Kelly *et al.*, 2003). A characteristic of heroin use in this country, as elsewhere, is the large proportion of users who live in their parental/family home. Data on almost 6,500 opiate users in treatment in Ireland in 2002 show that just over half were living in their family home at the time they were receiving treatment. If we can extrapolate from this data to the estimated total number of opiate users, and noting that some families have more than one user, then up to 7,500 families in Ireland are coping with a heroin user living in the family home. However, as periods in and out of the family home are characteristic of heroin users, over time the proportion of users who live intermittently with their families will be considerably greater and the number of families who have experience of coping with a heroin user in the family home will also be greater. Exploring how such families cope with the problem of heroin use, therefore, is both relevant and timely.

It is also timely to reassess the geography of the heroin problem in Ireland which has obvious implications for the provision of supports both for users and for their families. In the past, heroin use was largely confined to the working class communities of Dublin's inner city and disadvantaged suburbs. Now, there are clear indications that heroin use has broken free of the original and linked constraints of geography and class and has extended far beyond the disadvantaged urban communities in which it first took root. Between 1998 and 2002, for example, the proportion of all new cases seeking treatment that resided outside the Health Service Executive (HSE) Eastern Region increased from 4.4% to 21.5%. Similarly, in Co. Cavan, which has a predominantly rural population, the average annual incidence of treatment for an opiate as a main problem drug increased from 5.9 in 1998 to 10.3 in 2002 (DMRD, 2004^b). In effect, the socio-economic pattern of opiate use is now more heterogeneous, although this has not been fully reflected in public or policy discourse. Nor has it been fully addressed in research: the tendency for research into heroin use in Ireland has been to focus on disadvantaged urban communities. More recently, the link between disadvantage and heroin use has been intensified by the suggestion that even within disadvantaged areas, particular families are more prone than others to experiencing drug problems (Cullen, 2002). While Drug Misuse Research Division (DMRD) data indicate clearly that the highest levels of drug use are experienced in deprived areas, these data also show growing numbers of opiate users in areas that are not urban and/or do not correspond to the profile of urban disadvantage (DMRD, 2004^b). In this context, it is important to avoid an overemphasis on the links between urban deprivation and drug use while also acknowledging the specific and acute needs of deprived communities.

1.1 The Research Questions

The purpose of this study was to provide information on, and insight into the experiences of families coping with problem drug use in seeking support. The primary component of the methodology was in-depth interviews with the principal carer in thirty families coping with problem heroin use, augmented by interviews with another family member in the case of seven families. The vast majority of those interviewed were parents (and mostly mothers), while a small number were siblings or partners of the drug user. Consequently, the main focus of this study is on the experiences of the parents of the drug users in seeking support. For many of the families involved in the study, the problem of heroin use had emerged over fifteen years ago: for some of these families, the problem had been concluded, usually through the user abandoning heroin use: for others, the problem was ongoing at the time of the study. For the rest of the families, the problem was more recent, having emerged in the past eight years or less and all these families were still coping with the problem at the time of the study. This study, therefore, benefits from both a retrospective view of families using support services throughout the last decade and a half, together with a more contemporaneous perspective. From this, it is clear that despite the developments in policy and provision over the last number of years, the contemporary experiences of families seeking support in coping with heroin use are not fundamentally different from those of families in the past.

Specific questions that the research sought to address were:

- What support (and where) has been sought by the family/family member?
- What were their expectations in seeking this support?
- What support has been the most/least helpful?
- What are the barriers to seeking support?
- What would help family members to cope?

1.2 Structure of the Report

This report documents the research and its findings and makes recommendations for policy based on these findings.

Chapter 2 provides an overview of the context for the study. It looks at recent trends in treated heroin use in Ireland, it presents key findings on the impact of heroin on families from international and Irish research, it looks at the sources from which families sought support and it highlights the most relevant dimensions of the contemporary policy context in Ireland.

Chapter 3 provides information on the methodology for the study and highlights some of the research issues which arose. In particular, this chapter notes the need to reassess the implicit concepts in the research questions given the findings of the study.

Chapter 4 provides information on the localities within which the research was undertaken, it presents an overview of the families interviewed and highlights the main characteristics of the drug users in these families. This chapter also presents an overview of the range of supports accessed by families.

Chapter 5 looks in detail at how families engaged with the problem of heroin use. The various ways of engaging noted above are discussed and the implications for interaction with the support services highlighted. This chapter draws heavily on the direct voices of the families and direct quotations are used extensively in the discussion. The quotations in this section were selected on the basis of their representativeness of the views of families. When a minority view is being expressed, this is made clear.

Chapter 6 discusses more specifically the experience of families in interacting with the range of support services they accessed, it explores their views on the adequacy or otherwise of these services, it looks at the barriers to accessing the services which existed and it notes the views of families on what types of supports would have assisted them.

Chapter 7 summarises the main findings of the research, highlights some key considerations and presents the recommendations.

Chapter 2

Heroin Use, the Family and Support Services in Ireland

2.0 Introduction

This Chapter sets out the main parameters of the context for this study. It looks at contemporary trends in treating heroin use in Ireland, overviews Irish and international literature on the impact of heroin use on families, provides a classification of the sources of support to which families turned in responding to heroin use and highlights the most relevant aspects of the policy framework as it impinges on these.

2.1 Contemporary Trends in Treated Opiate Use in Ireland

Opiate use has been problematic in Ireland since the early 1980s, when the first heroin epidemics occurred in Dublin's inner city, with profound consequences for users, their families and their communities. The effects of this are still discernable, evident in problems such as second and even third generation drug use and the orphaning of children through drug-related deaths. The first national estimate of opiate use was conducted by the NACD in 2003 and indicated that in 2001, there were 14,452 opiate users in Ireland of which 12,456 were in Dublin (Kelly *et al.*, 2003). Current data, based on the numbers in treatment, show that the highest prevalence of opiate use continues to be in Dublin and continues to be clustered in areas of socio-economic disadvantage (DMRD, 2004^a). However, it is also clear that the problem of opiate use is spreading out to other areas: treatment data reveals a steady rise in the use of opiates outside of the Dublin area and even outside of urban areas (DMRD, 2004^b).

Since 1998, the number of heroin users on methadone programmes has increased dramatically and now roughly half of the estimated total of all users are on methadone programmes. Ongoing data collection at treatment centres allows a number of trends to be discerned in relation to those in treatment, including patterns of drug use, the socio-economic profiles of users, and the incidence of drug use in different areas. (In regard to the latter, it should be noted that this data is compiled on the basis of where users are living at the time of treatment, not on the basis of where the problem originated.) The following provides an overview of the key features of the current situation based on the treatment data:

Numbers seeking treatment for opiate use is increasing

National treatment figures show that the incidence (i.e., number of new cases) of opiate users has increased four-fold from 2.0 per 100,000 of the population aged 15 – 64 in 1998 to 8.3 in 2002 (DMRD, 2004^c). There is also evidence that the proportion of drug users presenting for treatment for whom opiates is the main problem drug is also increasing (DMRD, 2005).

There is an increased chronic element discernible

The prevalence (i.e., all cases) of treated problem opiate use has also increased greatly over this period, from 6.6 per 100,000 in 1998 to 25.4 in 2002. An increase of this magnitude in the prevalence of opiate use is seen as indicating a chronic element requiring continued care or repeated treatment over time (DMRD, 2004^c).

Treated opiate use is greater in the Dublin Region

Data on treated problem drug use shows that between 1998 and 2002 the total number of people being treated for opiate use in the HSE Eastern Region increased from 4,652 to 5,921, but the number of new cases decreased from 912 to 648. The most likely explanation for this was suggested to be a real decrease in the number of new opiate users, rather than an inadequate number of places to treat new users (DMRD, 2004^a).

Highest levels of treated opiate use are in areas of disadvantage

An analysis of the treatment data by Local Drugs Task Force (LDTF) area shows considerable variation in the incidence of treated opiate use in the different LDTF areas as well as changes in incidence over time. In brief, between 1998 and 2002, the incidence of treated opiate use has almost halved in Ballymun, the Canal Communities and Ballyfermot, while it has increased slightly in Bray and Finglas/Cabra. Despite these decreases, in 2002 the highest incidence of opiate use occurs in Ballymun, the Canal Communities and Ballyfermot, as well as Clondalkin and the North and South Inner City (DMRD, 2004^a).

Opiate use is spreading to other areas

Outside of the Eastern Region, the trends are equally clear. Between 1998 and 2002 the total number who sought treatment for problem opiate use increased by almost 300%, from 132 cases in 1998 to 511 cases in 2002. In contrast to the trend in the Dublin region, the number of new cases seeking treatment also increased: from 42 to 178 (DMRD, 2004^b). By 2002 therefore, the proportion of all new cases coming forward for treatment in the country as a whole that resided outside the HSE Eastern Region increased from 4.4% to 21.5% (DMRD, 2004^b).

Rural areas are not immune

When the rate of increase is assessed in terms of population, the data shows very high rates of treated problem opiate use in counties which do not have major centres of population: Carlow, Cavan, Louth, Meath. In these counties the rate of increase in heroin use has been described as startlingly high (DMRD, 2004^b), and draws attention to the growing non-urban profile of contemporary opiate use.

Mode of administration changing

The number of injectors has increased over the 1998-2002 period in all regions (DMRD, 2004^c). In the Eastern Region, the total number of treated injectors who acknowledged sharing injecting equipment increased by 54%, from 2,127 in 1998 to 3,285 in 2002.

Polydrug use is a particular problem

Polydrug use remains widespread and has been shown to impede successful treatment for opiate use and, consequently, knowledge of polydrug use remains very important for the correct and comprehensive management of opiate users (DMRD, 2004^c).

Socio-economic profiles

Available data also highlight some socio-economic and demographic features of treated opiate users. Outside the HSE Eastern Region, the proportion of males increased from 66% in 1998 to 74% in 2002 while in the Eastern Region, two-thirds of those treated were male.

Outside the Eastern Region, early school-leaving was considerably more prevalent in 2002 (22.9%) than in 1998 (11.8%). Conversely, the proportion of those treated who were in employment had increased from 20.8% in 1998 to 28.2% in 2002. In the HSE Eastern Region, 29% of treated cases were early school-leavers and less than one-quarter were employed.

In the context of the current study, two issues highlighted by the data are particularly important. First is the considerable time lapse that exists between commencing opiate use and starting treatment. In the Eastern Region, data shows that while young people are most likely to commence opiate use in their mid-to-late-teens, they are unlikely to seek treatment until their early-to-mid twenties. Outside the Eastern Region, the time lapse between commencement of opiate use and seeking treatment increased from 3.5 years in 1999 to 3.8 years in 2002. This very significant time lapse in starting treatment is problematic in that the drug problem itself can escalate during this period (for example from smoking to injecting opiates) while the associated problems of crime, homelessness and exposure to health risks can also worsen: for example, studies have shown that after the first year of injecting, the likelihood of needle sharing increased (Mullen and Barry, 2001).

The second issue of note is the proportion of opiate users who live in the parental/family home. Outside of the Eastern Region, in 2002, a total of 38.6% of all treated cases were living with parents/family, an increase from the 1998 figure of 27.3%. Among new users, the proportion was even higher with 45.4% living with parents/family. In the Eastern Region, the proportion of all treated users living in the family home was higher still at 56% in 2002, although it had decreased from 66% in 1998. In this region, the trend was similar for both new and previously treated cases.

2.2 Heroin Use and the Family

Ireland is not unique in the high proportion of opiate users living in their family homes. This is a feature in many countries and consequently the impact of drug use on the families of users has received some attention in the international literature, and to a lesser extent in the Irish literature.

A number of major themes or focuses have dominated this research and there are some notable differences between Irish and international studies in this regard.

- The international literature tends to take a broad focus in relation to the issue of problem drug use, looking at substance misuse in general without differentiating between different types of drugs and sometimes including alcohol misuse in the analysis. In contrast, in the Irish literature, there has been a greater tendency to focus specifically on heroin use.
- In the international literature, the tendency has been to look at drug use on a broad geographical basis: in Ireland, there has been a predominant focus on drug use in disadvantaged inner city communities, particularly in Dublin.
- The international literature takes a narrow focus in relation to the impact of drug use on the family, with much of the research examining the effects on the children of substance-using parents. Where the impact on the parents or siblings of drug-using children is examined, there is a tendency to focus on the family as a unit, without differentiating between family members.
- To date, the impact of drug use on family members has not been a feature of research. However, one Irish study did focus on the parents of heroin users who are involved in raising their grandchildren, thus highlighting what has been referred to as a forgotten population.

- Most of the research has focused on families as victims of drug use (i.e., as experiencing negative consequences of having a drug-using member) or as clients of services either for themselves or for the users. More problematically, some of the early work on families and drug use tended to hold the family responsible for the drug problems of its members, a perspective that has not entirely disappeared according to Copollo (1999).
- Finally, viewing the family solely as victim, or worse, as cause of the drug problem has meant that research has ignored the issue of agency on the part of families and consequently little attention has been paid to the potential role of families in supporting the user into recovery.

2.2.1 Impact of heroin use on the family

Notwithstanding the sometimes different focuses and national contexts of research, studies from different countries indicate a very high level of consistency in the adverse effects experienced by the families of drug users and the international findings are echoed in Irish research. The problems experienced by families are diverse and complex but they have been usefully summarised by McDonald *et al.*, (2002) who, in a review of the literature, highlighted four key areas within which problems tend to occur. These areas were identified as:

- the physical and psychological health of families
- the financial and employment well-being of the family
- the wider social life of family members
- family relationships.

Physical and psychological impacts

The physical and psychological well-being of the family members has been consistently shown by studies to be very seriously compromised by the problem of drug use. A wide range of studies have also shown that stress, which can be severe and long-lasting, leads to higher physical and psychological morbidity of family members and results in an increased rate of primary care consultations (Dorn *et al.*, 1994, Svenson *et al.*, 1995). In what is widely considered to be a conservative estimate, Copollo *et al.*, (2000) have suggested that in the UK every problem drug user will have a significant negative impact on the well-being of two other family members such that they require primary care consultations. Extending that analysis solely to families dealing with heroin use in Ireland, would suggest that close to 30,000 family members require primary care consultations directly as a result of the problem.

For parents in particular, heightened negative emotions can lead to contradictory feelings towards the user and further contribute to the experience of stress (Salter and Clark, undated). So too does the experience of powerlessness on the part of the family. Barnard (2005) found that parents and siblings experience anxiety as they attempt to adapt to the impact of drugs on their lives and that this anxiety is greatly compounded by the sense of being powerless to alter the course of the drug problem. In the current study, examples of the negative physical and psychological impact of drug use were widespread both among parents and siblings of drug users.

Financial and employment effects

International studies have shown that financial pressures on families stem from a range of factors associated with problem drug use. These include the cost of treatment, repaying users' debts and remedying theft on the part of the user (Salter and Clark, undated; McDonald *et al.*, 2002). Some Irish studies have focused explicitly on the impact of heroin use in Dublin's inner city, where drug misuse is seen both to derive from, and reinforce, social exclusion. These studies have also highlighted the vicious cycle between poverty and heroin use and the additional impact on poor families of coping with a user (Murphy-Lawless, 2002).

These problems were evident in the current study, which was not confined to deprived areas. In addition, some families were under severe financial pressure as a result of buying heroin or methadone for the user, of curtailing their hours of employment due to stress or the need to be at home, and a small number experienced financial problems as a result of looking after the children of their own drug-using children. More generally, the long duration of the problem had a negative impact on the financial well-being of families over time.

The wider social life of family members

Studies have shown that the wider social life of family members of drug users become circumscribed by social isolation, withdrawal and by their attempts to conceal the problem. In addition, the problems of caring for the drug user also have an impact on the social life of family members (Salter and Clark, undated) and these problems are exacerbated by health and other problems associated with drug use on the part of the user.

All these issues were identified by families in the current study, but so too were additional problems arising from the users' involvement in criminal behaviour and consequent tensions with neighbours which also restricted social life. In addition, families caring for grandchildren had highly constrained social lives.

Family relationships

Deterioration in family relationships has been frequently identified as an impact of drug use, often exacerbated by an increased risk of domestic violence and by other problems such as alcohol abuse on the part of those coping with the drug use of other family members. The mix of anger, sadness, anxiety and shame on the part of family members has been noted, compounded by the sense of being powerless to alter the course of the drug problem (Barnard, 2005). Marital and family break-up have also been identified as well as problems deriving from conflicts and tensions within the family over the correct approach to dealing with the problem, the manipulative behaviour of the user and the overall imbalance which drug use introduces into the family (Salter and Clark, undated). Again, all these findings are echoed in the current study along with the significant impact on the lives of siblings and on inter-sibling and sibling-parental relationships.

The few studies that have looked at the impact of drug use on different family members rather than on the family as a whole have produced some notable findings. The extent to which different family members experience problems is dependent on a number of factors, including their role and position within the family, their gender and their relationship with the user (Salter and Clark, undated). Studies have shown, for example, that parents experience more shock and stress than siblings (Bancroft *et al.*, 2002), whereas partners are more likely to experience violence (Velleman *et al.*, 1993). A major source of difficulty for siblings is the extent to which the family preoccupation with

the user results in neglect of other children (Salter and Clark, undated; Barnard, 2005). In addition, significant family conflict between the drug user and siblings has been identified, particularly if the drug-using child was stealing goods and money from the family home while conversely siblings often lamented the loss of relations with their drug-using brother or sister (Barnard, 2005). Some research has also identified the risk of exposure to drug use on the part of siblings and the increased likelihood that younger brothers and sisters would themselves develop drug problems (Barnard, 2005). The latter study also noted that the apparent intractability of the drug problem had a profoundly negative effect on the dynamics and functioning of most families.

A further relevant finding is that role and position within the drug users families are not the same thing, with siblings often assuming a caring role (Bancroft *et al.*, 2002). There is also a growing recognition in the literature that the experiences of some family members are under-documented. In particular, grandparents have been identified as a hidden population (McDonald *et al.*, 2002). One Irish study of grandparents involved in caring for the children of their drug-using children (Family Support Network, 2004) identified a general sense of helplessness and isolation on their part.

While most of the negative impacts of having a heroin-using family member derive directly from the practice of drug use and the associated behaviours, other factors external to the drug user's behaviour have also been identified as causing stress to families. Three such stressors have been noted in the UK context. The first of these is the stigma associated with drug use. While studies have shown that the experience of stigma on the part of families varies quite considerably, it can add significantly to stress levels and, more problematically, can inhibit parents from seeking help or from sharing their experiences with others (Bancroft *et al.*, 2002).

The second stressor identified is the lack of information available to parents. This has been shown to be an important contributor to the stress experienced by families (Copollo *et al.*, 2000). Moreover, McDonald *et al.*, (2002) argue that much of the information that is available to families is from questionable sources such as the media.

The third major stressor was the treatment system for the user. Studies of families coping with substance misuse invariably indicate high levels of dissatisfaction with the treatment system. A major point of criticism was the long waiting lists for treatment which left parents with responsibility for caring for the user. This caused frustration for parents as often the substance misuse got progressively worse during the waiting period (Salter and Clark, undated).

2.2.2 Coping with heroin use

How families cope with problem drug use has been investigated in the international context with the focus on describing rather than explaining coping behaviours. In general, studies have described different coping strategies on the part of families, which can change or be changed over time. These strategies can include denial and secrecy: for example Barnard (2005) found that at the outset, families try to solve the drug users problem alone, without recourse to agencies. In a similar vein, Salter and Clark (undated) noted the tendency for families to try to hide the problem, adding to their own stress levels. In the Irish context, differences in the responses of mothers and fathers have also been noted (Family Support Network, 2002).

Orford *et al.*, (1998) describe coping strategies as falling into three broad types: engaged coping includes attempts by relatives to modify or control the substance misusers behaviour; tolerant or inactive coping involves actions which are accepting of the use, for example through making excuses for the user; withdrawal coping involves putting distance between the family member and the user. Studies have also indicated that different coping strategies have different implications for the well-being of the family (McDonald *et al.*, 2002; Orford *et al.*, 2001). For example tolerant-inactive coping is associated with feelings of worry, guilt and powerlessness and with negative physical and psychological symptoms for relatives (Orford *et al.*, 2001).

A more recent study that focused on the families of substance misusers (including alcohol) also found that families adopted a number of different methods of coping and that these changed or varied quite frequently over time. These different methods of coping ranged from avoiding, accepting or dealing with the problem; non-confrontational coping in which the family did not confront the user; active coping involved actively trying to do something to improve the situation, day-to-day coping referred to living with and coping with the problem one day at a time and finally, parents were shown to respond to the problem by attempting to attribute a cause to it (Salter and Clark, undated). Salter and Clark also found that the coping behaviours of family members were not always based on a particular strategy or approach but was a response to the day-to-day uncertainties associated with living with a drug user. In a similar vein, Velleman (1993) identified oscillation between coping strategies as a feature of families.

This present study too has identified different coping strategies or, more accurately, different ways of engaging with heroin use on the part of families. Some of these echo the findings of Orford *et al.*, and Salter and Clark in that different ways of engaging have different implications for the way families interact with the drug user and for the way families protect themselves from the negative consequences of the drug user's behaviour. However, the actual ways in which families in this study engaged with the problem of heroin indicate a progression over time from an initial strategy of trying to cope alone (echoing Barnard, and Salter and Clark) to one where they can strategically and effectively support the user into recovery.

Moreover, the findings of previous studies regarding the oscillation of families between coping strategies are not replicated in the current study: while day-to-day reactivism may characterise certain stages in coping behaviours, once parents are 'helped to help' they appear to be much more likely to become both consistent and strategic in their management of the heroin problem, to stop being co-victims and to become co-agents of recovery.

2.3 Sources of Support for Families

In looking at sources of support for families responding to problem drug use, it is important to acknowledge two features of the current situation. Firstly, in Ireland, the predominant focus of service provision in relation to drug misuse has been on drug users themselves with little provision directly targeted on the needs of families. In looking at families use of services therefore, the emphasis is mostly on families seeking support for the user, which in effect is also a form of support for themselves.

Secondly, and somewhat paradoxically given the above point, there is no consistency in the way the term 'family support' is used in the context of heroin use specifically or drug use generally. At the most precise level, the term is used to describe the work of peer groups (and sometimes individuals) which do provide support and assistance specifically for family members and specifically to help them deal more effectively with the problem of heroin use. This is a very specific usage of the term and in this study the term 'family support' is confined exclusively to describing this type of provision.

More generally, and depending on context, family support services can be understood to include a broad range of statutory, private and voluntary sector provision focused on providing services of various sorts to families. For example, McKeown (2000), in looking at the role of family support services in assisting vulnerable families, developed the following typology of support services:

- Home-based Parent and Family Support Programmes
- Child Development and Educational Interventions
- Community Development
- Youth Work
- Therapeutic Work
- Parent Education Programmes.

The current study, which is looking at how families responded to the actuality of heroin use, took a broad view of the concept of support and developed a categorisation based on the actual sources of support which families had contact with. Three distinct sources of support were identified:

- Informal sources of support such as those provided by personal networks of friends, family and neighbours
- Sources of professional support which are not specifically focused on drug issues. These include, for example, medical personnel, teachers and personnel within the criminal justice system. (These are referred to in this study as non-specialised supports, or following McKeown, generic supports.)
- Sources of specialised supports, that is supports provided by the statutory, private and voluntary sector that are exclusively focused on providing supports and services to drug users and/or their families.

This categorisation, together with the specific elements which comprise it and the sectors within which these are located, is presented in Table 1.

Table 1: Overview of sources of support to families

	Personal networks	Community & Voluntary	Statutory	Private
Informal supports	Family Friends Neighbours	Parish sisters and other local religious		
Non-specialised supports			Hospitals Schools Social Workers Gardaí Probation Officers	Hospitals General Practitioners Counsellors Psychologist
Specialised supports		Family Support groups Family Support workers Drug counsellors Treatment centres CDTs	Methadone clinics Drug counsellors	Treatment centres

In both the Irish and international context, research has shown that the sectors within which supports are provided can have a bearing on how families interact with them. For example, some studies have shown that families seeking support in dealing with problem drug use find it difficult to receive adequate support from the statutory agencies (Orford, 1998; Salter and Clark, undated). In the Irish context, the delivery of supports to families was explored by Watters and Byrne (2004) in their study of the role of support services in preventing drug use, which was commissioned and funded by the NACD. Their study found that while 65% of service providers surveyed felt they had a legitimate role in responding to their client's drug problems, only 40% felt they had the necessary skills and knowledge to respond adequately. Moreover, as noted earlier, UK research shows that the treatment system itself can add to the stress levels of families.

More generally, in terms of providing supports to families coping with adversity (including, but not exclusively drug-related problems) there is a body of evidence to suggest that community sector supports are crucial to meeting the needs of families and are often more easily assessed and more highly valued than are those provided within the statutory services framework. In a study of families coping with socio-economic disadvantage – broadly defined – families valued the support provided by community organisations more highly than other sources of support, including support provided by their personal networks of friends and families. One of the reasons for this was that community groups were seen to constitute a domain of support located between statutory services and personal networks, within which they provided a greater degree of empathy than was possible for statutory providers combined with a greater degree of objectivity than was possible for friends and family. An important conclusion from this study was that community groups complemented rather than replaced other sources of support (Duggan and Ronayne, 1991). This is an important finding in the context of this study and is returned to later.

Similarly, a study of grandparents in Dublin, who are caring for the children of their own drug-using or deceased children found that service provision and practice varied across geographic areas and across service providers. The result was an unevenness in access to information, entitlements and services on the part of grandparents. The grandparents often needed practical support but were unaware of where such support was available, if at all. The study also revealed that the most important and valuable sources of support for the grandparents were their family and peer support groups and local networks. Within this, the most important element of support was the availability of an advocate for individuals, which was seen as of immense personal value (Family Support Network, 2004).

It is not surprising in this context, that in Ireland, as elsewhere, community-based peer support groups are increasing in numbers or that their proliferation is seen as a direct response to the poor level of support for families (DMRD, 2005). These groups, as noted, are usually termed family support and enable families to learn from and help each other in an empathetic environment and to reduce their isolation by meeting regularly with others in similar situations (Salter and Clark, undated). Significantly, such groups offer opportunities for increasing parents' knowledge and understanding of substance abuse issues and for aiding the development or improvement of coping mechanisms. It has also been found that once family members are able to talk to an informed person about their experience and options, their psychological health can improve very quickly, even if the substance misuse remains unchanged (Copollo, 2002).

Personal networks can also be an important source of support for families, although this can depend on the social or cultural context. A cross-cultural study, for example, found that family networks were far more important in Mexico than they were in the UK (Orford *et al.*, 1998). In a later study, the same authors also found that in the UK it is remarkably difficult for parents and partners of substance misusers to secure support from within their social network (Orford *et al.*, 2001).

As noted earlier, much of the literature of families and support services focuses on the needs of the family as victims of drug use. However, there is a growing awareness of the role that families can play in both prevention and in treatment of drug-related problems. Watters and Byrne (2004) have noted that internationally the role of the family in acting to protect against drug problems is gaining recognition although this has not yet become a feature of the Irish situation. Additionally, evidence from abroad suggests that involving families in treatment programmes increases the effectiveness of those programmes. For example, US studies have highlighted the effectiveness of delivering therapeutic interventions to the family of drug users, particularly where these are combined with similar interventions directed at the drug users themselves (Monitor on Psychology, Vol. 34 No 9). Sullivan *et al.*, (2002) also found that social models of responding to drug use can benefit from using the family as a resource in recovery from drug use. The current study also demonstrates the potential role which families can play in dealing effectively with their own problem and in supporting the user into recovery. As with other aspects of the family's role, this capacity is not fully recognised (or resourced) although recent developments in policy may point to changes in this in the future.

2.4 The Policy Framework in Ireland

The different types of support services available to families coping with heroin use straddle different policy arenas, including for example, health, children, education and criminal justice. Consequently, these supports are embedded within different policy structures and are subject to different policy processes. However, in the last number of years, some very significant initiatives at local, regional and national level have contributed to the emergence of a framework for the development and implementation of policy in relation to combating drug use in Ireland. These are the Local Drug Task Forces (LDTFs), the Regional Drugs Task Forces (RDTFs) and the National Drugs Strategy (NDS).

Local Drugs Task Forces

Local Drugs Task Forces (LDTF), which comprise a partnership between the statutory, voluntary and community sectors, are located in 14 areas perceived to be experiencing the worst levels of opiate misuse. These areas are Ballyfermot, Ballymun, Blanchardstown, Bray, Canal Communities, Clondalkin, Cork City, Dublin 12, Dublin North East, Dublin North Inner City, Dublin South Inner City, Dun Laoghaire/Rathdown, Finglas/Cabra and Tallaght.

Each LDTF has developed action plans, the focus of which is on the establishment of community-based initiatives to link with, and add value to, the programmes and services already being delivered or planned by the statutory agencies in the LDTF areas. In addition, the LDTFs provide a mechanism for the co-ordination of services in these areas, while also providing an opportunity for local communities and voluntary organisations to participate in the planning, design and delivery of those services.

The type of projects that are supported by the LDTFs include: local information projects, advice and support centres for drug users and their families, Community Drug Teams (CDTs), special projects aimed at children involved in drugs or at risk of becoming involved in drugs, the production of drug awareness materials, drugs training programmes for community groups, teachers, youth workers and other professionals, rehabilitation programmes and initiatives to allow local communities to work with the State Agencies in addressing the issues of supply in their areas.

In 2002, a review of the LDTFs was conducted and a series of recommendations were made, including a call for extra staffing to enable more timely and effective measures to be implemented at local level (Burtenshaw, 2002).

Regional Drugs Task Forces

In 2002, the LDTF model was expanded to cover the entire country through the establishment of the Regional Drug Task Forces (RDTFs). These RDTFs are based in each of the ten former Health Board areas. Each RDTF is charged with conducting initial research to establish the extent, nature and pattern of drug misuse in their respective regions. Based on the findings of this research, each RDTF is required to develop regional action plans for their areas to address the gaps in service provision.

The RDTFs were slow in getting established and staffing issues were highlighted as an impediment to their roll out. Now however, all RDTFs are in place and are implementing their action plans.

National Drugs Strategy (NDS)

The NDS was introduced in 2001 and will run to 2008. The NDS is based on four pillars: prevention, research, supply reduction and treatment and identified 100 actions across these four pillars. A wide range of agencies are involved in delivering these actions, including specialist and non-specialist agencies. The specific position of families in regard to heroin use was recognised in the NDS, but only one of the original 100 actions contained within the Strategy was targeted directly at families. In 2005, a mid-term review of the NDS was conducted and following this, the report of the Steering Group on the Mid-term Review noted the need to develop support and guidance for parents as well as children at risk. The report stated:

It was felt that parents and other family members are a neglected group who feel frustrated in seeking support for their children/relatives. Parents and other family members can find it difficult to know where to turn when the domestic situation is chaotic as a result of a drug problem within the family.

Equally important, the report acknowledged the role families can play in responding constructively to drug use:

The positive role families can place across all of the pillars of the strategy was emphasised. The work and role of families is seen as being in some ways unacknowledged, while at the same time being an untapped resource. In discussing the role of families, it was felt that it must be noted that the family needs to be recognised as a support and resource, as well as having their support needs addressed (Report of the Steering Group, 2005. p.14).

In line with this, the report made a number of recommendations to increase support to families and to underpin the role of families, and communities, in the NDS. These include:

- The provision of factual information for parents and families in dealing with substance misuse to be more easily accessible in appropriate locations such as Garda Stations, libraries health centres etc
- The strengthening of the role of the Home School Community Liaison Scheme and an expansion of its role with families dealing with drug misuse.

In relation to family support, the Review recommended the following:

- That the recommendations of the Watters and Byrne report (The Role of Family Support Services in Drug Prevention, 2004) should be implemented immediately, namely:
 - Increasing the capacity of services to respond through an appropriate level of resources and training for staff in services
 - Strengthening interagency links and networks by building knowledge of local community issues and attitudes thus improving communications
 - Developing relevant monitoring and evaluation tools to measure effectiveness of services.
- The NDST should actively encourage the LDTFs and RDTFs to prioritise the provision of family support services in the areas and action plans
- Family Support networks should be supported in their work in the areas of information provision and assistance to local family support groups.

These and other recommendations of the Steering Group are highly relevant to the current study and are returned to later.

2.5 Conclusion

Heroin use, as reflected in treatment data, is a growing problem in Ireland, both in terms of the numbers of people affected and in terms of the numbers of communities. The propensity for heroin users to live in the family home, even if intermittently, exposes families and family members to the adverse effects of the users' behaviour. These effects are both serious and long-lasting and can have significant implications for those affected. In coping with these adverse consequences, families resort to a wide range of supports and services including their own personal networks, generic services and the specialist providers.

However, while the family and family members must be recognised as victims of drug use, and supported as such, it is also the case that the family can play a very significant role in aiding the recovery and the rehabilitation of the user. This is now beginning to be recognised in Irish policy, but as yet there has been very little in the way of provision to support families in this role.

Provision for drug users, as distinct from their families, has increased in recent years and policy development has also been significant. In particular, the roll out of the LDTF and RDTF strategies reflects a growing recognition of the need to develop locally focused approaches to responding to problem drug use within the national framework. However, delays in the roll out of these strategies means that drug provision tends to follow rather than anticipate the problem drug use. Moreover, while the LDTFs and the RDTFs, together with the NDS, are charged with developing greater coherence across the various forms of provision that exist at local and at regional level, subsequent chapters will show that from the standpoint of families who interact with these agencies, the situation does not appear as coherent or integrated but as fragmented and counterproductive.

Chapter 3

Research Methodology

3.0 Introduction

The purpose of this study was to provide information on, and insight into, the experiences of families coping with problem drug use in interacting with the support services. Specific questions that the research sought to address were:

- What support (and where) has been sought by the family/family member?
- What were their expectations in seeking this support?
- What support has been the most/least helpful?
- What are the barriers to seeking support?
- What would help family members to cope?

The research did provide answers to these questions: but it also indicated that the concepts underlying these questions need to be reassessed. Specifically, the concept of 'coping' needs to be reassessed in light of the different ways of engaging with the problem of heroin use; the notion of 'expectations' on the part of families needs to be challenged given the chaotic dimension of much of their help-seeking behaviour; and the ability of families to assess the 'helpfulness' of services needs to be looked at in light of the lack of specificity with which they sought help. These issues are discussed later in this chapter; first, details of the methodology are presented.

3.1 Methodology

The major component of the methodology for this study was comprised of in-depth qualitative interviews with the principal carer in 30 families coping with heroin use, augmented by interviews with a second family member in seven cases. Most of the primary carers interviewed were mothers of drug users and overall, 20 of the 37 interviewees were female.

3.1.1 Sampling strategy

The sampling strategy used was theoretical rather than statistical. That is, it was primarily concerned with diversity, not representativeness, at both the level of the family and at the level of the social context in which problem drug use was experienced. Consequently, a two-tier sampling strategy was implemented.

Social context

The first tier of the sampling strategy was at the level of the locality or the social context. While not purporting to be a community study, the research sought to situate the experiences of families with a social context. The social context was understood to include the socio-economic profile of the localities, the prevalence and duration of a heroin problem, the personal and informal networks of supports (for examples, friends and family) available to families in their communities, the perception of drug use at community level and the extent and nature of the support services that existed in each locality. The rationale was that the social context within which families coping with problem drug use live would impinge upon how they used support services.

Three localities were selected which provided diversity both in terms of their socio-economic profiles and in terms of their experience of a heroin problem.

- a) The first locality was comprised of a number of adjacent inner city neighbourhoods in Dublin, with a concentrated and long-term incidence of heroin use.
- b) The second locality was comprised of a number of neighbourhoods in a peripheral suburban area on the outskirts of Dublin, where heroin use is extensive and long term.
- c) The third locality was comprised of a number of adjacent or semi-adjacent provincial towns, with rural or semi-rural hinterlands in the North East, experiencing more recent but significant levels of problem drug use.

In all three localities, support services were used in order to access families. In most cases, the families involved in the research were living in the locality in which the support services were based. In a number of cases, however, the families were not living in these localities, but lived in adjoining or nearby neighbourhoods.

Familial context

The second tier of the sampling strategy focused on the familial level. Here the concern was to include a range of family types and household circumstances. Families dealing with problem drug use take many forms: they include lone parent and two-parent families, families where the problem drug user is an adult (and perhaps a parent) and families where the user is a teenager. They also include families where the problem of drug use is long-standing and those where it is a much more recent experience. Consequently, the sampling strategy sought to ensure that the selection of participants allowed a broad spectrum of family types to be included.

3.1.2 Accessing families

In the localities selected contact was made with Family Support groups and their assistance was requested in accessing families to take part in the study. The groups that were contacted all agreed to provide support. The Family Support groups were hugely instrumental in brokering the research, in facilitating access and in providing venues and other supports for the interviewing process and for the interviewees.

In the inner city locality, three Family Support groups, operating in adjacent neighbourhoods, were contacted; in the peripheral sub-urban locality, two groups were contacted and in the provincial locality, one Family Support group was contacted. In this locality, the HSE was also asked to assist in locating families to participate and agreed to do so. In total, 26 of the 30 families were accessed through the Family Support groups, and four through the HSE.

In all localities, representatives of the Family Support groups and other providers were met with and the objectives of the research explained. The following points were stressed:

- Respondents would be fully informed of the objectives of the research. They would be advised about the type of questions that would be asked and the degree of sensitivity involved. They would not be under any pressure to participate. They could refuse to answer particular questions and could stop the interview at any point. It would also be made clear to respondents that the information they provided would be treated in strictest confidence and that they would not be identified either explicitly or implicitly.

- Despite these commitments, the possibility remained that the interviews might cause difficulties for some people, given the sensitive and painful nature of the issues. Family Support groups were asked to identify family members who would be unlikely to become distressed by the experience. The Family Support groups agreed to this and also undertook to provide people to whom interviewees could talk if the interview raised problematic issues for them.
- Family Support groups were advised that those who participated in the interview would be given a voucher to acknowledge their input. However, they were asked not to inform people of this in order to eliminate any possibility of inducement.

3.1.3 The interview process

As a result of contact with the Family Support groups and the HSE, a total of 37 respondents from 30 families (ten in each locality) were identified and agreed to participate in the research. The following outlines the key elements of the interview process.

Location

All of the family support groups facilitating the research were prepared to make their premises available for interviews. This allowed interviewees to choose where they wished to be interviewed. The preference of interviewees was as follows: in the inner city all interviews took place in Family Support group facilities; in the suburban peripheral area, seven interviews took place in community facilities, three in the respondents' own homes. In the provincial towns, three interviews took place in community facilities and all others in respondents' own homes.

Introducing the research

Interviewees were informed about the nature of the research, the likely sensitivity of the questions and the fact that they could stop the interview at any point. All interviewees were willing to proceed, most indicating that they were only too happy to contribute to knowledge on the issue of drug use, that they would participate in any endeavour that would help other people in their situation and that they would willingly share their experiences in the hopes of securing better policies and provisions for drug users and their families.

Data capture

Permission was sought to record interviews and all interviewees agreed to this. Some interviewees needed reassurance that what they said would be completely confidential – in particular, they needed reassurance that anything they said would not be used in any context other than the research context.

Formal consent

It was considered that introducing a formal consent form at the start of the interview would be disruptive and inappropriate. Instead, once the recorder was running, people were asked if they understood the research and were prepared to continue.

Acknowledgements

Each interviewee was given a €25 voucher at the end of the interview.

3.1.4 Topics covered

Most of the interviews were of between one and one-and-a half hours duration. Some were considerably longer than this and a small number were shorter. In all cases the interviewee was asked to 'tell their story', starting with the onset of the problem until the present day. Following this, the interview went back over the details of their story, probing in more detail the specifics of their experiences in coping with heroin use and in seeking support. The following points guided the interview process.

Contextual factors:

- demographic profile of respondent, family/household, and drug user
- length of time living in locality
- personal support networks available
- awareness of statutory and other services.

Experiential factors:

- experience of problem drug use
- duration of problem drug use, type of drugs involved
- support seeking from personal networks
- support seeking from statutory/community services
- interaction with these services
- types of problems presented
- types of support sought and received.

Perceptual factors:

- assessment of support received
- assessment of most effective supports overall
- assessment of what additional supports would have been helpful.

3.1.5 Data management, analysis and methodological issues

Following the interviews, all data was transcribed. Given the relatively small number of interviews and the very definitive focus of the research, it was not considered necessary to code the data and subject it to software applications. Instead, each interview was individually blocked out on a thematic basis, major themes were then identified and data allocated to these. As the interviews progressed, the themes were modified, refined or regrouped and a number of sub-themes in relation to the experiences of families responding to heroin use were identified. These sub-themes facilitated a more detailed analysis of the data. On this basis a framework was developed based on the patterns of help-seeking behaviours across the 30 families. This framework allowed the different positions families occupied with regard to the service providers and their different ways of engaging with heroin to be elaborated. While each family displayed slightly different patterns of behaviours, the framework allowed every interview to be accommodated within it.

All of the families who participated in this research were contacted through existing services. Consequently, families who try to cope without support from the services are not included. It is not known how many such families there are, but it is likely there is a substantial number. However, all of the families which are included in the research recalled phases, sometimes lengthy phases, when they too were isolated from support. Thus, their stories provided insights into strategies of coping that do not include seeking support from the services.

Many of the people interviewed had been coping with problem drug use for periods up to, and in excess of, 15 years. Consequently, in recounting their experiences they were frequently referring to a situation that prevailed up to, and over, a decade ago. In addition, both families whose problem began a long number of years ago and those for whom it had emerged more recently frequently referred to the chaos and confusion that surrounded their support-seeking activities. In view of both these factors, people's recall of the use of specific supports is not entirely comprehensive. Consequently, the analysis here is based on broad patterns of support use, rather than the fine-grained details.

3.2 Ethical Considerations

The research was guided at all stages by the ethical guidelines developed by the NACD and by the Sociological Association of Ireland. The general principles underlying these are:

- Professional competence
- Integrity
- Respect for human rights, diversity and equality
- Social responsibility.

In respect of the conduct of the research, the following key principles applied:

- **Proper identification:** Researcher should avoid giving false impressions of the research or the sponsor
- **Clear outset:** Researcher should inform the respondent of the type of questions and the degree of sensitivity of questions
- **Welfare of the respondent:** Researcher should avoid questions or issues that may cause embarrassment or guilt
- **Free and informed consent:** Respondents should not be under any pressure to participate and should be informed of the goals of the research
- **Right to privacy:** Private space of respondent must be respected and questions left unanswered, if the respondent so wishes
- **Right to anonymity:** Respondent should not be explicitly or implicitly identified
- **Right to confidentiality:** Information provided by the respondent should be used only for the purpose of the research.

3.3 Research Issues

As noted earlier in this chapter, the research questions which guided the research were relatively straightforward. In recounting their stories, however, the complexity of the families' interaction with the problem of heroin use became clear. In particular, the extent to which 'coping strategies' changed over time was evident along with the different ways of engaging with the problem of heroin use that families utilised. Seven distinct ways of engaging were identified and these had implications for how families used support services.

These ways of engaging with heroin use and ways of interacting with services were outlined in Chapter 1 and are more fully discussed in Chapter 5. At this point, however, note that the sequencing of these ways of engaging and the various support-seeking strategies associated with each one is central to understanding the interaction of families with various support providers and has implications for how the research questions are viewed. Specifically, the following points are important:

- Firstly, the concept of *coping* per se is problematic, given the different ways of engaging with heroin use (ignorance, reacting, learning, managing) that families manifest. At one level, all these ways of engagement might all be considered coping strategies of sorts, but nonetheless in understanding families help-seeking behaviours it is important to distinguish between reacting to the problem of heroin use and managing the problem of heroin use. This requires a move away from the singular concept of coping to a more diversified focus on ways of engaging.
- Secondly, the research questions effectively posit families of drug users as consumers of services, operating with a consumer rationale (means/end) and capable of assessing the extent to which any particular service meets their expectations. However, the data clearly shows that within certain ways of engagement with heroin use families operate in a context of confusion, desperation and panic. Consequently, to conceptualise them as *consumers* of services, operating with clear expectations and therefore able to assess effectiveness is inappropriate.
- Thirdly, and related to the above, is the fact that within the context of confusion, desperation and panic, families invariably seek any kind of help or support that might be available, rather than looking for a specific service or intervention. Consequently, the concept of their 'expectations' in seeking help must be reassessed.
- Finally, the fact that families often had no clear expectation of what help they were seeking meant that they had no clear basis on which to assess the adequacy of the support received and often any support provided was positively assessed regardless of its effectiveness. In addition, the generally accepted view of families was that the user cannot be helped if he or she does not wish to be helped or does not wish to abandon their heroin use. As a result of this, if supports don't work, the fault is perceived to lie with the user. In this context, too, the family has no basis for assessing the effectiveness of supports.

Chapter 4

Localities, Families and Supports: An Overview

4.0 Introduction

The fieldwork for this research took place over a two-month period between the end of June 2005 and the end of August 2005. A total of 30 families and 37 individuals were involved in the research, accessed through support service providers, and particularly through Family Support groups.

This Chapter presents a brief overview of the three localities included in the research, it provides details of the families involved in the study, discusses the nature of the drug problem and related difficulties which the families experienced and provides an overview of the range of supports they sought assistance from.

4.1 Profile of Localities

In selecting three localities, the objective of this research was not to produce community studies but rather to extend the wider applicability of the findings by exploring the experiences of families in different social contexts. Three social contexts were looked at: urban, suburban and provincial and in each the history of heroin use also varied. As noted, a number of the families interviewed did not live within the immediate locality within which the support service operated. Table 2 provides an overview of the number of neighbourhoods in each locality within which support services were approached and the geographical distribution of the families contacted through these.

Table 2: Overview of localities and families living therein

Locality	No. of communities	Total number of families	Number living within the locality	Number living outside the locality
Inner city	3 neighbourhoods	10	7	3
Peripheral area	4 neighbourhoods	10	6	4
Provincial area	4 towns	10	9	1
Total	11 towns/neighbourhoods	30	22	8

Despite this dispersal, the selected localities do provide a backdrop within which to locate the experiences of families. The following paragraphs therefore provide a brief overview of the socio-economic profile of each locality and note also some key elements of service provision.

4.1.1 Dublin Inner City

The inner city neighbourhoods included in this locality have, traditionally, experienced a considerable amount of shared population movement. Consequently, there is a high level of social interaction across the various neighbourhoods in this locality and this extends to both the experience of, and the reaction to, the problem of heroin use.

In the inner city neighbourhoods, the problem of drug use has been prevalent for almost 30 years. The result is a fairly intensive experience of the issue at community level, reflected in features such as the transference of the problem across three generations in some instances; the experience of fatalities resulting from HIV/AIDS and overdoses, and directly following on from that, the existence of families where the grandparents are rearing their grandchildren. These entrenched community-level problems were evident in this research: it was only in the inner city locality that families included in the research had lost children through Aids, were currently coping with children who were HIV positive, who had experienced all or almost all of their children becoming heroin addicts, and had seen their grandchildren become addicted to heroin.

As a result of the prevalence of drug use in this area, it is not uncommon for families coping with heroin use to have members of their extended family in a similar situation. One consequence of this, evident in the research, is that family members were instrumental in linking each other into support services. In addition, given the long-standing problem of heroin use, some support services are well-established and very visible in the community, which also facilitated access. However, even in the context of the scale of heroin use in the inner city, families spoke of the stigma associated with having a drug user in the family. This affected their help-seeking behaviours and their social well-being and in general, neighbours were not any more helpful in this area than in others.

A further important feature of the inner city locality derived from its socio-economic profile: the predominantly working class make up of the area was evident in an uncritical acceptance of professional discourse on the part of families in this locality and a lack of stridency in relation to demanding better services.

The locality is within the remit of an LDTF and has well-established Family Support groups. It is also adjacent to a number of other services which serve the Greater Dublin area more generally.

4.1.2 Peripheral suburb

In this locality, four neighbourhoods were selected. Two of these were local authority neighbourhoods and two were neighbourhoods with private housing. In the local authority neighbourhoods, the problem of heroin use is of relatively long duration, extending back at least 15 years. In the private neighbourhoods it is a more recent phenomenon. All of the families in this study, who were accessed through the Family Support group in the local authority estates, were living locally. Families accessed through the support group catering for the private estates were distributed over a much greater area including parts of adjoining counties.

The local authority estates are longer established, have a more developed sense of community and community sector and family networks are more prevalent. The private estates are more recently developed and people living on these or in adjoining areas are drawn from all parts of the country, thus are less likely to have family living nearby. A common feature across the areas, however, is the stigma associated with heroin use. Even in the local authority neighbourhoods, this was frequently commented upon, along with the associated difficulties between neighbours deriving from heroin use.

Social class differences were notable across the neighbourhoods. In the local authority areas, similar to the inner city, there tended to be an acceptance of, or at least acquiescence with, the dominant public and policy discourses surrounding heroin use. In the private areas, families were more likely to challenge these.

The area has both an LDTF and a CDT and there has been significant developments in the provision of drug services over recent years, with more and more services now being delivered locally. For those living in the area, this has reduced significantly the 'geography' of coping with heroin use. For those not living in the area, however, the issue of travel, transport etc. persists. Family Support groups are also well established and provide services to those in their own localities and to adjoining areas.

4.1.3 Provincial towns

The third 'locality' included in the study was comprised of four towns in two adjoining counties within one HSE region. In each county, two adjacent or almost adjacent towns were included. Three of the towns could be considered small 'provincial' towns, but one is a sizable town increasingly becoming part of the Dublin commuting satellite network. Until relatively recently, heroin was not perceived as a problem in these areas but over the past number of years this has begun to change. Now, in all four towns, there is a significant number of heroin users. In the more rural areas, most users are smoking rather than injecting heroin.

Reflecting the proximity to the Dublin commuter belt, two of the families from these towns, who participated in the research, were originally from Dublin and had left the city to try to escape their heroin problem. All others were local and had been living for most of their lives in the towns. More generally, community and family networks were mixed – stronger in the more rural areas – but all areas acknowledged the existence of stigma associated with heroin use and the additional problems caused for families of users.

The roll-out of the RDTF is underway in these towns, but at the time of the research, local provision was limited, although some services which did exist had a very high profile, facilitating access. Significantly, in the provincial towns and especially in the more rural towns, the role of the local Gardaí in the day-to-day lives of families coping with heroin use is very pronounced.

Family Support groups are unfunded in the area but a considerable amount of voluntary activity is underway. In particular, in the more rural towns, a very active group has emerged which has moved beyond family support per se and into seeking to develop a model of responding to heroin use appropriate to rural areas. Within this, there is a preference to embody drug-free solutions for the user.

4.2 Overview of Families

A total of 30 families were included in the research, ten in each of the localities. In the case of 23 of these families, just one member was interviewed. In the case of the other seven, a second family member was also interviewed. Table 3 provides an overview of the members of families interviewed in each locality. As can be seen from this table, most of those interviewed were parents of drug users. Consequently, the emphasis in this report is on parents' experience of responding to problem drug use on the part of their children. Where the experiences of partners or siblings in seeking support is markedly different from those of parents, the relevant issues are discussed as far as the data will allow.

Table 3: Family members interviewed

	Inner City	Suburban	Provincial	Total
Families where both Parents were interviewed	2	0	2	4
Families where Mother only was interviewed	5	8	4	17
Families in which Father only was interviewed	2	0	1	3
Families where Mother + Sibling were interviewed	1	0	2	3
Families where Sibling only was interviewed	0	1	1*	
Families where Partner only was interviewed	0	1		
Total families	10	10	10	30

* One interviewee in this locality was both a partner and a sibling of drug users.

Most of the parents interviewed were mothers, which in part reflects the fact that it is mainly mothers who act as the principal carers and who are also most likely to seek supports. It also reflects the fact that a high proportion of the families researched were headed by a female lone parent, particularly in the peripheral suburban area. However, from the accounts of families, it is clear that while mothers may be more predominant in the caring role, both parents are involved in coping with heroin use, in a broad sense. Consequently, in this study, reference is made to the strategies or actions of families or parents, differentiating between mothers and fathers only when it is particularly relevant to do so.

4.2.1 Profile of families, drug users and drug use

All of the parents interviewed for this research were in the later stages of child-rearing. Most were in the empty nest stage, when all the children have left home, and more would have been in this stage but for the user continuing to live with them, sometimes with their own child. The siblings or partners who were interviewed were younger and in family formation stages. Between them, the 30 families accounted for a total of 54 heroin users. This was due to the inclusion in all localities of families with two users and more specifically to the inclusion of families with a very large number of users in the inner city. In regard to the latter, the research focused on support seeking in relation to the youngest user in each family. On this basis, the total number of users covered by the study is 39.

Table 4: Number of heroin users in families, by locality

	Inner city		Suburban		Provincial	
	N families	N users	N families	N users	N families	N users
One member only	5	5	9	9	6	6
Two members	2	4	1	2	4	8
Three or more members	3	20	0	0	0	0
Total	10	29	10	11	10	14

Key features of the families and the heroin users include:

- Interviewees ranged in age from 30 to late 60s. Older interviewees were living in the inner city locality.
- Among the 27 families in which parents were interviewed, 17 were two-parent households and ten were lone parent, female-headed households.
- The families were drawn from very diverse socio-economic backgrounds. Included amongst the family members interviewed were people on social welfare, unskilled manual workers, unskilled non-manual workers, skilled manual workers, skilled non-manual workers, self-employed people and professionals.
- The vast majority of the families had been living for many years at their current address.
- The majority of users were male: of the 39 users covered by the study, 28 were male and 11 were female.
- The vast majority had started using heroin at about the age of 15 or 16. Almost all were in school at the time they commenced using but dropped out subsequently.
- The process of becoming involved in heroin use was not a focus of the research, but many parents indicated that their child had previously used cannabis or ecstasy before moving on to heroin. For male users, parents believed that it was friends who had first introduced them to heroin use. For female users, it was more likely to be their boyfriends.
- All of the users were opiate users and in all cases, the opiate used was heroin. Most were intravenous users, but in one of the provincial towns, all were smoking heroin. Some of the users were polydrug users, with cannabis the most frequent companion drug.
- For ten of the families the heroin problem had started over 15 years ago and for a further four it had started between ten and 15 years ago. In the case of six families, the problem started between five and ten years ago and for the other ten families it had started within the last five years.
- At the time of the research, five families indicated that the drug-using member had given up heroin and was living a drug-free lifestyle, 14 families indicated that the drug-user was on long-term methadone maintenance and ten families indicated that their family member or members were still using heroin.
- At the time of the research, in the case of 14 families, the user was living at home. No ex-drug-using family member(s) who had become drug-free were living in the family home, five of those using heroin were living in the family home and nine of those on methadone maintenance were living at home.
- In all cases, the drug-using member (or members) had lived with siblings in the family home at some point. In the case of the 14 families who had the drug user living in the family home at the time of the research, six had other children also living there.
- In the case of ten families, the drug-using member was himself or herself a parent (including two where the partner was interviewed). In six of these cases, the drug users' parents had a lead or principal role in looking after the child or children.
- Of the five users who had abandoned heroin use and were drug-free, all were working. Amongst those on methadone maintenance or using heroin, none were in full-time employment, but a few had irregular or part-time work.

- Male users had been very involved in criminal activity, including dealing, to finance their habit. Female users were less involved in criminal activity but tended to link up with drug-dealing boyfriends.
- Living on the streets or in hostels had been part of most users experiences. At the time of the research, five of the users were living on the streets.
- The health of users was impaired, some had experienced very acute crises, but there were only HIV-positive users in the inner city.

4.2.2 Family problems encountered

The actual nature of the problems encountered by families was not a focus of this research and interviewees were not asked to provide information on these problems. Inevitably, however, interviewees did refer to various difficulties that beset them at different times. By way of providing some insights into the reality of families' lives, the following provides an overview of these difficulties, but does not claim to be comprehensive or exhaustive.

Physical and psychological well-being

The level of stress that they had or were experiencing on a day-to-day basis was continually referred to by interviewees and most indicated that their own health had suffered as a direct result of having a heroin user in the home. Two parents said they had suffered breakdowns that required hospitalisation, and a number of other parents and family members had required medication to cope with stress. Three parents indicated that they had used alcohol excessively in trying to cope. Pressure on siblings was also referenced. Parents referred to low self-esteem, loss of confidence, dropping out of school or college and psychological problems on the part of the siblings of users, and particularly on the part of sisters.

Financial

Most families experienced some level of financial pressure as a direct result of the presence of a heroin user. The most frequently cited causes of financial problems were the user stealing money from the family home, parents buying heroin or buying methadone on the streets, paying off dealers, replacing stolen money or goods for neighbours or others, paying for treatment, travelling for treatment, reducing hours of work as a result of stress, reducing hours of work to look after the user or grandchildren, replacing items stolen from the family house, repairs to the family home necessitated by the actions of the user.

Social

The shame and stigma associated with drug use constrained the social lives of most families as did practical aspects of coping with heroin use. Difficult relationships with neighbours caused some people to limit their social activity in the locality. Having to stay in the house to mind the user also imposed. Normal experiences such as holidays etc. were interrupted by crisis and the process of responding to significant life experiences (such as births or deaths in the family) were also derailed by crises on the part of the users.

Family relationships

Family relationships were the most frequently cited problems. Among the difficulties that families experienced were conflict between parents leading in extreme cases to marital breakdown or total loss of communication, conflict between the user and siblings, lack of attention to the needs of other children and consequent difficulties downstream as a result.

In addition to the above problems which, for the most part derive from the behaviour of the drug user and the social reaction to that, families also experienced problems arising from the treatment system itself and from the lack of information available to them, both in relation to drug use per se and in relation to the treatment options. Both of these issues are discussed more fully in the following chapters. Also of note is the fact that even when the original problem of heroin use is resolved, the negative implications for the families can persist for long after.

4.3 Supports Accessed

The manner in which families coped with the problems of heroin use differed greatly over time: bearing in mind that many families had up to and over 15 years experience of coping with heroin use, it is easy to comprehend how the accumulation of experience, stress and knowledge over such a lengthy period would lead to different approaches and strategies at different points in time. What is more surprising is the very high level of consistency in the accounts of families as they recall the changes and developments in their approaches over time. As noted earlier, this has allowed a number of different ways of engaging to be identified, which provides a framework within which to understand the support-seeking behaviours of families and the adequacy of responses they received.

This framework is developed in the following chapter. By way of context, the tables below provide an overview of the arenas from which parents or carers sought support. These are classified as informal sources of support, non-specialist or generic sources of support and specialist sources.

Table 5: Overview of supports sought from informal networks

Source of support	Where located	Support sought or provided
Local religious	Local	In some localities, local priests and more especially nuns were used as sources of advice and support. Contact with priests tended to be once off usually to seek information or advice in the early stages. Contact with nuns tended to be more long-term and focused on support for the parent or carer.
Personal networks <ul style="list-style-type: none"> ■ Friends ■ Family ■ Neighbours 	Local	Personal networks were widely used by families. These provided emotional and practical support usually over an extensive period of time. Neighbours were less frequently used as a source of support, except in cases where they too were dealing with a drug problem.
Drug users	Local/regional	Drug users were frequently used by families in their efforts to cope with their own drug-using member. They were usually approached in the early or chaotic stages of managing and the help sought included: information on whereabouts and well-being of the user, information on where to buy heroin or methadone, on how much methadone to use and information on symptoms of various drugs.
Other	Local	Infrequently, families approached individuals such as local politicians, employers etc. to seek support or advice.

Table 6: Overview of supports sought from non-specialist services

Support	Location	Help Sought
School Personnel <ul style="list-style-type: none"> ■ Principals ■ Teachers ■ Counsellors 	Neighbourhood	School personnel were usually approached in the early stages of dealing with the problem or when the problem was first suspected. Support sought included: advice, counselling for the young user, requests to retain the young user in school, and requests to establish a drugs policy within the school.
Social Workers	Local	Social workers were infrequently approached for help; mostly their involvement was initiated by social workers rather than the families. Where they were approached, the help sought included removing very young users from third party houses, help in getting young users off the streets, help for grandparents in looking after children of drug users.
Health system personnel <ul style="list-style-type: none"> ■ Hospitals ■ Psychologists ■ Psychiatrists ■ GPs 	Local/Regional Local Local Local	These categories were widely used and particularly GPs. These were usually used in the early stages as a source of support for the parent or carer and as a source of advice and information on how to deal with the problem. Later, GPs were frequently used for methadone prescriptions. Psychologists and to a lesser extent psychiatrists were also used, both to provide support and assistance to the user and to the carers.
Criminal Justice System <ul style="list-style-type: none"> ■ Probation & Welfare Officers ■ Gardaí ■ Judges 	Local Local Regional	Interaction with personnel within the criminal justice system was rarely initiated by the families but came about as a result of the users involvement in crime. However, once within the criminal justice system, interaction between the family and personnel was often extensive. Probation & Welfare Officers were instrumental in providing direct interventions to the user, but also in supporting the family by acting as a reference point. Gardaí were sometimes approached to remove the drug user from the home, but usually their involvement was not at the family's behest. Nonetheless, they were often, not always, considered very supportive in assisting the family and in assisting the drug users. Occasionally, families made direct requests to judges regarding the imposition of custodial sentences.
General Counsellors	Local/Regional	General counsellors were quite often used as a source of support both for the drug user and for the parents/carers. Sometimes the help of the counsellor was already being sought for non-drug-related issues prior to the problem becoming evident.

Table 7: Overview of supports from specialist services

	Location	Help Sought
Drugs helpline	National	This was infrequently referred to and in the small number of cases where it was used, it was to seek initial assistance in identifying the existence of a problem.
Drugs Education/Awareness Programmes	Local	These were used by a minority of families. In some cases they were used in the early stages of a problem and were very instrumental in creating awareness and prompting a specific course of action; in other cases they were used much later on as part of a strategy to develop a more coherent approach to dealing with the problem.
Treatment/detox/maintenance centres	Local, Regional, National	Treatment, detox and maintenance centres were extensively used by families, usually at a certain stage in their coping with the problem. Many families had had contact with a very large number of such centres over long periods of time. Often these centres were approached for 'help' in a general sense, rather than a specific service or approach being sought out. Mostly, these centres were approached for help for the user, but in some cases this led directly to help for the families – through family support groups for example.
Community Drug Teams	Local/semi-local	In areas where they existed, the services of the community drug teams were widely used, primarily to provide assistance to drug users and to a lesser extent to provide support and other services to parents/carers. The key worker system was particularly used to assist parents in managing their communication with the drug user, particularly in the later stages of coping.
Drug Counsellors	Local/Regional	Drug Counsellors were widely used in all areas both to provide support and assistance for the drug user and for the parent or carer. Frequently, the initial contact was in relation to seeking help for the user, then progressing to assistance for the parent or carer.
Family Support groups and Family Support workers	Local	Almost all the families included in this study were contacted through family support groups, consequently almost all had some contact with these. Intensity of contact varied quite a lot but the main interventions sought or received from these groups related to information on drug use per se, advice on how to manage the problem and support in implementing the advice and personal support.

As will become clear in the following chapters, families interaction with support services varied over time and reflected the different ways of engaging with heroin use which characterised families' responses at different stages. At any single point in time, therefore, their interaction with the support services reflects a specific moment in their coping with heroin use. Over the time frame within which they were coping with heroin use, their interaction with the services was far more extensive than at a single point in time.

Noting this, the following table provides an overview of the extent of *regular* interaction with various supports at the time of the research:

Table 8: Interaction with supports at the time of the research

Sources of Support	No. of families regularly using this support at the time of the research
Family Support groups	20
Personal networks	11
Maintenance clinics/Programmes	9
CDTs	6
Medical personnel	5
Drug Counsellors	5
Personnel within the Criminal Justice System	5
Not using any support	3
Social workers	3
Local religious	2
General counsellors	2
Treatment Centres	2

Family support groups and personal networks were the supports most commonly being used at the time of the research. These supports were accessed in order to meet the needs of the family itself and particularly the parents. Other supports were more likely to be focused on the needs of the user or sometimes both the user and the family. Nine of the families had some level of contact with maintenance clinics/programmes. These were families whose loved one was living at home while on methadone maintenance and the level of interaction between the family and the clinic or those involved in the programme was slight and usually mediated through the drug user.

Just three of the families had no contact with support services. Two of these were families for whom the problem had been resolved by their loved ones becoming heroin free. One family was just beginning to come to terms with the problem of heroin use and had not yet made contact with the support services.

4.4 Conclusion

The localities chosen for the research provided different social contexts within which to explore the experiences of families: they had different socio-economic profiles, different experiences of a heroin problem and different levels of provision to respond to heroin use. The families were also diverse, in terms of social-class, structure, number of children who were heroin users and the duration of the drug problem.

The problems encountered by families echoed the findings of international research and include problems deriving from drug use per se and the drug users' behaviour as well as problems deriving from other factors such as stigma and the operations of the treatment system.

In responding to these difficulties, a very diverse set of supports were utilised by families and almost all families were in regular contact with at least one source of support at the time of the study. These data, however, belie the complexity of families coping strategies and the variations in these over time. This is discussed in the following chapter.

Chapter 5

Families Engaging with Problem Heroin Use

5.0 Introduction

This chapter looks in detail at how families engaged with the problem of heroin use on the part of a family member. The protracted time frame over which they did so, has already been noted. In many cases, this was up to, and beyond, fifteen years. As families recalled their experiences in seeking support over this extended period, clear patterns in their responses to heroin use became evident. These can be seen as different ways of engaging with the problem and, in total, seven distinct ways of engaging were evident. These ranged from not having enough information to allow them identify the existence of a heroin problem in their own family, through to acquiring sufficient experience, information and expertise to enable them to become support providers in their own communities.

The chapter looks at these different ways of engaging, explores the interaction with support services in each stage and highlights the factors which steered the responses of the family from chaotic help seeking to acting as agents of recovery on behalf of their loved ones.

5.0.1 Seven ways of engaging

The seven ways of engaging that can be identified in families coping strategies are:

(i) Unknowing (ignorance, confusion and denial)

This first way of engaging occurs in the period between the drug user commencing opiate use and his or her family becoming fully aware of it. During this stage, some parents or other family members were completely oblivious to the existence of any problem, some were worried and confused by the young person's behaviour but attributed it to adolescence and some did have some concerns about drug use but were in denial. A common feature of this way of engaging, however, was that nobody perceived that there was a problem to be dealt with, consequently they were not engaged in seeking support at this point, with the possible exception of some limited attempts to gather information about adolescent problems in general and, in a small number of cases, to seek information on drug use.

(ii) Coping alone

When they became aware of the fact that a family member was using heroin, the predominant response among parents was to react by attempting to 'seal up' the family: to attempt to keep the problem a secret and to deal with the situation themselves, without outside intervention. During this process, parents were acting without proper information on the nature of drug addiction or on the services that are available. Against this backdrop, they engaged in a process of 'super-parenting', reflected in actions such as buying heroin for the user and otherwise facilitating their drug use. Support seeking, for the most part, was limited to informal networks during this stage and damage to the family and the user began to become apparent.

(iii) Desperately seeking support

This way of engaging was also a very reactionary one, within which one or both parents began an exhaustive and exhausting series of attempts to get support for the user, and by extension, for themselves. Families still had little or no awareness of the nature of addiction and they had little information and often inaccurate information on the various types of services available. Combined with the complex and fragmented interface which the treatment system presents to families, this resulted in extensive and prolonged interaction with a huge range of service providers including

specialist and non-specialist services. Despite these intensive efforts to seek help, families invariably did not know exactly what help they wanted and consequently could not properly assess the value of any help received. Families recalled the extreme pressure and tensions they experienced during this phase as their efforts to cope with the user were now paralleled by their efforts to engage with the service providers.

(iv) Supported learning

The fourth way of engaging evident in the accounts of families was that of learning – learning about the drug problem, learning about responses, learning about taking care of the family and learning about managing the problem, rather than reacting to it. Within this way of engaging, families began to address the negative dynamic of heroin use, and in the words of one mother ‘steadied their wheel’. For the vast majority of families included in the study, this learning started when they began to participate in Family Support interventions. This way of engaging was a turning point in the experiences of parents and carers after which they were more likely to develop ways of managing the problem rather than continuing to react to it.

(v) Reclaiming the family

This fifth way of engaging started when parents or carers began to implement the learning that they had acquired. A central element of this was that the family or carer began to separate the problem of drug use from the family: they began to interrupt the negative dynamic that heroin use had introduced and that the manipulative behaviour of the user had fueled. Now the families began to reclaim their own lives, disengage from the user and often to distance the user – physically, socially and emotionally – from the family. Family Support interventions were very important during this phase too, but families tended to disengage from other services and particularly services targeted at the users, instead insisting that if the user wanted help, he or she should look for it themselves.

(vi) Supporting recovery

This way of engaging began when families or carers began to re-engage with the user within the context of supporting them into recovery. Supporting the user into recovery sometimes meant supporting them in a drug-free lifestyle. For most families who reached this stage however, recovery was based on long-term methadone maintenance. Because of this, families’ engagement with support services often increased in this phase and Family Support services also continued to be important. Within this way of engaging, families moved from being victims and carers to being agents of recovery. Their potential to play this role, however, was rarely if ever acknowledged by the treatment system.

(vii) Contributing

This phase or stage occurred when parents or carers, having benefited from the information, education and awareness of Family Support, began to work in their own communities to ‘give something back’. Sometimes parents became involved in assisting addicts in their locality, mostly though they got involved in Family Support groups or within the structures of the LDTF. This stage is not necessarily the last position that families occupy although most families who were acting as resources in their own communities or in some other forums were actively supporting their loved one into recovery. Some, however, were still at the stage of reclaiming the family.

As they recalled their experiences of coping with drug use, families described their experiences of the different ways of engaging in terms of a progression from an initial state of ignorance, shock and reaction through to a stage of understanding and managing. Many referred to this progression as a journey, or a road travelled. The metaphor of a journey is useful in that it implies a progression over time from a starting point to a desired destination. However, as this study shows, this progress is uneven: families may stall for a long time within one way of engaging, they may go backwards at some stages and many do not reach the desired destination. Significantly however, there is a place along the journey after which families are unlikely to slip backwards. Whereas, the first three of the seven ways of engaging are characterised by ignorance, lack of information and chaos (and families can come and go from stages two and three as though on a continuum), once they reach stage four (where information, education and support are the key features) families were far more likely to progress on to later stages (of management and strategic intervention), than to slip back.

5.1 Unknowing

For families, the long journey of coping with heroin use which they were about to embark on started without their knowing: as soon as their family member began using heroin and long before they became aware of it. This way of engaging, therefore, is not really within the framework of coping with heroin use per se, given that it precedes the discovery of the problem. It is, in effect, a pre-awareness phase but one which nonetheless has implications for the provision of support services for families. All families, without exception, referred to the fact that their child had been using heroin, often for an extended period, before they had become aware of it. Parent's estimates of the length of time that their child or children had been using heroin without their knowledge ranged from about nine months to two years. Families spoke of the ignorance and confusion that contributed both to their lack of awareness that a family member was using heroin and to their devastation when they finally found out. For many, both their ignorance of the possibility of their child using heroin and their subsequent devastation upon discovery was fuelled by stereotypes of heroin users which suggest these to be drawn only from certain types of families and certain types of localities.

The majority of parents estimated that their child or children had started using heroin at around 15- or 16-years-of-age. Most of these young people were still in the formal educational system at the point when they began using heroin while a minority were involved in youth training programmes, for example, Youthreach. At this point, before their heroin use had become evident, a small proportion of the young people had been getting into trouble in school, some had had brushes with the law and some had been brought to the attention of child psychologists for behavioural problems. Consequently, in one way or another, all of the drug users had been within the framework of public policy provision for young people at the time they started using heroin. Despite this, in only one case was a parent alerted to possible drug use on the part of their child by personnel in these services. The apparent failure of the various services to anticipate, identify or act on the problem meant that the young people could continue to dabble in heroin use, until finally developing a significant heroin problem.

5.1.1 Ignorance, confusion and denial

Parents attributed their failure to spot the early signs of drug use to the fact that they knew nothing about drugs, about the behaviours associated with drug-taking or about what to look for in their own children's behaviour that would suggest a problem with drugs. As a result, many had no concerns or suspicions at all about their children's behaviour.

"We were totally ignorant about drugs. I had no suspicions whatsoever... We were devastated. We just had no idea."

While the lack of information on drugs played a big part in keeping parents in the dark, so too did their perception that heroin use is a problem that only besets certain types of problematic families. As they did not consider their family to be of this type, they did not believe they could have this problem.

"We don't even smoke in this house. There was never as much as a sleeping tablet in this house. Me and their father spent every weekend driving them here and driving them there. They were never neglected."

Some parents had noticed changes in their children's behaviour, in the friends they associated with or in some other aspect of their lives. While they had begun to be concerned about these changes, they attributed them to the normal difficulties of adolescence. In some of the families included in the research, the drug-using child had had a prior history of childhood difficulties which had been brought to the attention of child psychologists in the past. When their behaviour deteriorated during adolescence, it was seen as a new manifestation of the earlier problems.

"My young fella was always very volatile. Then at this time, he started up again. Up and down all the time, going mad. I did not put all the symptoms together I thought it was puberty."

"When he was 16 I found out he was using heroin. He had been doing stuff before that but I didn't know. I knew nothing about drugs. I put it all down to him doing the Leaving, changing friends, we kinda put it down to his age."

Some parents had been aware that their child was smoking cannabis and in a very small number of cases parents were aware that their child had been sniffing substances. Families had different attitudes to cannabis use: some viewing it as relatively harmless; others unhappy with the fact that their children were smoking but unwilling or unable to intervene.

"Oh, I was terribly shocked when I found out he was using heroin. I would have known that he smoked hash, but I wouldn't of thought of anything else. Absolutely horrific."

"His behaviour had changed. He was back-answering, breaking curfews, rowing with his sister. I didn't know what was going on, but then I noticed he was hanging around with young fellas that were known to smoke hash, so I was a bit alarmed. But I thought it's only hash, it could be worse. I wasn't happy with it, but I didn't know how to deal with it."

While most families had no suspicions at all that their child was using heroin, a small number acknowledged that they had been in denial at this stage:

"In the beginning, we denied it. I denied she was on drugs, I kept saying no no no...before I saw the track marks."

5.1.2 Seeking help

During this phase, parents were unaware their child was using heroin, consequently, they were not seeking help for heroin usage. However, some parents who were concerned about the more general problematic behaviour of their children did begin to look for advice on coping with adolescence and in the context of this general support seeking, they occasionally engaged with sources of information on drug misuse. Three families, for example, had rung a drugs helpline, because they were becoming concerned about the possibility of their child using drugs. In addition, some parents had approached personnel in their child's school for assistance in relation to their child's use of cannabis, again in the context of more generally problematic behaviours. These efforts did not result in a satisfactory outcome.

“Well, he'd always been a bit of a troublesome child. When he got to about twelve there was problems in school, and I realised he had been smoking hash, and had kind of lost interest. I told them that he had been smoking hash, there was a school counsellor but they didn't know how to deal with the problem in the school. They weren't too interested either. So I was kind of let off on my own there.”

“One day he was caught in school with hash, giving it out to the others. I went to the school because they wanted to expel him. I did not want them to do that, I wanted them to bring a drugs policy into the school, where he could go for counselling and we could go for counselling. He could still go on with his education. They would not hear tell of that, they wanted him out at all costs, so he was expelled. It went down hill for him after that.”

5.1.3 The moment of discovery

This pre-awareness phase ended when an event occurred which made it clear to the parents that their child was using heroin. The nature of this event varied quite considerably. Sometimes parents were informed by a sibling of the user or by a friend or neighbour. Sometimes they had been suspicious enough to confront the user. Often, however, the event was precipitated by the user themselves when they told or otherwise made it known to their parents that they were using heroin. This disclosure was usually because the user was beginning to realise the problem had become too big for them to manage on their own; for example they disclosed as a prelude to the arrival of the police at their home, because they had health issues or because they were in trouble of one sort or another with drug dealers.

“He took off his jumper and he started crying and I will never forget the sight I seen in all my life. It was such a shock. I thought I was going to die when I seen his arms, I thought I'd have a heart attack. Me and his father just looked at each other. That was it now. It's clear now, whether you accept it or not.”

Regardless of the circumstances of their becoming aware of the problem, once this had occurred, there was no more ignorance, suspicion or denial. Instead, in the words of many parents, there was devastation, shame, guilt and fear. There was also responsibility: once they became aware of the heroin use, the parents assumed the key role in managing the problem. Their awareness that their child was a heroin user meant that the problem was substantially shifted from the user onto the parents or other carer, precipitating them into the role of coping with heroin use.

5.2 Coping Alone

When they became aware of heroin use in their family, parents were forced to embark upon the process of 'coping with heroin use'; effectively what began as the problem of the user, was now the problem of the parent. However, as they embarked on this process (or journey) parents were hampered by the same lack of information that had characterised and influenced the pre-awareness phase. Specifically, and without exception, parents indicated that at the point of discovery they knew nothing about:

- The uses of different types of drugs
- The effects of drugs on the user
- The behaviours associated with drug use
- The services that are available.

Consequently, parents had absolutely no idea of what they were dealing with and this lack of information and knowledge meant that rather than 'cope' with heroin use, they began to react to it. Again, most had difficulty accepting that their family could be beset by this problem. Combined with their lack of information, this resulted in an intense sense of shame and guilt and a desire to keep the problem a secret. Little or no help was sought from either specialist or generic services, instead parents resorted to a strategy of coping alone, sometimes with support from their extended families. Within this, they engaged in a process of super-parenting in which the normal parenting role became distorted from one of minding the child to minding the habit. Super-parenting also introduced intensified gender roles and brought discord between parents that the user was able to manipulate.

Almost all of the families included in this study spent some time implementing a coping-alone strategy. In just four cases, families avoided this phase by seeking help immediately upon discovering the problem. These were families who had other close family members, or neighbours, who were also coping with heroin and who were able to direct them to the specialist services.

5.2.1 Concealing the problem

The immediate consequence of the sense of shock and shame on the part of families was evident in their initial reaction to the discovery of a child using drugs: to conceal the problem within the family and to deal with it within the family. The result was that they engaged in a course of actions (or non-actions) that resulted in the negative consequences of drug use being reinforced for the user, for themselves and for other family members.

"We didn't know where to turn to, there was never any drugs in my family or in my wife's family and I didn't know anyone in the same situation we were in."

The lack of information on what they were actually dealing with facilitated a naivety on the part of parents which allowed them to believe that they could deal with the situation themselves.

"When I found out that he was taking drugs, I just collapsed. I didn't know what to do, I didn't know what to think. I thought I could handle it myself. I knew it would be a problem, but I thought I could do it, or we could do it."

At the same time, there was a parallel decision to keep the problem secret from those outside the family (and sometimes from others inside the family), reflecting the shame and self-blame that parents experienced.

“When I first found out that my lovely child was on drugs, I couldn’t believe it, he wouldn’t do that, he wouldn’t do that. His father especially, he couldn’t believe it. When we first found out, the first thing he said was, don’t tell anyone, don’t tell anyone.”

“I didn’t know where to turn. Absolutely didn’t know where to turn to. At that time you didn’t talk to your family. I didn’t want to put worry on them. We couldn’t tell anyone, nobody had this problem. It was like a secret shame. You can cope with drink, but drugs was something totally strange to everybody.”

5.2.2 Super-parenting

In keeping with the family turning inward at this point, the focus of the parents was on the user, with an emphasis on minding the user, on minimising the socially harmful effects of their drug use and, naively, on trying to make them better. However, as they invariably knew nothing about the problem they were dealing with, they responded by drawing on the only expertise they had – parenting – and intensifying the only role they knew: that of caring parents. Effectively, they began to super-parent. Far from having the desired effect of minding the user, far less making him or her better, the super-parent role quickly became degraded into an enabling mechanism as parents engaged in a series of behaviours and actions that facilitated and reinforced the problem.

At one end of the super-parenting spectrum was the naïve expectation that they could fix the problem:

“I thought he could just stop, I had no knowledge, I knew nothing about drugs. I hadn’t got a clue about how it affected him. We presumed he could come off it at the drop of a hat. I did anyway. I’d say give that up. I didn’t know what it was actually doing to the body, how he craved it, how he needed it. I just thought we’ll give out to him and he’ll come off it and he’ll be good.”

More generally, there were efforts to appease the user:

“I’d come home from work and he’d be sitting there. He never kept a job down for more than four months. I would try not to upset him in case he’d storm out looking for drugs. For birthdays and Christmas, he still got presents. I remember once buying him a leather jacket. I couldn’t afford it, but it was Christmas and I wanted to show him we still loved him. I bought him the leather jacket. It was gone in two weeks.”

And even to facilitate their drug use:

“He is smoking it now because his arms are so badly abscessed. I have to get up at six in the morning, to help him get it together. It takes him about an hour to prepare it all and smoke it. Then I drive him into work.”

The more extreme end of the super-parenting spectrum was when parents provided heroin or street methadone to the user. This was usually done to deal with a particular crisis or to prevent anti-social behaviour.

“She was really, really, really bad. We got the doctor up and the doctor said that we would just have to go and get her drugs. She was not doing well at all, so we went up to XXX and bought heroin in a flat.”

The super-parenting behaviour of parents reflected both their lack of information on what they were dealing with and their desire to keep the problem hidden as far as was possible. However, the negative implications of this approach was exacerbated by the capacity of the users to turn this situation to advantage by manipulating the parents.

"We didn't know where to go and the house situation was getting worse and worse and me and me wife were at loggerheads with each other and X was in the middle and he was playing me off her and her off me. We were just...we didn't know who to turn to and we were keeping the whole lot from the family."

"When I found out first, I had so little knowledge of it. She told me that if she did not have drugs she would die. I believed her. I got into the car and I drove to Dublin every night and bought drugs on the open market until I copped on. It was wearing me down and it took me a long time to cop on. There was no information, there was no-one to give me information."

5.2.3 Divisions between parents

A notable feature of two-parent families who were reacting to heroin use was the reinforcement of stereotyped gender roles and responsibilities which sometimes led to conflict between the parents. Fathers often exaggerated their role as fathers – becoming more authoritarian, more aggressive and more emotionally distant than normal. Mothers exaggerated their maternal roles, extending their 'caring' beyond all reasonable limits. These intensified gendered roles were of little use in resolving the problem, instead they introduced tensions and conflict between parents as they each implemented different approaches and provided opportunities for manipulation by the user.

"I had a different approach from my husband. He was always fighting and shouting at her. I tried to talk to her, and care for her."

"My first reaction was violence, hitting him, cursing him, calling him all the names under the sun. I realise today it was not because I was vicious; it was because I didn't know how to react."

Often one parent continued to play the super-parent, long after the other had washed her, or more usually, his hands of it.

"I used to get up out of me bed during the night, when me husband would be asleep, and go out and look for her in my nightie with me coat over it...everywhere looking for her. He was at a stage where he didn't want to know her, but I was like a headless chicken running around after her."

In some families, these different approaches caused significant problems between the parents, in others, one parent pulled back allowing the other to 'get on with it'. In the case of a small number of families interviewed, one of the parents moved out of this coping alone phase more quickly than the other one. This usually occurred when one parent made a decision to seek help for themselves or for the user while the other parent felt unable to take this step.

"My wife is a strong person and she was involved in adult education for years and had a lot of contacts. She knew where she could turn to for help for herself and for me, but I turned it down."

5.2.4 Support seeking

Within this way of engaging, parents were attempting to deal with the situation themselves, consequently there was little or no support seeking. Exceptions to this was when a health crisis precipitated medical intervention. Apart from this, the limited support seeking that took place during this phase was confined for the most part to looking for help in implementing their super-parenting strategy. Sources of support that parents turned to during this stage were more likely to be informal sources. In some instances, drug users were a source of information for families.

"His face was all swelled up. I didn't know what was wrong and I couldn't trust him to tell me. He'd a said what suited him. I asked another drug addict I know from around and he said that happens sometimes from some drugs".

"I use to go to xx to buy heroin for him. I got the address off a user."

Extended families were also a source of support at this point. Although many parents or carers did not divulge the problem to their extended family for a considerable time, when they did, they invariably received support.

"I told me family, I didn't care, but all my family were brilliant. They were more concerned for me."

Sometimes, however, the extended family assumed the super-parenting role and the support provided allowed the behaviour to be displaced to a different setting:

"I decided to send her to her uncle in Mayo, just to get her away from everything. But sure she was as bad down there. I used to go down during the week to visit her, but she was as bad down there. Back to the normal thing, stealing from the uncle..."

At this early stage in coping with problem drug use, displacing the problem to a different context did offer respite to the families. However, it also meant that the extended family who were involved in providing support also became victims of the user and in the longer term when parents learnt to manage rather than react to problem drug use the extended family often misguidedly continued to facilitate the user, undermining the families' strategy.

5.2.5 The end of coping alone

Parents usually abandoned their go-it-alone strategy when they realised they could not help the user on their own. In general, families had already experienced a very significant degree of difficulty and the drug problem itself had worsened considerably by the time they realised that they needed help. Sometimes it was an impending crisis that drove the first serious effort to find help, often from the specialist services.

Judy had been looking after her drug using son for about two years at the time of the research. During this time, she had sought very little help for herself or her son, believing the best thing was to try to look after him herself. At one point he spent several days in intensive care due to drug use. At another point he spent time in prison due to drug-related crime. He was released from both the hospital and the prison without follow-up support. After his release from prison, he resumed using heroin. His mother financed his habit, running up huge bank debts in the process. Finally, she began to seek help for her son. The only option she could find was a methadone maintenance programme. She had concerns about him going on methadone, but given his physical condition and her financial situation, she did not think there was any choice. At the time of the research, he had been about two months on a waiting list. Judy was very hopeful that the methadone programme would sort things out.

5.3 Desperately Seeking Support

The defining characteristic of this third way of engaging was that parents or carers now began to look for help and specifically help for the user from the specialist drug services or from other non-specialist services. While implementing this way of engaging, parents were still largely ignorant both of the effects of drugs on the user and of the different responses to heroin use that are available within the treatment system. Some parents or carers had picked up bits and pieces of information along the way, but in general, families did not have a coherent overview of the problem they were dealing with. In addition, they continued their super-parenting into this phase and continued to assume responsibility for dealing with the problem. Consequently, often, though not always, it was the parents rather than the user that initiated and continued contact with the treatment services.

As already noted, a small number of families sought help immediately upon discovering their child was on heroin, but most did not. For the latter, by the time they entered this phase, the situation in the family was often quite problematic on a number of fronts: parents were experiencing high levels of stress and physical and mental exhaustion; other family members were also suffering, sometimes quite significantly; conflicts and tensions within the household and especially between spouses were becoming more pronounced; financial pressures were becoming difficult; and often the users themselves were experiencing serious health problems or other threats to their well-being. Consequently, as they embarked on the process of seeking help, the level of need on the part of the family was very high.

In this context, initial attempts to seek specialist help were often precipitated by a health or other crisis on the part of the user or more generally by deterioration in the overall situation such that families realised they could no longer cope on their own. As a result, when they started looking for support, they were seeking whatever help was available rather than seeking a specific response or intervention. This has a significant implication for families' capacity to assess the effectiveness of the supports or services they received: because they were desperately looking for any help that was available, they tended to perceive almost any type of response as positive. Any support that was provided to the user took some pressure off them, hence families tended to see it as good even if it was not effective.

In so far as there was any specific aim behind the support-seeking strategies of parents it was that the problem would be fixed i.e., that their child would stop using heroin. Some did, usually only for short periods, but most didn't. The result was that the efforts on the part of the family to seek help were repeated over and over again, as they went from one agency to another over, for what was for many, a very lengthy period. If confusion and naivety were the key words of previous ways of engaging, then those of this way were despair and desperation.

5.3.1 Seeking support

When parents began to actively seek support for their child they operated with the same lack of information which had characterised the earlier phase. Many naively believed that having been unable to cure their child themselves, they would now find some agency or service which would cure him or her. In retrospect, parents could recognise this delusion:

"I had no knowledge. I hadn't got a clue. We presumed he could come off it, with the doctor's help. I didn't know what it was actually doing to the body, how he needed it. I just thought, he'll come off it."

Some of the families were well past this stage at the time of the interview and their comments, like the one above, were informed by the greater awareness they had acquired in the intervening years. However, a number of families were interviewed at the point where they were just beginning to seek specialist help and from their stories it was clear that the idea that a quick cure is available still prevails.

“He’s down now to go into Y as soon as he can get a place. Please God that will be the end of it, because we are worn out looking after him.”

“He is very bad now. He is smoking now because his arms are so infected he can’t inject. He’s on the waiting list now for a methadone programme so hopefully that will be that....”

Once they decided to seek help, people turned initially to a wide range of sources. These included drug counsellors, generic medical services, and prominent people in the locality, such as priests or even politicians. The outcome of this initial help seeking was very variable and the inadequacy of the response from some sources highlights important issues for the provision of services for families.

5.3.2 Specialist services

In general, those who approached the specialist services – specifically drug counsellors – received the most adequate help, both at the point of initial contact and subsequently, and this help included assistance for both the carer and the user. Amongst these were families who had sought help early on and who had been directed to drugs counsellors by family members or others who were themselves dealing with drugs. While the ultimate effectiveness of this support for the user varied, the fact that the counsellor acted as an ongoing point of reference and advice was valued very highly by families.

“About two years ago, I found out the son was using heroin. I made him come to the local drugs counsellor. He was great, he advised me. I have to thank him. My neighbour, who’s child is on heroin told me about the counsellor. He saw me and the wife together. We brought the son later. He got him into XXX, a residential place.”

“I noticed the track marks on her arms. That’s how we found out. From there we tried to get her help. We brought her to a drugs counsellor that we knew and she got us help. My sister worked in the family centre and she got me in contact with the drugs counsellor. I used to bring me daughter down to her every week. She got a bit of counselling and the counsellor got her into XXX.”

5.3.3 Non-specialist supports

For families who approached non-specialist services, mostly their local GPs or hospitals (in situations of crisis) the outcomes were much more variable. Some did receive very effective assistance, but most were disappointed or even distressed by the response from these services. In fact, the likelihood of receiving effective help from the generic medical services were on a par with that of receiving effective help from prominent people in the locality, such as priests or politicians.

“First we went down to the local doctor and she advised us, and she was great, couldn’t say a thing about her, from that day to this. She looked after him. She was fantastic, she was the first person I went to and I would give her 100 out of 100. She referred us to X and referred us to the counsellor in the XX.”

“We went to the priest thinking he would steer us in the right direction. What he was telling us was rubbish. It was no help whatsoever. We went to our doctor. He hadn’t a clue, no idea.”

"I went to my local doctor, I just wanted to know what to do. He just said to me, some kids turn out to be scum."

Those who approached hospitals for support had similarly mixed experiences. If they approached with a crisis, that was addressed but the user was discharged without follow-up or referral. Sometimes, however, there was a complete failure to respond, which threw families back onto their own resources:

Respondent: *My husband got an appointment for him in the (local hospital) and they said he wasn't bad enough to help.*

Interviewer: *You mean he wasn't bad enough physically or in terms of the addiction?*

Respondent: *I don't know, that's all he said. We felt just completely alone. We tried a few detoxs, I even bought methadone on the street.*

Interviewer: *What put that into your head?*

Respondent: *Sheer desperation, sheer desperation.*

Interviewer: *And how did you know how much to use?*

Respondent: *Just from talking to addicts...*

The inadequacy of the response which families received from the non-specialist services meant that they experienced further delay in getting appropriate treatment for their loved one, which further compounded the negative implications of the time-lapse between the commencement of the problem and the decision to seek support.

5.3.4 Interaction with treatment centres and programmes

Eventually, almost all families came into contact with the treatment system. The exception was a small number who were in the very early stages of coping with heroin use at the time of the research. Once they made contact with the treatment system, the families became embroiled in a repetitive process whereby they sought or facilitated the user to seek access to a treatment centre, they tried to support the user in treatment and when it did not work, which was very often, they picked up the pieces and started over again.

For the most part, the pattern of interaction with specialist services now took the form of a protracted series of contacts with different treatment centres in different parts of the country, interspersed with interactions with other services, principally drug counsellors and personnel within the Criminal Justice System. Most families had such extensive experience of the treatment services that they could barely recall the details. What they were clear about were the problems that arose for them as they tried unsuccessfully to get help for their loved one.

"We brought him down to X. He would have been about 19 or 18. Off we went, brought him down in the car. He went down there, six weeks later he ran out. We used to go down once a week and bring him cigarettes and toiletries, give him a fiver. We went down one week and he was gone. We didn't see him for two days. I thought he was dead. But in anyway he came home, just himself, with nothing, everything gone, sold and back to where we originally started. That kept going on and going on and we'd do our best and try helping and then there'd be murder in the house."

The prolonged period of contact with treatment centres stemmed from two different factors. On the one hand, there was the tendency for drug users to either abandon treatment without completing it, or to relapse back into drug use shortly after completion.

"I went to the drugs counsellor and he said to me would she go into residential. He rung up and he got her in. I was delighted. She was detoxing but one day she ran out, but we got her back in again. She stayed that time and got herself clean. She came out and she was beautiful, she was detoxed off everything. Then she went back on everything again. It was like being in hell and back."

"He was in a residential unit for 11 months. He was out and got an interview for a job in Dublin. He came up to Dublin on the bus, and he was only back one hour and he went back on drugs, after 11 months. That was the first relapse. It was hard. But the next time it was easier."

As a result of this, what families had hoped would be the solution to their child's drug problem and the associated behaviour, now became absorbed into the problematic behaviour. Consequently, rather than finding the solution they had sought, now the family was having to cope with the user, the heroin problem and the series of interactions with the treatment centres.

The second factor driving this dynamic was the manner in which the treatment centres themselves operated. The plethora of treatment centres that exist throughout the country are effectively stand-alone agencies, each operating within its own philosophy, providing specific services and with largely self-determined eligibility criteria. From the point of view of each individual agency, this is no doubt a coherent and rational *modus operandi*. However, from the point of view of the families who engage with the multiplicity of agencies, it presents a complex and fragmented interface with which it is extremely difficult for families to engage. This causes confusion and frustration to family members and adds to their burden of care. Again, the result is they are often thrown back on their own resources.

"I was trying to get him into X and I brought him nine times to see the doctor there. On the ninth time, I went in and I asked what he could see in my son that I could not see, that he would not take him in. All he would say was bring him back in two weeks. I started crying, I was in the bottom of a big black hole. I said what am I going to do now, I thought I'll give him money for heroin and that will keep him going. We went off to Dublin to get the heroin."

During all of this, the parent or carer tried to cope as best they could, usually continuing the 'super-parent' role – organising appointments, driving the user to treatment centres and clinics all over the country, pleading with treatment centres and other services to do something and when all that failed, picking up the pieces all over again. Despite the lack of success in bringing about a long-term abandonment of heroin on the part of the user, families were uncritical of the treatment centres. The main reason for this was that they appear to attribute all responsibility for failure to the user.

"I sent her here and sent her there and sent her into residential care a few times, three or four times, into various places without any success. She would come back home and it would be the same carry on again. I suppose if the people you are dealing with aren't going to do something about themselves, you can do nothing."

"She went to X for twelve months and came out as bad as she went in. They tried hard."

The ongoing interaction of users and their families with the treatment centres, often over many years, added very significantly to the level of stress experienced by families. This in turn was exacerbated by the fact that the drug problem itself often deteriorated while families were desperately trying to find a source of support. In this context, this way of engaging was one of the most negative and problematic for families.

5.3.5 Constancy of support

For some families the difficulties associated with coping with heroin use and coping with trying to find services for the user were ameliorated somewhat if they had a constant reference point to which they could turn for support or advice for themselves or for the user. One such reference point was provided by drug counsellors and for families who had approached these in the initial stages, they did act as an ongoing source of assistance, although this was usually intermittent rather than constant.

“The Drugs Counsellor was very good. I could ring her anytime. She was always there.”

In those areas where CDTs exist, these too acted as an ongoing source of support. In particular, the key-worker model implemented by the CDTs was seen as very helpful in providing families and carers with an ongoing point of contact to which they could refer.

“It’s much better now with the CDT. It’s much quicker, there’s no going from place to place and crying and all this. Their priority is the user. The CDT is there for them during the week, they can go in and learn and they can do courses. X has done a lot of courses there now, because a lot of the time they don’t even know about the drugs themselves.”

While the CDTs’ primary focus is on the user, they can also provide a range of services for families and can assist in supporting families manage their interaction with the drug user:

“He’s with YY in the CDT. She was instrumental in getting him into the XX project. She did a lot of work to get him in there, but then he didn’t go. I meet him now at the CDT, because other times I met him he was aggressive. So now I meet him there with his project worker.”

A further, more unexpected source of constancy in support was that provided by personnel within the Criminal Justice System. Approximately half of the families involved in this research had involvement with the Criminal Justice System (primarily where the user was male) and particularly with local Gardaí and probation officers. In most cases, families did not seek support from these sources, but had it imposed upon them as a result of their child’s criminal activity. However, once the contact was made, probation officers in particular proved very helpful to families. Local Gardaí were also considered helpful, particularly in rural areas.

“The probation officer would make a recommendation (to the court), she’d be talking to me like and she’d be listening to me. She really is excellent. She comes here to visit X and he has regard for her.”

“I rang the arresting officer. He was fantastic. He would come to court when I was there. He was friends with the Probation Officer. They were so good, they would ring me up and say he’s doing fine. Even the guards were the best counsellors ever, they would say to him: “we know how things are, you will get through this, you will turn everything around, you are so bright.” They were great, that’s what he needed to hear. Locally, everyone thinks they (drug users) are scum.”

5.3.6 The end of desperately seeking support

For most of the families included in this study, it had taken many months for them to approach services to seek help. When they did take this step, however, their efforts to seek help were frequently impeded by the inadequacy of the response they received. Consequently, even more time elapsed before their loved ones were provided with any form of specialist support. However, this did not resolve the problem, instead the fragmentation and lack of integration within the treatment system presented more problems for families, hindering their capacity to locate appropriate support and adding to their experience of stress. In this context, sources of support that provided consistency of contact, even if they did not actually resolve the problem, were highly valued.

For most families, this way of engaging prevailed for many years, often with the situation deteriorating rather than improving. It ended only when parents or carers began to learn about the problem they were dealing with and about more effective responses to it. This learning characterised the fourth way of engaging.

5.4 Supported Learning

In contrast to the reactionary ways of engaging that characterised families' initial responses to the problem of drug use, supported learning is a reflective way of engaging where they had an opportunity to learn about the problem, to consider a more effective response to it and, crucially, to begin to look after their own needs. The key intervention that enabled them to take up this way of engaging was the provision of information in a supportive environment and the key providers of this were Family Support groups. The defining characteristic of Family Support is that it is focused on the needs of the family and not on those of the user. More specifically, it is focused on making the family aware that they have needs that are separate from those of the user and that these needs must be addressed. Consequently, the parental ownership of the heroin problem that characterised the previous reactionary ways of engaging was challenged.

Although Family Support has a very unified focus, in practice, it covers a number of interventions. The full range of Family Support activities that families were involved in across the three study localities comprised counselling, peer support groups, outreach, educational programmes, therapeutic interventions and recreational or respite interventions. These interventions were delivered in various ways, to individuals or to groups, in community settings or in the family home, in very informal ways or in structured ways. Some families or carers preferred one-to-one support, others preferred peer or group support. An important part of Family Support was that families were not just provided with information, but with the support to enable them to make use of that information to improve their own situation. There were also very significant differences between women and men, most notably in relation to their initial willingness to become involved in family support. Women were more likely than men to avail of family support and consequently, in two-parent families, the parents were often at different stages and different levels of awareness in terms of the way they could accept or deal with the problem.

5.4.1 Finding supported learning

At the time of the study, all those involved in Family Support were participating in community support groups rather than support groups linked to treatment centres. Most were seeking Family Support in their own local areas, however, a small proportion were travelling to other areas – some because there was no Family Support available in their own area and some because they preferred to go to localities in which they were not known.

Families initial engagement with family support occurred at different times in their 'journey' and took very different forms. A very small number found their way to family support very quickly, others spent many years in turmoil before they discovered it. Some had had brief encounters with family support groups which did not engage them fully but had later found other family support interventions which they could engage with. In general, while family support linked to treatment centres was often instrumental in introducing families to this type of intervention, it was usually community-based family support that enabled them to avail of the various support services in the longer term.

Where families linked in quickly to family support, the main factor in this appears to have been that they knew somebody who was involved in family support. In urban areas this was usually a friend or relative. In the most rural area in the study, it was linked to the visibility of the family support group, and particularly the visibility of a number of parents who had spoken out on drugs in the area.

For families that did not link into family support quickly – and these were the majority – acknowledging their need for help for themselves was often difficult. One woman who had benefited from family support and who had since gone on to become very active in providing family support in her own community, succinctly captured the 'journey' that many families had to make before they reached family support and their difficulties in coming to terms with the information and learning they were now receiving.

"That's the sad thing about it, the horrible thing is that you have to go that road. You are suffering in silence in your own home for so long and you're trying to cope and you're trying to get your children well and you're trying to show the world that everything is fine, we are coping, we are grand, there is no problem in here. The first step is looking for support, that's the hardest step you take. You're admitting you have this big problem, that you can't cope, that you need help. The embarrassment of it, the shame of it, the loneliness, people look down on you, all these things are all in you. When people go to the support group first, they think the problem will be fixed, they'll say, when will he get well, will he get well next week. We'd say, if we had that magic answer none of us would be here. It's very hard to get the message across, but when you are feeling well yourself, you can hear that message."

In their first approach to family support, families often had no real expectations of what sort of benefits they might find. However, once they did engage with family support, parents and carers tended to become regular users and to benefit from a wide range of interventions.

5.4.2 Participation in supported learning

The most frequent forms of family support availed of were the following:

Information/educational programmes

Lack of information was a major factor in inhibiting parents' capacity to respond effectively to problem drug use. Once their need for information was addressed, they began to acquire the resources they needed to develop a more effective response.

"We went to YY and there was a woman there and she was able to tell you the ins and outs and the facts and then we did a weekend with them and that was the beginning of the learning."

Pursuing information and education took different forms for different people. Some were content with the information the support group could provide, others went on to participate in a range of training and educational programmes.

Peer support groups

The most frequently used form of family support was peer support groups. These were mostly local, although some people did travel to other areas due to necessity or preference. Most support groups were convened on a weekly or fortnightly basis. Most were resourced by a facilitator, but in all cases, the involvement of families in similar circumstances was a huge factor in their impact, both during the group session itself, and subsequently.

"The support group was excellent. There was a very good facilitator. When I went initially, it was dreadful talking in front of people. But then I realised we were all in the same boat. You get a lot of feedback at the support groups. You realise you are not alone."

"I wouldn't be without the support group. I wouldn't be without the guys. I know I only have to pick up the phone and one of them will be there for me."

Most of the men interviewed for this research were involved in support groups specifically for fathers and expressed a strong preference for single sex groups.

"We went to one family meeting, but I didn't feel right. We went to a few meetings in X but I didn't feel I could express meself. If me and me wife were fighting when we went to the meetings, I didn't know whether to bring the argument out or keep quiet and not upset the apple cart. Our relationship was intertwined with the kids...if we talked about them...our relationship would come up. I found the men's group helped...I could say things without upsetting me wife...she used to go to the meeting for the women and she could say what she wanted."

Most of the women were also involved in single sex groups, but that tended to be because they could not get their husbands or partners to come along, rather than because this was a preference. The different levels of involvement of mothers and fathers in family support often meant that in two-parent families, one parent (usually the mother) began learning a more strategic approach to managing the problem than the other, although sometimes, women carried the message of family support home to their husbands or partners.

One-to-one support

One-to-one support was also a significant feature of family support, usually provided by a family support worker, some of whom were volunteers. For some families, one-to-one support was combined with their participation in the support group, for others it was the only element of family support they availed of. In some families, both parents had one-to-one support and sometimes had joint sessions with the family support worker. In a small number of cases, siblings of users also had one-to-one support. Outreach is also a dimension of one-to-one support.

"Only for X I would go mad. She helps me so much. I find her wonderful."

"I didn't want to know and I was drinking meself to death you know. Me wife got in touch with a friend of hers and the family support worker came out to me. He actually came out to me to the house. He is fantastic. He is. If he said to me, jump off Liberty Hall, I'd think about it. That's how much respect I have for him."

"I just come to see X. Whether we come together or one to one, it's fantastic. We really came for ourselves because we were breaking up. But now we get loads of help from him."

Recreational and therapeutic inputs

The benefits of recreational and therapeutic inputs and activities were also referred to by families. The extent to which family support groups could provide these opportunities depended largely on the funding available.

"Now we do a fun activity once a month, away from everything. This month we are doing pitch and putt and we'll have lunch. Last month we did art. And we went away for a respite weekend, it was lovely. Some of the people do be very stressed, some of their stories are very sad. I'm a little bit up the ladder so it doesn't hurt me as much, but some of them are only beginning to realise the problem they have."

Challenge of different personal preferences

Being able to respond to individuals' readiness to avail of Family Support is a particular challenge, as is meeting the different personal preferences. Some families perceived an imbalance in the interventions they received:

"The advice was to put him out of the house, there is nothing else you can do. That is what I did in the end, but I felt I should have been counselled, you need to be listened to, you cannot just be told you have to throw him out."

"I felt I was mollycoddled in the support group, you need to be told what's what."

5.4.3 The impact of family support

While there was considerable variation in the type of family support availed of by parents and in the mechanism of delivery, there was a very high level of consistency in terms of the benefits derived. Among the most important of these were:

The release from stress afforded simply by being able to express their feelings:

"The support group was a place for me, where I could go up and say I had a terrible week, I hate my husband, I hate my child. It was a safe place, you knew that people felt the same way, you needed to be able to get your feelings out and the fact that people could talk about their experiences, that was a great learning process for me."

The realisation that the problems they were experiencing were affecting other people too:

"I went on my own. My husband wouldn't go. It was good, very good. That's how I am, where I am today. I found the family support great. It was great. I was new. A lot of the lads were a lot older than my young fella. When you're listening to all the stories... where I lived, heroin was not heard of, and my neighbours were horrible, horrible to me, because my kid was on heroin. It was a great help for me because I could understand where people were coming from."

The awareness that they could not fix the problem and were not to be blamed for not having fixed it.

"What do I get from family support? I suppose realising that my kids have a problem and I cannot do anything about it. Accepting that, accepting that there is nothing I can do, that nothing will help if they don't help themselves."

Being able to recognise their own needs:

"Through the support group you learn how to look after yourself. And when I started to look after myself, I was able to take back control. We learned how to say no. Now it was an awful hard life, I'm glossing over it, but at that stage it was a nightmare. We didn't know how to cope."

Most important of all, perhaps, was the extent to which family support enabled parents to begin to deal constructively with the issue.

"I was goin' up and down to the family support group as well as doing the parenting course. One thing was supporting the other, I was learning how to develop a framework for my family to work from and to give me the confidence in my parenting and to set the consequences for his behaviour. He knew what the rules were, he agreed the consequences, some of the time, so that gave him responsibility for his own actions. That gives me freedom as a parent, I wasn't the baddie. That was liberating for me. It took the whole guilt thing off."

Family support, more than any other support, conveys the message that the parent or carer cannot change the behaviour of the user: only the user can do that. The implication of this is that the parent has to stop doing what they have been doing for years – reacting to heroin use – and instead, have to develop a new way of managing it. This means ending the 'caring' role they had deployed for so long. This was a very difficult message for parents to accept and it invariably took some time for them to fully accept it.

"You just cannot let go like that, you have a bit long journey to do, I've had an eight year journey."

5.5 Reclaiming the Family

The key message that Family Support conveys is that parents or carers must reclaim the family from the negative dynamic of heroin use. When parents heard this message, and acted on it, they moved into this fifth way of engaging. They were equipped with information, they recognised manipulative behaviour, they stopped the 'super-parenting' that had characterised earlier phases, they stopped enabling drug use and they began to disengage from the user. From the earlier ways of engaging, where they had been reacting to the problems caused by the heroin users' behaviour, they now began to take a more strategic approach.

Parents or carers frequently began the process of reclaiming their family as the result of a fairly mundane incident: they had simply become worn out from the problems they were encountering both with the user and with the ongoing interaction with treatment centres. For most parents, the starting point to reclaiming their family was realising that there were other needs to be addressed than those of the user, including their own needs. To put that another way they began to realise that the needs of the user were not the needs of the family. Effectively, at this point they began to dismantle their previous practice of allowing the entire family dynamic to revolve around the heroin user and they began to isolate the user.

This process started with the parents or carers taking back control of the family situation, interrupting the cycle of manipulation that the user had established, passing the management of the drug problem back to the user and distancing the user, physically, socially and emotionally. This usually meant putting the user out of the family home, often resulting in their living on the streets.

Distancing the user in this way was a process rather than a once-off event and carers, particularly parents, found the process extremely difficult. In families where the drug user was a daughter who had had a child, the process was even more problematic. In such cases, parents were torn between trying to withdraw from the negative dynamic of their daughter's addiction, while still providing support to her child or children.

Because they had handed responsibility for the drug problem back to the user, parents or carers had little or no contact with the treatment services at this stage. They did, however, have extensive contact with Family Support and, to a lesser extent, with drug counsellors and with Community Drug Teams in the areas where these exist. The support from these sources was hugely instrumental in enabling parents and carers to begin the process of reclaiming their family and to persist with it over time. However, families trying to reconcile care of their grandchildren with a more strategic and effective approach to responding to their daughter's addiction came into contact with other support services and these were less favourably assessed.

5.5.1 Taking back control

The negative dynamic of drug use that families had experienced meant that parents invariably prioritised the needs of the user over their own needs and, usually inadvertently, over the needs of their other children. Drug users had been able to manipulate this situation to their own advantage, resulting in their parents unwittingly facilitating their drug use. The preliminary step for families therefore was recognising that this had been happening and beginning to take steps to redress it.

"I made up me mind: there is two ways of doing this – if I keep looking after the habit, it's not going to go away. If I quit looking after the habit, it might be better."

5.5.2 Handing back responsibility

At the outset, when parents realised that a family member was using heroin, their initial response had frequently been to assume responsibility for the problem and it was in this context that they established the practice of super-parenting. Once they began to understand the problem they were dealing with, to understand the nature of addiction, they accepted that they could not bring about any changes in the users' behaviour and that the user would have to assume responsibility for this.

"The things you done because you wanted to see your child well. Buying heroin for them on the streets. People would say, are you mad, mad? But they didn't have to look at their child dying in front of them. When you think of the depths you go to get your child normal. Would we do it now? No, today I wouldn't. He'd have to do it for himself. I've given it over to him, I've handed it all back to him."

"One day I got a phone call. Dad, I'm coming off drugs. I said that's your business not mine. If you're quitting, go and get yourself in someplace."

5.5.3 Distancing the user

The next logical step was to ensure that any negative implications that resulted from the choices the user made were experienced by the user, rather than the family. Parents now began to distance the user from the family. Sometimes this was a physical distance, where they put the user out of the family home. Sometimes the parents were willing to allow the user to remain in the family home but under strict rules, however this often precipitated the user leaving of their own accord. In two-parent households, there was frequently conflict between the parents when they took different approaches to this. It is telling of how difficult this stage is for parents, that while they often had difficulty recalling the facts of their interactions with support services, they had no difficulty in remembering their emotions at this time.

"Then one day he was going out and he said he'd be back in a bit and I said bring your things because you won't get back in here. We fought and he went off and didn't come back. And I was heartbroken, I couldn't stop crying. I thought my heart was breaking."

"One morning I heard him coming home about 5 and it was black dark. He was knocking to get in. We had decided at this stage that he wasn't getting in. So he was banging and banging and we never answered the door. My husband said, let him in, just let him in. I said no. I can remember looking out the window, seeing him walking up in the black dark and thinking I don't know where he is going, I don't know what kind of trouble he is going to get into, I don't know if he is going to survive the night. It was horrible, horrible."

In some instances, putting the user out of the home had an immediate positive impact on the behaviour of the user.

"It was amazing. It felt as if the two of us had reached a new level. I could have a conversation when I met him, but then walk away. I was accepting him at the level he was at and walk away. I think that made a difference, because I gave him complete ownership of what he was doing."

"When I really changed, she changed. That's when she moved on."

This was not always the case, however, and a number of families had to accept that their decision to let go on its own was not enough to influence the user.

“He’s on everything now. He’s taking heroin, he’s taking coke, e, everything. I threw him out of the house about 8 weeks ago. I couldn’t take it anymore. He’s living in a hostel in town now.”

Not all families, however, were in a position where they could distance the user, even when they wanted to. Families where the drug user was a daughter and where she herself had had children, invariably found themselves providing at least some care to these children. Consequently, they had to reconcile managing their way of engaging with their daughter’s addiction with caring for her children. Likewise in families where the user was HIV positive, it was necessary to reconcile the twin objectives of more effectively managing the problematic behaviour of the user while also continuing to extend care to him or her.

5.5.4 Support during this phase

Because they handed back responsibility to the user at this stage, families interaction with treatment services or most other sources of support was very limited within this way of engaging. The exception here was Family Support, drug counsellors and in those areas where they exist, the CDTs. In all cases, the most important support derived at this time was in relation to maintaining the new approach.

“He’s been texting saying if he could come home and had his nice house, he’d get off the drugs and get a job. But I’ve heard it all before. There’s a parent support group, once a week, that’s great. They give me the strength to keep on going. I am seeing a counsellor too. The good thing is she’s free because I paid a fortune before. She said I was right to throw him out, that I had to think about myself as well. Because I’d be terribly stressed and she tells me to let the stress out. The CDT also have a massage once a week and that helps with the stress a bit.”

Several families included in the study were actively providing support to a grandchild or grandchildren. In just two cases, the grandparents had formal custody of the children and had raised them from infancy. In other cases, the children were still with their mothers, sometimes, but not always, in the family home. In these cases the parent or parents had great difficulty trying to break the negative dynamic of their daughter’s drug use while also extending some care to the grandchild. The gravity of the situation required a level of practical response that families had not encountered.

“I tried to get her a place of her own, because she has a little baby. She was getting aggressive. I said to her you’d be better off in your own place. We’d visit you and make sure you’re happy and the baby’s happy. But the social workers won’t let her move out of the house because of the child. Now they are saying that she can’t stay on her own in the house and they want me to give up work. They say they’ll take the baby if I don’t give up my job. I’m in a state now. I talked to the support group here. It’s very serious. I will sit down and talk to her key worker. My head is wrecked.”

“We had everything to show we were minding the child, but we couldn’t get child benefit. We never claimed for the child, we didn’t know about it.”

Families whose child or children were HIV positive also encountered difficulties in terms of the longer-term implications of providing care in the context of insufficient practical support.

5.5.5 Distance, not abandonment

It is important to stress that even when parents put the user out of the family home and insisted that they take over the management of their problem, this did not mean that they withdrew all support. On the contrary, families continued to be willing to provide support to the user, but now it was conditional on their following a certain course of action. Once the user accepted the need to do something about their drug use or at least to protect the family from the impact of their drug use, parents were prepared to provide all the assistance and support necessary.

“That way I was able to detach and give him ownership. He knew he could talk to me if he had a problem, that I wasn’t going to lep down his throat. I just kept giving it back to him the whole time: it’s your choice, if you want it to change, do something. I will give you a hand when you decide what you want to do.”

5.6 Supporting Recovery

This is the final way of engagement in coping with problem drug use. It was the aspiration of all families that their drug-using child would abandon heroin use and many did, albeit after years of difficulty. In all cases families were involved in supporting the recovery of the user. That is, they were involved in assisting the user to move on to, and maintain, over a period of years, a heroin-free lifestyle. For most of those who reached this stage, this meant methadone maintenance, often over prolonged periods. For just five of the users included in the study, it meant a drug-free lifestyle, usually also after a period on methadone.

The majority of the drug users who did maintain a heroin-free lifestyle over a number of years had had many previous unsuccessful experiences of trying to give up heroin use. Just as coping alone and desperately seeking support can be seen as a continuum along which families may move back and forth, so too are reclaiming the family and supporting recovery. The distinction between this way of engaging and other efforts at recovery described earlier is that (a) the user is ready to take serious action to address their problem and (b) the family is in a position to provide real help. Parents and carers now had enough information and understanding of the problem of drug use to be able to support and assist the users in implementing their decision to stop heroin use.

At this point too, carers or parents were more likely to have an understanding of the process of recovery and consequently they were willing and able to play a role in supporting this process. As they had also handed back responsibility for managing the problem to the drug user, it was the users who were responsible for contacting treatment centres, turning up for appointments, ensuring they met the eligibility criteria and so on. However, at this point, parents and carers were also willing to re-engage with the treatment services as they sought to provide emotional and practical support to the users who were receiving treatment and who were on methadone programmes.

Notwithstanding the families’ own perceptions of their changed role in relation to the drug user and the treatment process, this did not appear to be acknowledged by the treatment centres. Families perceived that they were not being provided with sufficient information on the treatment options available, that they were not being kept sufficiently informed on the progress or well-being of their loved one, that opportunities for involving the family more closely in the process of recovery were not being availed of and that the families’ or carers’ roles in providing support to the user during recovery was not acknowledged.

5.6.1 Re-engaging with service providers

For most of the users, the decision to do something about their heroin problem involved a period in a residential treatment centre. Sometimes, they re-entered a centre they had already spent some time in, sometimes they went to a centre they had had no previous contact with. The duration of their stay varied quite a bit – from a few weeks to several months, and the approach to withdrawing from heroin also varied – from a methadone-based model to a drug-free, therapeutic model. An additional variation across the range of treatments was the availability of aftercare. In some instances no aftercare was provided, in some cases there was provision for aftercare but there was no guarantee of access, while in still other cases there appeared to be a smooth transition from the primary service to follow-up support.

While their family members were in treatment centres, families played an ongoing role in providing emotional and practical supports. Most, however, were prepared for a greater degree of interaction with the treatment services, and a greater level of involvement in the care of the user, than was facilitated by the centres.

"We did not have enough contact. There should be more done with the family. For years, I did not know how to talk to me kids. I could roar at them, but I couldn't talk to them. But there's a chance when your son or daughter is in treatment, in counselling, seeing someone. If they had their father and mother there to talk to them and to be able to discuss how they're hurting them. When they're vulnerable and opening up themselves, they might see that they really are hurting you. They should have something there for families."

"Nobody from there approached us or came near us. A few times, I rang to speak to the nurse, but the nurse wasn't there. But they don't deal with the family there."

When the carer was not a parent, but a sibling, the lack of engagement with the treatment centres appeared even more marked.

"Everything they did was confidential. There was nothing for the family. We could not ring them, they would not tell us anything. We did not know if he was using or not. They would not tell us if he was failing the tests. The other part was that being a sibling, I found it terrible. People feel that parents are more entitled to know what is going on. When you are a sibling it's a different story. It is terrible for siblings."

"I think a lot of people don't believe that a sibling is that interested in helping the addict. A lot of people also judge the parent – they say where is his mother?"

The lack of interaction between service providers and families is not confined to treatment centres. Families noted also that drug counsellors, who were valued as an ongoing source of contact, were just as unlikely to acknowledge that sometimes families can extend their supporting role into one where they can make very strategic and effective choices for the user.

"The court ordered probation and methadone. The methadone programme was monitored but I made him go back to the drugs counsellor as well. I knew the counsellor would not interact with me, but I was happy because the probation officer was so good. When you are kept involved you have more faith."

5.6.2 Methadone maintenance

For most of the users who stopped using heroin, methadone programmes played a role at some point – either following a stay in a treatment centre or separately from the treatment centres. The issue of methadone maintenance was problematic for parents in a number of ways. Often, families were content that their children go on methadone programmes because their behaviour was so chaotic, or because their health was threatened. The decision to opt for methadone was therefore more to deal with the specific and acute problems they were dealing with at the time, than a thought-out strategy to intervene in the best way possible in their child's problem.

“It did stabilise him, he wasn't out robbing, at night we weren't saying “where is he, where is he?” If he took the methadone, it was holding him and he was grand. In those days, it was your one aim to stabilise them. I did not even think about counselling.”

However, in retrospect, many families acknowledged that they had not been made aware of the long-term implications of methadone maintenance.

“They did not discuss putting him on methadone with us. Nothing was explained to us. There were no options. Methadone was it.”

“Well, he went out robbing. He was always robbing. We had problems before he went on methadone. He was only a child, for 12 months non-stop, he went on a robbing binge. But when he went on the methadone that all stopped. But I don't like him being on the methadone. I don't know why there isn't something else, cause it makes them stupid. It keeps them out of prison, but it does not help them get better.”

“We don't discuss his programme very much. He is on carry-outs because he has had no dirty urines in five years. He is also on valium. I don't like methadone but at least he is alive. The downside of the methadone is they don't encourage a detox. I would prefer if he was off the methadone but I don't go on about it.”

Some parents or carers were satisfied with the management of the methadone programme, but some were highly critical of the approach taken. In particular, lack of attention to the overall well-being of the user and the failure to encourage a withdrawal from methadone were the most frequently cited criticisms.

5.6.3 Drug-free outcomes

There were a number of families in the study who did not want a methadone solution for their children. These were families who were living in areas where the problem of heroin use is relatively new and whose experience of coping with heroin use is relatively recent. As these areas have a different socio-economic profile to those traditionally beset by heroin problems, it is likely that social class factors are operating here. These families appeared to have greater awareness of the long-term implications of methadone use and were actively seeking drug-free solutions to their children's problems:

“She never went on methadone. I have strong views about it. It's grossly over-used. It's not right the way they use it.”

“I just knew I didn't want him on methadone. They just pump them full of methadone, sleeping tablets, anti-depressants. They don't care. I seen what happens. It isn't successful.”

Some families were able to steer their children into drug-free solutions without any involvement in methadone programmes, others sought to ensure that once on methadone they would scale down their usage until eventually becoming drug-free.

"He had the assessment and he got in. I was so happy. They detoxed him for two weeks. I was with my group for about a year at this stage. He did around six months in aftercare and I started visiting him there. Then he came back here and I said you have to get a job and I said to him, you'll be out the door if you use. He is still drug-free."

"He started on very low doses of methadone. By this time he was trying to turn a corner himself. So he started on a very low dose. He is not on methadone now. He was on a very low dose and he brought himself down. He is not using anything now. He chose to continue going back to the counsellor and the probation officer, who was really, really good. He kept in touch with her and goes once a month, even though his probation is finished."

5.6.4 Returning to normal life

Just five families in this study had experienced their loved one moving on to a completely drug-free lifestyle, and in all cases, the ex-user also went on to live a normal life: securing employment, establishing relationships and so on. For other families, and even those for whom heroin use itself was no longer a problem, difficulties persisted in the longer term.

These difficulties stemmed from a number of factors. Firstly, as already noted, there were the long-term commitments and responsibilities of parents who were caring for grandchildren or for their own HIV-positive children. For these, the negative impact of heroin use was ongoing.

Secondly, however, there were families who were supporting their loved ones on methadone maintenance within the family home. For these parents and carers, normal living could not be resumed so easily. There was always the possibility of their loved one relapsing back into drug use, which left them tense and watchful.

"He's afraid to leave the house, afraid to go to the bus, in case he meets someone. It's there in your face, someone asking... do you want something... If you think about it, 14 years on drugs. How do you adjust without that crutch?"

There was also the fact that even when the heroin use had stopped, the user had not received sufficient, if any counselling, leaving them with a residue of personal problems and difficulties.

"They've fixed her body. But her head still isn't right."

Thirdly, there was the ongoing need to engage with the providers in the context of methadone maintenance and to satisfy the programme requirements which were seen to impinge on the day-to-day life of the user, and by extension, his or her family.

Finally, and significantly, there was the fact that for those on methadone maintenance, the prospects of employment were limited and their ability to participate in training or education circumscribed by the interaction with provider agencies.

"He needs to work. He is just sitting there day, in day out. But what work could he get? Who'd give him a job? Maybe if there was a training course or something. But he is up and down to the clinic."

More generally, even when a degree of stability is secured by the user through methadone maintenance programmes, parents can find it difficult to fully relinquish the fear that a relapse or worse is still possible:

“He has a little job now, he is doing his own thing. He can’t come to my house because there’s money not paid and he’d be battered or shot. So, he is in his own place now and I’m telling you I’m enjoying it to the full and so is my daughter. But I still wait for that knock on the door, saying he’s dead... you still wait for the knock on the door. You get flashbacks, you think you hear the police banging at the door. You’re living with that, but I am enjoying the peace.”

5.7 Contributing

This final way of engaging, which is not part of the family’s journey per se, but is an outcome from it, begins when people realise the expertise they have acquired through their own experiences and begin to contribute that expertise for the benefit of their community. In nine of the families included in the study, at least one member, and in some cases two, was involved in working at community level, in either a paid or a voluntary capacity.

The specific contribution of these families in responding to heroin use within their communities took a number of forms. These included ongoing participation with family support groups, organising and facilitating family support groups, working directly with drug users, developing community-based strategies in response to drug use and involvement in LDTFs and RDTFs.

Most of the contribution which family members made to their communities was focused on supporting parents who were coping with problem drug use, usually, but not always, heroin use. However, awareness raising amongst the wider community also featured as did providing supports to addicts. An important dimension of the contributing role was the efforts on the part of some families working in their communities to create greater cohesiveness at local level across the service providers.

5.7.1 Types of contributing

Most of the work that families did in contributing to their local communities was in the context of directly providing family support. Sometimes family members became very active in organising and facilitating their local group, sometimes they just turned up to participate. In all cases they were conscious that their own experiences and their own expertise would be of assistance to other parents and carers:

“Now I am well, so I come here to help people who are not well.”

“It helped me so much. That’s why I’m here because I want to pass it on, give something back. I’ve been through all this and now is my chance to give something back.”

“Now I can give it back to other people and if I can be of any help to anybody that’s going through it I will. I wouldn’t want people to go through what I went through.”

The full range of activities engaged in by families comprised the following:

Organising and facilitating family support groups

In many areas, the ongoing organisation and facilitation of peer support groups depended upon the input of families who reached a certain level of understanding and knowledge about the process of coping with heroin use themselves and were in a position to assist others. In the provincial towns, in particular, voluntary involvement of families was vitally important in maintaining peer support.

Providing outreach support to families

Outreach support to families coping with heroin use was frequently engaged in by family members. In most areas, parents or carers who had been involved in their family support group for some time, made themselves available to new families on an informal basis and would, if necessary, visit families in their own home. For families just beginning to come to terms with their need for outside help, the confidentiality and privacy of outreach was particularly valuable.

Highlighting the value of family support, particularly for fathers

A number of the fathers included in the research were involved in developing and performing a play on the issue of family support for fathers and were taking the play to different communities in Dublin and beyond to increase awareness of how men can benefit from peer support.

Raising awareness amongst the community generally

Families' involvement in community-based activity was mostly focused on providing direct support to other families coping with heroin use. But in some areas, families were also involved in raising awareness amongst the community generally. Organising public meetings, working through local media, bringing information on drugs to other local meetings, contacting local politicians to raise awareness and so on, were amongst the types of general community awareness-raising activities engaged in.

Providing educational and drugs awareness courses for parents generally

In one area, members of the family support group were involved in organising courses for parents in general on the issue of effective parenting in the context of the potential for drug use on the part of their children.

Developing cohesion at local level

The expertise and experience of families represents a very significant body of resources in responding to problem drug use at local level. One dimension of this was the efforts by some families, in the context of their family support groups, to build greater integration and cohesion at local level across both generic and specialist providers and more generally, to embed family support within the framework of local provision. These efforts had a mixed response from the providers and some Family Support groups perceived an unwillingness on the part of professionals to accord value to their work, evidenced in their refusal to provide information to families on the availability of Family Support.

Assistance to addicts

Some parents or carers extended their contribution to their community to providing services to local drug addicts. Sometimes this occurred in a formal setting (for example, the local methadone clinic where parents would provide refreshments and so on to users), sometimes it took place informally, when parents would look out for addicts on the streets of their community.

Participating in Local and Regional Drug Task Forces

As well as playing a role in supporting other families coping with heroin use, families are also contributing in a more structured way to developing an appropriate local response to problem drug use in their own communities. In the urban areas where LDTFs exist, some families were working within the structures of these, contributing their expertise at the level of planning, policy and review.

5.8 Conclusion

The journey undertaken, involuntarily, by families of heroin users, is long, complex and the destination often unsatisfactory. Initially beset by a lack of information, families were unaware of the existence of a problem for considerable lengths of time. When they did finally seek professional help, they were often met with inadequate and counterproductive responses. Eventually accessing the specialist services meant little improvement in their circumstances – instead adding the extra task of interacting with the specialist agencies to their already over-stretched caring role.

Learning about the problem and how to cope with it brought positive changes, but their newly established potential to support the user into recovery was not acknowledged. Moreover, even beyond the duration of heroin use, problems remained for the families, extending the impact of heroin use on the family into the longer term.

The dominant discourse of heroin use in Ireland, which embodies a strong association between deprivation and heroin, appears to have added to the problems which families encountered, in particular, by making it difficult for families to realise that they had a problem, and for the sense of shame they experienced when they did realise it. It also appears that the implicit perception of the family as problematic continues to influence policy responses to heroin use, with the resulting tendency to see the family as part of the problem, and the failure to acknowledge its capacity to exercise strategic agency in both supporting the user and in working at local level.

Chapter 6

The Views of Families on the Adequacy of Existing Support Services

6.0 Introduction

The previous chapter looked at the different ways of engaging with heroin on the part of families and the different implications of these for how families sought support. This Chapter narrows the focus to look in detail at the families' perceptions regarding the adequacy of the different support services in meeting their needs as they progressed – or otherwise – along their 'journey' of coping with heroin use. The barriers to accessing support services are also discussed and the views of families on what is required to meet their needs are presented.

To recap briefly, the range of sources from which support was sought by families was extensive and included specialist sources, non-specialist or generic sources and informal networks. To an extent, these sources came into play at different stages in the families' 'journey' in coping with drug use: generally informal supports were most important in the early stages when the family was attempting to cope without recourse to external agencies, but many families relied on their extended family in the longer term too. Generic sources of support began to feature, although often ineffectively, when parents or carers started to seek help, while the specialist services also featured at this stage and subsequently. Notably, however, there were very significant time delays between the point of commencement of heroin use and the initial accessing of services, and for a large proportion of those who initially approached generic services, there was a further delay before they too accessed specialist services. Moreover, even when specialist providers were contacted, there was often a considerable time lapse before services could be accessed and positive outcomes achieved, if at all.

6.1 Informal Sources of Support

Almost all of the families interviewed for this research had access to informal sources of support through their own personal networks. Members of the extended family were by far the most important source of informal support. With a small number of exceptions, neither friends nor neighbours featured as sources of support. In fact, neighbours were often unhelpful and even hostile except in some instances when they too were coping with a drug problem. The extent to which hostility from neighbours reflected their own direct negative experiences of the drug users (for example, through being burgled) or a more generalised community-level process of marginalising families coping with drug use cannot be determined from this study. It is notable, however, that lack of support from neighbours was a feature of all localities, even those in which the problem of heroin use was extensive and of long duration.

Sometimes, through their involvement in family support groups, people made very good friends with other parents who, especially but not exclusively in rural areas, might also be neighbours. In these cases the distinction between support from friends, neighbours and peer groups became blurred.

6.1.1 Extended family as a source of support

Many parents responded to the discovery that their child was using heroin by trying to keep it a secret. Consequently, they told no one of the problem, including members of their own extended family. Inevitably, however, as time passed by and as problems became more pronounced, other members of the family were told and in almost all cases they became an important source of support. The type of support provided by families was diverse. Sometimes, simply knowing that their family members were available to them and that they were not judgmental was a significant benefit to families. More generally, families provided emotional, financial and practical support. In those cases where a member

of the extended family had experience of coping with a heroin problem, these were very instrumental in linking families quickly into the support services.

Often, particularly in the stage where they were desperately seeking help, parents sent their drug-using children to stay with a relative. This was usually a close relative such as a grandparent, an aunt or an uncle. While this provided an important respite for the parent or parents, it often meant that the relative assumed the role of super-parent and facilitated rather than challenged the user. Consequently, in this study there were no examples of successful surrogating on the part of family members.

In families where there were other adult children, these too were often quite important in providing support to parents. Three of the carers included in this research were in fact siblings of users and these had assumed the lead role in coping with the problem. In other families, adult children were important as a source of support to parents. Notably, older children tended to become important when parents began to manage the problem rather than react to it and often played a role in assisting the parents to remain steadfast in the process of distancing the user, for example. This was not the experience of all families, however. In some, the rift between the drug user and their siblings was too deep and affected the sibling's capacity to provide support to either the user or the parents.

The availability of family members to provide support was important in reducing somewhat the burden on parents or carers. However, their availability also meant that they too were touched by the heroin problem and exposed to some of the negative consequences. Aunts, uncles and grandparents had money and goods stolen, had their houses raided, had found the user unconscious and so on. They too became victims, but the extent to which they were supported was very limited. One woman noted that her family support worker also provided support to a relative who was close to the user. But this was the exception. The lack of support to siblings and to grandparents in particular is problematic.

6.1.2 Other informal sources of support

Other informal networks were less likely to provide support, although occasionally, they did offer some assistance to families or carers.

■ Friends

Personal friends did not feature as a source of support except, as noted earlier, when parents formed friendships with others attending the Family Support groups. In general, carers and especially parents did not have extensive networks of friends, possibly reflecting the social consequences of having a drug user in the family.

■ Neighbours

Far from being a source of support, neighbours, for the most part, often added to the burden on families, particularly in the early stages when the sense of shame and guilt was most intense. This was the case even in areas where heroin problems are widespread and suggests processes of stigmatisation and marginalisation operating at community level.

■ Employers

An unexpected source of support for some people was the understanding and empathy of their employers. In each of the localities, there were parents who had confided in their employer, usually in the context of a crisis or in anticipation of being fired, because their work was suffering as a result of the pressure they were experiencing. In every case, the employer had responded with sympathy and understanding and in some cases had allowed the parent to restructure their working week to facilitate the situation.

■ Local religious

In one locality, parish sisters were an important source of support to families, offering personal support, providing information on services and assisting with setting up family support groups.

■ Drug users

Drug users, and especially heroin addicts, were used as a source of information by parents and carers. The information sought from drug users included assistance in locating the whereabouts of drug-using children, information on where to buy heroin or methadone, guidance on how much heroin or methadone to use and information on the effect of different drugs on the user. The recourse to drug users reflects the lack of formal sources of information available to parents as well as the ingenuity displayed by families as they sought help for their loved one.

6.2 Support from Generic Services

Non-specialist or generic services and supports were initially used in the early reactionary phase of responding to heroin use when parents first began to look for help. Some, like GPs, had a role in later stages too. In addition, generic services such as those provided within the context of the criminal justice system, played a significant role although these were usually imposed upon, rather than sought by carers. Parents and carers were often in a state of chaos and distress when they initially approached these services and consequently, they were frequently seeking any kind of help that might be available, rather than having a specific support in mind. As a result of this generalised support seeking, it was difficult for families to assess the adequacy of the support they received except in the most general terms. As already noted however, the generic services often failed to provide any meaningful support to the family or to the user, frequently sending them away with nothing and sometimes making their situation more difficult.

Three main arenas of generic sources of support were utilised. These were services delivered within the framework of provision for young people (schools, Social Workers, Child Psychologists etc.); services delivered within the framework of the health system (including hospitals, GPs, Psychiatrists) and services delivered within the framework of the criminal justice system (notably Gardaí and Probation Officers).

6.2.1 Provision for young people

Most of the drug users had started using heroin around the age of 16. They were consequently still within the policy framework of the educational system and the child welfare system. Although many parents did not discover their children's use of heroin until they were over the age of 18, there were some who did come upon it sooner and who did seek support from personnel within the educational or child-welfare system.

School Personnel

The vast majority of users were still in the school system at the time they commenced using heroin and some were getting into trouble in school as a result of generally problematic behaviour. In none of the cases included in this study, did school personnel raise the possibility of drug use with parents and in general, contact between parents and schools in relation to the issue of drugs per se was very limited.

A small number of parents did seek support from their children's schools in the early stages of the problem. Unlike approaches to other sources of support, in approaching schools the parents were quite specific about the type of assistance they required. School personnel were mostly approached to provide help with the following:

- (a) identifying the problem, that is, the parent would seek the advice of the school personnel to determine what was wrong with their child
- (b) to provide stability for the drug user by not expelling them from school
- (c) to promote drug awareness in school so that other parents could be helped.

Families expressed serious levels of dissatisfaction with the response, or more accurately the lack of response, they received from school personnel. Families perceived that school personnel either could not help because they did not have the expertise or information, or they would not help because they did not want the taint of drugs associated with the school.

Social Workers

Quite a few families had interactions with social workers, some of which they sought themselves, some of which were imposed upon them. Families had different reasons for going to social workers – sometimes it was to seek help with a drug-using child, sometimes it was to seek help in looking after the children of a drug-using child and a small number had made a general appeal for help to the social work services.

In general, the capacity of social workers to support or otherwise provide services to families was not highly evaluated by families. The following criticisms were made:

- Social workers were unable to provide any level of practical support to parents
- Social workers focused very narrowly on the well-being of the child client without taking on board other issues and difficulties that families experienced, including the well-being of siblings or of the parents
- Families perceived that social workers had a lack of understanding of the complexities and realities of heroin problems as they beset families
- As a result of the lack of understanding, social workers were considered by families to be naive or overly officious in their interactions with users and families.

Child Psychologists

In the case of a small number of families, the drug-using child had been brought to the attention of child psychologists at a young age. In some cases, the contact was ongoing at the time of the discovery of heroin use, in other cases, the contact was re-established at this point. While the number of cases are too small to warrant drawing conclusions, in general, these services did not seem to be effective in linking parents or users into appropriate support services.

6.2.2 Services within the Health System

Given the health implications of heroin use for the user, and the role of doctors in providing methadone, it is not surprising the families had frequent and ongoing contact with personnel within the health system. Frequently too, families first attempts to seek help were directed to GPs or hospitals. Family interactions with personnel within the health system were not always satisfactory and the extent to which people in situations of ongoing difficulty and vulnerability (including young users) were able to come in and out of the health services without receiving an adequate response or appropriate referral is particularly problematic.

Hospitals

Parents and carers interacted with hospitals in a wide variety of ways. Sometimes, they sought hospital care for themselves, sometimes for the user and sometimes for the children of the users. In general, parents sought help from hospitals in the context of a crisis of one sort or another and their objective in seeking help was to have the crisis addressed. In all cases, parents expressed the view that the crises had been addressed and to that extent they were satisfied with the level of support received. However, in no case was a parent offered follow-up support or referred or recommended to any other source of support. Even in cases where the situation was acute, no follow-up help was offered.

- Generally, when parents sought help for themselves from a hospital, it was psychiatric care that was required, directly as a result of the stress they were experiencing. Most expressed high levels of satisfaction with the medical care they received, but in no case were they referred to a source of support for the drug user or to family support services for themselves.
- When parents or carers sought help from a hospital for the user, it was invariably in the context of a health crisis. Again, parents were satisfied that the health issue was attended to, but there was no further support or follow-up offered. In one situation, a relatively recent user aged 20 spent five days on life-support following kidney failure. He made a recovery and was discharged without follow-up.
- Hospital care was sometimes sought for the children of users, sometimes in situations of crisis stemming from child neglect. The young grandchild of one interviewee was rushed to hospital having drunk her parents' methadone. She was treated and discharged back into the care of her parents.

General Practitioners

For many people beginning to come to terms with the problem of drug use, their GP was the first person they turned to for help. Most people who did so did not have a clear idea of what they wanted the GP to do – they were simply looking for help in a general sense and some were vaguely hoping that the GP could provide them with, or point them in the direction of a speedy solution to their problem.

The support that the families received from the GPs was very variable. In some instances, the GP was extremely helpful and effective, providing advice to the family and referring the user on to the specialist services. In other instances, the GPs offered no help whatsoever and in a number of instances, the response of the GP actually made the parent's situation worse by increasing their sense of hopelessness and despondency and impeding their search for support from other sources. Given that GPs were often the first source of support sought out by families, the haphazardness of their response to the parent and their failure to recognise the vulnerability of the young user is particularly problematic. In general,

it appears that the probability of securing adequate or even any help from a GP is due more to good luck in choosing a GP who happens to have taken an interest in the issue and is aware of the supports available to families and users, than to any policy of primary health care for users and their families.

GPs were also involved in prescribing methadone for users and so many families had ongoing direct or indirect interaction with them in this context. Again, experiences and perceptions of adequacy were very mixed. Some parents were very satisfied with the level of care extended by the GP to their loved one. However, there were also strong criticisms. In particular:

- Some parents perceived that GPs were lax in monitoring the overall health of their loved one while they were on methadone
- Some parents perceived that the possibility of covert drug use on the part of the user was not being monitored effectively enough by the GP
- Some parents perceived that GPs involved in administering methadone did not encourage people on methadone maintenance to reduce their dosage.

Psychologists/Psychiatrists

Psychologists and psychiatrists were infrequently used and usually only in cases where either the user or the parent/carer had had a prior contact. For the most part, these families tended to be from localities more recently affected by a heroin problem. Sometimes parents or carers sought out this support from themselves, sometimes for the user. For the most part, parents self-referred to psychologists or psychiatrists, often in a haphazard way, and the outcomes were variable although sometimes very valuable.

6.2.3 Criminal Justice System

Interaction with personnel within the criminal justice system was widespread across the families involved in the research, although criminal behaviour was much more prevalent amongst male drug users than amongst female drug users. With the exception of interaction with Gardai, contact with personnel in the criminal justice system was not initiated by families but by the personnel themselves or by the courts. Local Gardai were an exception here as sometimes they were approached by families to provide specific help. In general, families assessed their interaction with the criminal justice system very favourably. This is particularly true of their interaction with probation workers in all areas and with contact with the Gardai in rural areas.

Gardai

Interaction with the Gardai was both sought by, and imposed upon, families. It was imposed by virtue of the behaviour of the drug user which often drew the attention of the Gardai, not just to him or, less frequently, her, but to the family home as well. It was sought on occasions, when parents required the assistance of Gardai in removing violent users from the home, in some other crisis situation or in rural areas especially, in their routine management of the problem where the social proximity of the Gardai meant they were often encountered on a day-to-day basis.

In relation to the interaction both between Gardaí and drug users and Gardaí and families, the experiences of families were mixed, but mostly positive. Most families perceived that the Gardaí were sensitive to their situation and were sympathetic to the drug user. In rural areas in particular, where the local Gardaí were often in daily contact with drug users and their families, they were perceived to play a constructive role in providing support to both families and to drug users: often this support was little more than showing some concern for the family and respect for the user. However, local Gardaí were also involved in offering advice to families, in keeping families informed of how court cases against their child were proceeding, and sometimes in passing on information about children who were living on the streets. In some cases too, families reported that local Gardaí had been helpful to the drug users, attempting to advise them and to encourage them into treatment.

While the role of the local Gardaí in rural areas was very much shaped by good community relations, in urban areas, the situation was more variable. Sometimes Gardaí were sensitive to the families' situation, but a number of families had had very bad experiences of the local Gardaí and believed their drug-using members were treated unfairly and sometimes illegally by the Gardaí.

Probation and Welfare Officers

Probation and Welfare Officers were another one of the supports which families did not seek but which were imposed on them. More accurately, Probation and Welfare Officers were imposed on the users, but it appears that in most cases they extended their work to supporting the parents. In doing so, they provided one of the most valuable supports available to families, especially in the early and chaotic stages of coping with problem drug use:

- Most families who had had interactions with Probation and Welfare Officers perceived them to have a genuine empathy with, and concern for, the young person
- The support which Probation and Welfare Officers provide was seen as very helpful and effective. This support related to areas such as advocacy for the user in court cases, encouraging the user into treatment, providing information on treatment programmes available, providing information on welfare entitlements and training opportunities
- Often the Probation and Welfare Officer stayed involved with the young person even beyond the duration of their formal responsibility
- Probation and Welfare Officers also provided support directly to parents and most families that had involvement with Probation Officers noted that they could contact the Probation Officer at any time.

In the context of the complexity of provision for drug users and the ongoing and erratic interaction families had with this, the consistency of support from probation workers and the fact that they provided a constant reference point appears to have been very valuable for families.

Judges

A good number of families had experience of going to court with the user and in some cases would have requested, via the Probation and Welfare Officer or the arresting Garda, that the Judge consider certain issues in deciding a sentence. In some cases, the desire was for a custodial sentence, in other cases the family desired the opposite. Most of the families who had gone to court found the judges sympathetic to their point of view, although the constant deferring and rescheduling of cases caused distress and practical difficulties.

6.3 Specialist Drug Services

Interactions with the specialist drug services were widespread and prolonged. Overall, families evaluated the responses and services they received from the specialist services quite highly with some exceptions. However, in relation to services for the user, the basis for their evaluation was often that the service tried to do something, rather than that it actually achieved anything. The interventions accessed by families within the framework of the specialist drug services include Regional Drugs Helplines, Drugs Counsellors, Community Drug Teams, Treatment Centres, Methadone Maintenance Programmes and Family Support.

Regional Drugs Helplines

Only three families referred to using regional drugs helplines. All had done so in the early stages, when they were beginning to become concerned about their child's behaviour and the possibility of them being on drugs. They did not find the helplines useful and perceived that the information provided was too general to provide the specific responses they were seeking.

Drugs Counsellors

Drugs counsellors were frequently used both to provide support to families and to the users. For some families these were the first port of call when they went looking for help and in some cases, the families interaction with the drug counsellor extended over a lengthy period. Although they were often approached in the context of a general search for assistance, for the most part, specialist drug counsellors were considered very helpful and effective both for the user and for the family.

In terms of their perception of how helpful the counsellor was for the user, families highlighted the following:

- Drugs counsellors associated with voluntary agencies tended to be consistently available over time which meant that the user always had the possibility of contacting the counsellor regardless of their situation at any point in time
- Drugs counsellors were considered to be effective in providing advice to the users
- Drugs counsellors were also seen as effective in linking the users with treatment centres.

In terms of the helpfulness of the counsellor in providing support for families, the most frequently mentioned factor was that the drugs counsellor was 'always there', thus helping to overcome the 'freefall' situation which families found themselves in when other services failed to provide support.

Two problems with counsellors did arise:

- The first was when the counselling service was directly linked to a methadone maintenance programme. In these cases, families were unhappy with the fact that users who went for counselling were automatically steered towards a methadone maintenance programme, often without the implications of that being explained.
- The second problem was the fact that some family members did not feel they were getting enough information from the counsellor. This latter problem was particularly marked for siblings, although it also existed for parents.

Treatment Centres

There was very extensive interaction between the families and a wide range of treatment centres. Some families had had intermittent contact with treatment centres extending over a period of ten or more years. Some families had had contact with up to ten or twelve different agencies. Most families had travelled throughout the country to enable their loved one to gain admission to a residential facility and to support them while there. It was not possible to quantify the interaction between families and treatment centres because parents' recall over such a long and often chaotic period was not fully comprehensive. Nevertheless, it appears that between 5 and 11 episodes in treatment centres was normal.

Treatment centres were most usually approached, for the first time, in the context of an almost total lack of information on the part of families regarding the nature of the problem they were dealing with. They were also usually approached in a state of confusion and distress. As a result families tended to resort to whatever service was available or whatever agency would accommodate the user and they accepted uncritically whatever help the agency offered.

In particular, they did not select an agency on the basis of their understanding of, or their preference for, the approaches or services of that specific agency. Consequently, it was difficult for families to assess the effectiveness of the support that was provided by the treatment centre. As noted earlier, the fact that the treatment centre accepted the user and tried to help the user was sufficient for the family to assess the service in a positive light. If the outcome of the intervention was unsuccessful, the fault was fully attributed to the user.

Positive aspects of treatment centres were noted:

- Empathy of personnel with both families and users
- Genuine attempts to provide help and assistance to the user
- Counselling and advice offered to families, often informally
- Family support groups were provided by some treatment centres and were generally highly evaluated

Amongst the specific criticisms that were made of treatment centres were the following:

- Waiting lists were too long
- Eligibility criteria were too strict or appeared counterproductive
- Treatment centres did not provide sufficient information to the families
- There were limited aftercare options available to users
- There was insufficient attention paid to providing training or education programmes

In addition, for families attempting to support their loved one in recovery, there was a perception that the centres failed to acknowledge their capacity in this role, and that they maintained an unnecessary and unhelpful distance from the family.

Treatment centres operate as stand-alone units with their own self-selected criteria and regulations. Users often don't meet the criteria or cannot accept the regulations. Consequently, they are frequently rejected or ejected and left in the care of the family. It is not within the remit of this report to comment on the eligibility criteria or on the *modus operandi* of the treatment centres; undoubtedly from the standpoint of the agencies, their practices are coherent and rational. However, from the standpoint of the families who are dealing with a multiplicity of agencies over time, this diversity presents as an entanglement of bureaucracy, the procedures and requirements are extraordinarily difficult to penetrate or negotiate. It is particularly problematic that the agencies that seek to assist drug users to recover present such a problematic interface to the families upon whose support that recovery is often predicated.

Methadone Maintenance Programmes

Most of the families experienced their drug-using member being on methadone maintenance programmes at some point and 14 families had members on methadone programmes at the time the research was carried out. Some families had sought out methadone maintenance programmes for their loved one because they were concerned about his or her health and welfare or because they could not tolerate their disruptive behaviour any longer. In other cases, the drug user was put on a maintenance programme without the full knowledge of the family. In these cases, parents acknowledged that even if they had been aware that the user was going on a maintenance programme, they would not have understood the implications.

Families were more critical of methadone maintenance programmes than they were of any other service provided to users. Criticisms extended to both the use of methadone per se and to the manner in which the methadone maintenance programmes were operated.

Specific criticism included the following:

- Families were not informed that their child was being put on a methadone maintenance programme
- Families were not fully informed of the implications of their child going on maintenance
- There were not enough alternative, drug-free options available for users
- Waiting lists and eligibility criteria for some programmes appeared to families to be counterproductive
- The system of administering prescriptions and methadone and monitoring the user was overly complex and fragmented and made it impossible for those on methadone maintenance programmes to work or undertake training
- There was insufficient attention paid to the overall health and well-being of the user while they were on maintenance programmes
- Covert drug use on the part of the user was not properly monitored
- There was a lack of training, education or employment opportunities for people on methadone maintenance
- There was insufficient opportunities for counselling for people on methadone maintenance.

It also appears from the data that there is a growing awareness of the longer-term implications of methadone and an emerging criticism of the perceived over-reliance on methadone maintenance as a response to heroin use. A number of families felt aggrieved that their loved one had become methadone dependent, that this was the only option available and that while the methadone may deal with anti-social behaviour, it did not really help the user to return to drug-free living. Some families actively rejected methadone maintenance and sought out other drug-free solutions. In some of the areas newly affected by drug use, the tendency for parents to prefer drug-free solutions was particularly marked.

Community Drug Teams (CDT)

In the areas where they exist, the CDTs were widely used in a variety of ways including seeking advice, guidance and support for the user and for information and support for the parent/carer.

The CDTs were highly regarded by those who had contact with them and there appears to be a number of reasons for this:

- Firstly, the CDTs provide information on what services are available, which means that families have a single source of information and can respond more quickly and more effectively to the problems that arise
- Secondly, the CDTs provide a relatively constant point of contact for both users and parents or carers to which they can refer whenever they feel the need. As a result, parents no longer feel so acutely that they are on their own or that there is nowhere to turn to
- Thirdly, the CDTs address different aspects of the problem of drug use – effectively acting as a one-stop shop – consequently they are instrumental in enabling the families develop a more strategic approach to managing the problem
- The approach taken by the CDTs, and particularly the key worker model, appears to be redressing, in some respects, the stand-alone dimension of some supports

On a more negative note, the hours of operation of the CDTs were seen as too limited and particularly the lack of weekend provision was criticised.

Family Support

Almost all of the families that participated in this research were contacted through family support services and a lot of the families had extensive interaction with these groups over a long period. For some families, their first contact with the Family Support resulted from the drug-using member going into a treatment centre which required the parents or carer to attend family support meetings. For other families, their first contact was with support groups or workers in their own or adjacent locality, often on foot of fortuitously discovering their existence. In general, Family Support groups were very highly rated and for most of those who used them, the support from the groups marked a turning point in the way they responded to the drug problem.

Family Support offers a number of services, but the three most important dimensions evident in the account of families are:

Providing information on drugs, drug use, drug addiction and treatments

Lack of information on drug use and treatments was a huge factor in fueling families' initial ineffective reaction to problem drug use. Family Support addressed this by providing accurate information which allowed families to understand what they were dealing with. This also allowed them to begin to separate their response to their child or loved one, from their response to the addiction and thus to begin to reconcile the conflicting emotions they experienced.

Providing ongoing advice and guidance on how to manage the drug user and specifically on how to disengage from the negative dynamic of drug use

A key message that families got from Family Support was that they could not change the users' behaviour: only the user could do so. This message was instrumental in enabling families change their way of engagement with the heroin problem from one of reacting to one of managing.

Providing ongoing support to families to implement managing strategies and to reclaim the personal lives of the parents and the family

As they reclaimed their lives, families and carers continued to need support to enable them put in place new management strategies. Ongoing support, including counselling and other interventions, was very important in facilitating parents to challenge the users' behaviour, and potentially to support them into recovery.

Some criticisms of family support were also noted. These were:

- Family Support tends to focus very predominantly on parents, there is insufficient focus on siblings and other family members
- Family Support needs to be more differentiated with regard to parents, particularly by providing more opportunities for single-sex groups
- Some parents perceived that Family Support groups tend to be over-emphatic in conveying their message, making it difficult for families to make the journey in their own time.

6.4 Barriers to Accessing Supports

The families involved in this research have had extensive interaction with a wide range of support services, both generic and specialist and their experience of interacting with these usually extended over many years. Despite this level of engagement, it is possible to identify a number of barriers that exist in relation to seeking support and, more specifically, in relation to seeking support in an effective and timely manner. This discussion looks at these barriers and refers both to barriers to accessing specific supports and to the broader set of barriers that inhibit effective help-seeking on the part of families.

Barriers which inhibit the development of effective strategies of help-seeking on the part of families arise within three arenas:

- Firstly, there are those barriers that derive from the dominant discourses of drug use that prevail in Ireland and the acceptance of, or acquiescence with, these discourses on the part of families, service providers and the wider community
- Secondly, there are the barriers that stem from the lack of information on the part of families with regard to drug use and with regard to different responses to drug use
- Thirdly, there are the barriers that arise from within the current treatment system and more generally, the framework of service provision, both generic and specialist.

While these different arenas can be delineated separately at an analytical level, in practice, they impact upon each other in complex and accumulative ways, compounding the obstacles to effective support seeking.

6.4.1 Barriers arising from discourses of heroin use

The predominant discourses surrounding heroin use in Ireland were referred to earlier and their potential for negative implications noted. These discourses present heroin use as a problem that besets problematic localities and problematic families, they present heroin users as solely responsible for the situation they find themselves in and implicitly they present the family as dysfunctional and in some way culpable for having a drug-using member.

The implications of these discourses were evident in the accounts of families in terms of their ability to recognise the existence of the heroin problem, in terms of their initial response to it, in terms of their interaction with the treatment system, in terms of their capacity to evaluate the adequacy of services and in terms of their being allowed to play an active role in supporting the user into recovery.

Stereotyping of heroin use

The dominant perception that prevails with regard to heroin use is that it is a problem associated with disadvantaged communities and, more especially, disadvantaged families. This perception was shared by families included in this research with the result that most were totally unsuspecting that a member of their family was using heroin. Consequently, because they did not perceive that heroin use was something that could affect their family, they often missed or misinterpreted the early signs of use. Thus, valuable time was wasted in seeking help for the user at an early stage.

Stigma associated with heroin use

Associated with the stereotyping of heroin use is the perception that if a family has a heroin problem, there must be something wrong with the family. In this way, the stigma associated with heroin use extends to the family of the user. Consequently, when families did discover that one of their members was using heroin, they experienced intense shame and guilt. Their response to this was to try to hide the problem from outsiders and to cope with it themselves. Again, this impeded their capacity to develop effective help-seeking strategies and allowed the problem to worsen.

Attribution of blame

There is also a predominant perception that heroin users are exclusively responsible for the situation in which they find themselves and, further, that that situation renders them socially undesirable and undeserving. Most families appeared to subscribe to, or at least acquiesce with, this perception. This had implications for their interaction with and assessment of the support services and the treatment system more generally. In particular, families tended not to make demands for better services for their loved one, implicitly accepting the status quo. Notably, the concept of a rights based approach to provision for heroin users was absent from the views of families. Similarly, the repeated relapses into heroin use experienced by most families were attributed entirely to the user, even though the absence of aftercare and the limited opportunity for training or employment were recognised.

Seeing families as part of the problem

Finally, the attribution of blame also extends to the family, who are implicitly seen as part of the problem rather than part of the solution. The result of this is that even when families are in a position to support the user move into recovery and to work strategically with the agencies achieve a positive outcome, their potential role in this is not recognised.

6.4.2 Barriers arising from information deficits

At almost every stage in coping with the problem of heroin use, families were beset by a lack of information, which seriously hampered their ability to seek help, to identify the type of help they needed and to be able to assess the effectiveness of the help, if any, that they received.

The main information deficits related to:

■ Lack of information about drug use and its effects

Without exception, families referred to the fact that prior to discovering that they had a heroin problem and subsequent to it, they knew nothing about heroin or its effects. Moreover, their lack of information prevailed over many years and had a determining influence on their initial reactive and ineffective response to heroin use.

■ Lack of information about the services and supports that are available

The lack of information about drugs on the part of families was paralleled by their lack of information on the supports available both locally and otherwise. Even in areas where quite a few supports were available locally, families were often unaware of the existence of these. In general, it was only in cases where a member of the extended family had prior experience of coping with heroin use, that families had speedy access to good information on what type of supports were available.

Again, this lack of information had a determining effect on support-seeking strategies and contributed significantly to the situation in which families wasted valuable time by approaching services that proved inadequate.

- **Lack of information about the implications of different types of treatments**

Finally, families were inhibited in their help seeking strategies by a lack of clear information on the implications of different types of treatments for heroin addiction. In particular, the longer term implications of methadone maintenance programmes were often unknown to parents prior to them actually experiencing them. The failure to provide information on this meant that parents were invariably 'groping in the dark' when it came to the issue of their children going on methadone programmes. Further, in cases where families were part of the decision making process on this issue, they were invariably acting out of constraint rather than choice.

6.4.3 Barriers arising within the context of services provision

These barriers can be differentiated between those that arise in the context of the specialist services and those that arise in the context of the generic services. These are looked at separately here.

Generic services

Earlier chapters have noted how, when they began to seek professional help, families frequently approached non-specialist or generic services. Predominant amongst these were GPs and hospitals. A major impediment to accessing appropriate services stemmed from the fact that frequently, the generic services could not themselves provide an adequate response to families and did not provide an onward referral to more appropriate supports.

Consequently, inadequacies in the generic services themselves acted as a barrier to effective support seeking on the part of families.

Specifically, two areas of inadequacy are highlighted:

- The lack of information on drug use and on responses to drug use amongst some generic service providers
- The lack of good practice amongst some generic service providers in relation to referring people onto specialist services for the user or support services for the families.

The variability of the response from the generic services contributed to the frustration and stress of families and delayed access to more effective treatment for the user.

Specialist services

Within the framework of the specialist services a significant number of barriers were identified which impeded, in one way or another, the capacity of families to access these. Again, it is worth stressing, that one of the most striking aspects of the current range of services, both specialist and non-specialist, is the extent to which these operate as stand-alone units, each offering a specific service or services with little or no linkage or connectedness to other sources of support. This situation increases the stress on the family, contributes to the chaotic help-seeking behaviour and can lead to the reinforcement rather than the alleviation of the original problem. It also acts as a serious impediment to enabling the family develop a coherent help-seeking strategy.

More specifically the following barriers were also identified:

■ Services not available locally

Most of the families that took part in this research had travelled extensively to find services and supports for their loved one. But most also acknowledged the difficulties that arose from not having local services and the benefits that incurred when local supports were established. Costs of transport to non-local services were also an issue here.

When families were seeking to hand back responsibility for the problem to the user, the lack of local treatment services became a much greater problem. In addition, in areas where methadone maintenance programmes were not localised (mostly rural areas), the additional travel implications made it difficult for users to become involved in education, training or employment opportunities.

■ Lack of choice in terms of services

The lack of drug-free options in particular was cited by some families as a particular barrier to effective help-seeking on their part. Although a number of families in this study did succeed in assisting the user to become drug-free, many more would have wished for more support for this approach.

■ Costs associated with accessing services

The cost of the services themselves or the cost of supporting a user to access a service did not appear to present a very significant barrier to support seeking on the part of the families included in this study. This was because the families were prepared to make considerable sacrifices and to go into debt. While not acting as a barrier, therefore, these costs did contribute significantly to the financial burden on families.

■ Waiting lists

Waiting lists were one of the most frequently referred to barriers to accessing support for drug users. Waiting lists that impeded access to services when users had acute health problems were particularly distressing for families.

■ Lack of integration across services

The lack of integration across the existing services was a very significant problem for families once they had begun to seek help. This fragmentation, coupled with the lack of information available to families, resulted in a very problematic interface between families and the treatment system.

■ Very stringent eligibility criteria

Some families referred to what they considered to be the overly-strict criteria which some services applied and which they felt made it difficult for the drug user to avail of.

■ Hours of operation

The hours of operation of some supports were also identified as a problem and particularly those supports that provided assistance in emergencies. The limited support available at weekends was particularly noted.

■ Parents/Carers excluded by services

As noted in the previous section, many families felt that they were being kept at arms length by some of the agencies providing services to the drug user. Thus they believed that they were not being provided with enough information on the care and treatment of their family member and they also believed that their own role in supporting that treatment was not being acknowledged.

■ Distrust/fear of professionals

A number of families expressed a fear, distrust or lack of confidence in professionals that prevented them from seeking certain types of support. Examples of this ranged from fearing that social workers would take their children into care if they brought the drug problem to their attention, to believing their problems were too complex for professional help.

6.5 What Supports would help Families?

The research also looked at the types of supports which families believed would have helped them to cope better and which they would wish to see in place for other users, families and communities in general.

Some families had very strong views on these issues and had, particularly those who were active in family support groups or other services in their communities, given some thought to the issue. Other families were somewhat less emphatic but were drawing on their own experiences. The views of families are looked at here under three headings: supports to help drug users; supports to help families; and supports to promote greater capacity at community level to respond to the problem of heroin use.

6.5.1 Supports for drug users

One of the main activities that families undertake as they try to cope with heroin use is to seek support for the drug user, both to enable the user to avail of professional support and to relieve themselves, albeit temporarily, of the burden of care. As such, support for drug users potentially equates with support of families: however from the stories of families recounted here, it is clear that the efforts they must go to in seeking support for drug users, adds further to the burden of care on families.

In this context, families identified a number of specific issues which would improve upon, and compliment, existing provision. These elements were:

- The elimination of waiting lists for treatment centres and methadone maintenance programmes
- The introduction of more user-friendly and flexible eligibility criteria for participation in treatment centres and methadone maintenance programmes
- Greater recognition of the role of the family in supporting recovery and the development of more synergies between the care provided by treatment centres and the care provided by the families
- Greater opportunities for aftercare and smoother transitions from treatment centres to aftercare settings
- More facilities for counselling for drug users, including in the longer term

- Provision of support to drug users that would be constant across time and across different interventions
- More educational/training options for drug users, particularly those on long-term methadone maintenance, to enable them find employment and return to normal living
- More drug-free options for users
- More locally-based provision and an elimination of the fragmentation that exists across different forms of provision.

While the specific elements can be itemised like this, it is clear that families were identifying what are effectively elements of a specialised, comprehensive and client-centred approach to responding to the needs of the user at local level.

6.5.2 Support for families

As well as interacting with the support services to seek help for the user, families also interacted with support services to seek help for themselves and to seek help to help the user. In relation to both these roles, they identified issues which could improve or compliment the current range of supports that are in place:

- Timely, accurate and accessible information should be available to families on all aspects of the drug problem, from early identification to understanding different treatments
- A constant point of referral at local level to support and advise families in coping with problem heroin use
- Availability of family support at local level, embodying sufficient diversity to meet the needs of parents, siblings and other key family members
- Recognition of the role of the family in supporting recovery, greater resourcing of the family to play this role and greater recognition of the rights of the family in recovery situations
- Support for families in coping with long-term effects of heroin use, in particular looking after grandchildren, coping with children who are HIV positive and supporting unemployed children on long-term methadone maintenance.

6.5.3 Support for communities

Drawing on their own experiences, families also identified a number of issues that could impact positively on responses to drugs at community level. These included the following:

- Education for parents in general to make them aware of the possibility of a drug problem and of effective parenting in the context of drug use
- The introduction of drugs policy in all schools
- The need to promote greater awareness generally at community level and in particular, to address stereotypes of drug users
- The establishment of family support groups in every area.

6.6 Conclusion

Families' experiences of dealing with support services were diverse and their assessments of the effectiveness of these were also varied. In general, the specialist services were more positively evaluated than the non-specialist or generic services. It is worth reiterating here that the despair and trauma experienced by parents as they sought help, together with their lack of information on different types of help available, meant they were frequently seeking anything that might be available, rather than a specific service. Because of this, they had no real basis upon which to assess the helpfulness or effectiveness of the support they received.

However, two particular features of support provision do appear to have made a significant impact on the well-being of families and by extension on the users. Firstly, there were family support interventions which were hugely instrumental in interrupting the negative dynamic within families and in enabling the families to help themselves and to help the user.

Secondly, there was the availability of a constant point of reference for the user, which took the burden of care off the family. In this study, the most frequent such points were provided by drugs counsellors, CDT key workers and probation workers.

Chapter 7

Conclusions and Recommendations

7.0 Introduction

In the context of the ongoing heroin problem in Ireland together with the increasing awareness of the negative effects on the families of users, this study examined the experiences of 30 families seeking support in coping with heroin use. These families were living in, or close to, three localities chosen to provide diverse social contexts within which to explore their experiences. The time frame over which these families had been coping with heroin use was both extensive and varied: for some the problem had emerged over 15 years ago, for others it was far more recent. Notwithstanding the different social contexts, the different time frames and more significantly, the extent of policy development in recent years, the experiences of families currently coping with heroin use were remarkably, and problematically, similar to those of families who were coping with the problem 15 years ago.

Consequently, there was a high level of consistency in the families' stories, as they recounted their experiences of seeking support in coping with problem heroin use, the details of which have been discussed in previous chapters. This final Chapter recaps on these stories, presents the main findings of the research, draws out the implications for practice and policy in relation to problem drug use and makes a number of recommendations to improve both policy and practice at national and at local level.

7.1 Coping with Heroin Use

It is clear from this study that the problems that beset families of heroin users in Ireland are similar to those that have been identified in the international research. They include health, financial, social and familial difficulties as well as problems deriving from stereotyping of heroin users, the experience of stigma and the operations of the treatment system. Families coping with heroin use, therefore, find themselves responding not just to the drug problem per se, but also to the negative reactions of their communities and to the difficulties presented by practices within the treatment systems. Over time, families responded to these problems in different ways, ranging from (a) denial or ignorance to (b) reactive ways of engaging in which the family either tried to manage without external support or else engaged in frantic and ineffective attempts to seek help, to (c) supported learning and (d) eventually on to more strategic ways of managing the problem.

Once they began to engage with the support services, families also occupied different positions with regard to these, which interacted with and mutually impacted upon their ways of engaging with heroin use. The interaction between the families' ways of engaging internally with heroin use and externally with support providers can be summarised as follows:

- Firstly, families interacted with supports as co-victims of drug use. In this context, families sought support for themselves in responding to the problems they experienced as a result of the drug user and the drug users' behaviour. Families drew on a range of supports depending on the nature of the problem being experienced. Informal supports were important: extended family members played a positive role in providing empathy and practical support while employers were also a source of practical support. In contrast, the hostility of neighbours added to the experience of social isolation.

- Professional support also featured. Families brought problems of stress and other mental health issues to personnel within the health system and for the most part these personnel were deemed to have adequately addressed the issues brought to their attention. Notably, however, there was a failure on the part of the generic health services to refer families to more specific and specialist sources of support either for themselves or for the drug user.
- Secondly, families interacted with support services in what they perceived as their caring role. In this role, family members, and particularly parents, sought support for the drug users. Again, they did so from a very wide range of sources, including informal sources, non-specialist service providers and specialist service providers. The family or parental caring role, however, was impeded and even distorted by the lack of information available to the family, by the behaviour of the users and by the complexity of the interface with the support providers. The result was that families were unable to secure effective help for the drug user and were forced into a reiterative process of ongoing searching, lasting many years. This had implications for both the family and the drug user in that over the extended time frame the negative consequences of drug use intensified.
- Finally, families played a role in supporting the drug user into recovery and into maintaining a heroin-free lifestyle. In this context, the family became critical to the care continuum and effectively assumed the role of agent of recovery, facilitating and reinforcing the work of treatment centres, methadone maintenance programmes and other supports. For families to play this role, however, it was necessary that the earlier patterns of inefficient help seeking were interrupted and that the family was resourced to support the drug user. When families were enabled to act as agents of recovery, they not only supported the user but could also address their own needs as a family.

Clearly, from the perspective of drug users and their families, the role of the family in acting as an agent of recovery is by far the more desirable situation. Moreover, the benefits of this accrued not just to families but also added value to the work of treatment centres and provided resources at community level, through involvement in peer support groups. However, the ability to achieve this potential is not an automatic outcome of the families' journey and most spent many years locked into ineffective help-seeking strategies before being facilitated to develop this role.

7.2 Summary of Key Findings

Against this backdrop, the key findings of this research are summarised below.

- In the early stages of the problem, families' own lack of information and awareness prevented them from recognising the existence of the problem and their need to take action to address it. The stereotypes associated with heroin use were a factor in this. The professionals within the child provision services with whom the young users came into contact also failed either to anticipate or notice the existence of a problem or to act on it. As a result, there was a considerable time lag between the initial emergence of the problem and the parents becoming aware of it during which time the drug problem became well established.
- Subsequently, when they did realise there was a problem, the same lack of information, together with their sense of shame, prevented families from recognising the need for external support, leading to them attempting to deal with the problem themselves, over relatively long periods. Again, this time lag allowed the drug problem to worsen and the negative impact on the family to become significant and the destructive family dynamics associated with heroin use to become established.

- When they did begin to seek support from outside agencies, families frequently made their first approach to non-specialist agencies or providers. Their efforts were frequently thwarted by the inadequate nature of the responses they received from these non-specialist services and this further delayed the delivery of effective services to the user or their family. The failure of the non-specialist services to direct families to more appropriate forms of support was particularly notable.
- When they did finally get linked into the specialist services, the ongoing lack of information, the multiplicity of stand-alone agencies and the lack of integration across these meant that the task of seeking specialist care and interacting with the specialist agencies added to, rather than alleviated, the burden of care on families, causing further delays and enabling the problem to become more entrenched.
- This situation changed for families only when they began to learn about the nature of the problem they were dealing with, about the need to look after their own well-being and about more effective and strategic ways to manage the problem of heroin use. This learning facilitated families to reclaim their own lives and to interrupt the negative dynamic which heroin use had introduced into the family.
- For those families whose loved one moved into recovery, there was insufficient acknowledgement within the treatment system of the role of the family in supporting the recovery and the potential role the family could play in reinforcing the work of the treatment centres. Consequently, families felt they were not being given sufficient information on the treatment or progress of their loved one, and were not being sufficiently involved in decision making regarding treatment.
- When families experienced a resolution of the heroin problem itself, they often found themselves having to deal with the long-term implications of heroin use: including rearing grandchildren, caring for children with HIV and Hepatitis C, the ongoing worry of their loved one relapsing and the long-term implications of dealing with the unemployment and other problems of the ex-drug user.
- Finally, and despite all of the above, many family members found the time and energy to use the expertise they had acquired over the years to give something back to their communities by becoming involved in peer-led family support groups. These support groups were often the only source of support to families coping with heroin use. However, the lack of resources available to them and the lack of acceptance of their legitimacy and the value of their work by other professionals hampered their ability to play this role.

7.3 Issues for Consideration

Drawing on this body of data, and prior to making recommendations, there are two issues which warrant consideration. These are:

- The contemporary position of the family within public policy and provision to combat drugs
- The social context which characterises the current manifestation of the heroin problem in Ireland

7.3.1 The position of the family within public policy

The families of heroin users are intrinsically and deeply implicated in the experience of the heroin problem in Ireland: families are victims of heroin use, they are carers for heroin users and potentially they can be agents of recovery for their loved ones.

In all of these potential roles, however, the family is both unacknowledged and un-resourced. The provision of support for families is inadequate, ad hoc and often dependent on the voluntary effort of peers, who are themselves coping with drug use. The inadequacy of information provision, the practices of treatment agencies, the lack of integration across agencies and the gaps in the treatment services means that for families, coping with the services becomes part of the problem of coping with heroin use. Finally, the absence of any concept of the agency of the family, of its capacity to be a strategic actor rather than a victim (or in line with the stereotyping, a cause) of heroin use, means there is no conceptual or practical basis within the treatment system or within the policy that frames it, to incorporate the family as an agent of recovery.

In this context, what is required now is a paradigmatic shift within the National Drugs Strategy, which recognises the centrality of the family to the heroin problem, which acknowledges the needs of the family and which recognises the potential of the family within the continuum of care. While recognising that not all families can play a role in the latter, this understanding of the family should underpin and inform the development of policies, provisions and practices which:

- Recognise the needs of families as victims of drug use and ensure that adequate supports for families are in place to minimise negative impacts
- Acknowledge and address the problematic interface which the treatment system presents to families seeking support
- Acknowledge the long-term implications for families coping with drug use including those for whom the initial problem has been resolved but who continue to deal with the negative implications
- Ensure that families coping with drug use, and the user, are brought within the framework of the treatment and support services as soon as possible
- Recognise the potential of families to support the user into recovery and take steps to resource families to play this role
- Facilitate the provision to families of the necessary information, education support and opportunities for participation in the development of services.

Such a paradigmatic shift requires radical rethinking in relation to contemporary provision and practices within the treatment system and within the policy that frames that. In particular it is necessary that the issue of confidentiality between service providers and clients is reassessed. Currently, this confidentiality is considered to present an insurmountable obstacle to greater involvement of the family in the treatment of the drug user and the principle of confidentiality is frequently invoked by service providers even when the client is prepared to forego it. While the confidentiality of the client/provider relationship is enshrined in policy and in legislation, service providers also have a duty to care – a duty which evidence from this study (and others) suggests can be supported by involving the family. A reassessment of the underlying principles of confidentiality, therefore, is more appropriate at this stage than its continued blanket application. At its core, the principle of confidentiality concerns the agreed or assumed limits of disclosure to just those who need to know in order to achieve the purpose for which the information was obtained or revealed in the first place. At this point in time, the inclusion of the family amongst ‘those who need to know’ must be considered.

A second issue which needs to be reassessed in the context of a paradigmatic shift in policy for families is the role of peer-led Family Support groups. This research has highlighted the fact that these groups are hugely instrumental in providing information, education and support to families in order to help them understand the issues they are dealing with, to deal more effectively with the problem and to look after their own needs. While Family Support groups cannot make the problem go away, they can help families to minimise the negative impact of it. Currently, however, Family Support groups are not recognised as having a valuable role to play in supporting families coping with drug use. Their work is not validated by professionals or service providers either within the generic or specialist services. As a result, Family Support groups are not included in the continuum of care and very few service providers recommend these groups to their clients. Consequently, families are deprived of access to a valuable resource. In addressing policy provision for families in the context of problem drug use, the role of Family Support groups must be acknowledged.

7.3.2 The social context of heroin use in Ireland

The growth of the heroin problem in recent years, as evidenced by the treatment data, has been characterised by its encroachment into new areas: both geographically and socially. Heroin misuse is now extending to areas previously unaffected, including rural areas, and to areas with very different socio-economic profiles than those traditionally affected. While the most severe levels of the problem are, beyond doubt, within areas of urban deprivation it is important also to recognise this new pattern.

The focus of this study was on families: however the location of the study in three very different areas allowed the social dimension to be explored to a limited extent. From this, there is some evidence to suggest that significant urban/rural differences and class differences exist in relation to families' responses to problem drug use. For example, there appears to be a greater propensity to critique the professional discourse and to challenge the dominant treatment paradigm within middle class and rural communities than within working class and urban communities. There is also some evidence to suggest that the use of private sector services (such as psychiatrists, counsellors etc.) is also more prevalent amongst middle class families. In rural areas too, the fact that the key actors in responding to problem drug use may be both socially and geographically close, provides a particular local context that is not always replicated in urban areas. Conversely, the experience of stigma, possibly indicating processes of marginalisation at local level, was a common experience across all localities.

In this context, there is a particular challenge in ensuring that the actual level and nature of need within different areas and different types of areas are identified and addressed. A 'one size fits all' approach is not appropriate for users or their families and it is not appropriate for the range of localities in which they live. The regionalisation and localisation of drugs policy needs to be finely attuned to the reality at local level and in particular needs to:

- Challenge the stereotypes of drug use and drug users (and families with drug users) which inhibit timely action on the part of families and which fuel stigma and marginalisation at local level
- Ensure that the establishment of supports and services at local level anticipate the problem of drug use or at least, hastily responds to it
- Recognise the local social context including differences between urban and rural communities and develop models appropriate to both

- Ensure that within the development and roll-out of services and interventions, class biases are not introduced and that the needs of different types of communities are identified and addressed
- Acknowledge and address the needs of families and localities who are continuing to cope with the long-term problems that have resulted from the original heroin epidemics.

The fine-tuning of services and supports to local needs can be facilitated by inter-sectoral working at local level. This has been acknowledged within the LDTFs and RDTFs which bring together actors from all relevant sectors, including the community sector. In this context, it is important to recognise and resource the full potential of the community sector. Supports within the community sector have been identified by research in both Ireland and elsewhere as the most easily accessed and often the most effective for families in need. Importantly, research has also found that community sector provision reinforces and compliments other sources of support (including personal networks) by providing a new domain of support with greater empathy than can be provided by the statutory or private sectors and greater objectivity than can be provided by personal networks. In this context, the role of peer-led support groups at community level should be fully recognised and resourced, not just in relation to providing support to families but also in relation to their capacity to identify local needs and to participate in the development and delivery of services to meet those needs.

7.4 Recommendations

To address these policy objectives the following measures should be undertaken:

- 1 The needs of families coping with problem drug use should be addressed by recognising, valuing and resourcing the role of peer-led Family Support groups in assisting families in coping with heroin use.**
 - 1.1 Throughout the country, peer-led Family Support groups should be sufficiently well resourced to provide families with the level and nature of support which they require. Resourcing of family support groups should include provision for the employment of **peer** support workers (who could be drawn from support group members) as well as provision for support, education, information and respite activities.
 - 1.2 Family Support groups should be further resourced through funding networks and networking activities at local, regional and national levels, to reinforce, add value and facilitate shared learning and to promote common standards of good practice.
 - 1.3 The value of Family Support in assisting families cope with problem drug use and in facilitating them support the user into recovery should be explicitly acknowledged within the continuum of care, and service providers in both generic and specialist services should, as part of their own good practice in responding to drug use, recommend family members to Family Support groups.
 - 1.4 The value of Family Support should be recognised within the structures of the NDS, through the formal representation of local and regional Family Support networks in the LDTFs and RDTFs and at national level through involvement in the NDST.

2 The burden of care on families arising from the lack of constancy of support to drug users should be addressed through the deployment of specialist personnel at local level to provide ongoing support to drug users and ongoing liaison with families.

2.1 Throughout the country, specialist personnel should be established at local level to work primarily with drug users but also, as appropriate, with their families. These locally-based specialist personnel would:

- (a) act as supports to, and advocates for, drug users in dealing with all medical, social and economic dimensions of their lives
- (b) liaise with the families of drug users on an ongoing basis.

2.2 Such specialist personnel should be a central dimension of responding to drug use at community level. They would work with the drug user, and as appropriate, in conjunction with the family, in developing personal maps to guide the transition into a heroin-free lifestyle, incorporating links into education, training and employment opportunities.

2.3 These personnel should be independent of any service provider within the treatment system and should be available to provide assistance and advice to the drug user and to liaise with their families on an ongoing basis, regardless of the treatment status of the drug user.

3 The problems encountered by families as a result of the fragmentation of provision and the problematic interface with the treatment system should be addressed by establishing formal links between family support groups and specialist personnel.

3.1 Formal links at local level should be established between the specialist personnel referred to in Recommendation 2 and Family Support groups/workers referred to in Recommendation 1. These links would ensure a comprehensive continuum of provision within which the needs of the user and those of the families are addressed.

3.2 Specialist personnel and family support groups/workers should also be active in promoting greater consultation, on an ongoing basis, between families and the treatment system in order to improve the interface between families and the range of service providers within the treatment system and to facilitate more effective involvement of families in supporting recovery.

3.3 There should be active consultation, on an ongoing basis, between these specialist personnel and Family Support groups/workers at local level and the structures of the NDS, RDTF and the LDTF regarding the development of community-based responses to heroin use, including greater exploration of drug-free responses.

4 The difficulties encountered by families arising from the inadequacy of support to families from the generic services should be addressed by developing codes of practice in relation to information provision.

4.1 All non-specialist providers – including GPs, counsellors, hospitals, youth services, schools etc. – who come into contact with heroin users or their families should be provided with up to date and accurate information on the services available within the treatment system.

4.2 All service providers, both within the generic and specialist sectors, should, without compromise or prejudice to the delivery of their own services to drug users, inform drug users of the availability and role of the specialist personnel referred to in Recommendation 2.

4.3 All service providers, both within the generic and specialist sectors, should, without compromise or prejudice to the delivery of their own service to the family members of heroin users, inform families of the availability and role of family support groups.

5 In the ongoing development of responses to problem drug use, the spatial and social diversity that now exists in relation to patterns of heroin use should be acknowledged both within policy discourse and provisions.

5.1 Measures to create greater awareness of the prevalence of the threat of heroin use and the growing social diversity amongst those affected, should be implemented, with the specific objective of challenging existing stereotypes of heroin users, of families with heroin problems and of communities with heroin problems.

5.2 The provision of information and services to local communities throughout the country should anticipate rather than react to the emergence of problem drug use, with a particular focus on the transfer of identified best practice in relation to support for users and families.

5.3 It is also important to recognise and respond to the deep and complex problems that beset families and communities where a heroin problem has been endemic for generations. Adequate supports should be put in place for such families and communities to cope with the long-term consequences of heroin use: these include support for grandparents looking after their grandchildren and support for families caring for those with HIV or Hepatitis C.

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