

# Effective Interventions Unit

## Supporting families and carers of drug users: A review

### What is in this review?

This review examines the impact of drug use upon families and carers and identifies their needs. It examines and describes the range of provision and methods of addressing the needs of families and carers. It gives particular attention to the development of family support groups. It also offers information about resources available to agencies, service providers and family support groups.

### What is the aim?

To provide information and evidence to strengthen the range of support available to families and carers in Scotland

### Who should read it?

Anyone involved in providing support to families and carers. This includes DATs and service commissioners, primary health care workers, drug agencies, social work services, voluntary sector agencies and those involved in family support groups and through the wider community.

### Who conducted the review

Davy Macdonald, Patricia Russell, Nick Bland, Anita Morrison and Christine De la Cruz conducted and compiled this report. The literature review was conducted by the Centre for Research in Families and Relationships, University of Edinburgh. The qualitative study was conducted by Marion Fisher Associates.

## Contents

|   |    |
|---|----|
| <b>Chapter 1:</b> Introduction  | 1  |
| <b>Chapter 2:</b> Family Support: Concept, Aims and Benefits          | 5  |
| <b>Chapter 3:</b> The impact of drug use on families and carers       | 9  |
| <b>Chapter 4:</b> The needs of families and carers                    | 15 |
| <b>Chapter 5:</b> Methods of support                                  | 29 |
| <b>Chapter 6:</b> Current provision                                   | 45 |
| <b>Chapter 7:</b> Family support groups                               | 54 |
| <b>Chapter 8:</b> Principles and practice of effective family support | 71 |
| <b>Chapter 9:</b> Resources   | 76 |
| <br>  |    |
| <b>Appendix 1:</b> Membership of Reference Group                      | 83 |
| <b>Appendix 2:</b> Drug Action Team contacts                          | 84 |
| <b>Appendix 3:</b> Summary of EIU literature review                   | 87 |
| <b>Appendix 4:</b> Summary of EIU qualitative study                   | 89 |
| <b>Appendix 5:</b> Summary of EIU conference survey                   | 91 |
| <b>Appendix 6:</b> References   | 95 |

## CHAPTER 1: INTRODUCTION

In recent years, there has been increasing recognition of the impact that an individual's drug use can have on other family members, including extended family and friends. Evidence suggests there is a significant impact on physical and mental health, financial circumstances and family relationships.

A major contributor to this wider recognition of the difficulties faced by families and carers has been the growth of **family support groups**. A number of these groups have also become active in developing other areas of service provision in their wider communities. They may take on a lobbying role as in Glasgow and Edinburgh where they campaigned for the development of drug treatment services in the early 1980's. Today, family support groups are increasingly playing a key role in support for families, carers and friends of drug users and provide a range of support, such as complementary therapies, provision of information and training.

Family support groups, however, although very important, are only one method of supporting families. There has been growing interest from family members, Drug Action Teams (DATs), Social Work, drug agencies and others in expanding the support available to families. To date, however, progress has been limited, in part due to the lack of research evidence about effective approaches. There are also limited resources currently available to assist those seeking to develop ways of supporting families.

### The background and context

The Ministerial Drugs Task Force report "Meeting the Challenge"(1994) recognised the impact of drug use upon families. It stated that drug misuse can have a 'devastating effect on the families and friends of the individual, leading to the break-up of relationships and the breakdown of family life'. It recommended that **carers and family members should be represented upon local Drug Forums** in order to ascertain, co-ordinate and express the views of this group so that they could be incorporated into developments within the DAT Action Plans.

More recently, Tackling Drugs in Scotland – Action in Partnership (Scottish Office 1999) stated that **DATs should work more closely with local communities**, including building better connections with Social Inclusion Partnerships and Community Safety Partnerships, to further strengthen the participation of communities in informing the work of the DATs. A key objective was to enhance the support for families coping with a relative's drug use.

Discussion at the national Drug Conference on Communities and Drugs (Scottish Executive 2001) reiterated the need for further developments at both DAT and national level in community engagement and support for families. A survey of community groups carried out by the Scottish Drug Forum on behalf of the Effective Interventions Unit had highlighted the **'piecemeal' fashion of engagement** and the lack of uniformity in what was defined as community engagement and involvement. This lack of engagement means that responses to supporting families have been limited to date.

A further development in recognising the needs of families and children was the publication of Getting our Priorities Right (Scottish Executive 2001). The document acknowledges the significant role that family carers play in relation to caring for the children of drug users and makes several recommendations in support of their needs.

In the last 12 months, however, there has been increasing activity designed to improve and enhance the support available to families and carers. One interesting development is the creation of **local coalitions**. In Argyll and Clyde, family support groups have come together with the aim of extending support to families by setting up a helpline. The support groups involved will share the organisation and the workload of running the service.

Another development is the appointment of **family support workers** who may help the formation of family support groups, provide direct support to family members and develop links with other agencies to widen access to other methods of support. These posts may be managed by agencies such as carers' organisations or drug agencies.

A **national Family Support Conference** took place in May 2002, jointly run by family support group members from throughout Scotland, Argyll and Clyde Alcohol and Drug Action Team, The Scottish Executive, the Scottish Drugs Forum and the DAT Association. This marked a major step forward in identifying the issues that affect the families and carers of drug users, and also raised the profile and importance of family support. Key issues to emerge were:

- the need for **increased recognition** by Drug Action Teams, drug agencies, Social Work, Health and other service providers of the importance of supporting families
- the need for **two way communication** between local communities and DATs and their partner agencies
- the benefits of **sharing experience** between local support groups
- the enthusiasm for **more networking and liaison** at a national level.

In October 2002, the First Minister announced that £180,000 would be made available from recovered criminal assets to help with the implementation of the key recommendations from the conference. These are: the establishment of a national network of family support groups; training in counselling skills; helping families to cope with relatives coming out of treatment and rehabilitation. It will also help to support grandparents and other family members who are caring for the children of drug using parents.

### **Aim of report**

The **aim of this report** is to provide a body of evidence and information that can underpin and support the design and delivery of support to families and carers whether that takes place through the statutory sectors, voluntary agencies and organisations, or from within the community.

From our review of the evidence, the report sets out for **DATs and service commissioners, managers and practitioners in the statutory and voluntary sectors, and in the community:**

- the impact of drug use on families and carers and the nature and extent of their needs
- the role and purpose of different approaches to family support, including models of family support groups
- examples of practice
- sources of support and funding

## How we gathered the evidence

The development of family support at all levels has been variable across Scotland. This may be due to a lack of knowledge about the way in which families are affected by the drug use of a family member and a lack of evidence about effective ways to support them.

We undertook a number of exercises to draw together this work on family support:

### 1. Reference Group

A Reference Group was established to draw on expertise from health, social care and the voluntary sector to support the EIU in the development of the family support work. This Group met on three occasions during the course of the work. Membership of the Reference Group is set out in Appendix 1. The EIU are very grateful for their support and contributions.

### 2. EIU Literature Review

The EIU commissioned a review of the relevant research and policy literature (Bancroft et al., 2002). The review had four key objectives: to establish:

- what is known about the support needs of families of drug users
- what is known about the effectiveness of interventions designed to address those needs
- what is known about family support groups, the difficulties they face and how they become effective sustainable groups
- whether involving families in treatment programmes has beneficial outcomes for the family member and/or the drug user.

This review was conducted by The Centre for Research on Families and Relationships at the University of Edinburgh. Standard bibliographic search techniques were used, including both medical and social science databases. A wider internet search using a search engine was conducted in order to identify projects and literatures not indexed elsewhere. 'Grey' literature (unpublished work and items located through the World Wide Web) was obtained wherever possible, for example, directly from agencies themselves.

### 3. EIU Qualitative Study

The EIU commissioned a qualitative study aimed at eliciting the views and experiences of families affected by a relative's drug use. The study also sought the views of agencies and service providers involved in the treatment of drug use, those offering support to family members and service commissioners. The intention was to identify the varying needs of family members and what methods were most effective in supporting these needs. A total of 17 focus groups and 71 interviews were conducted in Glasgow, Dumfries and Galloway, Grampian, Lanarkshire and Tayside to investigate any demographic differences. The study was carried out by Marion Fisher Associates. Copies of the report are available from EIU on request.

#### **4. EIU Mapping Exercise**

The EIU conducted a mapping exercise to identify and review existing models of support across Scotland. This involved family support groups, the voluntary sector, drug services and social work services. This component involved a questionnaire survey of agencies and groups to establish what services they offered and highlight issues of importance to them. A total of 262 questionnaires were sent out and 122 returned. We acknowledge that this mapping is not comprehensive but we believe it represents a reasonable picture of the support for families and carers across Scotland.

#### **5. EIU Conference survey**

The EIU conducted a conference survey with family support group members attending the national Family Support Conference 2002 to elicit the experiences of individual family members in coping with drug use, seeking support and what support would be most beneficial to them. A total of 51 questionnaires were completed (over three quarters of those attending). The results of this survey also appear in the Conference Report.

#### **6. EIU Interviews**

The EIU also conducted a series of interviews with families and service providers to identify key themes and issues to be addressed in the report; and to provide examples of current provision.

#### **THANK YOU**

**The EIU would like to thank the families and carers, agency workers and DAT officers who participated in our evidence gathering**

#### **Structure of report**

**Chapter 2** discusses the concept and aims of family support. It also identifies a number of benefits from offering support to families and carers.

**Chapters 3 and 4** draw on the evidence to describe the impact of drug use on the family and the range of needs that arise among family members and carers.

**Chapter 5** examines and discusses the variety of methods of supporting families coping with a relative's drug use.

**Chapter 6** describes the range of support that is potentially available to families and carers. The Chapter also examines and discusses the factors that influence effective support by agencies and service providers.

**Chapter 7** discusses the concept of a family support group and provides examples of practice. It also discusses some of the difficulties and challenges.

**Chapter 8** identifies core principles to underpin effective support for families and carers and sets out key issues to address for DATs and partner agencies, agencies and service providers and family support groups.

**Chapter 9** gives information about resources available at national and local level.

**Appendices** are listed at the back of the report. These contain membership of the EIU Reference Group, DAT contact list and summaries of the literature review, the qualitative study, the conference survey and the mapping exercise.

Throughout the report there are summary boxes showing key findings from the evidence and highlighting the main points of different methods and approaches.

## CHAPTER 2: FAMILY SUPPORT: CONCEPT, AIMS AND BENEFITS

This Chapter discusses and examines the concept of family support drawing on the findings of the literature review, the qualitative study and the views of the EIU Reference Group. It also identifies a number of benefits.

### 1. What is family support?

There seems to be no single, agreed definition of family support. The EIU evidence shows that there is a **variation in views and experiences** on the nature and purpose of working with families of drug users. It may be that the term “family support” will – rightly – cover a range of possible support activities.

The research evidence shows that interventions involving family members have often been aimed at getting the substance user to engage in treatment. As a result, evaluations have focused on this outcome rather than on the benefits to the family (EIU literature review). We know that families often seek support for their drug using relative rather than for themselves. The underlying assumption by both family and agencies seems to be that the recovery of the drug user will reduce the stress experienced by the family and, consequently, the need for family support. This outcome is dependent, however, on whether the drug user is willing to undertake treatment and whether stabilisation or abstinence is achieved. This can be a long term process. Even if the drug user does make progress, it does not mean that the family’s health, social and financial circumstances improve straightaway. In Chapters 3 and 4 we describe in more detail the impact of drug use upon families and carers and the range of their needs.

In the EIU qualitative study, participants from social work, health and other agencies reported that they perceived a wide range of support services to be available to families. This included many services aimed primarily at the drug user or relevant to drug using parents and dependants. In contrast, family members reported that they saw little support being available to them. This may be due in part to lack of knowledge among families about what support exists and how it can be accessed. However, it may also point to differences in perception about **what constitutes an appropriate service to meet the needs of families.**

As noted above, the first approach to services by the family may be to gain information and support for their drug using relative but families can seek support for a range of reasons:

- to gain information and knowledge about drugs, their effects and available treatment
- to seek support to help them to cope emotionally
- to seek practical assistance for themselves or other family members e.g. in caring for grandchildren, financial problems

Responses from agencies to the EIU mapping indicated that agencies and service providers may tend to think about family support primarily as a way of improving the support for the drug user. This may be a benefit of working with, and supporting, families. However, the evidence that we have gathered strongly suggests that, to be effective in helping families, the service that is being offered should have clear **aims and objectives** specific to that client group. This is a **key issue for DATs and partner agencies when assessing needs and planning and commissioning services for families and carers in their area; and for agencies and service providers from all sectors, including the community, when designing and delivering services.**

## 2. What does family support aim to do?

The overall aim of family support is **to limit the harm to family members that can result from their relative's drug use**. It aims to minimise the personal stress of family members and to ensure they are not left alone to cope with situations where they may have little knowledge or understanding. It also aims to help them recognise their own needs and the importance of that recognition to their own health and that of other family members. This, in turn, can enable family members to cope better with their drug using relative.

Provision of support to families should aim to meet the wide range of needs that families experience when faced with coping with a relative's drug use. Families may need **emotional support** which may be addressed by approaches such as family therapy, counselling and support groups. Other needs may have to be addressed through the provision of **practical support**: for example, respite, advocacy and complementary therapies. Support can also be given by providing **information** to assist the family member gain a level of knowledge that improves how they understand and deal with their circumstances.

## 3. Who is support for?

The term 'family' can be defined broadly. Over the years, family support appears to have focused mainly on mothers, through their traditional role as the 'carer'. The qualitative study confirmed that it is often the mother of the drug user who is most likely to be active in seeking support. Almost three-quarters of those attending the Family Support Conference 2002 were mothers. One tenth were fathers.

### EVIDENCE

There is a common assumption throughout the literature that 'family' means 'parent' and 'parent' means 'mother'.

EIU literature review

This can have a direct impact on how the needs of families are recognised and how responses to supporting families are developed. For agencies and service providers, it is important to recognise that, although other family members may not be active in seeking support, it does not mean they do not have individual needs. It may require alternative methods of contacting such 'hard to reach' individuals and the development of a range of methods of providing support in order to best meet these needs.

For the purpose of this document the definition of 'family' covers:

- family members (immediate and extended)
- significant friends
- carers - the term carer covers those caring for a drug user or caring for dependants of drug using parents
- dependent children of drug using parents



#### 4. What are the benefits of supporting families?

Providing effective support to families and carers can be a difficult task, in part related to the circumstances and issues they face. Families and carers say that they can feel judged and stigmatised (EIU interviews; conference survey). This demonstrates that there can be certain risks associated with offering support to families. Sometimes, the desire to assist can result in families develop unrealistic expectations. Support given in the shape of advice, with the best of intentions, can leave the family member feeling worse. It may also create greater conflict within the family.

However, the evidence strongly suggests that support that is **well structured, consistent and addresses the needs of families and carers can produce significant benefits to their personal health, well being and relationships.**

From our review of the evidence and the responses to our consultation, we have identified a number of benefits for family members from appropriate support to meet their needs:

- **Helps families and carers to recognise and understand their own needs and seek help.** Providing support directly to families gives them the opportunity to identify their own health, social and emotional needs and offers a source of information and help.
- **Improves the family's understanding of drugs, dependency and treatments.** If the family has a better understanding of the situation they face, it can reduce their anxieties, and demystify the drug users' behaviour. It can also help to minimise collusion and manipulation within the family.

'It enables you to know what to expect and do, rather than worry with uncertainty. It also helps prepare you emotionally'  
(EIU conference survey)
- **Everyone working together towards a shared goal.** Where the drug user is receiving treatment, giving support to families helps to create a common goal for the agency, drug user and family to work towards rather than the family having expectations that may be unrealistic at that time e.g. abstinence rather than stabilisation. This can reduce pressures put upon the drug user that may be counter-productive (EIU mapping exercise).
- **Improves communication within the family.** Support for the family can reduce the level of tension within the family and allow family members to address and discuss their feelings. By being able to talk about issues, rather than conceal them, families can rebuild trust and relationships. It can also mean that families respond to the drug user in a consistent way (e.g. all refuse to lend money rather than one giving in to demands) which reduces conflict within the family.
- **Reduces isolation.** Support can reduce the isolation experienced by families. Information about other appropriate support services can also extend the pool of support and the networks available to family members.
- **Identifies and can address family issues.** Support for the family can allow for an integrated approach to other issues and problems within the family that impact either on their well being or the recovery of the drug user. It can also ensure that the needs of children are identified.
- **Increases support for the drug user.** As noted above, this is recognised as a benefit by drug agencies, although it should not be the prime objective. If support helps the family to deal with the problems arising from drug use, they may be able to offer support to the drug user.

### KEY FINDINGS

- There is limited research evidence on effective ways to help families. There is a need for **more evaluation**
- There should be a clear distinction between support for the family and support for the drug using relative. DATS, agencies, service providers in all sectors, including the community should agree **clear aims and objectives** for family support services.
- Families include **immediate and extended family, friends, carers and dependent children.**
- Support that is **well structured, consistent and specifically addresses the needs of families and carers** can produce significant benefits to their personal health, well being and relationships.

### CHAPTER 3: THE IMPACT OF DRUG USE ON FAMILIES AND CARERS

This Chapter sets out the evidence on the impact that drug use has on families, carers and significant others. It draws on a range of evidence, which includes the EIU literature review, the EIU qualitative study and the EIU conference survey.

#### 1. Estimating the extent of the impact of drug use on families

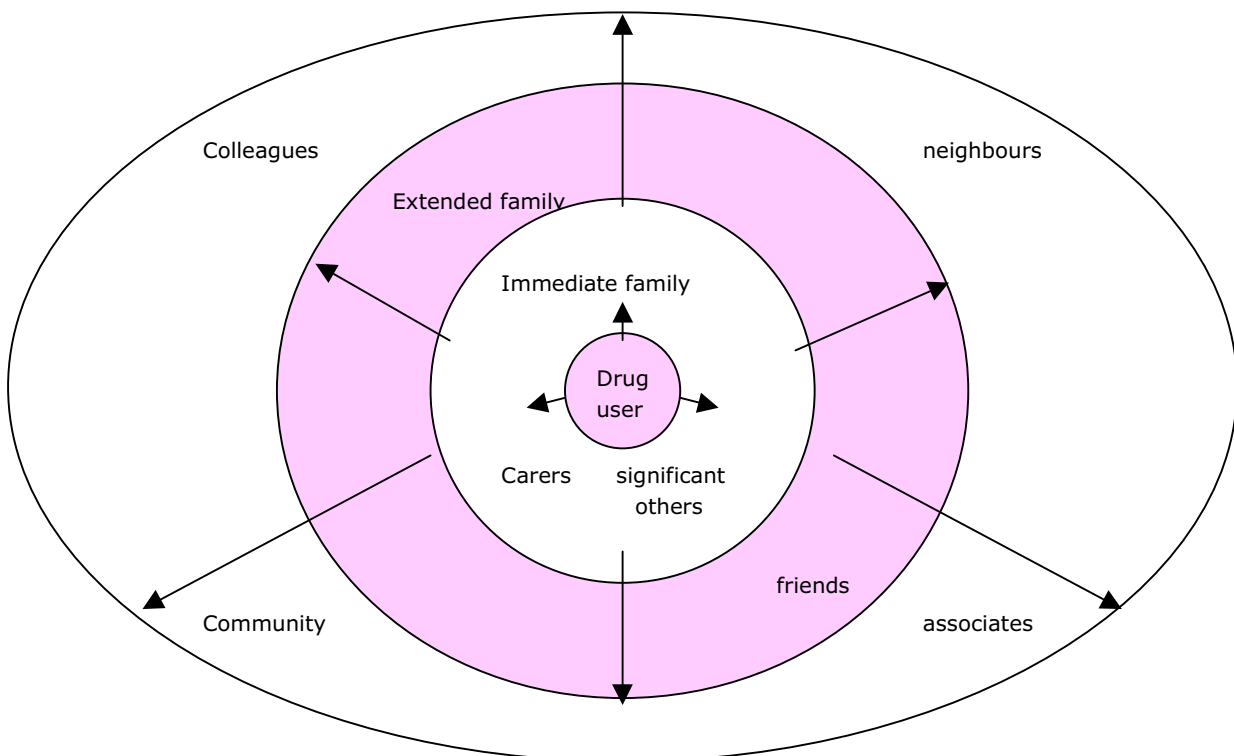
Putting an exact figure on how many families and family members are affected by a relative's drug use is a difficult task. The hidden nature of drug use and the concealment of drug use by the family means that there is probably a large number of drug users and affected family members unknown to treatment and care services. Estimates of the extent of the problem can be made from a number of sources.

Present estimates of the levels of drug use within Scotland put 'problematic drug use' within the population at 55,800 (Hay et al, 2001). This figure refers strictly to those people using opiate and benzodiazepine drugs only. It is important to note that concern from families about a relative's drug use will often involve any illegal substance, including cocaine, ecstasy and cannabis. A recent report on psychostimulant drug use in Scotland identifies the small, but increasing, number of cocaine users in Scotland (SACDM Psychostimulants Working Group 2002).

Velleman (2002) makes the conservative assumption that 'every substance misuser will negatively affect at least two close family members' to a sufficient extent that they will require primary health care services. Therefore, it may be reasonable to estimate that the number of family members within Scotland affected in some way by a relative's drug use will be in excess of 100,000.

The precise number of family members, carers and significant others affected by drug use cannot be identified. Nonetheless, it is clear that the impact of any one individual's drug use can spread widely from close family members to friends, work colleagues and the wider community as a whole (see Figure 1).

**Figure 1: The impact of drug use on families**



## 2. The nature of the impact of drug use on families, carers and significant others

A consistent picture of the way drug use impacts on families emerges across the studies we carried out. The impact on families can be identified in four key areas:

- physical and psychological health
- family relationships
- finance and employment
- social life

### Physical and psychological health

It was clear from across the studies that the experience of living with drug use in the family produces a great deal of stress leading to a range of physical and psychological problems. The literature review identified research on short-term effects which include anxiety, guilt, loneliness, worry, fear and confusion. Longer-term effects include significant physical ailments such as shingles, ulcers, raised blood pressure and psychological problems such as depression, panic attacks and anxiety disorders.

“You feel helpless and hopeless. You can't sleep and you suffer from nerves”

(EIU conference survey)

Such problems were a common experience for respondents to the conference survey: over three quarters had experienced physical and psychological problems. The incidence of heart and stomach problems was highlighted in both the conference survey and qualitative study. Colds and flu were also attributed in the qualitative study to the strain felt by family members. Depression and anxiety were the most frequently mentioned psychological health problems from both the conference survey and qualitative study. The qualitative study also highlighted the emotional impact on carers, such as grandparents, due to their worry about the impact on children in the family.

Worryingly, the literature review also identified some research showing an increase in 'appetite-related behaviours' such as drug and alcohol use, eating and smoking among family members. The qualitative study also found this: some families admitting that one or both parents had started to drink heavily to cope with stress. The potential longer-term impact of such substance misuse on both physical and psychological health is clear.

### Family relationships

The literature review identified how family dynamics can be affected by a relative's drug use. A common example of this is family members having to fulfill a role that differs to their position in the family. This situation occurs, for example, when grandparents take on the caring role for children of drug misusing parents or children have to take on parenting responsibilities for younger siblings or even for the drug using parents themselves.

The conference survey and qualitative study both highlighted the range of ways in which drug use can impact on the relationships between family members. This may vary depending on the degree to which the family is united about how to deal with the situation. But often family members view the problem, and cope with it, differently and this will produce conflict not only with the drug user but also with each other. For example, the qualitative study highlighted that the attention given to the drug user can result in other family members feeling neglected or excluded. There can also be disagreement about how to treat the drug user. Attempts to try and maintain some sense of normality can result in some family members colluding with the drug

#### EVIDENCE

"My grandchildren live with us and my other daughter feels she gets no help and that her children are neglected by us"

(EIU qualitative study)

user, and this may involve lying. These experiences are common: almost all respondents to the conference survey felt that relationships with immediate family members had been affected.

The results of such difficulties can include:

- increased arguments
- breakdown in communication
- increased tensions within the family

The qualitative study reported that in extreme cases, the stress had caused splits and rifts between families. For example, relationships between spouses/partners were so seriously affected that separation or divorce occurred.

## Finance and employment

Financial problems and difficulties at work emerged as a common problem for families in both the qualitative study and the conference survey.

Financial difficulties arose both as a direct result of the drug user's behaviour and through families' attempts to help. The most frequently reported problems from both the conference survey and qualitative study were:

- theft of money and possessions by the drug user
- repaying users' drug debts
- paying for rehabilitation treatment for the user
- costs associated with caring for dependants

The qualitative study reported examples where debt problems were compounded by parents purchasing drugs for the user themselves. They felt this was the only way to keep the drug user safe. Grandparents caring for grandchildren reported problems arising from child benefit books being held by loan sharks to cover debts incurred by the drug user.

"I pay off debts to keep dealers away from my house. If we don't give them money they'll steal to get it. I don't want prison for my son"

(EIU conference survey)

"I had to give up my job because of the stigma"

(EIU conference survey)

The qualitative study reported some examples where financial difficulties were increased because family members had given up working. They felt unable to cope with the demands of work and the stress resulting from drug use in the family. Over half of the respondents to the conference survey had experienced difficulties at work because of the impact of drug use on the family. Problems included:

- being unable to concentrate at work
- having to take time off, due to their own health problems, or to care for the drug user, or other dependants
- being embarrassed that colleagues knew family circumstances
- reduced confidence in carrying out work

## Social life

The qualitative study and conference survey highlighted that the difficulties associated with drug use in the family frequently had an impact on the social lives of family members. For some in the qualitative study, the stigma that can be associated with drug use and their own embarrassment about the situation had led to increased isolation from extended family and friends. For others, it was the practical demands of dealing with all the problems associated with drug use that had prevented them maintaining social contacts.

Over half of respondents to the conference survey reported problems with their social life. The most common issues they identified included:

- being alienated by family and friends
- being afraid to leave the drug user alone at home
- coping with the demands of looking after dependants
- feeling of being talked about by others
- having little energy to go out

"being embarrassed at family gatherings and feeling a failure as a parent"

"zest for life has evaporated"

(EIU conference survey)

### 3. Differences in impact

The discussion above identified where problems commonly occur in families of drug users. However, it should not be taken that this indicates that this range of problems impacts universally on all families of drug users. The qualitative study reported that family members felt that there was no single way in which families or family members were affected. The impact could be highly individualised.

The literature review similarly highlighted differences in impact:

- differences between family members
- differences in impact of different substances

#### Differences between family members

The literature review identified some research studies that treated the family as a single unit but highlights others that have examined the differential impact of drug use on family members depending on factors including:

- their role and position in the family
- their gender
- their relationship to the user

Examples from the review where there may be differences in the way drug use impacts upon individual family members include:

- **parents are often initially more shocked** than siblings who may already be aware of drug use.
- **siblings may conceal the drug use** to minimise the impact it can have upon parents and their reaction to the drug user. Siblings may also be resentful towards the drug user and the level of family attention that they receive, resulting in animosity and conflict. Evidence also suggests that siblings are more at risk of using drugs, in part relating to their increased chance of exposure to drug use.
- **fathers can be less likely to seek support** and will often reduce their relationship with the drug user and internalise their own needs.

- **children of drug using parents** can be at risk of receiving poorer physical, intellectual, emotional and social development. This can result in them being socially withdrawn, displaying aggressive and erratic behaviour, and displaying greater risk taking behaviour.
- **partners/spouses may experience greater levels of verbal and physical abuse,** mood swings and pressure for money from users.

The literature review points to a lack of research on different family structures and considers this an important area given that social change has led to increasing family diversity.

Ethnicity was rarely considered as contributing to a diversity of impact. Findings from the qualitative study suggest that the context of religion, custom and the perception of family life may be important factors affecting issues of shame and stigma in families from different ethnic minorities.

### **Differences in impact of different substances**

The literature review also highlights that the use of different substances can be associated with very different impacts on the family. It identifies three factors:

- the social contexts associated with the substance use.
- the moral and social connotations of the substance user's behaviour, mood and physical health
- the effect of the substance on the user

The review highlights differences in family impact between drugs and alcohol. One clear example reported is that families of drug users often have to cope with stealing by the drug user. Families affected by alcohol problems do not report this problem. Across reviewed studies, families tended to want to deal with alcohol problems within the family but were more likely to look for formal help from services in the case of drug problems. The review also highlights differential family impact by different drugs. For example, one reviewed study showed that relatives of people addicted to tranquillisers experienced fewer problems than those associated with illegal drug use.

Stigma and shame continually appear to be significant factors for families and carers. There appears to be a greater stigma surrounding drug misuse than that associated with alcohol problems use.

#### **EVIDENCE**

**ADFAM**, is a UK organisation that supports families affected by drug use. Findings from a series of consultations on supporting families affected by drug use in Wales showed that, although the harm caused by alcohol exceeded that of drugs:

- drugs were feared more
- those using drugs were vilified by society more than those using alcohol
- society was more tolerant of problems caused by alcohol
- prejudice (either perceived or real) was a major barrier to accessing support
- fear of being judged was a major barrier to accessing support

There can be significant differences in the traits one drug produces in comparison with another and how that may affect those around the drug user. Certain substances, in particular alcohol and benzodiazepines, are more associated with violence and aggression: other stimulant drugs such as amphetamines are associated with mental health problems such as paranoia and psychosis. This can have a direct effect on how a relative's drug use may impact upon the family and also on the needs they may have.

#### 4. How do families respond to the stress associated with a relative's drug use?

Family members will respond to the negative impacts of drug use in a variety of ways. The response may, however, increase the problems experienced. Often it is not until behaviour is analysed that people see that they are employing methods of coping and that these can have positive and negative effects upon the individual, family members and drug user.

Often families go through a process where at first they may deny and refuse to acknowledge that there is a problem. Some family members may then attempt to conceal the drug use from others within the family in order to protect other family members or the drug user from the consequences of it being discovered. Many families will wish to conceal the drug use from others outside the immediate family because of the shame and stigma they experience. It may only be after a significant period that eventually the family may seek support and assistance (EIU literature review).

Ways that families respond to drug use include:

- **Denial:** The family denies there is a problem. This can be a viable response in avoiding confrontation, although its effectiveness is usually short-term. Long term denial tends to store up issues rather than addressing them which can result in greater upset and turbulence
- **Self blame:** The family takes responsibility for the situation; for example, parents blaming themselves for child's drug use. There is a danger that this is reinforced if family is regarded as part of the problem rather than the solution. This can be a substantial barrier to accessing support.
- **Blame:** The family assign responsibility for the situation to others: for example, drug user's peer group, social workers or drug workers for not 'solving' the problem. This can result in animosity and anger towards agencies. That makes it difficult for supportive relationships to be developed.
- **'Tough Love':** Families can respond by creating distance between themselves and the drug user; either physically or emotionally. This can range from ensuring the family does not give in to pressure from the drug user, to extremes such as removing the drug user from the family home. This can demand a substantial amount of detachment from feelings that the family may have towards the drug user.

#### KEY FINDINGS

- The stress that families endure can have a direct impact on their physical and psychological health.
- Relationships are affected as stability within the family becomes more difficult to maintain.
- Families face financial hardship whether through caring for the children of the drug user, helping with drug debts, or even through theft and violence.
- Social lives are restricted either as a result of fear of leaving the house, embarrassment or sheer lack of energy to do something for ones' self.
- Family members will be affected differently, respond differently and have individual needs.
- There are significant differences between alcohol and drugs in the stress and strain experienced by families coping with drug use because of illegality and associated criminality, level of stigma and level of guilt and shame felt by parents



## CHAPTER 4: THE NEEDS OF FAMILIES AND CARERS

The impact of drug use creates a range of needs. These can differ from family to family and also family member to family member. In this Chapter we examine the needs of the families and carers of drug users and set out a range of resources available in Annex A. We discuss **general needs** first and then the **specific needs** of certain families.

### General needs

The lack of research into how families cope with drug use means that little is known about their needs, the methods of meeting these needs and the effectiveness of these methods. The EIU literature review found that:

- the diverse needs of all family members are not well documented, especially those of wider kin such as grandparents but also of siblings. The research there indicates that they amount to a significant 'hidden' population of carers for children affected by drug misuse and that they enjoy only limited support from service providers.
- much of the focus of 'need' is on children and on parents but even here needs are not often directly assessed from the viewpoint of family members themselves.
- this leads to a tendency to report professionally defined needs which may or may not correspond with user defined needs.

From our review of the evidence we have identified the following needs:

#### EVIDENCE

Family members and users reported that prejudice was a main barrier to accessing services. Sometimes the prejudice was real, as in where family members were excluded from primary care services. On other occasions, the fear of being judged prevented families (and users) from coming forward for help and support.

(ADFAM: Families in focus - Wales 2002)

#### Coping with stigma and discrimination:

Families say that stigma and discrimination can inhibit them from accessing support either for themselves or the drug user and increase the likelihood of 'concealment' in the family. The negative effects this can produce within the family are discussed in Chapter 3.

**Accessing treatment services and to be involved in treatment process:** Families report unsatisfactory experiences when trying to access support for the drug user. A particular issue that impacts upon them is waiting times to access treatment. There is particular concern about the lack of aftercare services for supporting the drug user. The family may attribute a relapse in the progress made by a drug using relative to a lack of support from agencies. This can result in frustration and can affect the family's relationship with the agency.

#### EVIDENCE

Information on treatments and services was identified as a top priority for family members.

(EIU conference survey)

Where services do exist, our research showed that families do not know about them, or how to access them.

(ADFAM: Families in focus - Wales 2002)

**Assistance with how best to help their relative:** As discussed in Chapter 3, there are a variety of ways of coping that families adopt: and some may actually damage the family and inhibit recovery for the drug user. It can be difficult for family members to understand how they could both help and hinder recovery without assistance to discuss and analyse their circumstances.

**Access to information and training:** Many family members receive their information on drugs and related problems through the media and from the community. The accuracy of information can be questionable and the family is not fully informed about drugs, their effects and the nature and course of dependency.

"It helps being aware of what the relative is experiencing"

(EIU conference survey)

**A range of support options to be available for families and carers:** Since family members and carers react and cope differently, it is essential that there is a range of appropriate support available to them. Families and carers also need to possess the knowledge of what support exists and how they can access that support.

**Emotional support:** The anxiety and stress that families and carers commonly experience in relation to a relative's drug use often requires varying degrees of emotional support either from informal sources such as friends and relatives, or from more formal sources such as counselling. Relationships within the immediate and extended family can be affected, increasing the individual isolation of family members. The result is in an even greater need for emotional support. Respondents to the EIU conference survey identified the following as meeting the emotional needs of families:

- availability of local family support groups
- availability of counselling to families and carers
- telephone helpline service

**Practical support:** The routine pattern of the lives of families and carers may be significantly affected by the impact of drug use. They may have to cope with situations such as: a relative undertaking detox; supporting them through withdrawal; caring for dependants. This often impacts upon aspects of their lives that are crucial to their well being, such as employment, finance and social lives. Respondents to the EIU conference survey identified the following as meeting the practical needs of families:

- advocacy
- befriending
- assistance with child care, especially with regard to those caring for dependent children of drug users
- methods of coping with stress, such as complementary therapies
- access to respite

**Financial assistance:** The financial problems that can affect families were outlined in the previous chapter. Families relate experiences of receiving little support and the difficulties they encounter when dealing with the welfare benefit system or Social Work department.

**Health information:** It is imperative that families and carers receive accurate health information, especially about intravenous drug use and the associated health risks such as HIV / Aids and Hepatitis C. Without such information, they may be unable to take the necessary precautions to prevent the risk of cross infection. This is especially the case with Hepatitis C given the high prevalence among the drug injecting population and the ease of transmission.

## Specific Needs

Any responses to meeting the needs of families and carers will need to understand and address the diversity of needs of such individuals. Families who may have specific needs include:

- families and carers coping with HIV/Aids or Hepatitis C
- ethnic minority families and carers
- carers
- men
- young carers
- siblings
- families in rural and remote areas
- bereaved families

### 1. Families and carers coping with HIV/Aids or Hepatitis C

The **stigma** surrounding HIV/AIDS can be extreme (EIU interviews). This seems in part to be due to the lack of a cure, its ability to be transmitted to others and the lack of understanding within society. The degree of stigma can have the effect of increasing stress among family members and their feelings of isolation. The perception of HIV/AIDS as a disease that largely affects homosexuals can cause difficulties and embarrassment for families, especially if there is a homophobic culture within the family or community. There can often be difficulties in getting the family to accept the situation and come to terms with the long-term reality of supporting someone with HIV/AIDS. Families talk of friends no longer wishing to associate themselves with the family for fear of 'catching something', and of how this, combined with their caring duties, had reduced their social lives considerably (EIU qualitative study).

The lack of a cure for diseases such as HIV means that the family may have to prepare to support their relative until they die. The often harrowing circumstances impact directly on families' own **health and well being** (EIU qualitative study). Often families experience **financial difficulties** which can be as a result of taking on the care of dependants, costs associated with the relative's treatment (e.g. travel costs to hospital) or in relation to their relative's drug use. There is also a **lack of support services** reported in the EIU interviews for families and those affected by HIV, especially outwith the main cities in Scotland.

#### EVIDENCE

Eighty percent of primary carers coming into the HIV carers and family support group reported experiencing reduced health which they contributed to the impact of HIV/AIDS upon their family.

(EIU interviews)

### WHAT CAN HELP:

- Access to a support group to help overcome shame and stigma felt
- Knowledge about the diseases
- Knowledge about current treatments and drugs
- Training on managing stress
- Greater access to counselling and bereavement counselling
- Assistance with supporting other family members
- Aftercare support for the family (when contact with agency has finished)
- Greater respite opportunities
- More childcare support
- Emergency fund to help families financially when required

## 2. Carers

The term 'carer' can apply to those caring for:

- dependent children of drug users
- a drug using relative
- a relative with an illness or disability related to their drug use

Taking on a caring role can vary in its intensity. Some may take on full time care for family members and may apply to the courts to award an order giving them responsibility for the care of dependants. Other carers may have more informal arrangements and care may be for a temporary period: for example, when the drug user is accessing treatment such as residential rehabilitation. Such informal care arrangements can create difficulties for carers involved with other agencies regarding the welfare of the dependant, e.g. on education and health issues. Often there can be tensions created around what is best for the child, with some carers highlighting how the child could be used as a bargaining tool by the drug using parents. Examples of relatives being manipulated with the threat of them not being able to see their grandchildren were not uncommon and produced enormous strain within families (Aberlour 2002).

'Many of the children had arrived on the relative's doorstep with nothing but the clothes that they were wearing'.

(Aberlour, 2002)

Carers are likely to experience the range of problems identified in Chapter 3. More specific needs of carers relate to issues including:

- recognition of the carer's role and their rights
- family dynamics
- care arrangements
- accessing benefits

## Recognition of the carer's role and their rights

Family members involved in caring for drug users or their dependants often report that they do not see themselves as 'carers' and as a result perceive that they have few rights. This appears to be reinforced by an analysis of publicity and information on carers' organisations.

The EIU conference survey suggested carer organisations were the least used form of support and that families had not found the assistance offered helpful. This raises two issues:

- some carer organisations may not recognise families as 'carers'
- organisations may be unfamiliar with how best to support them.

These factors will make it more difficult for carers to access information regarding their rights. Carer organisations provide a wide range of support that is well developed and structured. They have a lot of knowledge and expertise that can help families and carers e.g. about their rights, benefit issues.

### EXAMPLES

- **Edinburgh Family Support Network (EFSN)** operates within the Vocal Carers Centre. Vocal provide a range of services to carers from all walks of life, such as advice and information, counselling, advocacy and training opportunities. The EFSN provide a person centred service and works with anyone affected by someone else's drug use whatever the relationship. The service provides telephone support, one -one work and group meetings. By being a part of the organisation EFSN can access services provided by Vocal such as counselling and training. EFSN can also access expertise from staff and access to resources that may be difficult for the project to obtain as a stand alone project. Contact: 0131 622 6262
- **Renfrewshire Family Support Worker:** The worker organised an event at the local carers centre to attract family members who were caring for dependants of drug using parents. The aim of this was to give family members knowledge of the work that the Carers Centre do and what it can do to support them. The worker also obtained the service of a family lawyer to assist families in understanding their legal rights and options as carers. A buffet was provided and the turn out made the event extremely worthwhile. Many carers voiced their appreciation at being able to obtain information easily within a friendly and supportive atmosphere.

## Family dynamics:

Carers state that there is significant pressure on them from the strain of both looking after dependent children and their concern for the drug user. This can be further compounded by some of the behavioural dynamics that can affect dependent children living with drug use, such as isolation, hyperactivity, risk-taking behaviour and aggression (EIU literature review). This presents carers with added difficulties in coping with their new roles and responsibilities. Dependent children may need support to:

- promote social confidence
- strengthen inter-personal skills
- increase self-esteem
- develop skills and problem solving strategies
- decrease social isolation

(EIU literature review)

Such support would benefit the child but also assist the carer in reducing the behavioural and emotional difficulties they have to cope with. It may also reduce risk-taking behaviour and the chance of the dependant developing their own problems with drugs: something highlighted as a main concern of carers bringing up teenage dependants (EIU interviews).

### **Care arrangements and carers' rights:**

The EIU interviews found that carers often felt insecure about their rights in relation to care arrangements. Some carers spoke of being unsure of what their position was and also of being wary of seeking support or information from statutory organisations in case this had an impact on the dependant, themselves or the drug using parents. Others had sought assistance legally but this often had a significant financial cost unless Legal Aid was available.

In general families have three options regarding the care arrangements for dependent children:

- **Voluntary agreement** between carer and parent: this has the advantage of being relatively easy to arrange but can leave the carer having little control over the situation and with little rights regarding the child's welfare.
- **Legal process:** a number of orders can be applied for through the Court system. These can sometimes take a considerable time to be heard and also costs can be significant.
- **Children's Hearing system:** considers what best supports the needs of the child and will involve input from various agencies as well as independent panel members. Decisions can be reviewed over specific periods of time

Many carers involved in the EIU interviews said that taking on full time care of dependants was a considerable commitment. Informal arrangements often left the carer feeling insecure and with no rights regarding the child and what was best for them. Carers identified a need for some 'middle-ground' to be developed such as **temporary residency**. This could involve temporary residency being given to the carer while the drug using parent was unfit to look after the child adequately. This could be changed once the parental circumstances had improved. While this often happens within informal care arrangements, it can produce difficulties because the carer has no rights over the dependent and their welfare.

The '**Getting our Priorities Right**' consultation paper (Scottish Executive 2001) highlights how extended family carers do not receive the same level of support as foster carers who are recognised as local authority employees. It further recognises that placement within the family should be the first option to explore regarding the child's welfare. The document recommends that carers should receive support in identifying options of **care arrangements** for the child, such as court proceedings or Children's Hearing system. Further, the report recommends that:

- a high degree of **skill, sensitivity and tact** is required by workers to assist families to explore the best options for the welfare of the child/children in question.
- extended family carers should receive a **similar level and quality of support** as that of foster carers, who are recognised as local authority employees.

## Accessing benefits

Chapter 3 highlighted the financial difficulties that families can experience. Taking on the care of dependants also carries a substantial financial burden for carers but they may be unable to access benefits to help. Many local authorities provide no direct financial support to carers to assist them with coping with the financial impact of looking after dependants. Unlike foster carers, they do not receive an allowance.

The main benefits available to extended family carers are either:

- Child Benefit
- Income Support

There are numerous difficulties faced by carers in accessing such benefits. Issues identified through the EIU interviews included:

- informal care arrangements meant that carers were reliant on the drug-using parent to pass on such benefits to them. Often this did not happen: the money may be used to maintain the drug user's addiction
- delays experienced in transferring of benefits from the drug-using parent to the carer
- accessing financial support can impact on other benefits the carer may be in receipt of such as Housing Benefit

This indicates that there is a need for assistance in dealing with benefit issues and addressing some of the delays that arise.

### WHAT CAN HELP:

- Easier access to financial and material support
- Assistance for carers in dealing with agencies, such as education authorities, and the parents
- Access to respite support
- Assistance in negotiating agreements and decisions regarding the child, with agencies and parents
- Assistance in understanding their relative's drug use and methods of discussing the matter with dependants

## 3. Young carers

Young people may take on a caring role for a number of reasons: they may support a drug using parent or other family member; they may also have to support the main carer when they are not fit enough to cope, taking on a substantial burden of responsibility. It is important that support should attempt to meet their needs in regard to the role they have in the family. Evidence suggests that when children take on a parenting role, it can impact on their own subsequent parenting experiences and their use of substances (EIU literature review).

Being a young carer can impact upon several aspects of their lives:

- anxiety and worry for the wellbeing of the person they are caring for
- isolate them socially from other peers
- reduce their capability to study and cope with their education
- reduce career opportunities
- feelings of isolation and stigma
- ill health, poverty and low income

Support should aim to address such issues and reduce the isolation and responsibilities that they have. The Community Care & Health Act 2002 when fully implemented, will allow young carers under 16 years of age to request an assessment of their needs without their parent (s)/guardian consent.

#### WHAT CAN HELP:

- Having someone to talk to who will listen
- Assistance in recognising their role as a carer.
- Information about their relative's condition.
- Information about services, support and how to access them.
- Practical forms of assistance and support e.g. diversionary activities and respite

#### 4. Families in rural and remote areas

A recurrent theme of the EIU interviews was the needs of families living in rural areas. In the past, there has been a **lack of resources** available to support the drug user and their family. There is a perception that agencies see families as coping adequately and are unsure what support could be offered to them. As a result, families are left to cope alone as best as they can.

There are 3 key factors to the needs of families in rural areas:

- **Visibility:** Families seeking support often feel vulnerable because it is difficult to remain anonymous in a small community. It may be that the family will know the person they seek support from or are afraid to be seen seeking support by others. Confidentiality is thus an issue (EIU literature review). As a result, increased levels of concealment may be common. Such concealment could prevent families from obtaining knowledge about service provision and support. This was also highlighted by the EIU literature review as an issue in rural areas. Feelings of exposure can lengthen the time taken for a family member to seek support. It can also mean that they may experience greater levels of crisis before seeking support.

#### EVIDENCE

There exists in the area a feeling of ostracisation and judgementality [sic] from professionals towards community members, and a widespread use of inappropriate language that does not assist the family members in coping with their situations.

(EIU interviews)



- **Stigma:** Linked to visibility is the level of stigma associated with drug use. Participants in the EIU interviews felt that not only drug users but also their families were viewed very negatively by their community and by agencies.
- **Accessibility of services:** Accessing support in a rural area can involve travelling substantial distances. Almost sixty percent of drug projects are based within the main cities of Aberdeen, Dundee, Edinburgh and Glasgow (SDF Directory). Transport can be limited and expensive so that access to appropriate services can become virtually impossible.

All these factors limit the type and array of support available to the family and decrease the chance of them accessing a method of support that is appropriate to their needs. The support that is available may then experience pressure in trying to accommodate and meet the needs of families.

#### WHAT CAN HELP:

- Seek ways to develop methods of support that can maintain **levels of anonymity**. Helplines provide an ideal way for someone to access information and support without feeling visible but not everyone is happy to use telephones.
- Location - support could be located in **more generic centres** such as carers' projects so as to reduce visibility of family member attending
- Limited resources - there is a need for **good communication and willingness to maximise the resources available** within rural areas.
- Using a **community development approach** can help break down cultural barriers towards drugs and reduce community backlash to initiatives as well as improve understanding. All this can help families and also assist the drug user to 'move on' in their recovery.

## 5. Ethnic minority groups

Ethnic minority groups make up approximately 1.5% of the Scottish population (Source: Labour Force Survey, 1999 data). A large proportion of this population originates from Pakistan, Bangladesh and China. Although people from minority groups live throughout Scotland a large percentage reside within the main urban cities of Glasgow, Edinburgh and Dundee. Agencies working with ethnic minority drug users are focused in these areas. There are several needs that should be taken into account when offering or developing support for families and carers within this group:

- **Language difficulties:** Not all people speak English. This is more likely to be the case when a parent or grandparent seeks support. Difficulties can also arise from the lack of information available in different languages: ADFAM and Lifeline produce drugs information in Punjabi and Bengali (See Chapter 9).
- **Cultural sensitivity / family dynamics:** Within some cultures it can be seen as inappropriate to seek support from outside the family unit. There can also be difficulties of age and gender, in that a young white male support worker may be an inappropriate choice to work with a middle aged Muslim mother.

- **Mistrust of external agencies.** There can be a reticence to involve services such as social work due to mistrust, unfamiliarity and stigma.
- **Different types of drug use:** There can exist different cultures of drug use within different ethnic minorities. The use of stimulants such as cocaine and crack appears to be more common among certain ethnic minorities. This can affect the behavioural issues that families have to cope with and may require different approaches.

#### EXAMPLE

**Eshara** is a black and ethnic minority drugs project in Glasgow. Although it operates under limited resources, it had obtained funding from Scotland Against Drugs to host community events aimed at informing black and ethnic parents about drug use. Information events were held Woodlands, Govanhill, and Pollockshields in Glasgow. The format was the use of a video to promote discussion of issues and problems parents face regarding drugs. The main finding of the workshops was the lack of resources for black and ethnic minority families. This resulted in a sub-group being formed to look at applying for funding for a specific families worker.

Contact: 0141 420 8100

## 6. Men

Evidence gathered from the EIU qualitative survey, interviews, and from the literature review highlighted consistently that mothers were most likely to seek support. This can result in the support being tailored towards the needs of women and particularly mothers. The needs of men may remain hidden and unidentified.

#### EVIDENCE

Parents for Prevention, a Birmingham based parents drug initiative, recorded that 80% of their helpline callers were women (mothers, grandmothers, aunts and carers).

(Familiar Drugs – Working inclusively with families about drugs Flemen 2001)

There are numerous factors that can contribute to this situation:

- the mother (or other family member) may conceal the drug use and its effects from the father to minimise conflict in the family.
- the reaction of some male family members may be to demand that all ties are cut with the drug user. This may create conflict with family members who perceive that the drug user needs support from them.
- men may have greater difficulty discussing their feelings and emotions and internalise and ignore them as a way of coping. This can lead to an increase in their own use of substance such as alcohol and further tension thus being created.
- men can react differently towards a drug using relative depending on whether the relative is a daughter or son.

(EIU literature review)

### WHAT CAN HELP:

- Telephone helplines offer the chance to discuss concerns anonymously.
- Promote the involvement of support for males in all publicity and information
- Opportunities to develop support that is accessible through the workplace

## 7. Siblings

There can be a considerable impact upon brothers and sisters and again there can be little support available to assist them in coping. The EIU literature review identified that the needs of siblings are not well documented by research. We have identified a number of key factors likely to impact on their specific needs:

### EVIDENCE:

Siblings can often display envy towards what can be seen as preferential treatment towards the young offender.

(EIU interviews)

- **Isolation:** Siblings can be ignored in the family as all focus tends to go towards the drug using relative. Siblings may themselves withdraw from the family in response increasing their isolation within the family.
- **Relationships and dynamics:** The impact that the drug user can have on the relationships and dynamics within the family can reinforce the isolation experienced by siblings and the concealment they adopt in coping, the negative consequences of which are discussed in Chapter 3.
- **Preferential treatment towards the drug user:** Sometimes the drug user may be seen to be receiving preferential treatment which can result in siblings adopting similar behaviour (EIU interviews). There can also be an increased chance of substance use among siblings, in part related to the exposure to drug use and access to substances.

### WHAT CAN HELP:

Support to:

- overcome the isolation siblings may experience
- assist in understanding the situation in the family
- maintain social and educational opportunities
- improve their knowledge and understanding of drug use

## 8. Bereaved Families

Families who have had to cope with bereavement may still require support for a considerable time. The impact of bereavement can affect ongoing relationships in the family and also the well being of family members:

- they may be left with feelings of guilt and responsibility that they could not prevent the death of a relative
- parents do not expect that they should outlive their offspring
- sometimes bereavement can occur after recovery and be in part due to the physical damage that the drug user has suffered previously.

### WHAT CAN HELP:

- Someone to talk to
- Attending a support group
- Access to information about bereavement, practical and financial matters
- Support in responding to dependent children in the family

(Cruse Bereavement Care)

### KEY FINDINGS:

Families and carers have a wide range of:

- information needs
- practical needs
- emotional needs
- Families need support to minimise the effects someone's drug use and behaviour can have on them: physically, psychologically and practically.
- Specific groups have specific needs and this may mean applying different methods in order to meet them.
- The needs of families and carers should not be presumed by agencies and workers but rather should be explored with them.

## RELEVANT LEGISLATION AND RESOURCES

### LEGISLATION:

The main legislation governing carers and dependants are:

#### **The Children (Scotland) Act 1995**

[http://www.hmso.gov.uk/acts/acts1995/Ukpga\\_19950036\\_en\\_1.htm](http://www.hmso.gov.uk/acts/acts1995/Ukpga_19950036_en_1.htm)

The Act covers: parental responsibilities and rights, guardianship, court orders, support for children and their families, children's hearings, protection and supervision amongst other areas.

#### **The Carers (Recognition and Services) Act 1995**

[http://www.hmso.gov.uk/acts/acts1995/Ukpga\\_19950012\\_en\\_1.htm](http://www.hmso.gov.uk/acts/acts1995/Ukpga_19950012_en_1.htm)

A Carer is someone who provides regular and/or substantial care to a relative, neighbour or friend. Where a person is eligible for a Community Care Assessment, their carer has the right to request an assessment of their own needs as a Carer. The Carers Act requires the Local Authority to have regard to the result of the Carers Assessments when making decisions about services to be provided to the user.

The aim of this Act is to give greater recognition to the needs of Carers.

#### **The Community Care and Health Act (Scotland) 2002**

<http://www.hmso.gov.uk/legislation/scotland/acts2002/20020005.htm>

The Act covers the implementation of free personal and other care, the regulation of charging for social care, and rights of assessment for informal carers including young carers.

#### **Social Work (Scotland) Act 1968**

Section 12 of the Social Work (Scotland) Act 1968 places a general duty upon local authorities to promote social welfare in their areas and to provide advice, guidance and assistance for certain categories of people in need, aged over 18 years.

### RESOURCES

#### **Blood Borne Viruses:**

##### **HIV/Aids Carers Group - 0141 221 8100**

<http://www.hiv-aids-carers.org.uk/>

The Group provides a range of services including:

- Telephone support service
- One-to-one support
- Home visits
- Hospital visits
- Counselling
- Information on HIV-AIDS, bloodborne viruses, testing, safer sex, carers issues, addictions etc.
- Respite
- Mutual support groups
- Advocacy
- Stress therapies

##### **Terence Higgins Trust - 0845 1221 200**

[www.tht.org.uk](http://www.tht.org.uk)

The Trust provides direct services to those affected by HIV and delivers health promotion campaigns relating to HIV. It also publishes a range of publications.

**National Hepatitis C Resource Centre: 020 7735 7705**

[www.isvad.com/hepccentre/main.htm](http://www.isvad.com/hepccentre/main.htm)

Provides information to people living with hepatitis c, healthcare professionals and the public.

**Carers:**

**Princess Royal Carers Trust** - provides training and support to carers centres. Also offers a range of grant schemes and carers relief fund.

Tel: (0141) 221 5066

<http://www.carers.org/home/>

**Children in Scotland** - national agency for voluntary, statutory and professional organisations working with children and families.

0131 228 8484

[www.childreninscotland.org.uk/index.html](http://www.childreninscotland.org.uk/index.html)

**Family Rights Group** - provide advice and support for families whose children are involved with social services

020 7923 2628

<http://www.frg.org.uk>

**Bereavement:**

**Cruse Bereavement Care: 0870 167 1677**

[www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

Provides Helpline support, information about local groups, publications and website

**Young Carers:**

**Young Carers Initiative (YCI): 01962 711511**

[www.childrenssociety.org.uk/youngcarers/initiative.htm](http://www.childrenssociety.org.uk/youngcarers/initiative.htm)

YCI work with young carers' projects and other organisations to develop good quality support and information for young carers, their families and those who work to support them. The aim of YCI is to develop a coherent National Focus for young carers, their families and those who work to support them and to promote common standards and to work towards realisation of equitable services.

**Young carers good practice guide:** Published by the Princess Royal Carers Trust with support from the Scottish Executive, the document aims to build on existing good practice, ensuring that the highest quality services are offered to young carers. The document covers:

- how to develop a young carers project
  - day to day operation of the service
  - management responsibilities
  - policies and complaints
  - good practice procedures
- [www.carers.org/docs/Young%20Carers%20GPG.pdf](http://www.carers.org/docs/Young%20Carers%20GPG.pdf)

## CHAPTER 5: METHODS OF SUPPORTING FAMILIES AND CARERS

This Chapter examines and discusses the variety of methods of supporting families coping with a relative's drug use. Evidence has been drawn from the literature review, the mapping exercise and the qualitative study. It also incorporates views from the EIU interviews and the Family Support Conference survey. It sets out:

- methods of support
- the aim of these support interventions
- examples of methods

Although there is a wide range of types of interventions to support families theoretically, the extent to which these interventions are available in Scotland varies considerably from area to area. This was demonstrated in the EIU mapping exercise. Overall, there was limited availability of intensive types of support such as family therapy and counselling and where these were available they were often oversubscribed.

### Methods of Support

There appears to be evidence that there are particular benefits from certain types of support. In the EIU literature review, a study by Toseland compared the benefits of **group** support interventions with those of **individual** interventions. Both types of intervention aimed to provide:

- validation of care giving experience
- encouragement and care
- reassurance about coping
- support in managing difficult situations

The findings were that both types of intervention were beneficial to participants but:

- more formal, informal and social support was gained from groups
- individual interventions were more problem orientated and allowed the individual to explore a wider range of personal issues

The evidence shows that different types of interventions have different benefits. It also suggests that different types of interventions can **complement** each other. Individual interventions e.g. one-to-one support or counselling, may be more appropriate and effective at early stages of contact. The aim might then be to support the individual to move on to participate in group methods of support, such as family support groups.

"Most clients would not go near a group."

(EIU interviews)

### 1. Family Therapy

Family therapy is an approach that aims to assist people experiencing difficulties in their own lives and their family lives. The Association for Family Therapy and Systematic Practice in the UK state that family therapy is based upon the idea that:

'the behaviour of individuals and families is influenced and maintained by the way other individuals and systems interact with them. This way of working involves engaging with the whole family system as a functioning unit'.

Family therapy can be delivered on a one-one basis or within a group work setting.

There is a diverse range of family therapies in existence. In relation to substance addiction, many of these have been used in the field of alcohol misuse and have focused upon the key outcome of altering the behaviour of the drinker. Family therapy is now being used to work with families affected by drug use and there is some evidence of effectiveness in relation to the drug user: for example, reducing drug use; reducing psychological harm; reducing social problems (Drug Treatment for Young People Research Review, EIU 2002). Recent developments have seen family therapy interventions that focus primarily on addressing the stress experienced by family members (Copello, Velleman et al, 2002).

We set out below a number of types of family therapy that have been subject to evaluation. Further information can be found in the EIU literature review ( EIU 2002).

### **Community reinforcement training (CRAFT)**

CRAFT was originally developed in working with the partners of problem drinkers although has been widened out within the field of substance addiction. CRAFT training can occur on a one-to-one basis and within a group setting. Support is offered on the expectation that the family member will play a significant role in the treatment and support of the substance user and secondly, that it will bring benefit to the family. It does not assume that the **concerned significant other (CSO)** is in any way responsible for the drinking or drug problem of the loved one.

The key elements are:

- understanding that responsibility for the problem belongs to the drinker
- motivating the partner
- improving communication
- using positive reinforcement
- reducing behaviour by the partner that inhibits the drinker from acknowledging the action and consequences of their drinking
- the process encourages the **concerned significant other** to consider their own needs rather than solely that of the substance user to improve their own well being and stress
- broadening their social activities
- taking time away from the substance user
- getting space away from the pressures associated with coping with substance use

In the EIU literature review, a study by Kirby et al investigated individual and group counselling methods of delivering 'Community Reinforcement Training' (CRAFT). They found that the CRAFT intervention:

- reduced the number of self-reported problems of family members, particularly relating to areas of finance
- improved mood states
- increased social functioning and family functioning
- self-esteem did improve but not significantly
- the drug user was more likely to enter treatment

For further information on CRAFT see: <http://casaa.unm.edu/bib/cra.html>



## Unilateral family therapy (UFT)

Again this approach was developed to work with partners of alcoholics to encourage the drinker to enter treatment and has been widened out to work with drug users. It has a similar approach to CRAFT in that the therapist meets with the partner over a period of months and aims to: **address how the partner copes with the impact of substance use; reduce the level of substance use; and engage the substance user in treatment**

The partner goes through a series of modules aimed at addressing:

- the severity and impact of substance use
- ways of enhancing the relationship
- constructing obstacles to reduce opportunity for using substances
- counter productive responses
- improving the wellbeing of self and other family members

On completion of the modules the aim is for the partner to encourage the substance user to engage in treatment.

Research concentrated on outcomes associated with the substance user and not on the family member/partner. Studies found that 61% of drinkers whose partners were involved within UFT engaged in treatment compared to none of the drinkers whose partners had no UFT. The 'wellbeing' of the partner was not reported on (EIU literature review).

### Pressures to change

This intervention again focuses on using the partner as a catalyst to engaging the substance user in treatment. The partner attends one to six sessions based on:

- providing information regarding the 'change' process
- planning activities that make it hard to use substances
- how to respond: assisting the partner to identify acceptable and unacceptable levels of substance use; encouraging abstinence; encouraging and supporting substance user to seek support
- contracting and boundary setting
- involving others to support process

In the EIU literature review, a study by Barber & Gilbertson into the Pressures for Change process looked at three groups of partners: those engaged in counselling; those engaged in group work; and those on a waiting list. They also compared the study with a group engaged within Al-Anon. Results indicated that those engaged in individual counselling and Al-Anon reported a reduction in the level of personal problems they experienced. A self-help manual was later developed and this was found to have a similar impact as that of counselling.

#### EXAMPLE

The Children and Families Alcohol and Drugs Service (**CAFADS**) is a service that provides a range of support methods to families, including 'systematic family therapy'. Sessions focus on issues such as:

- Alcohol and drug education
- Relationships and communication
- Individual and family needs and coping methods
- Working effectively with professionals

CAFADS also provide training and consultancy to professionals

Contact: 020 8983 4861 / [www.cafads.org.uk](http://www.cafads.org.uk)

## **Stress-coping-support model**

This intervention developed by Birmingham and Bath University is currently being piloted in England with primary health care workers and general practitioners and complements previous work conducted by them on coping mechanisms. This research is linked to a larger research exercise by the World Health Organisation investigating the role of primary health care workers in supporting families coping with addiction.

The primary aim of the work in comparison with previous models of therapeutic intervention is to support the 'family' in their own right rather than to engage the relative in treatment, although that may be a secondary outcome.

Orford et al has developed three broad definitions of methods that people use in coping with someone's drug use (1998).

### **The 'Tolerant' approach**

This approach relates to where the family is tolerant of the drug use and the associated behaviour of the drug user. Examples of this approach include turning a blind eye to drug use, clearing up after the drug user and lending money to the drug user even though you suspect it may be to buy drugs. Orford indicates that this form of coping is associated with feelings of worry, guilt and powerlessness.

**This form of coping rarely effects any change in the drug use although a form of stability may be maintained within the family by reducing the occasions of conflict.**

### **The 'Engaged' method**

Families that use an 'engaged' method of coping are often attempting to change the behaviour of the drug user and supporting them in addressing their drug use. Examples include organising treatment appointments for the drug user, checking up on their every move, being supportive and defending the drug user, encouraging and rewarding the drug user. Orford suggests that this method can be of benefit to the family in that they feel a degree of power and involvement, they are being positively supportive, and they are able to display emotion within the family.

**This style of coping is driven by the desire to resolve the problem but can be very stressful due to the energy and perseverance often required from the family.**

### **The 'Withdrawal' model**

This approach is related to the family withdrawing from the relationship they have with the drug user. Examples of this include avoiding the drug user as much as possible, making the drug user tidy their own "mess" and not rescuing the drug user from situations of their own making. Orford suggests that this method of coping can allow the family to feel greater control and independence over one's own life.

The main feature of 'withdrawal' as a model of coping, in contrast to the 'engaged' or 'tolerant' approach, is that **it focuses upon the family rather than the drug user.** However, it may also be of benefit to the drug user in that by taking responsibility for their circumstances they are more likely to address their drug use.

All of the above methods of coping can produce positive and negative outcomes for the relative and can also generate uncertainty for the relative over the best ways of coping. From this the researchers were able to construct a '**Stress-Coping-Health Model**' (SCHM), and develop an intervention package for **primary health care workers and general practitioners.**

The key concepts associated with the use of SCHM are based on five strategies:

- **listen, reassure, explore** concerns
- **get to know** the relative and the problem- identifying stresses and strains
- provide relevant **information** - an important contributor to stress is the lack of accurate knowledge about alcohol/drugs, their effects and issues of dependence. Information should be targeted and not overwhelm the client
- **counselling** about **coping** - focusing on the actions and feelings of family members; and about **social support** - the level of social support available to relatives can have a significant impact on their ability to cope and their experienced stress
- discuss needs for other sources of **specialist help** - professionals should be familiar with what services are available locally and the appropriateness of them when referring either relative or drug user

These concepts became the basis of developing a **Training Manual** for primary health care workers to use when engaging with families affected by addiction.

The research trials and analysis should be completed by the end of 2002, at which stage the findings will be disseminated and methods of marketing the training package will be identified. The picture emerging is very positive with almost all relatives reporting great benefits from practitioner intervention, and a slightly less positive response from those using the 'self-help' model.

Further information can be obtained from: Alex Copello, Consultant Clinical Psychologist, Birmingham University [a.g.copello@bham.ac.uk](mailto:a.g.copello@bham.ac.uk)

#### SUMMARY

Family therapy aims to:

- help the drug user to reduce their drug use and consequent effects e.g. psychological harm
- improve family functioning
- reduce problems of family members

#### Resources:

**Institute of Family Therapy** - The Institute offers a wide range of training courses, clinical services, mediation service and consultation.

**020 7391 9150**

<http://www.instituteoffamilytherapy.org.uk/index.htm>

**Association for Family Therapy and Systematic Practice in the UK (AFT):** A main aim of the organisation is to develop practice and standards for training within family therapy. It looks to promote best practice in training, practice, management and research.

**Contact: 01925 444414**

<http://www.aft.org.uk/mainpages/jft.html>

## 2. Counselling

Counselling is similar to family therapy in that the individual is encouraged to explore their concerns and issues in a safe environment, and to examine ways of managing these in a more beneficial manner. Counselling can include work with an individual, couples or groups of people. It can be carried out over a short period of sessions or for a significant period of time.

The British Association of Counselling and Psychotherapy states that counselling may be address:

- developmental issues for the individual
- resolving specific problems
- making decisions
- coping with crisis
- developing personal insight and knowledge
- working through feelings of inner conflict
- improving relationships with others

'I found this helpful on a one-one basis as well as going to a support group'

'one-one help is a great benefit in coming to terms with feelings of guilt, helplessness and depression'

(EIU conference survey)

There are a variety of counselling approaches such as psychotherapeutic, cognitive behaviour therapy and person centred/humanist. Individuals may find one approach is more suited to them than another approach or that it compliments other support they are receiving.

Participants in the EIU conference survey identified counselling as a key method of providing emotional support to family members.

It is important to note that there is no requirement at present for a person to have a specific counselling qualification in order to practice. At present anyone can call themselves a counsellor without any qualification or experience. This has the risk that untrained people can be delivering support that may be counterproductive and damaging to the individual. **It is important that people providing counselling or using counselling skills have the appropriate training and are supported in their work.**

Provision of counselling for families coping with a relative's drug use is limited within Scotland. In the EIU mapping exercise, 37 family support groups and 39 drug services stated that they offered counselling to families. Where there was such provision it was often oversubscribed and under- resourced for the demand. In Glasgow there was one counsellor attached to the Glasgow Association of Family Support Groups. The service was 'stretched to the limit', but it highlighted a significant benefit in that it could attract people who may not have attended a support group. Some support groups were able to offer access to counselling within other agencies, such as Carer organisations.

### SUMMARY

Counselling aims to:

- assist family members in coming to terms with the circumstances they face
- complement other methods of support such as family support groups
- allow the participant to explore personal issues and ways of responding to these issues
- support people who may not access support through a group setting

## Resources:

**Counselling and Psychotherapy in Scotland (COSCA)** supports and promotes good practice in counselling and the use of counselling skills throughout Scotland. COSCA facilitates preparation for appropriate professional regulations, develops and supports high standards of competence in counselling training and practice covering counselling and counselling skills.

**Contact: 01786 475140**

[www.cosca.org.uk](http://www.cosca.org.uk)

**The British Association of Counselling and Psychotherapy(BACP):** BACP aims to provide a complete reference point for anyone seeking information on counselling and psychotherapy in the UK. It provides nationally recognised standards in training and practice, and training within counselling and psychotherapy.

**Contact: 0870 443 5174**

[www.bac.co.uk](http://www.bac.co.uk)

### 3. Parenting Skills

Some statutory and voluntary sector agencies provide assistance for parents where there are difficulties with the behaviour and drug use of a child. Often this is carried out through Social work departments and voluntary agencies such as Barnardo's and Save the Children. This process aims to engage the whole family in altering dynamics in the family that can also assist the young person to change or modify their behaviour.

The content involved of such courses can include:

- assertiveness training
- crisis intervention
- themes in adolescent behaviour
- communication skills
- knowledge of resources and support

A main aim of the process is to bring parents together who are experiencing similar issues and difficulties to share experience and learn new skills in coping with the behaviour of their child.

#### EXAMPLE

**Freagarroch**, a Barnardo's project based in Stirling, works with persistent young offenders to keep them within the family and community and to address their offending behaviour. Often there is an association between the young person's behaviour and substance use, which can be a key concern for the family members. The project aims to help the young person to reduce their offending behaviour, improve the dynamics within the family, and reduce the stress within the family.

The project runs a parents group to give additional support to parents. It operates with a male and female facilitator and looks at issues such as assertiveness, crises, adolescence and the work of other agencies. Members also get access to respite facilities. The majority of attendees are mothers with children aged pre 16. The project had previously experienced difficulty in integrating new members and this highlighted the need for preparatory work to be carried out with the new member prior to them joining the group.

**Freagarroch Project**  
**01786 450963**

## SUMMARY

Parenting skills aims to:

- improve trust between family members
- improve communication between family members
- improve extended family and other support networks for the family

### Resources:

**Parent Network Scotland (PNS)** is a registered charity based in Aberdeen. It is a parent run organisation providing education and support to help improve their parenting, communication and relationship skills.

**Contact: 01224 867951**

**Parentline Plus** offers help and information parents and families. The organisation works with local and central government to develop initiatives that increase support for families. It works to ensure that families have access to good quality support and information on issues they face.

**Contact: 020 7284 5500**

## 4. Telephone Helplines

There are a number of telephone helplines now in existence. They cover a wide range of subject matter, including drugs. Some have a national remit, such as Childline, whereas others provide a more locally based service. Details of helplines are set out in Chapter 9.

Helplines aim to provide accurate information and support to the caller, using a counselling skills approach. It is important to give careful consideration to the structure and operation of helplines to maintain standards, quality and consistency of the service.

The key advantages of helplines are that:

- they are accessible for people who may not be able to visit a centre based service
- there is anonymity for the caller
- there are no transport or childcare difficulties

Disadvantages can be:

- they tend to be used only at times of crisis – can mean that the helpline feels underused, especially if operational 24 hours a day
- such services can require substantial resources e.g. costs of training, publicity
- requires access to a telephone by the individual

The EIU conference survey indicated that 'helplines' were a popular source of support for families, especially when staffed by those who had experience of living with drug use. There were some concerns, however, that callers were not always listened to or given relevant information.

#### EXAMPLE

##### HIV/AIDS HELPLINE

The HIV/AIDS Family Support Group in Glasgow recognises the benefit of 'having someone who understands and is in a similar situation to theirs'. The project offers a range of services but one of the most used services is that of the **Helpline** service. Calls come from all over Scotland and beyond, enabling clients to talk through issues affecting them in a safe and supportive atmosphere. The caller is encouraged to explore the choices of support the group can offer. Staff and volunteers go through a standardised training to equip them with skills needed.

**Contact: 0141 221 8100**

From the EIU mapping exercise, over one third offered some type of helpline service. This could vary from a group member providing 24 hour support from their own home to members staffing a phone in an office environment for a limited amount of hours.

Local helplines offer a greater awareness of the services and resources that exist locally and people also feel there is a local familiarity.

An important issue to be considered is that, like counselling, there can be a wide variance of standards of practice and the quality of helplines can differ. Those offering support via a helpline

should ensure there is consistency of practice, this is best achieved through the delivery of appropriate training.

#### SUMMARY

Telephone helplines aim to:

- provide information
- provide support
- offer anonymity

#### Resources

**Telephone Helpline Association (THA)** provides advice, consultancy and training on establishing and maintaining helplines. Members of the **THA** include Childline and the Samaritans. They also provide publications such as a Quality Standards Workbook and a Helpline Directory

**Contact: 0141 221 1514**

[www.helplines.org.uk](http://www.helplines.org.uk)

**PADA** - as well as operating a UK wide 24 hour helpline service, PADA provide training to family support groups and others in establishing a helpline service. (a full description of the range of work PADA do is contained in Chapter 9)

**Contact: 0151 356 1996 / 08457 023867 (helpline)**

[www.pada.org.uk](http://www.pada.org.uk)

## 5. Respite

It is increasingly being recognised that respite provides a useful method of support to families affected through drug use. This is especially the case when grandparents or other relatives take on the parenting role of children whose parents are drug users. Several groups and agencies provide a range of respite models.

Respite can be delivered in a variety of ways:

- **centre based respite** – where either the carer or dependant attends activities provided for them
- **family based respite** – this can allow the carer time away from the house without the dependant who is looked after by a worker or volunteer. This can be for a short period of time or longer periods such as a weekend
- **home based respite** – this is where the dependant is taken away from the house for a period of time to allow the carer some time for themselves or other family members
- **holiday based respite** – this is provided to give families a break from their environment, which they could not otherwise obtain

Twenty percent of family support groups involved in the EIU mapping exercise offered some form of respite. It can also be provided by more generic based projects that work with families in various circumstances. This can have advantages in that the family support group does not have to acquire the resources and skills to manage such a service if it can link with the work of other more generic projects.

### EXAMPLES

**Glasgow Association of Family Support Groups** runs a holiday respite service for families affected by a relative's drug use. They own a caravan on the East coast which families can book for a week at a time throughout the year. The caravan allows families that often could not afford a holiday (in part due to the financial implications surrounding coping with a drug using relative) to get a break from their circumstances. It can also be beneficial to reducing some of the stress they may be experiencing.

**Contact: 0141 420 2050**

**Geeza Break** is a community based Project in the East End of Glasgow. It is managed by a voluntary management committee and provides a flexible, family based respite care service to local families with children aged, 0 – 16 years. Respite can be provided in the carer's own home or in the family's home. The project also offers an out of school club for children aged 5-12 which operates within school holiday periods. This can be especially useful for carers who are working and may face child care difficulties.

**Contact: 0141 550 2828**

### SUMMARY

Respite aims to give families and carers:

- the opportunity to get a break from their everyday situation
- maintain some form of social activity
- maintain the quality of life both for carers and for those they care for

## Resources

**The Scottish Executive** has published material looking at national care standards within the provision of respite care services. The document provides a useful resource for those considering providing respite provision.

<http://www.scotland.gov.uk/library3/social/ncssbrc-00.asp>



## 6. Advocacy

Advocacy can be defined as giving protection to people who are vulnerable and discriminated against by assisting them to access their rights. It is also about empowering people to express their own needs and make their own decisions. ('Advocacy: A guide to good practice' (Scottish Health Advisory Service, Scottish Office 1997)

Advocacy is recognised as an important method of enabling people to make informed choices and have a degree of control over the issue they are experiencing difficulty with. It has recently started to gain greater prominence for issues relating to drug users' rights of access to treatment and support. Chapter 4 describes how those taking on carer roles can often experience difficulties in dealing with agencies such as the NHS, Benefits Agency and education services. This experience, along with the self blame and guilt that families can feel, can result in them having little energy or confidence in challenging decisions or systems.

### EXAMPLE

#### SCOTTISH ACTION ON SUBSTANCE (SAS)

The Scottish Action on Substance is a voluntary organisation that aims to draw attention to the difficulties experienced by those seeking treatment for their substance use problems. The group does this by encouraging people to use the Complaints System and by making direct complaints themselves. SAS offers information and support to drug users and their families with regards to complaining and challenging. It also actively promotes the rights of those with substance misuse problem, and those supporting them.

Contact: SAS, 123 West Street, Glasgow. G5 8BA

There can also be personal benefits to be gained from receiving advocacy support. The experience can be an empowering one for the person concerned, in that they can develop skills of assertiveness and also increase their self confidence. This in turn can mean the individual is better equipped to cope with stressful situations.

Many support groups offer forms of advocacy. A third of respondents in the EIU mapping exercise stated that they offered advocacy support. Advocacy work should be structured and there should be policies and guidelines in place to ensure good practice and consistency.

### SUMMARY

Advocacy aims to assist people by:

- supporting people to question
- giving people confidence
- giving people information
- promoting respect for the rights, freedoms and dignity of vulnerable people, both individually and collectively.
- ensuring people receive the care or services to which they are entitled, and which they wish to receive.

### Resources:

Assistance and copies of guidance in relation to establishing and operating an advocacy system are available from the:

**Advocacy Safeguards Agency** - Tel 0131 538 7717 Email [general@shstrust.org.uk](mailto:general@shstrust.org.uk)

**Scottish Action on Substance (SAS)** - 123 West Street, Glasgow. G5 8BA

## 7. Befriending and Peer support

Befriending offers a supportive and consistent relationship to individuals who may experience isolation and exclusion from the wider community. Often befriending is provided by volunteers and has been used extensively in the areas of mental health, disability, children and families and social exclusion.

Family members say that being able to share experiences with someone with similar experiences can be beneficial. It can allow them to feel safe to explore in-depth some of the feelings and emotions they experience.

### EXAMPLE

Home-start is a UK wide voluntary organisation that aims to promote the welfare of families with at least one child under five years of age. They provide regular support, friendship and practical help through the use of trained volunteers.

Home-start also state their aim is to:

- Reassure parents and encourage them to enjoy family life
- Encourage the parents' strengths and emotional well being
- Increase the family's access to other opportunities and support

The 'Home-start' model of befriending could be of benefit in reducing the isolation of family members especially those taking on the care of dependent children.

To be successful it is necessary for befriending to be a positive experience for the person giving and the person receiving the service. Befriending should also be well thought out and clearly structured. It should have policies and guidelines in place to ensure consistent standards of practice.

Assistance may be available from local agencies such as the local Volunteer Centre and national organisations such as Befriending Network Scotland.

### SUMMARY

Befriending aims to assist people by:

- increasing opportunity for the person
- reducing isolation and the negative effects of such isolation
- increasing self esteem and confidence
- increasing the person's support network
- improving coping

### Resources:

**Befriending Network Scotland:** BNS acts as an umbrella organisation for for befriending projects in Scotland and works to promote the value of befriending as a means of support to individuals. They provide information, training and support which aims to assist projects in developing best practice.

**Contact: 0131 225 6156**

[www.befriending.co.uk](http://www.befriending.co.uk)

### Home-start

**Contact: 0800 68 63 68**

[www.home-start.org.uk](http://www.home-start.org.uk)

## 8. Developing personal coping skills

There are a variety of methods of supporting family members and carers to develop their personal coping skills. Stress and anxiety are significant factors for families coping with drug use. It has a considerable impact on both the physical and psychological health of the person.

**Stress management** is the ability of an individual to manage the perceived pressures they face on a day to day basis. This may be through a variety of techniques including reducing or re-appraising the pressures and enhancing coping ability and resources. (International Stress Management Association UK)

Some of the most common signs of stress are:

- Mood swings
- Skin problems
- Muscle tension
- Changes in sleep patterns
- Low self esteem
- Anxiety
- Tiredness
- Poor concentration
- Changes in eating patterns
- Poor memory

It is very important to take positive action when faced with stress as, if experienced over a period of time, it can seriously impair mental and physical health

Participants in The EIU qualitative study identified that the ability to manage stress better and learning to be more assertive would assist them in coping with their situations. It would also assist them to maintain and develop their self-confidence.

Other methods of coping with stress include **complementary therapies**. There is a wide range of complementary therapies available. Some can be quite intense and require a degree of effort such as types of yoga. Others are very easy to gain benefit from and require little from the individual apart from the ability to give it a try. Such activities as reiki, relaxation and breathing exercises can be done by anyone regardless of their fitness. It is important to ensure that, if therapies are being done in a group setting, the activity is suitable for all participants.

### EXAMPLE

**Cranhill Mothers Against Drugs** has trained family members involved within the project to deliver **auricular acupuncture** within the community. This therapy involves the sticking of small needles onto the ear in order to reduce, stress, cravings and also detoxify the body. As such it useful to family members coping with a relative's drug use as well as the relative.

Many family support groups have used different therapies either as one off events with members, as part of their regular meetings, or have completed training to deliver specific therapies.

Other complementary therapies include

- Breathing Exercises
- Yoga
- Massage
- Aromatherapy
- Tai chi
- Auricular acupuncture
- Reiki
- Reflexology

## SUMMARY

Developing personal coping skills aims to improve:

- the physical health of family members and reduce the chance of stress related illnesses such as heart problems
- the emotional health of family members
- their ability to cope
- their ability to support

### Resources:

**International Stress Management Association (UK):** Aims to promote sound knowledge and best practice in the prevention and reduction of human stress

**Contact: 0700 780430**

[www.isma.org.uk](http://www.isma.org.uk)

## 9. Diversionary activities

There are a wide range of diversionary activities that can benefit family members and carers. They can be a useful method of supporting siblings, who can often become withdrawn and isolated (EIU literature review). Activities can provide an escape from the circumstances that families and carers live with. In turn this can reduce their stress for a period of time but that alone can be of value.

### EXAMPLE

**Gallowgate Family Support Group** provide an art therapy service. This involves members attending a weekly class and gives them 'a chance to re-focus and be at peace for two hours. Work produced is of such a standard that it is then used for raising funds for the group. Such activity can also ensure that all members feel they have an active and positive contribution to make towards the success of the group.

Other examples of diversionary activities include:

- activity based work such as drama, music, photography etc
- outdoor activities and sports
- trips and visits

## 10. Education and information

For families coping with a relative's drug use, trying to understand what is happening and why, is one of the most challenging tasks they initially face. The person they previously knew may have changed dramatically in terms of their physical appearance and in their personality.

Initially, families' knowledge and understanding of drugs and addiction can be limited. Much of their knowledge may come such sources as the media. This information can often have a very negative perspective and also lack accuracy, both of which are unhelpful to families affected by a relative's drug use.

Much of the emphasis on the production of drugs information and education focuses upon information for parents informing them about the general effects of drugs and what they can do as a parent to prevent or reduce the risk of their child using drugs. Families coping with drug use require information and education specific to their situation to assist them in making sense of their circumstances. To date the provision of such information has been limited and accessing such information can prove difficult.

EIU interviews with those working with parents constantly stated that lack of information inhibited the parents and family from being able to best cope and manage their family circumstances. There was also a need for agencies and workers to have access to information and education. This would help them to gain a better understanding of the effects of problem drug use upon family members.

#### EVIDENCE

**ADFAM**, a national organisation that supports families coping with drug use, carried out a series of consultations throughout England and Wales. Findings consistently showed that families identified the importance of:

- Having relevant information easily available
- Education for workers around the effects upon families and what support is helpful and available

Other relevant information that can assist families and carers include:

- Health issues
- Rights of families as carers etc
- Other support available
- Legal issues
- Methods of coping

Information can be delivered in a number of formats:

- Written information
- One-one setting
- Video
- Verbal information
- Group settings
- Internet

Information should be available in a variety of formats. It is also beneficial if families can access information supported by discussion to assist and clarify understanding.

#### **Internet / world wide web**

There is a growing body of information available through the internet. This has the advantage that:

- an individual can access the information at any time and when it is suitable to them
- anonymity of the individual is maintained
- easy to update with new information

#### EXAMPLE

**Stirling Family Support Service** developed a web site to promote the project and enhance access to support for families living in rural areas. The website also gave workers within education, health etc easy access to information and the work of the project. The construction of the site was done entirely by volunteers and apart from the cost of hosting the page there was no other financial outlay.

Contact: 01786 470797

<http://www.stirlingfamilysupport.homestead.com/aboutus.html>

The main disadvantage of the internet as a source of information is that there is no guarantee as to the quality of the information. Information can be unhelpful in that it can give biased opinion and misinformation. It is also reliant on families having access to a computer which is something that should not be taken for granted by agencies. There are a number of websites been developed which focus specifically on supporting families. Examples of these can be found internationally and nationally. These sites are useful for individual family members as well as support groups in that they can provide useful links, ideas and information.

**A comprehensive description of available information is provided in Chapter 9.**

#### **SUMMARY**

Information and education should aim to:

- enable family members to make informed choices and decisions
- reduce the opportunity for family members to be manipulated
- reduce fear that can be caused through the sensationalising of issues around drug use by sectors of society
- improve understanding of effects, addiction and treatments so the family are better equipped to cope
- reduce any potential health risks such as hepatitis B and C

## CHAPTER 6: CURRENT PROVISION

This Chapter describes the range of support that is potentially available to families and carers from the statutory and voluntary sectors, and from the community. Much of this information comes from the EIU mapping exercise but it is supplemented by the EIU qualitative study and interviews. The Chapter also examines and discusses the difficulties and challenges faced by **agencies and service providers** in providing support to families. The difficulties and challenges facing family support groups are discussed in Chapter 7.

### 1. What support is currently available?

What families seek support for, and where they seek it can vary greatly. They may seek support informally from those close to them e.g. relatives, friends or colleagues, or formally from agencies. There is a range of agencies and professionals who can and do offer support to families and carers. These include:

#### GPs and health workers

GPs are likely to be one of the first professionals from whom families seek support, either for themselves or for the drug user. GPs can provide support to the family on the effects a relative's drug use is having upon the health of the family. They are also able to provide information on other types of support and services available, either for the family or for the drug user, and make referrals to other workers and agencies. The current development of a programme to assist those working in primary care to make interventions and support family members is discussed in Chapter 5.

Research has shown that these relatives have a high risk of developing mental health problems... Primary care professionals therefore need to be confident that they have the knowledge and skills to respond.

( Orford, 1999)

#### Drugs agencies/workers

Drug agencies are frequently approached by family members for assistance with their circumstances. The main methods of support offered by drug agencies participating in the EIU mapping were:

- providing information and advice to families
- training
- home visits
- advocacy
- counselling
- family support

n.b. family support was not defined and may have included services aimed at drug using parents and their children, as found in the EIU qualitative study

Agencies identify many benefits from involving the families at some level, including the increased understanding that allows the family to be more supportive towards the goals of treatment (EIU mapping exercise). A further significant benefit was contact with the wider family if issues emerged about the welfare of children. Most agencies saw that the

family could play a positive role in supporting the drug user. They also saw that support could improve communication and reduce conflict in the family.

## **Social Work**

Families usually seek support from social work services either in relation to a drug using relative (who may be a social work client) or through caring for dependants of the relative. The majority of social work respondents involved in the EIU mapping exercise provided services primarily aimed at working with the drug user, or supporting drug using parents and their children. Few focused primarily on supporting families and carers, although some did employ family support workers. Often, although the emphasis was on supporting the drug user, this work also included supporting other family members.

The range of work undertaken by social work services involving those other than the drug user included:

- providing information
- making referrals
- supporting young carers
- providing diversionary activities
- carer assessment

The majority of work undertaken by social work services involved working in partnership with other statutory and voluntary sector agencies. However, there is variation in the nature and level of services for families and carers of drug users across Scotland.

Social work respondents in the EIU mapping highlighted that using a 'whole family approach' helped to increase the self-esteem and confidence of family members. It was also seen as enhancing stability within the family.

## **Family Support workers**

The establishment of dedicated 'family support' workers is a recent development in Scotland. Some areas have been able to access funding opportunities e.g. Social Inclusion Partnership funding, to employ workers to support family members, helping to set up family support groups and developing further methods of support. Family Support Workers can provide a range of support including one-to-one support, advocacy and referral work. The structures within which Family Support workers operate varies from area to area. Some are involved in organising volunteers to deliver support; others may be part of an agency and can facilitate access to the services provided by the agency.

## **Carer organisations**

Often those caring for drug users and dependent children of drug users do not see themselves as carers and deserving of support. Carer groups and organisations have a lot of experience in supporting people who take on a caring role to cope with the resulting stress. They provide a range of services including advocacy, referral work, complementary therapies and stress management.



## Other community based projects

There are many local projects that can provide support to families, such as respite, advocacy and diversionary activities. Such practical support can often be highly beneficial to families, especially once they have recognised that they must look after themselves and consider their own needs rather than focus upon the needs of the drug user.

## Family support groups

There is a full discussion of Family Support Groups in **Chapter 7**.

## National support

There are also a number of national organisations who offer a range of advice and information and practical support. Details of these are set out in **Chapter 9**

## 2. Key factors that influence effective family support by agencies

From our consultations with agencies and service providers, including drug agencies, Social Work Departments and primary health care, and from the qualitative study, we have identified a number of factors that influence the effectiveness of support provided by agencies and service providers.

### Confidentiality

This can present difficulties for agencies and service providers where the emphasis of contact is with the drug using client. The clients should be able to expect that confidentiality is maintained on what is discussed. Information may be shared with other providers, with consent and appropriate safeguards, to ensure integrated care (Integrated Care for Drug Users; Principles and Practice, EIU 2002). However, the need to respect the client's confidentiality is likely to mean that **agencies can be restricted when engaging with families**, especially in discussing details of their work with the client. Agencies report that often the client may not want any family 'interference'. For families this can result in them feeling that they are excluded from the process and act as a substantial barrier to engagement.

'Many young drug users do not want parental involvement'

EIU mapping exercise

The key factor will be **the level of engagement** that the family seeks from the agency. They may wish to know specific information about the drug user and details of their treatment and care. Equally, they may wish only to talk through their concerns and obtain **information about drugs and treatments** rather than discuss their relative's details. In such cases, agencies can provide valuable information without any breaches of confidentiality. This can also help maintain a good relationship with the family and, by improving their understanding of the situation, how they cope with the impact. It can also improve the standing of the agency within the wider community.

The family may be keen to play a role in the treatment of the drug user. This should be considered during **the assessment process** when discussing with the client what support mechanisms exist for them, any difficulties with these support mechanisms, and what level of family involvement they are happy with. Although some clients may wish no family involvement others can be happy and indeed keen that there is someone outwith the agency to support and assist them. If agreement can be reached between the agency, client and family, the agency should then be able to recognise and support the agreed level of family involvement without fearing any breach of confidentiality.

## Resources

The workloads faced by many agencies in coping with the demands for services means that there are limited resources available with which to provide support to the families and carers. Also, agencies recognise that working with families, especially if that work is at a demanding level, requires staff to be suitably skilled and equipped to perform such work adequately.

Agencies and service providers should **identify the training needs of staff** who are likely to have a role in supporting families and carers. Some agencies, such as Turning Point have trained family members as volunteers who can offer appropriate support. It also enables support for the client and the family to be separate and has the benefits of 'peer' support.

The relatively new role of family support workers has offered an additional resource. However, workers have experienced a range of difficulties associated with their work. These include the **short term nature of funding** which often restricts the development of support methods and also results in much of the worker's time being taken up with securing future funding. **Accessing suitable premises** was also highlighted as an issue of concern that could impact on the service they offer. Some workers experience **negative reactions** from family support groups, in part relating to their belief that peer support is best and that the worker does not share their circumstances. This can especially be an issue if the worker is attached to an outside agency such as a Carers centre or local drugs agency. The family support group may feel that they have lost an element of control over the purpose of the worker. This highlights the need for clear negotiation and agreement when proposals for a family support worker are being considered, especially when this involves consultation with local support groups. It is also advisable **to establish the exact purpose and remit of the worker and their relationship to local support groups** in order to reduce any detrimental effect on the appointment of workers or the autonomous nature of the Group.

It can reduce the energy of support groups and members, and lessen their personal commitment. It can also cause friction around issues of a paid worker not having the circumstances that the group face.

EIU interviews

## The impact of drug use on the family's motivation and ability to sustain contact

It can be difficult for families and carers, whose lives are disrupted by the effects of the behaviour of the drug using relative, to sustain the motivation or energy to maintain contact with agencies. They may, for example, find it hard to keep appointments. Conversely, when things are going well, families sometimes fail to keep appointments. (EIU qualitative study). **Agencies could ensure that families and carers are not penalised for missing appointments and maintain an 'open door' referral system (especially if trained volunteers are on hand)**. They could encourage early contact if appointments are likely to be missed so that alternative arrangements can be made. The availability of 'home-visits' may also address difficulties the family may face in attending a service.

### **Differing expectations and aims.**

Families can want a 'quick fix' and cure for the drug problem. It can be difficult for them to accept the concepts of 'harm reduction' and substitute prescribing. Families also sometimes have preconceived and negative views about services designed to minimise harm, such as needle exchanges and substitute prescribing, which they see as encouraging drug use rather than about keeping people safe. It can take a lot of time to overcome this (EIU qualitative study). This can result in conflict between the family and the agency over the goals of the treatment programme.

To try and overcome these preconceptions, agencies and service providers, should **provide appropriate information verbally and in written form**. By taking opportunities to explain the nature of dependency and addiction, the family is more likely to understand the aims of the treatment. This kind of dialogue also provides agencies with an opportunity to discuss what the family can expect in terms of changes in the relative's behaviour and physical condition. It can be very disconcerting for families to cope with the experience of supporting a relative through detoxification or going onto a methadone programme without this information. It also provides an opportunity to encourage and support the family to consider their own needs and provide information on how to access other support that meets these needs.

### **Mistrust and negative attitudes.**

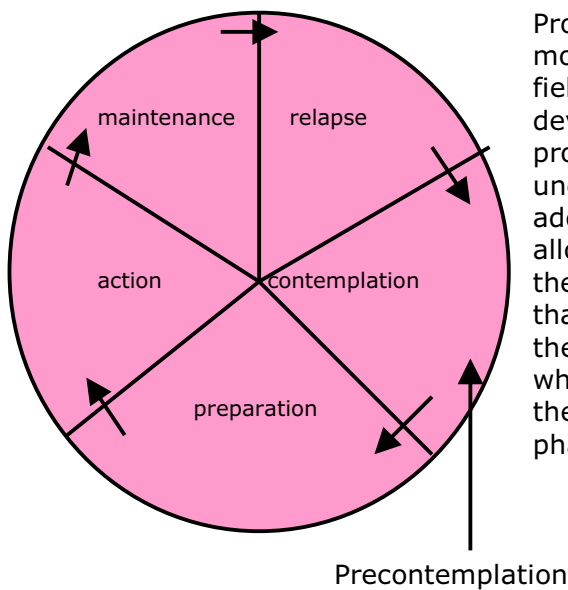
There is a consistent theme across the findings from all the research and evidence that families do perceive the level of support that they are offered as unhelpful. In some cases, they perceive the attitudes of staff in agencies towards them to be negative. The consequences can be that the family member feels worse about their situation and may become reluctant to try any other form of support. **Agencies and service providers should recognise the sensitivities of those seeking support and ensure that staff do not display what can be viewed as negative attitudes to families of drug users or indeed the drug user.**

Agencies report that the communities in which they operate often have very negative attitudes to both drug users and service providers. This can in part be due to communities not seeing any change in the impact drug users have on their lives. Drug services, by the nature of the work they do, are seen as being there to **cure drug users** regardless of the complexities involved. An apparent failure to do so, can lead to the view that the work the agencies undertake is ineffectual and lowers the community's, and the family's, opinion of the service.

Social work services also report a high level of suspicion towards them, much of which is based on concerns that dependent children will be removed from the family. Families believe that staff in agencies would benefit from having a greater understanding of the way that the drug using relative's behaviour affects their daily lives (EIU qualitative study). More discussion with family members and family support groups could improve this understanding as well as improving relationships between agencies and families. A recurring comment throughout the consultation by families was that they wish services would be up front and honest about what they **can and cannot do**. Agencies should also try **to promote knowledge and understanding about the nature and purpose of their work**. This kind of discussion would also assist agencies in developing **clear guidelines and policies and standards of practice to ensure consistency in working with families and carers of drug users**.

## Lapse and Relapse

This can have a significant impact upon families and carers. The experience of seeing progress and then witnessing the relative relapse to their previous state can result in the family feeling that their situation will never change and decrease their motivation to seek support. It can also lead to increased stress and reduce their ability to cope. Agencies can **provide support to families and carers to help them understand the process of change**. Relapse can and does happen when drug users attempt change. It is more likely to be a **stage** in the process, rather than the end. With support, the family may also be able to identify what they could do to reduce the chance of relapse: for example, trying to help the drug user to avoid exposure to previous environments associated with their drug use.



Prochaska and DiClemente's '**Cycle of Change**' model of dependency is frequently used in the field of drug treatment, although was first developed to treat nicotine dependency. It can provide a useful tool for families to assist them to understand better the varying factors in addressing dependency and addiction. It can also allow the family to identify ways of best coping at the stages of change in the drug user. It may be that a 'withdrawn' approach to coping can assist the drug user to move to contemplation stage, whereas a more 'engaged' approach may assist the drug user through the action and maintenance phase.

## Family relationships and behaviour

Families may function and cope in ways that prevent recovery or progress of the relative: for example by being 'tolerant', clearing up after the drug user, lending them money in order to have a quiet life or supplying them with prescription drugs. Such behaviour inhibits the chance for the drug user to face up to the consequences of their behaviour. Families often know that "tough love" is the best way forward but may feel guilty about being 'tough' with their drug using sons/daughters. Families often feel that they have divided loyalties which can lead to collusion to try to keep the family together (EIU qualitative study). One way in which agencies can help is to **assist the family to understand the necessity for, and benefits of, boundaries and support them in establishing such boundaries**.

Support can encourage **greater communication and allow family members to address and discuss their feelings**. By being able to talk about, rather than conceal, issues, families can rebuild trust and relationships. It can also mean that families respond to the drug user in a consistent way (e.g. the family all refuse to lend money rather than one giving in to demands), reducing the scope for conflict within the family and improve family dynamics and stability.

## Other family issues

There are other issues within the family that can present difficulties when working with the client or the family. If these can be identified at initial stages of engagement with either the client or the family member, it would allow the agency to assess the appropriate level of involvement for the family and also identify circumstance that may adversely affect work with the client.

### 3. Strengthening support to families and carers

From the EIU qualitative study and mapping exercise, and the work of other organisations such as ADFAM, we have identified some ways to strengthen family support offered by agencies and service providers:

#### Offer a wider range of support

Agencies and organisations should recognise the wide range of support required to meet the individual needs of families and care. This should include:

- **practical** support, such as respite, advocacy and financial advice
- **emotional support**, such as counselling, befriending and group work
- support to **increase knowledge and skills**, on drugs, their effects and treatments; personal development, including stress management and assertiveness training; and how to access other support
- **financial support** to assist with caring for dependents and crisis situations
- **access to** drop-ins, dedicated workers and support groups

(EIU qualitative study).

This wide range of support should also aim to target specific groups such as **children and siblings, men and ethnic minorities**.

#### Increased resources

A greater level of resources would allow agencies to strengthen and develop the support they offer. There was a strong view from agencies that the short timescales often attached to funding bids reduced the opportunities for consultation to **identify needs**. This can often mean that need is more likely to be defined by 'professionals' rather than by the families. At worst this can mean that inappropriate methods of support are developed, or barriers remain unidentified through the lack of consultation. Further, the short term period of funding can make it difficult for new service provision to become sustainable. This is a **key issue for commissioners of services and funding providers to address**. Many respondents to the EIU mapping exercise stated how support could be strengthened by having a dedicated worker to support families and carers of drug users.

## **Work with children**

There was acknowledgement throughout agencies of the need for extensive support to children. Areas identified that would assist in improving support included the need for child-centred information to be available, diversionary activities and also intensive support such as counselling. Improved access to such supports as nurseries, childminding and respite would be of particular use to those taking on a caring role.

## **Staff training**

Drug agencies, Social Workers and primary health care staff highlighted that support could be strengthened by staff being more skilled in how best to support families and carers (EIU qualitative study). Training could help staff to develop a greater appreciation of how someone's drug use impacts upon the family and how they can respond in supporting them best. The training could be enhanced by incorporating sessions with family members and/or family support groups

## **Increasing access**

Agencies and service providers should ensure that support is made as accessible as possible. A variety of factors can create difficulties for families and carers:

- the choice of location: can support can be taken to the family rather than the family having to attend at a venue?
- transport difficulties
- provision for child care.

Improving access should ensure there is maximum take up of support offered.

## **More effective networking and partnership working**

Clear benefits can be gained from agencies and service providers collaborating in the support they offer to families and carers. It is also essential that agencies should know about each others services and what they can offer so that families and carers can be made aware of what support exists and how they can access it. As noted in Chapter 2, there is a difference in perception between agencies and families on the level of support available. This may partly be due to lack of knowledge about what support exists and routed of referral. This could be rectified by clearer communication between organisations and information about what support was available locally. It could be put into **information material for families, which could then be used by all the relevant agencies.**

Better understanding between agencies could also mean that **resources are best targeted to filling gaps in the provision of support** rather than duplicating work done by other agencies. Such networking should be broad and include the work of agencies such as Carers groups, health alliances and healthy living centres. This would also raise the profile of families and carers amongst organisations not normally associated with providing support and also address some of the stigma associated with drug use.

## **Evaluation**

The lack of research into the effectiveness of services supporting families and carers means that little is known or written about what constitutes best practice and how the effectiveness of support can be measured. Significant benefits could be gained by evaluating support in order that best practice can be developed within the agency providing support but also that such practice can be promoted to others. The EIU Evaluation Guides are available at:

<http://www.isdscotland.org/goodpractice/effectiveunit.htm> **The EIU will produce an Evaluation Guide on family support in 2003.**

### **CHECK LIST FOR AGENCIES AND SERVICE PROVIDERS OFFERING SUPPORT TO FAMILIES**

- **Is your agency/service clear on what support they can offer to families and carers and what support they can't?**
- **Are there any training implications for staff?**
- **Are there boundaries such as confidentiality that need to be established?**
- **Do any existing policies need to be reviewed such as assessment procedures for drug users to establish if and to what extent they may wish families and carers to be involved in joint working?**
- **Are there any resource implications to offering support and how can these best be met?**
- **Have you established relevant family issues that may restrict the support offered?**
- **Has your agency got good knowledge of other support that may be available locally and how to refer people onto that support?**
- **Can working with other support providers strengthen the support you offer?**
- **Are there any barriers that may prevent people accessing support and can these be minimised?**
- **Has your agency/service developed a method of evaluating the support they offer to families and carers?**

## CHAPTER 7: FAMILY SUPPORT GROUPS

This Chapter discusses the concept of a family support group and examines why people become part of these groups. It also looks at the potential benefits of family support group membership and the difficulties that groups and individuals face. This chapter also provides some examples of family support groups and points the reader to further resources. We have used evidence from the EIU literature review, the EIU mapping exercise, the EIU Reference Group and from the Family Support Scotland Conference 2002

### 1. What is a family support group?

A support group can be described as a group made up of individual members who have an issue or difficulty to cope with in their life that is common to other members. Support groups exist for a wide range of reasons including dealing with health issues such as HIV/Aids, mental health problems and addiction.

#### EVIDENCE

Those who are anxious and under stress might find that talking to someone is helpful but have little opportunity to do so, or they may discover that the number of people who will actually listen is not large. The support group provides that audience – and much more.

(Lockley 1995)

In relation to drug use, family support groups are made up of family members who are affected by a relative's drug use. When first attending a family support group, often the family member is feeling isolated, confused over what to do, and to a degree, to blame for their family circumstances and difficulties. The support group can provide a safe environment to explore issues that are a concern to the individual members. The fear of being judged may have held them back from seeking support elsewhere, but it may feel safe with people who know and face similar situations.

The support group helps members to make sense of their situation and allows them the opportunity to examine and recognise how they cope with the drug use, and the consequences of the methods they employ to cope. This can allow the family members to view themselves more positively and reduce feelings of responsibility for the difficulties they face.

#### EVIDENCE

Families attend groups for a wide variety of reasons:

- to reduce isolation
- to increase knowledge on drugs and coping with drug use within the family
- to share concerns and experiences with others in similar circumstances
- to get a 'break'
- lobby and campaign for better resources for drug users and their families

(Family Support Conference report 2002)

**The aim of family support groups is to collectively support each member through difficulties they may be facing within a group setting.**



## 2. Benefits of attending a support group

The EIU interviews emphasised that support and information provided by **others facing similar circumstances** was key to the ethos of family support groups. The support given can assist family members in various ways to cope with their personal circumstances:

- to improve understanding of drug use and its effects upon individuals
- to achieve a positive impact on their physical and emotional health by reducing stress and assisting them to cope in less damaging ways
- to reduce the isolation and loneliness being experienced by the member. It can also reduce the sense of responsibility felt by helping the family member to put ownership of the drug problem with the drug user

Overall, attending a family support group can have an impact how the family member views, copes and responds to the issues affecting their lives. This will often lead to improved stability in the family but it is also useful to recognise that changes in views, attitudes and methods of coping can also lead to destabilisation in the family unit, especially at the initial stages of such changes.

From the evidence that we have gathered, we have identified the following benefits.

- **Members become part of a collective voice.** This can give members increased confidence and make it considerably easier to challenge and ask questions of others, such as Drug Action Teams.
- **The group is non-judgemental.** Everyone else within the group faces similar circumstances and difficulties. This means that they are less likely to judge or show shock at others' circumstances. This creates a safe environment for members to disclose their problems.
- **Members become more informed about drugs and less likely to be manipulated.** By being more informed, the family gains a wider understanding of drug use, behaviour, and dependency. They are then less likely to react or cope in ways that may be inappropriate and unhelpful either to themselves, other family members, or the drug user. Addiction of any sort is often accompanied by manipulative behaviour aimed at maintaining the addiction. Becoming more informed reduces the chances for the family to be manipulated in such a way.
- **Reduces likelihood of member becoming dependent on the support from a one-one relationship.** The fact that everyone within the group should be able to support each other is helpful in building up an individual member's network of support. It can also reduce the possibility of a member becoming overly reliant or dependent on any one person giving support. This is seen as a key benefit of group support in preference to one-one support (EIU literature review).
- **Reduces stress experienced by the family member.** The sharing of information and experience can reduce the anxiety of members and the isolation they feel. By hearing of others' experiences and gaining reassurance through obtaining accurate information, family members are more informed and able to realistically assess their concerns (EIU literature review)

- **Builds confidence for coping.** Being able to discuss their circumstances enables members to look at how they cope, think about the advantages and disadvantages associated and adapt their coping strategies.
- **Empowers the family member.** By acquiring new knowledge, skills and growth in self confidence gained from attending the group, the family member can increase their capacity to manage internal and external issues affecting their lives (EIU literature review).
- **Development of skills.** Members can develop skills associated with giving support and listening. They can also develop organisational skills related to the running and management of the group.
- **Improved communication with other family members** Discussion of their circumstances and gaining knowledge within the group can help family members to improve communication and discuss issues within the family (EIU literature review).

The EIU literature review also found that attending a support group could provide benefit where family, friends and professionals could not.

It is important to note, however, that providing support can have **both a positive and a negative impact** for the member. Support given with the best of intentions can sometimes make the member feel worse, more personally isolated and anxious. Negative elements that can come from attending a support group include:

- possibility of raised anxiety and despair amongst members from listening to others' experiences.
- fear of not being anonymous.
- feeling that you are not being listened to or that your opinion or experience is being dismissed by other members.

Although the aim of a group is to support, this can require a high level of sensitivity and consideration for the members.

#### EVIDENCE

- Support is not simply being nice to people or always agreeing with them. It should be honest, and those supporting should be themselves.
- Supporters should keep personal boundaries, and not be overwhelmed by situations but be able to comment on them. They should suggest options and challenge the person being helped if this is appropriate. Support may even be considered somewhat unpleasant at times, as those supported have to face themselves and the actions of others close to them.
- Being supported can involve personal change, and any form of change may be disconcerting and potentially upsetting.
- Support is not feeling sorry for someone, as this can merely reinforce someone who sees the world in a negative way. Nor is it trying to cheer someone up as this fails to acknowledge and deal with how that person feels.
- Support is not telling people what they should be doing. It is entering into a formal relationship with individuals and helping and being helped through those relationships. The assistance has to be given in a structured way (Moos, 1974) to be really useful, ensuring mutual interaction through good relationships.
- Support is not a process where one person is always receiving support and another is always giving it. Such one way help is more likely to engender personal dependency and to diminish personal responsibility.  
(Lockley 1995)

### 3. Different types of support

Support can take different forms and some members may be better at giving and receiving certain types of support than others. Someone who is uncomfortable with expressing emotion may be more comfortable receiving information and support in a problem solving context, rather than through emotional support. Similarly, the type of support they need will differ from the needs of other members. This suggests that support should be flexible.

**The support offered by family support groups can take a variety of different forms:**

- **Emotional support**
- **Social support**
- **Advocacy**
- **Information support**
- **Problem solving**
- **Practical support**

(Lockley 1995)

Fundamental to the functioning of a group is the concept that support is a **two way process**. Members may receive support but they should also be active in giving support to others within the group. If this fails to happen, then some members may feel aggrieved and exploited by other members, in that they are consistently giving support to other group members whilst their own support needs are unrecognised and unmet.

### 4. Different types of support groups

Groups can be structured and operate in a number of ways. The **objectives** within family support groups can also differ. Groups may exist primarily to support family members, whereas others may focus more on lobbying and campaigning, particularly for the development of services for drug users. This can have the advantage of making members feel as though they are making a difference to others.

Groups can be **open** to new members attending or may operate a **closed group** that runs for a specific period of time and where potential members are assessed before accessing the group. Some groups will operate under a **definite structure and programme** whereas others will operate under a much **looser format**.

It may also occasionally be necessary to look at establishing **different types of groups in order to meet the specific needs of family members**. As noted above, members may potentially have different issues with regards to their relative's drug use: i.e. a mother whose 14 year old son is occasionally using cannabis may experience heightened anxiety attending a group where a mother is relating her child almost overdosing on heroin. Likewise a father may find it difficult feeling at ease in a room full of women. Other areas where it may be appropriate to establish specific groups could include 'bereavement', 'young people and siblings', and 'HIV'. (see Chapter 4: The needs of families and carers)

#### Running of groups

There are 2 main approaches to running groups: **self-help groups and facilitator-led groups**. ADFAM (2000) identify the relative advantages and disadvantages of self-help and facilitator led groups. There are valuable points to note for those involved in support groups.

**Self-help groups** are run solely by the members:

**Advantages**

- Empowering
- Members can develop new skills and abilities
- No 'professional' involvement
- Autonomy / owned by group

**Disadvantages**

- Negative experiences may depress member and heighten anxieties
- Responsibility for group can lie with a few key members

**EXAMPLE:**

**Families Anonymous**

A well known example of the 'self-help' format is based around the Al-Anon movement. This has been adapted to take on board the needs of families affected by a relative's drug use. This type of group follows what is termed as the **12 step approach**. The core principles of this are the behavioural, spiritual, and cognitive aspects of it's members. Families Anonymous describes itself as a fellowship of friends and relatives of people involved in the abuse of mind altering substances. It currently has seven groups functioning in Scotland. The Families Anonymous model aims to provide mutual support and allow members a safe environment to explore and share anxieties and concerns. Although there is often a perception that there is a religious aspect to the work of Families Anonymous, the organisation uses a spiritual basis and is open to members, whether believers or non-believers of any specific religion.

**EXAMPLE:**

**Pollock Family Support Group**

The support group has been running from 1997, receiving support from the local community worker and also from Social Work Addiction services who provide accommodation for the group. The support group operates with a chairperson, secretary and treasurer and all members have a say in the in the decision making of the group. The Group meets weekly and attendance varies, usually around 10-14 people. It is discussion-based and quite loose in format. If anyone is wanting specific information, they organise getting someone in, such as a health worker coming in to talk about Hepatitis C and HIV. The Group also organise social activities and use this to assist with fundraising as well. They try to involve all members of the Group within these activities, as it appears to motivate members, and gives everyone a job and a purpose within the Group.

The support group also provide:

- Helpline service
- Advocacy work
- Access to counselling
- Holiday respite

**Facilitator led groups** are led by a **facilitator** who assists in supporting members and ensuring everyone has opportunity to express themselves.

### Advantages

- Can ensure no-one dominates the group
- Can motivate the group through difficult periods
- Someone to take responsibility for the running of the group
- Facilitator can maintain a more detached position, enabling the group to work in a more constructive way
- facilitator can keep a balance between sharing difficulties and dwelling on them too much
- can reduce the organised workload for group members
- can enable members to discover strengths and to identify and meet their own needs

### Disadvantages

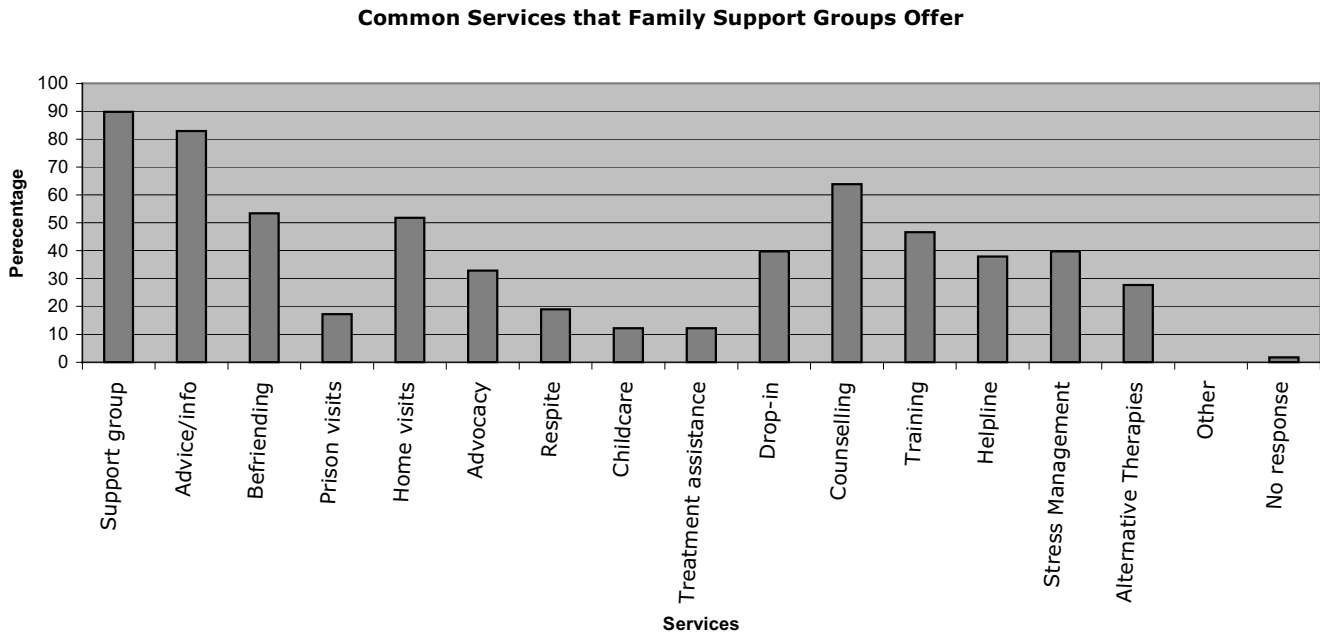
- Poor facilitation skills can deskill and disempower members and groups
- May raise concerns about around confidentiality
- The facilitator can be seen as remote and not having the same understanding if not also living with drug use

#### EXAMPLE OF CLOSED / FACILITATED GROUP

Simpson House is a Church of Scotland run drugs project within Edinburgh. It runs a family support group that operates through offering a six week course to parents and family members. The process used by the facilitators is to assist the members to step back and consider their own needs. They explore the roles that family members take on in order to cope with their circumstances, and what their concerns are that make them take on this role. Through exploring possible other responses the member is able to assess potential benefits and drawbacks of their actions within the safety of the group. The group ends with an evaluation where family members reflect upon any changes within the family that have occurred during the course.

## 5. What other services do family support groups in Scotland offer?

Many support groups offer a considerably wider range of support than that of group meetings. The support groups that participated within the EIU mapping exercise showed that they offered a considerable range of services, or have access to such forms of support through relationships with other agencies.



This highlights the diversity of family support groups within Scotland and demonstrates their determination to find the most beneficial support for others facing similar circumstances as themselves. The mapping, however, did not investigate what structure and operation was behind such services, or what difficulties groups faced through operating them.

Advantages of support groups providing other services are that members can acquire new skills and confidence in either delivering the service or through obtaining the resources to establish it. It then also provides a greater diversity of support for members, and potential members, to access.

### EXAMPLE

#### **Glasgow Association of Family Support Groups (GAFSG)**

GAFSG has now grown to provide a wide range of support to families, carers and other family support groups, primarily within the Glasgow area:

- offers a range of support groups including a bereavement group, a grandparents group and also an ex drug users group.
- advocacy work with family members
- counselling service
- holiday respite
- helpline service
- art therapy
- prison liaison work
- support to those wishing to establish family support groups

## 6. Difficulties faced by groups

Family support groups can face difficulties in providing support and in the running of the group. Those that receive little by way of support from workers, agencies or other groups can be left isolated to try and find solutions to some of the difficulties that can be common when running a group.

Evidence gathered from the EIU mapping exercise, consultations and the Family Support Scotland Conference indicated that the main problems groups faced include:

### Who supports the supporter?

The establishment of groups is often down to the determination of a family member/s to establish a group in their community. This can create difficulty particularly if ownership for the successful operation of the group lies with a few members. These members often have their own difficulties and support needs and this can result in their personal stress being worsened through the stress of keeping the group intact. It can also be the case that such people can give more support than they receive from the group by the nature of the role they play within the group.

#### WAYS TO ADDRESS:

- Try and ensure that support is given and taken equally by **all** members. Ensure members know the process of support is about **giving and receiving**.
- Often the issues raised within the group can be disturbing. **Seek outside support** if you feel overwhelmed either in the responsibility of supporting or through organisational issues. Remember to consider the **confidentiality** of the group and discuss your feelings and the impact of supporting the group, not particular accounts of meetings that may breach confidentiality in the group.

### Attracting new members

Many groups stated that they experienced difficulties in attracting family members to the group. Groups highlighted that a lack of confidence and understanding of what a support group could offer could inhibit people from attending the group. Joining a group can be an intimidating experience. New members have to meet a roomful of new people and also discuss personal and difficult issues they face.

Other factors to be considered are:

- transport issues,
- lack of child care,
- being visible as a family with problems (**this is especially the case within rural areas**)

Over half of support groups (59%) who participated in the EIU mapping exercise contain 1-10 members. It should be noted that within the nature of support groups it can be beneficial that numbers of members are not overly high as this can reduce the opportunity for members to participate fully.

#### WAYS TO ADDRESS:

- Try and **publicise widely** to increase people's awareness of the group. (Stirling Family Support Service was able to advertise the service on the local authority payslips)
- Try and find an **attractive and neutral venue** that is 'safe' for people to attend. A drugs agency may be a possible venue but can scare people from attending in case they meet their relative or someone they may know. A local carers centre may be more accessible and also be able to provide information and expertise.
- Develop a system of **introducing new members**. This could involve an initial visit to discuss how the group works, or accompanying new members to their first meeting.
- Is there a **creche facility** that the group can access, or funding to cover child minding for members.
- Identify if afternoons, evenings are the **best time to hold meetings**. Is a particular day more suitable than another?

#### Stigma

Many groups involved in the EIU qualitative study and interviews described how the stigma attached to drug use was a major factor that meant families were unwilling to come forward for support and share their experiences. Kenny (2000) found that 'there is enormous stigma attached to being the parent of a drug user or being a member of a family in which there is a drug user. Groups also state that there can be a backlash from the community and officials to the setting up of a group in their area. This again can relate to stigma, prejudice and ignorance from others.

#### WAYS TO ADDRESS:

- **Raise awareness** of the impact of drug use upon families and of the effects that stigma can add to their suffering. People's prejudices can be the result of being ill informed and lacking understanding.
- **Challenging attitudes as a group** is a lot less daunting than challenging as an individual.
- Seek to **influence those with the power** to influence others, i.e. the media, councillors, MSPs and DATs.



## Resources and funding

The running of support groups requires a certain amount of funding for costs such as accommodation, phone costs, publicity and stationery. Groups highlighted that **accessing sources of funding** was a difficulty. The result can be that group members who may be experiencing financial hardship in relation to their family difficulties are also financially out of pocket for activities related to operating the group. Obtaining funding was often a further stress for those whose responsibility it was and groups regularly cited receiving little assistance from 'professionals'.

**Receiving funding** can also bring about issues for the group in that it may affect the autonomy of the group and their degree of self control. Throughout the EIU qualitative study some groups highlighted difficulties they had experienced since receiving funding. These included difficulty in accessing funds when they were managed by outside agencies and groups feeling as though they did not have enough control over the purpose and use of funding.

The short term nature of funding can restrict a support group from developing long term objectives, cause insecurity about the future of the group and affect the motivation of members in supporting each other.

### WAYS TO ADDRESS:

- **Seek support from 'professionals'** such as a local community worker in identifying and applying for funding, or voluntary sector organisations that can assist.
- Work out with the group the **exact purposes of funding** – what you aim to do with the money.
- Groups have to take on **structure and organisation** to obtain funding. It will be necessary to form a committee, establish a constitution and open a bank account. This should be done democratically to ensure no members feel excluded.
- If working with others, as in a larger organisation managing the funding, ensure there is **clarity over roles, responsibilities** of each body.

## Accommodation

Finding premises to conduct meetings is a problem for many family support groups. Having **appropriate accommodation** is seen as essential in the success of the group. Venues such as schools, drug agencies and social work premises may be seen as a threat to families not wishing to come into contact with services, regardless of whether these organisations have direct involvement with the support group or not.

### WAYS TO ADDRESS:

- Make sure premises are **accessible**
- Make sure they maintain **anonymity**. Using a drugs agency can be seen as threatening to family members who may wish not to be seen by their relative.
- Make sure conversation cannot be heard by others using the building
- Try to find a **neutral venue** such as a carers centre or community centre

## Confidentiality and anonymity

People may fear coming to family support groups because they are worried that they are exposing their situations and are uncertain whether it is safe to do so. They may have concerns that what they say may be repeated elsewhere. At its worst, this can carry significant risks. In discussing such topics as the dealing of drugs personal safety can be compromised if information is given to others. Any breach of confidentiality can result in the member not being able to trust the group and reduce their capacity to share their experiences and feelings in safety. This issue is of particular importance within rural areas where there is an increased likelihood that potential members may know others in the group.

### WAYS TO ADDRESS:

- Ensure members have an understanding of the **meaning of confidentiality** and how it feels if it is breached.
- Develop a **confidentiality agreement** or even a contract for members to sign. Make sure that this is done in relation to the above point and not something imposed upon members.
- Discuss how the group should deal with issues such as **breaching confidentiality**, and what action should be taken if it is breached.

## Group dynamics

Groups can face numerous difficulties. They may contain personalities who either dominate proceedings or exclude others. They can also become 'stale' in that one meeting can become very like the next one and members become disillusioned. Personalities may clash and it can become difficult to provide or take support in such an environment. Such difficulties can be hard to resolve and require sensitive handling.

### WAYS TO ADDRESS:

- This is where there can be advantages in having a '**neutral**' person such as a **facilitator** to deal with such difficulties. The EIU literature review found evidence that the role of the facilitator advantageous in maintaining the group and in **screening potential members**. This last point indicates that it may be useful to assess potential members, not to exclude, but to assess whether it would be the best form of support for them at that particular point. This is of course dependent on their being other forms of support available.

## Keeping direction

Maintaining motivation of members can be difficult when coping with a relative's drug dependency or addiction. The despondency felt by members can mean the content of meetings, by the very reason for their existence, can often be negative and despairing. Consequences of this can be that members decide not to attend and make it further difficult to maintain the motivation of the remaining members. All this can have a negative impact upon those sustaining the group.

Family support group meetings may tend to deal with the same issues repeatedly and members may question the usefulness of attending in such cases.

#### **WAYS TO ADDRESS:**

- Using a **facilitator** to help structure the content of meetings
- Trying to always identify a **positive aspect** of the meeting
- **Seek support** from outside the support group on how to ensure the content of meetings varies occasionally.
- Introduce **new elements to the group** such as a social activity, complementary therapies, visits and speakers, training etc.
- Activities such as **fundraising** can give members focus and a more positive outlook.
- **Extend the form of support available.** Many groups offer a range of support methods including counselling, respite and befriending.

#### **Recognition by others**

Throughout the UK this is identified as a major grievance by support groups (Kenny, 2000). It is common for family support groups to feel **isolated** from other agencies and structures. Groups regularly say that they are **not taken credibly** by others or are seen as a **nuisance**. Often support groups can feel remote from the **decision making** and that their voice is not heard at strategic level. Therefore, the understanding of those making decisions (**DATs**) can be limited in relation to families and drug use, and their needs.

#### **EVIDENCE**

'some parent groups are viewed with mistrust as "do-gooders" who are obsessed with their own personal experience and have nothing to offer to the field of drug intervention'  
(Kenny 2000)

Of the family support groups involved within the EIU mapping exercise, over two thirds were involved with their local drugs forum, under a fifth were involved at DAT level. It is also the case that such involvement can be a negative experience, especially if there is no perceived benefit to the support group or family members. It can therefore, be difficult to achieve positive working relationships.

The EIU mapping showed that almost a fifth of groups stated they experienced difficulty in establishing positive relations with other agencies.

#### **WAYS TO ADDRESS:**

- **Establish structures** that give the group aims and guidelines to ensure that others take the group seriously. It also helps the group to maintain its purpose and direction.
- Think of ways of **improving relations** with other organisations, i.e. invite them to come along and discuss issues and opportunities for working more positively.
- Make sure **agencies know of your existence**. Network with DATs, drug agencies, social work, education, GPs and health workers
- Establish the **limitations of working relationships**, what are their aims, and roles and responsibilities.
- Hostility towards other agencies and workers only reinforces negative attitudes and does not foster good relations. If you have issues, **challenge constructively**.

#### **7. Who assists family support groups?**

Although some family support groups identify that they have received little or no support in becoming established and in the running of them, other groups highlight a range of organisations that have assisted them. A wide range of agencies has a responsibility to ensure that groups are supported to access opportunities and in assisting them in dealing with difficulties. Such agencies include:

**Drug Action Teams(DATs)/ Drug Forums** – can assist in accessing funding and in keeping group informed within decision making. It also ensures that issues for families and communities are heard at strategy level. Most DATs have co-ordinators that can assist with information regarding the work they do and what assistance they can offer. (A list of DAT contacts is contained within Chapter 9 Resources)

**Social Work departments** – can provide assistance with accommodation, funding, access to resources such as facilitation and accurate information

**Drugs Agencies** – can provide help with accurate information and other resources

**Community workers** – can provide support in forming committees, constitutions, accessing funding, accommodation, publicity, training etc

**Voluntary sector** – can provide support in forming committees, constitutions, accessing funding, accommodation, publicity, training etc.

**The Church** – can provide accommodation, financial support and access to other resources.

**Other family support groups** – can provide knowledge of their experience in how their group operates and also moral support.

**Social Inclusion Partnerships** – can provide funding and access to other resources (only applies within SIP areas – see Chapter 9 Resources)

**Politicians** – can provide support and lobby for the issues affecting families to be addressed. Can also challenge attitudes and stigma at a high level.

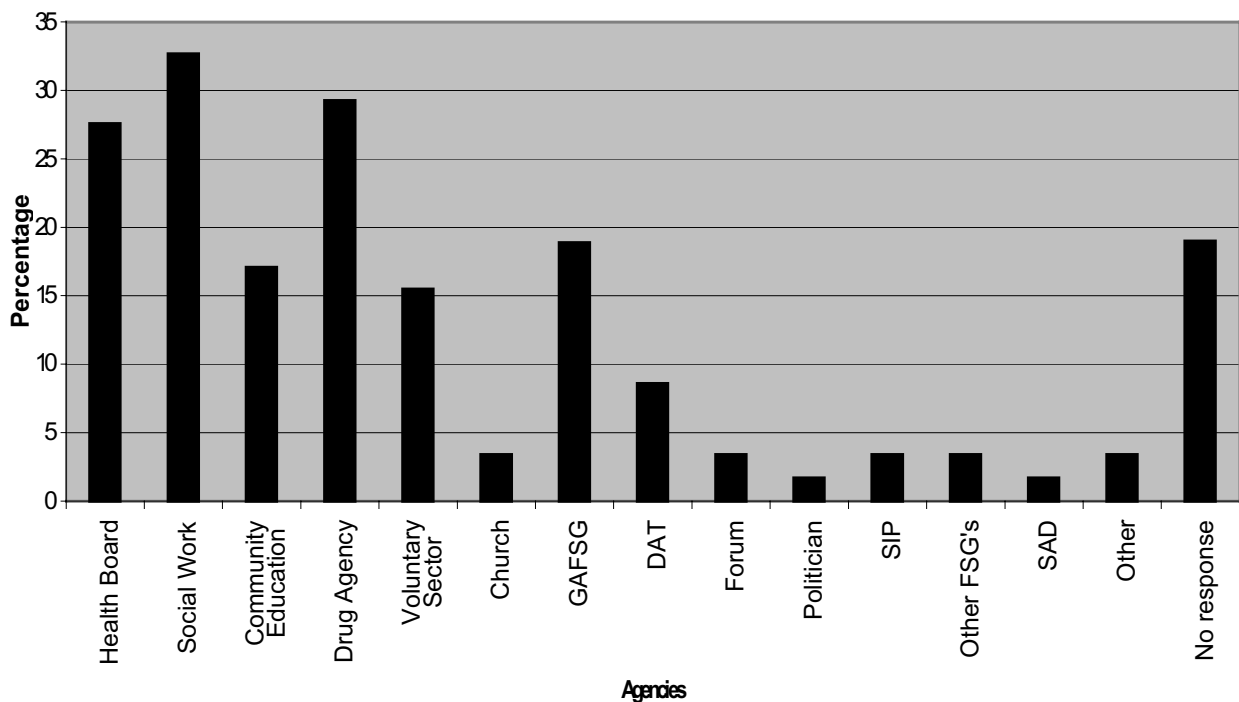
**National organisations**

- **Scotland Against Drugs** – can assist with funding, development of groups and projects
- **ADFAM** – provides specific resources to establish and maintain family support groups, training for support groups and information resources
- **PADA** - provides accredited training for volunteer members in family support groups, help and advice on obtaining charitable status
- **GAFSG** – can provide assistance with becoming established, committees, constitutions etc. Also can provide peer support to maintain motivation and helpful hints.

**(full details of services available from the above organisations are in Chapter 9)**

The EIU mapping exercise asked family support groups what agencies etc had given them assistance, either in first becoming established or, in maintaining the support group:

Agencies that have Assisted in Establishing Support



## **8. Strengthening support to family support groups and their members**

From the EIU interviews, conference survey and the qualitative study we identified a number of areas that support groups felt could strengthen the work they do:

### **Access to wider range of types of support**

These include opportunities to share experience within group and one-one settings. Opportunities for self development including stress management, assertiveness skills and increased knowledge regarding drugs and treatments were also seen as being of benefit. Agencies should seek to establish relationships with local support groups and develop links to offering support.

### **Easier access to information**

Accessing information regarding support for families, drugs, support for drug users is a frequent concern for families and carers. Some support groups also state that they receive little communication from DATs and forums, which means that both families and support groups are isolated. All agencies should ensure that information on supporting families is easily available and in jargon free language. DATs should ensure that local support groups are kept informed about their work, what they can do to support local groups and develop a point of contact between the DAT and local support groups. They should also attempt to involve groups and families through consultation and involvement.

### **Increased resources and financial support**

Support groups often stated how a lack of financial support sometimes left family members who were coping with the financial hardship of living with drug use, also financially affected from assisting the group to function. Often this was associated with telephone and administrative costs. Groups often state that they seek support also in practical terms such as accessing premises, transport and childcare. Agencies should examine if they are in a position to offer support either in accessing funding or sharing resources.

### **Local coalitions**

An interesting development towards strengthening family support groups has been in the development of '**coalitions**' of locally based groups. There are significant benefits to be gained through groups coming together:

- It can reduce the isolation that groups can often experience, especially if they are unrecognised by other agencies.
- It can also strengthen the voice of family members and make it more difficult for their plight to be ignored by decision makers.
- Joint funding can be obtained to provide area wide service such as counselling
- Larger initiatives can be developed such as a helpline which is staffed by members from all groups, thereby sharing the workload and responsibility
- Training can be organised involving all groups rather than groups struggling to obtain training independently

#### EXAMPLE

##### **Lanarkshire Coalition of family support groups**

Family support groups in Lanarkshire have come together to form a coalition. This has been done with the assistance of the local drug development officer who has supported the coalition in obtaining funding to employ a development worker. The main aims of the coalition are for groups to share experiences and give family members a stronger voice within decision making structures. It also aims to improve networking, communication and sharing of issues and practice. The development worker has a remit to assist in the establishment of other family support groups and developing other methods of support.

### **The forming of a national network of family support groups**

The Family Support Scotland Conference 2002 identified the development of a national association or network as a key issue to take forward. Such a body has the potential to act as a vehicle for sharing of good practice between groups, access to resources and training and raise the profile of support for families at a national level. It would also assist in ensuring the experiences and needs of families and carers are taken on board at a strategic and national level.

#### EXAMPLE

##### **Family support in England**

Current work in England is looking into developing a **National Federation of family support groups**. The federation would act as a central body, giving access to information, a louder voice for families and carers and also enhance sharing best practice. The federation could also influence national policy and provide training opportunities.

(contact PADA for further details - 0151 356 1996)

### **Development of training**

Support groups could benefit in their practice from the development of a range of training opportunities. These include personal development skills as noted above. Other areas include listening skills, facilitation skills and engaging with decision making structures such as DATs. Support groups can also be highly motivated in learning skills that they can then utilise in offering as support to others. A range of training provision is included in Chapter 9.

### **Monitoring and evaluation**

As has been highlighted within the EIU literature review there has been very little research into the workings and benefits of family support groups. This has no doubt contributed to the difficulties that support groups can sometimes face, in that they have very limited resources with which they can utilise in addressing such difficulties. Groups could benefit significantly if there is clear aims and outcomes to the work they do. This can only be assessed for its success if there is a form of evaluation to see if the work of the group is achieving its aims. The EIU Evaluation Guides are available at: <http://www.isdscotland.org/goodpractice/effectiveunit.htm>

#### **CHECK LIST FOR ESTABLISHING A FAMILY SUPPORT GROUP:**

- **Have you investigated if a group is needed?**
- **Have you established who the group is for and who it is not for?**
- **Have you established aims and objectives for the group?**
- **Have you thought whether a self-help group or a facilitated group would be best?**
- **Have you established who can give you support (practical, financial and emotional) with developing the group / maintaining the group? (see who can assist groups)**
- **Have you developed guidelines for the running of the group such as confidentiality, dealing with conflict etc?**
- **Are there any management procedures that may need to be developed such as a committee, bank account, constitution etc- especially if you are applying for funding of any sort.**
- **Do group members require any training to help run the group**
- **What is the best time for holding meetings?**
- **How are you going to promote the group and attract new members?**
- **Is the venue for meetings accessible?**
- **Is there going to be a cost to establish and run the group?**
- **Is child care an issue - can anyone assist with this?**
- **Have you identified barriers that may prevent certain people from accessing support and looked at ways these could be minimised?**
- **Have you developed a form of evaluating the work of the group and what members get out of it?**
- **Have you thought how new members could be introduced to the group and whether to evaluate when someone leaves the group?**
- **Is there links to be made with may offer support to other carers that can assist the group?**
- **Have you thought how work can best be shared to avoid over-reliance on certain members?**
- **If you are going to use volunteers have you thought what training, support needs they may require?**
- **Have you made contact with your local Drug Action Team?**



## CHAPTER 8: PRINCIPLES AND PRACTICE OF EFFECTIVE FAMILY SUPPORT

In this Chapter, we set out the core principles that seem to underpin effective support to families and carers and identify issues that can influence the development of effective practice. These are drawn from our review of the evidence.

### Principles of Family Support

- **The prime focus of family support should be to address the needs of the family and the carer.**
- **Family support services should be open, accessible and non-judgemental.**
- **Families and carers should be involved in assessing needs and designing services.**

### Key Issues for Effective Practice

We have identified a number of key issues that influence and promote the development of effective support for families and carers. Some of these issues are common to the range of agencies both at strategic and operational level who have a role in family support. Other issues are more directly relevant to specific agencies and service providers, family support groups and wider community groups. We have set out these issues below under

- DATS and partner agencies
- Agencies and service providers in the statutory and voluntary sector
- Family support groups

**There is some overlap but this reflects the fact that some issues require action at different levels**

#### 1. Issues for DATs and partner agencies

- ✓ **Agreeing clear aims and objectives** for family support services in their area. It is necessary from the outset to establish a clear understanding of the purpose of family support: **what it is and what it is not**. Specifically, DATs and partner agencies need to be clear about the distinction between the needs of families and carers and the needs of the drug users and the **implications for the purpose and nature of service provision**.
- ✓ **Assessing the needs of families and carers**. This is the first step towards planning comprehensive and relevant services. A needs assessment should consider the need for practical, emotional and financial support, the scale of existing support and the gaps in provision. Information about how to conduct a needs assessment is contained in the EIU document "Integrated Care for Drug Users: Principles and Practice" (EIU 2002), <http://www.drugmisuse.isdscotland.org/eiu/intcare/intcare.htm> EIU will publish a more detailed Guide to Needs Assessment in early 2003.

- ✓ **Consulting with families and carers.** This is a key component of needs assessment. The support needs of families and carers, and of individual family members, vary and may change over time. DATs should **actively engage** with families and carers to identify the range of needs and obtain the families' views on the kind of support that they want. The EIU Guide to Community Engagement may offer some help on methods of engagement. It is at:  
[www.drugmisuse.isdscotland.org/goodpractice/EIU\\_commeng.pdf](http://www.drugmisuse.isdscotland.org/goodpractice/EIU_commeng.pdf).

Another source of help and advice is the **Scottish Drugs Forum** who now have a key role in developing and supporting community engagement and carer involvement across Scotland.

- ✓ **Providing a central source of information.** DATs are in an ideal position to compile **information about sources of support** (practical, emotional and financial) and to ensure that both agencies and families have access to such information. DATs should also ensure that they keep local family support groups informed about their plans, what they can do to support local groups and develop a clear point of contact between the DAT and local support groups. DATs should also consider providing training for family support groups in organisation and financial management.
- ✓ **Working with others.** The range of needs among families (see Chapter 4) clearly indicates that DATs and partner agencies should work together to meet those needs. This requires a common understanding about what constitutes family support, good communication and liaison arrangements and agreements on referrals, information sharing and confidentiality.
- ✓ **Ensuring that staff have relevant skills and training.** DATS and partner agencies and service providers should recognise that it is important that all staff have a thorough understanding of the impact of drug use on the family members and the need for sensitivity in engaging with them. They should consider sources of **appropriate training. There may be scope for joint training with other agencies and with members of family support groups.**
- ✓ **Funding.** Tight timescales and short term funding can reduce the time for DATS and partner agencies to consult thoroughly with those whose needs they aim to meet. This can mean that need is defined by others (professionals) rather than by the "clients". Making it a condition of submitting funding bids that families and carers are involved or that they are represented on bodies awarding funding could ensure that they are an integral part of decision making processes and developments. At a practical level, DATS could consider how they can offer **financial support to family support groups** to help with administrative costs.
- ✓ **Monitoring and Evaluation.** Systematic monitoring and evaluation is crucial to establishing how and why family support is or is not working, and to highlight areas for improvement. Good evaluation has the potential to improve services and maximise their co-ordination by identifying what works, what could be done better and what is ineffective. It helps to ensure that families and carers are receiving the best possible support to meet their needs. More information about Monitoring and Evaluation is contained in the EIU document on Integrated Care (see above).

## 2. Issues for agencies and service providers in the statutory and voluntary sectors

- ✓ **Setting clear aims and objectives.** This is necessary to ensure that agencies and service providers are clear about the nature and level of support that they can offer. It is also crucial that families or carers share that understanding in order to reduce the likelihood of misunderstanding or unrealistic expectations being raised. This can be especially important for drugs agencies for whom there may potentially be conflict about working with the drug user **and** supporting the family. If the family is going to be involved in the support being given to the drug users, it is essential that they have a clear understanding of boundaries such as confidentiality. Families and carers are more likely to appreciate it when services are honest and up front about what they can do and what they cannot.
- ✓ **Support should be accessible.** When planning support services it is vital to identify potential **barriers** that may prevent people from accessing that support. Such barriers include **location and time**. It is important to consider:
  - is the location remote or difficult to reach by public transport?
  - will families be concerned that the location that attendance will threaten their anonymity and confidentiality?
  - is the service/support offered at appropriate times e.g. to take account of childcare responsibilities?To be accessible, support needs to be **well publicised**. Finally, services should be **open** and **approachable** to combat the fear and apprehension often felt by families. Reception staff, as the first point of contact, should be suitably skilled to deal sensitively with families.
- ✓ **Providing appropriate information verbally and in written form** in user friendly and accessible formats on:
  - the aims and objectives, and the approach used by the agency/ service provider
  - types of drugs and their effects, and the nature of addiction and dependency
  - arrangements for maintaining confidentiality, referral
  - opening times, childcare facilities, what to do if appointments are unsuitable or missed
  - services available from other providers and how to access them
- ✓ **Training for staff.** This should be designed to increase their knowledge and understanding of the impact of drug use on the family and to ensure that they have the skills to help them recognise and respond appropriately to the sensitivities of those seeking support. In particular it is vital to ensure that staff do not display what can be perceived as negative attitudes to families of drug users or indeed the drug user. Such attitudes often heighten the guilt, embarrassment and stress that families and carers experience and can prevent them from seeking support. As noted above, **there may be scope for joint training with other agencies and with members of family support groups.**

- ✓ **Consult with families and carers about how support can meet their needs.** The support needs of families and carers, and of individual family members, are complex and vary over time. Agencies and service providers should **carry out an ongoing dialogue** with families and carers to identify the range of needs and obtain the families' views on the kind of support that they want.
- ✓ **Consider involving families and carers in providing support.** There is clear evidence that support given by people who have faced similar circumstances can be highly beneficial to families and carers. There are also a number of examples of family support group members developing new methods of providing support to others and, in addition, enhancing their own level of personal skills.
- ✓ **Work with others who provide support.** By doing so, agencies and service providers will gain a wider knowledge of what **other methods of support exist in local areas, who offers it and how to refer families and carers on.** It can also mean that information, practice and resources can be shared to maximise their benefits. By working with others, there can be opportunities to develop support methods that may otherwise be difficult for one single support provider to achieve. This could include respite, advocacy, counselling, and financial advice

Specific areas where **joint working arrangements and procedures** can help to ensure effective support are:

- joint training where there are common training needs for staff
  - communication and liaison arrangements between statutory, voluntary and community agencies such as local family support groups.
- ✓ **Ensure practice is consistent by** developing clear policies, guidelines and standards of practice
  - ✓ **Constantly monitor and evaluate practice** in order that best practice is developed. Agencies should be open to change and seek to identify ways in which support could be strengthened. The setting of clear aims and objectives is essential for evaluation. The EIU Evaluation Guides are available at <http://www.drugmisuse.isdscotland.org/goodpractice/effectiveunit.htm>.

### 3. Issues for family support groups

- ✓ **Setting clear aims and objectives.** While family support groups have a core aim of supporting family members, some groups extend their remit: for example to include lobbying for treatment services, providing practical support with transport or childcare. It is crucial that the aims and objectives are **agreed and clearly understood by the members.** They should also be clearly communicated to the DAT, agencies and professionals who may seek to engage with the group.
- ✓ **Engage with DATs.** Engagement is a two-way process. Family Support groups should capitalise on opportunities for engagement with the DAT, whether through the Drug Forum or other community engagement initiatives.

- ✓ **Engaging with agencies and service providers.** It is important to forge links with “professionals” who may be able to offer support in finding sources of funding, accommodation and establishing organisational structures. Above all, there are major benefits for the groups and for family members and carers in **creating channels for the exchange of information.** Family Support Groups have a potentially valuable contribution to make to the assessment of needs by the DAT and to the shaping of service provision. They may also be able to take on a “volunteer “ support role for families working with agencies.
- ✓ **Work with others.** Families and carers can benefit from access to a wider range of support e.g. stress management, complementary therapies. Family Support Groups could work with agencies or other community groups to share knowledge of other types of services and collaborate in providing them.
- ✓ **Making support accessible.** Accommodation has to be appropriate the needs of families as well as easy to access in terms of **location and timing.** Common venues for meetings such as schools and health clinics may be seen by family members – initially at least - as too closely associated with agencies who are potentially threatening ( e.g. where there are children involved). Premises should be **neutral and able to offer anonymity.**
- ✓ **Financial support.** Members of family support groups often find themselves meeting the costs of transport, telephone and administrative costs. This is an issue where they should consider approaching the DAT and other agencies to negotiate some level of funding to help to achieve their **stated aims and objectives.**
- ✓ **Developing training.** Family support groups offer a range of support and this may include one-to-one support and counselling. There is a need to consider what type of training may be necessary to ensure that members are **equipped to deal with sensitive and difficult issues** that may arise. There are also training needs associated with organisational and administrative functions as groups become constituted and start to manage funding. DATs may be a source of advice about training opportunities.
- ✓ **Providing information.** Families and carers need good information about the nature of drug misuse and its effects on the individual. They also want information about types of treatment and what is available in their area. Family support groups have an important role in providing **reliable information.** DATs and agencies should be able to help with sources of information and may be willing to come along and talk to groups directly.
- ✓ **Monitoring and Evaluation.** This is equally as important for family support groups as for DATS and agencies. It is crucial that groups can demonstrate that their services are relevant and meeting the aims and objectives that they have agreed. This matters for the groups themselves so that they can improve their services where necessary; and so that they can demonstrate to DATS and other agencies that they are providing effective support. The EIU Evaluation Guides offer a useful resource in a user friendly format on the key aspects of designing and carrying out an evaluation. The Guides are available at <http://www.drugmisuse.isdscotland.org/goodpractice/effectiveunit.htm>.

## CHAPTER 9: RESOURCES

### INFORMATION FOR FAMILIES:

**ADFAM** produce a range of information for families and for family support groups, they also provide a range of training and consultancy packages.

**Contact 020 7928 8900**

[www.adfam.org.uk](http://www.adfam.org.uk)

#### **Living With A Drug User – For the Partners of Drug Users**

The booklet is designed to help drug users and also their partners think about positive ways of helping themselves or partners in tackling substance misuse.

#### **Living with a Drug User – For the Parents of Drug Users**

This booklet aims to help parents think of positive ways of helping their drug user and coping with the situation themselves. It contains more comprehensive information on: 'understanding drug use', 'communication', 'what help is available' and 'what if they continue using drugs'.

**(This booklet is also available in Bengali)**

#### **Prisons, Drugs and You – A booklet for the families and friends of prisoners**

This booklet for families and friends of imprisoned drug users contains practical information and useful suggestions for coping with drugs and imprisonment. It also suggests positive ways that families can help themselves and support their drug-using prisoner.

#### **Are you worried about your mum, dad or carer using drugs or alcohol**

The booklet is designed for children to assist them in understanding more about drug use, what you can do to help themselves and their guardian/parent

**LIFELINE** - produces publications specifically aimed at parents of young people who may be using illicit drugs. The leaflets are designed to expose commonly believed myths and provide accurate information on drug use.

**Contact: 0161 839 2054**

[www.lifeline.org.uk](http://www.lifeline.org.uk)

#### **Drug Myths – A Parent's Guide**

A guide to parents to the common myths around drug use which can lead to fear and misunderstanding.

#### **Drug Facts – A Parent's Guide**

A guide to parents about different types of drugs, their street names, the long term effects, the risks involved in taking them and legality. It also provides information on what can you do as a parent and where to go for help.

**The South Asian Community and Drugs (Urdu)**  
**The South Asian Community and Drugs (Bengali)**

Written in English, Urdu and Bengali these illustrated guides provide information on drugs and drug use specifically aimed at the South Asian community.

**HEBS – Health Education Board for Scotland**

**Contact: 0131 536 5500**

[www.hebs.co.uk](http://www.hebs.co.uk)

HEBS aims to ensure that people have adequate information about health and factors which influence it. In terms of drug misuse, the website offers information on substance abuse through various articles, library journals and statistics. The website also provides contact address and numbers of support groups all over Scotland and informs the public of health promotional projects related on drug misuse. HEBS produced the document **The Facts About Drugs: A Parent's Guide**. It is a very popular and easily understood guide for parents listing commonly-misused drugs, legal information, first-aid advice and where to go to for help.

**KNOW THE SCORE**

**0800 587 5879**

[www.knowthescore.info](http://www.knowthescore.info)

Know the Score is the Scottish Executive's Drugs Communications Strategy providing the public with information and advice on drugs issues. The initiative operates the following functions:

- media campaigns
- website
- an information line
- produces drugs information materials

The web site contains information for everyone from young people and parents, who simply want the facts about drugs, to those who might be looking for more detailed advice about the potential harmful effects of drugs misuse. As well as clearly sign-posting you to a range of useful information, the Know the Score web site gives the opportunity to find out what is being done to tackle the harm caused by drug use across Scotland.

**SAD – Scotland Against Drugs**

**Contact: 0141 331 6150**

[www.scotlandagainstdrugs.org.uk](http://www.scotlandagainstdrugs.org.uk)

Scotland Against Drugs operate a range of funding programmes, produces information, develops media campaigns and operates a website. The aim of SAD is to help prevent drug misuse and its consequences impacting on local communities in Scotland:

### **Families Anonymous**

**Contact: 0845 1200 660**

[www.famanon.org.uk](http://www.famanon.org.uk)

Families Anonymous provide a **Helpline service** which operates 24 hours a day providing support and information regarding support in the caller's area. In addition to this they provide assistance in **setting up groups** locally, along with **information resources** for families and those working with the families of drug users.

### **Glasgow Association of Family Support Groups (GAFSG)**

**Contact: 0141 420 2050**

As well as providing a number of services locally, they also provide a **telephone service** which is used by people throughout Scotland. Callers can gain information and support from staff and volunteers, who are often family members who have faced similar difficulties and experiences. GAFSG also have a number of support groups from throughout Scotland affiliated to them and can **inform callers of their nearest support group**, meeting times etc.

## **INFORMATION FOR FAMILY SUPPORT GROUPS AND THOSE SUPPORTING FAMILIES**

**ADFAM** (see 'Information for families for contact details)

### **A Guide to setting up a family/friends support group**

A comprehensive guide containing initial methods for:

- identifying needs,
- establishing a family support group
- management of a family support group
- dealing with difficulties in the group.
- working with professionals
- fundraising

### **Working with drug family support groups** (Paul Lockley, isbn 1-85343-337-3)

The resource includes:

- defining and planning support
- facilitating support groups
- keeping groups going
- specific areas of work



## **PADA**

**Contact 0151 356 1996**

[www.btinternet.com/~padahelp/](http://www.btinternet.com/~padahelp/)

PADA operate a 24 hour helpline service for family members. Family support groups from throughout the UK can arrange to link into this service through a call divert arrangement (contact PADA for further details)

PADA can provide support groups with help and advice regarding becoming established, obtaining charitable status etc.

## **Glasgow Association of Family Support Groups (GAFSG)**

(see information for families for contact details)

GAFSG can provide assistance with becoming established, committees, constitutions etc. Also can provide peer support to maintain motivation and helpful hints.

## **TRAINING FOR THOSE PROVIDING SUPPORT TO FAMILIES AND CARERS:**

**PADA** run a volunteer training package for volunteers supporting families and friends of drug users. The training is accredited by the Open College. Content includes:

- history of drug use
- knowledge about drugs
- understanding different types of drug use, addiction and dependence
- signs and symptoms of drug use
- understanding adolescence and risk taking
- helping and support skills

**ADFAM** run a range of training packages for those involved in supporting families and carers:

- setting up a helpline
- setting up a family support group
- drugs and the family (for drug workers)
- families and the community
- training the trainer
- communication skills
- family dynamics and conflict resolution

Training can also be tailored to individual needs. Adfam also offer consultancy work to policy makers, practitioners and grassroots groups

## **HIT**

**Contact: 020 8533 9563**

[www.hit.org.uk](http://www.hit.org.uk)

HIT provide a wide range of publications, training course and other services. Training with regards to those supporting families covers:

- attitudes towards parenting and young people's drug use
- current research
- ways of working with parents
- available resources

### **Scottish Training on Drugs and Alcohol (STRADA)**

**Contact: 0141 330 2335**

[www.projectstrada.org](http://www.projectstrada.org)

STRADA provide training throughout Scotland to drug workers, health and social workers, and voluntary groups. They offer a range of courses including:

- Children and families affected by problem drug use
- Understanding drug and alcohol issues
- Young people: drugs and alcohol
- Blood borne viruses

They also offer a Certificate in Addictions course.

### **Scottish Drugs Forum (SDF)**

SDF is an umbrella organisation for workers and agencies which aims to provide a link between drug service users, agencies and policy makers. It aims to promote best practice and offers a range of services including research and consultancy, information and advice. A further aspect of SDF's work is around 'community engagement'. SDF offer a range of support including:

- capacity building, support and networking for existing community groups
- training for community groups
- specific community engagement work
- information and advice to existing groups
- development of a toolkit for drug action teams.

### **FUNDING SOURCES:**

#### **Drug Action Teams**

**Contact details are provided in Appendix 2**

Drug Action Teams are a good first source of financial support as they often manage monies distributed by The Scottish Executive and co-ordinate developments within their specific areas.

### **Scotland Against Drugs - SAD**

**Contact: 0141 331 6150**

[www.scotlandagainstdrugs.org.uk](http://www.scotlandagainstdrugs.org.uk)

SDA operate the 'Communities Programme' which aims to assist in establishing community based initiatives to respond to drug issues. The Community Programme aims to:

- provide practical support and advice to community groups and organisations in planning new initiatives by contributing, as appropriate, to local events, workshops and meetings with groups and agencies;
- provide financial support to community groups and organisations for significant new initiatives and innovative projects to enable local people to identify solutions to drug misuse and develop projects appropriate to local needs.

### **Lloyds TSB - Partnership Drugs Initiative (PDI)**

**Contact: 0870 902 1201**

[www.ltsbfoundationforscotland.org.uk](http://www.ltsbfoundationforscotland.org.uk)

The programme is run in partnership with the Scottish Executive, charitable organisations and local Drug Action Teams. It aims to promote work with vulnerable young people and children. The programme would be highly suitable for developing any work to support siblings and dependent children who may be in the care of a relative. Applications are prepared and submitted by local Drug Action Teams in partnership with voluntary organisations and awards are made directly to the voluntary organisation (recognised charitable organisations only). PDI will fund up to 50% of the cost of the proposal with the DAT identifying the remainder.

Lloyds TSB also run a programme of Capacity Building Grants. This programme provides organisations with funding to obtain expert advice in areas such as financial management, fundraising, information technology, marketing, strategic planning and staff development.

### **National Lottery**

**Contact: 0845 600 2040**

[www.awardsforall.org.uk/scotland](http://www.awardsforall.org.uk/scotland)

Awards for All is a small grant scheme that funds community groups and initiatives. The aim of the scheme is to fund projects which bring people together in their community, improve their quality of life and increase their involvement, through activities etc. Funding amounts range from £500 to £500. Applications can be made at any time and decisions of an award are made quickly.

### **Changing Children's Services Fund: Scottish Executive**

**Contact local DAT for details**

The Changing Children's Services Fund - £80m over 2002-04 - is aimed at providing funding to help local authorities, the NHS and the voluntary sector to re-orientate and better integrate children's services. It includes a strand aimed specifically at children and young people affected by drug misuse, either their own or their parents - £6 million a year for 3 years. This fund has enabled a broad range of new and enhanced services for children to come on stream, including substance misuse. Applications must be approved by the local Drug Action Team and involve a range of partner agencies.

## **Social Inclusion Partnerships (SIPs)**

SIPs are local forums made up of statutory and voluntary representatives from throughout their local community. Representation also includes the private sector. SIPs aim to act as local managers to develop strategies to address social exclusion and fund locally based projects. The Scottish Executive has allocated funds to SIPs to specifically address drug misuse in their communities. Several family support services have been established from receiving SIP funding.

A useful source of information regarding SIPs is the Scottish Council for Voluntary Organisations (SCVO), which has a web site explaining what SIPs are and where they exist.

### **SCVO**

**Contact: 0141 221 0030 / 0131 556 3882**

[www.scvo.org.uk/sip/about/abt\\_sips.htm](http://www.scvo.org.uk/sip/about/abt_sips.htm)

## **Appendix 1**

### **Reference group membership:**

Isabel Berry, Open Hands Family Support Group

Gordon Costa, Falkirk Council

Ray de Souza, Edinburgh City Council Social Work

Susan Green, Glasgow City Council Social Work

Jim Harrigan, Glasgow Association of Family Support Groups

Lis Hill, Tayside Alcohol and Drug Alliance

John Irvine, Monklands Family Support Group

Jackie Johnstone, Bo'ness Hope Project

Dr Brian Kidd, Forth Valley Community Alcohol and Drugs Service

Davy Macdonald, Effective Interventions Unit

Katy McTiernan, Edinburgh Family Support Network

Dr Kerry Milligan, General Practitioner in Glasgow

Patricia Russell, Effective interventions Unit

## Appendix 2

### DAT Contacts – Drug Development Officers

#### Aberdeen City DAT:

Kay Geddes  
Tel: 01224 523011  
Email: [kgeddes@commdev.aberdeen.net.uk](mailto:kgeddes@commdev.aberdeen.net.uk)

#### Aberdeenshire DAAT:

Grace Ball  
Tel: 01224 558515  
Email: [grace.ball@ghb.grampian.scot.nhs.uk](mailto:grace.ball@ghb.grampian.scot.nhs.uk)

#### Angus DAAAT:

Iain Turnbull  
Tel: 01307 461460  
Email: [turnbullid@angus.gov.uk](mailto:turnbullid@angus.gov.uk)

#### Argyll and Clyde ADAT:

Donna Reid  
Tel: 0141 8427210  
Email: [donna.reid@achb.scot.nhs.uk](mailto:donna.reid@achb.scot.nhs.uk)

#### Ayrshire and Arran ADAT:

Sharon Hackney  
Tel: 01563 851338  
Email: [sharon.hackney@aapct.scot.nhs.uk](mailto:sharon.hackney@aapct.scot.nhs.uk)

#### Borders DAAT:

Julie Murray  
Tel: 01896 825500  
Email: [julie.murray@borders.scot.nhs.uk](mailto:julie.murray@borders.scot.nhs.uk)

#### Dumfries and Galloway DAAT:

Tel: 01387 272711

#### Dundee DAAAT:

Tel: 01382 596979  
Email: [jessie.stewart@tpct.scot.nhs.uk](mailto:jessie.stewart@tpct.scot.nhs.uk)

#### East Lothian DAAT:

Hazel Morrell  
Tel: 01620 827375  
Email: [hmorell@eastlothian.gov.uk](mailto:hmorell@eastlothian.gov.uk)

**Edinburgh City DAT:**

Tel: 0131 5538364

Email: [ray.desouza@edinburgh.gov.uk](mailto:ray.desouza@edinburgh.gov.uk)

**Fife DAAT:**

Eric Corstorphine

Tel: 01592 412008

Email: [eric.corstorphine@fife.gov.uk](mailto:eric.corstorphine@fife.gov.uk)

**Forth Valley SAT:**

Marion Logan

Tel: 01786 457288

Email: [marion.logan@fvhb.scot.nhs.uk](mailto:marion.logan@fvhb.scot.nhs.uk)

**Greater Glasgow:**

Margaret Walker

Tel: 0141 2014877

Email: [margaret.walker@glasgow-hb.scot.nhs.uk](mailto:margaret.walker@glasgow-hb.scot.nhs.uk)

**Highlands DAAT:**

Brian Gardner

Tel: 01463 717123

Email: [brian.gardner.hhb.scot.nhs.uk](mailto:brian.gardner.hhb.scot.nhs.uk)

**Lanarkshire DAAT:**

Alison Paterson

Tel: 01698 332558

Email: [patersona@northlan.gov.uk](mailto:patersona@northlan.gov.uk)

**Midlothian DAAT:**

Liz Coates

Tel: 0131 2713680

Email: [liz.coates@midlothian.gov.uk](mailto:liz.coates@midlothian.gov.uk)

**Moray DAAT:**

Tish Carter

Tel: 01343 552211

Email: [tish.carter@comm.moray.gov.uk](mailto:tish.carter@comm.moray.gov.uk)

**Orkney DAAT:**

Karyn Tait

Tel: 01856 870690

Email: [karyn.tait@orkney-hb.scot.nhs.uk](mailto:karyn.tait@orkney-hb.scot.nhs.uk)

**Shetland DAAT:**

Catriona Oxley  
Tel: 01595 743003  
Email: [catriona.oxley@shb.shetland.scot.nhs.uk](mailto:catriona.oxley@shb.shetland.scot.nhs.uk)

**Tayside DAAAT:**

Lis Hill  
Tel: 01382 596979  
Email: [lis.hill@tpct.acot.nhs.uk](mailto:lis.hill@tpct.acot.nhs.uk)

**Western Isles ADSAT:**

Angus Mackay  
Tel: 01851 702712  
Email: [angustolsta@hotmail.com](mailto:angustolsta@hotmail.com)

**West Lothian DAAT:**

Catherine Evans  
Tel: 01506 774082  
Email: [catherine.evans@westlothian.gov.uk](mailto:catherine.evans@westlothian.gov.uk)



## Appendix 3

### EIU Literature Review - Support for the Families of Drug Users

This review was conducted by The Centre for Research on Families and Relationships at the University of Edinburgh. The full report is available as an EIU research report and is also available by visiting the EIU website.

[www.isdscotland.org/goodpractice/effectiveunit.htm](http://www.isdscotland.org/goodpractice/effectiveunit.htm)

#### Executive Summary

It is now increasingly recognised that drug abuse affects the whole family and wider kin. There is a growing concern about the needs of families affected by drug use and the best ways of meeting those needs.

A literature search and review was conducted using standard bibliographic search procedures in order to:

- establish what is known about the support needs of families of drug users
- establish what is known about effective ways of addressing those needs
- examine whether, and how, family support groups and services link with other services
- examine whether involving families within the treatment or service offered to the drug user has beneficial effects upon the family and the drug user

Studies were typified as focussing on *needs* or experiences of families of drug users; *descriptive* studies outlining particular interventions or services; *evaluative* studies that assessed the impact of interventions or services; *policy/professional guidance* literature aimed at improving professional practice; and *grey* literature. Although 104 articles were found and reviewed, there was little literature that directly related to the needs of families of drug users or how those needs might best be met.

Effects of drug use on family members include: depression; adjustment and behavioural disorder; deterioration in family relationships; increased likelihood of domestic violence; criminal behaviour; isolation; withdrawal; stigma; and concealment. Although some of these effects are reported in research on alcohol abuse, it is important to recognise the diversity of substance abuse and its effects, and explore differences between different substances.

'The family' is often treated as a single unit, although some studies have shown that different family members have different experiences and perceptions depending on their relationship to the drug user. A concern for the child is prominent, and the emotional and behavioural effects of parental drug use are documented. Some children play a caring role in their families. Other research focuses on parenting, although this is almost exclusively on mothers, whether or not they are drug users themselves. Isolation may be a barrier to seeking support and the families of drug users, especially grandparents, are a hidden population.

Coping styles have been identified, such as toleration, engagement and withdrawal. These may relate to different family members and change over time. Coping styles may influence support sought or the nature of the service provided. Most interventions aim to change family dynamics, but there is little reflection in the studies reviewed about what family characteristics or types are important.

A range of supports are described in different studies, although these are seldom generalisable. Although some research identified significant improvement in a person's substance abuse problem and in other measures relating to the family, most improvement was small, and sometimes there was none at all. However, support for parenting seemed to be rated highly by service users, and wraparound services similarly had some positive outcomes. Many services described support for family caregivers, though these were most commonly aimed at mothers or partners. Group or individual interventions may have beneficial effects in different areas of a caregiver's life.

There is almost a complete absence of documentation and research into family support groups. What there is suggests they are effectively in addressing some family issues. Their family focus balances out the priorities of intensive interventions, which tend to prioritise the needs of the user rather than the family. The support needs of grandparents are little documented, although there may often continue to be a parenting role for both their children and grandchildren.

The involvement of family members in treatment programmes has been shown to improve their effectiveness as regards positive outcomes for the substance abuser. There is less research on possible improvement in families themselves. Interventions where the primary focus was on support of the families per se were less common. This reflects the service based focus of many of the studies; it is possible that interventions which develop from family support groups may be oriented more around the family as a whole and less around the behaviour of the drug users, but they are not reported in the literature. Evaluations of unilateral interventions are rare, although such interventions do not directly involve the drug user.

This review of the literature on support for families of drug users suggests that although there is a wide diversity of articles, these are most often descriptive pieces about service provision and development; most of the evaluation studies reviewed fall short of the established methodological criteria for establishing rigour. There was seldom a direct link between assessment of need and service provision, although that may have taken place at an informal level as part of service delivery.

- In terms of establishing what is known about the support needs of families of drug users, the review suggests that the diverse needs of all family members are not well documented, especially those of wide kin such as grandparents but also of siblings.
- In trying to establish what is known about effective ways of addressing those needs, this review suggests that the match between service provision and need is not always explicitly derived from a needs assessment that prioritises users' own views.
- The review could shed only limited light on whether or how family support groups and services link with other services, as few articles reported on the work of family support groups, neither did they take a holistic view of the range of services an individual or family may be accessing.
- In terms of whether involving families within the treatment or service offered to the drug user has beneficial effects upon the family and the drug user, the review suggests some beneficial effects upon the drug user and to a more limited extent upon the family.

## Appendix 4

### EIU Qualitative Study

The EIU commissioned a qualitative study aimed at eliciting the views and experiences of families affected by a relative's drug use and also of those who provide support. The study was conducted by Marion Fisher Associates. Copies of the study are available on request from EIU.

#### **Executive summary**

The aim of this study is to elicit the views, attitudes and experiences of families affected by drug use and the providers of family support, to identify the needs of family members and the most effective methods of support. The study addresses a number of key areas: issues for family members; issues for support agencies; issues for drug users. The research also looked at issues facing families affected by HIV/Hepatitis.

The geographical spread of the research was determined by the Scottish Executive and a wide range of consultees were contacted. A combination of focus groups and one to one interviews were conducted with the issue groups.

The response from families to the consultation process was high and resulted in 50% more focus groups being held than was intended.

Families tended to describe the impact of drug use in the family in terms of the internal and external impacts. Internal impacts include how families feel about themselves and the drug user. This included feelings of guilt and stigmatisation by the community. External impacts included the financial costs incurred both by the loss of property, often stolen by the drug user and costs for care and rehabilitation.

Support provided by family support groups was seen as very valuable and ranged from help with childcare to active prevention work. Some groups/family members were critical of the professional support which they received with reasons ranging from the attitudes of professionals to the lack of knowledge about drug users behaviour and the effect this has on families.

Whilst families were generally against closer integration of services for families and drug users some did feel that joint work on relationship building and anger management would help them deal more effectively with the problems.

The knowledge of families and family members about the services available to support them seemed to be at odds with the views of professionals about what is available.

Interviews with individual family members raised many similar issues to those highlighted by family support groups. However the feeling of isolation seemed to be more acute than for those supported by other affected families. Some of these issues were brought more sharply into focus by families looking after the children of their drug using family members. Many grandparents said that there was no available support but this has to be balanced against the fact that many said they did not have enough knowledge about where to go for support. Financial costs were also highlighted in relation to the drug user and to looking after their grandchildren. They also pointed out that other family members feel rejected and that all the family's emotional and financial resources are directed towards the drug user.

For families affected by HIV/Hepatitis the impact on families is understandably focussed around specific health and attitudinal issues together with significant emotional distress

and anxiety about loss and bereavement. Isolation and loss of social contacts and friend also features highly for those affected by Hepatitis and HIV. Specialist support services were well thought of but it must be acknowledged that there are not many of these around and that the groups consulted do have access to what is available.

A clearer understanding of the disease and the treatments available would be beneficial. Also training in stress management and counselling including bereavement counselling would be beneficial. Some families also felt that they would benefit from help on how to support others within the family. All felt that joint work would be beneficial to families and the affected person. Agencies supporting families including medical services were broadly in agreement with the views of families.

There are specific issues around access to services for Ethnic minority families which include the thin spread of specialist services, and language and cultural issues.

The difficulties expressed by Family Support Development Workers in working with families are family support services are often poorly funded or funded on a short term basis. The funding available often does not allow for all the needs which families present with and premises are often not appropriate for the needs presented e.g. often no crèche facilities. They felt that there is a wide range of practical, emotional and professional support available to all family members. Existing service providers are overstretched and young carers may be an under served group.

Service providers felt that there was a significant range of services available to families. As previously stated, this is at odds with the views of families. Many service providers felt the advantage of working with families is that it allows them to develop a clearer, more objective understanding of what is happening to them, including a better understanding of the nature and manifestations of drug using behaviour. This can be essential when difficult decisions have to be made about the service offered to the drug user. By so doing this can help to bring a consistent approach to working with the drug user.

Social Workers highlighted that a major barrier in engagement with families was their statutory role within child care and the suspicion that caused. Other difficulties were reported – sexual abuse, stealing, with second generation drug users.

In looking at improvement of service to families, G.P.s felt that training of professional staff, plus a team approach would help. They also felt that a Family Needs Assessment should be commissioned.

Drug users are clear that their use has significant impacts on their relationships with their parents, their siblings and their own children. Some drug users were able to articulate that their drug use created inconsistent responses in relation to their children – sometimes spoiling them and at other times neglecting them. Generally the attitudes of many professional to the drug user and to their children were seen as a barrier to securing support.

## Appendix 5

### Family Support Scotland Conference

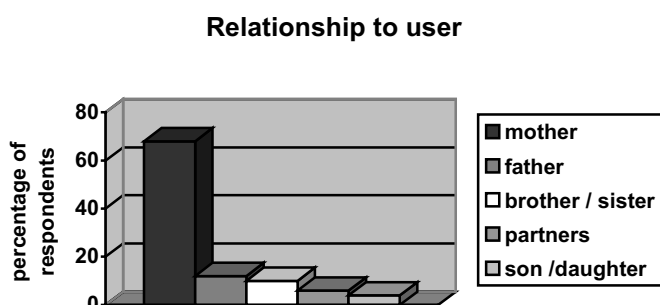
#### Summary of Survey Responses

The aim of the survey is to provide data for the current work that is being conducted by the Effective Interventions Unit into 'family support'. The questionnaire was designed by the EIU with assistance from the Conference Steering Group whose input was greatly appreciated.

The questionnaire was designed to gather family members experiences of coping with drug use, identify how it impacted on their lives, what support they had sought to assist them, and what their views were on the priorities of offering support to families.

The survey questionnaire was completed by 51 participants during the course of the conference out of a total of 67 attendees. The exercise was voluntary and a number of people chose not to complete the questionnaire. The primary reason given was that it was too emotionally painful. Further, some attendees at the conference were workers within family support, rather than individuals coping with a family members' drug use.

It is worth remembering that all respondents were active within family support groups and that this reflects their views and not those of family members' outwith family support groups.



Of the completed forms returned, the majority were mothers of drug users.

This reflects current evidence that suggests that fathers are significantly less likely to seek support with regards to family drug use.

A third of respondents had the drug using relative living at home with the family on a frequent basis. A quarter had the drug using relative living at home with the family on an occasional basis. Almost half responded never having the drug using relative living with them.

Over three quarters of respondents stated that their physical health had suffered through coping with a relative's drug use.

Over half stated that other family members physical health had suffered.

The most frequently mentioned factors were:

- stress
- exhaustion
- heart problems

Three quarters of respondents stated that their emotional health had been affected significantly. Half of all respondents stated that other family members' emotional health had been affected significantly.

The most frequently mentioned factors were:

- depression
- nerves
- stress

Three quarters of all respondents stated that their relationship with their partner had been affected.

Responses varied from:

- affecting communication with partner
- frequent arguments
- divorce/separation

Almost all respondents stated that their relationship with immediate family members had been affected.

Many respondents stated:

- They felt they had neglected other family members through attention being given to the drug user.
- There was tension within the family through family members having a different understanding
- Communication between family members had been affected

Half of all respondents stated that their employment had been affected.

Respondents stated that:

- They were less confident within work
- They felt embarrassment through others being aware of their situation
- They suffered from an inability to concentrate on work
- They'd had to take time off work because of their health being affected by the stress of drug use or through caring for the drug user

Almost all respondents stated that their own financial position had been affected.

Over half of all respondents stated that drug use had affected other family members financially.

The main factors were

- Theft from the family home or from the person
- repayment of debts
- lending money to the drug user
- costs related to caring for dependants of drug users.

Over half of all respondents stated that their social life had been affected.

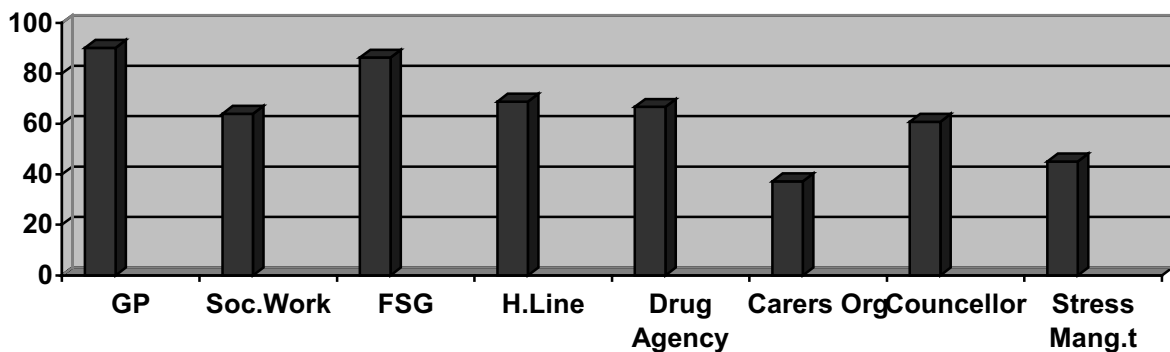
The main factors were:

- Concern over leaving the drug user at home
- care implications for dependants
- reduced self confidence
- lack of energy

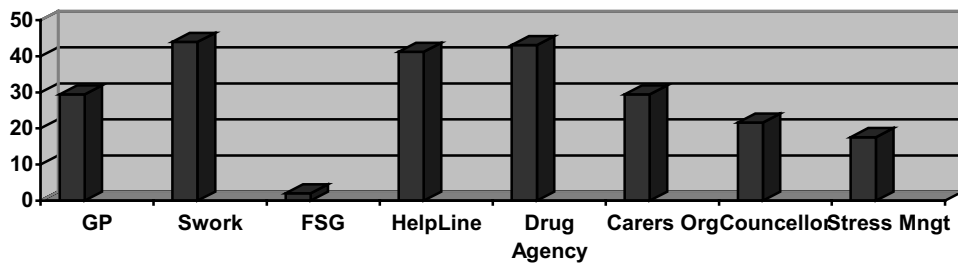
### Seeking Support

Respondents sought support from a wide range of agencies and services. They were asked to state whether the support they had received was: 'very unhelpful', 'unhelpful', 'helpful', or 'very helpful'.

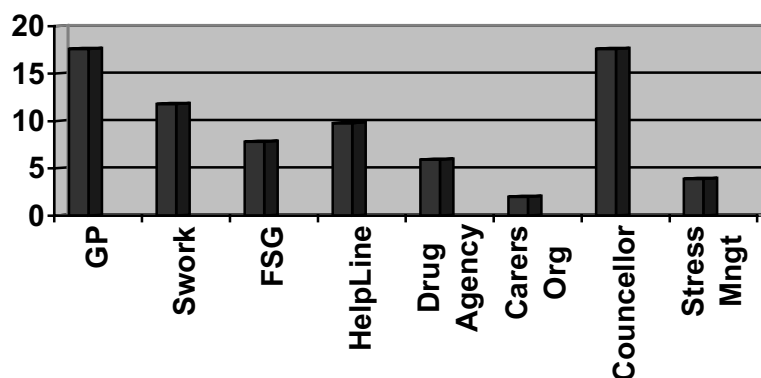
### WHERE PEOPLE SEEK SUPPORT



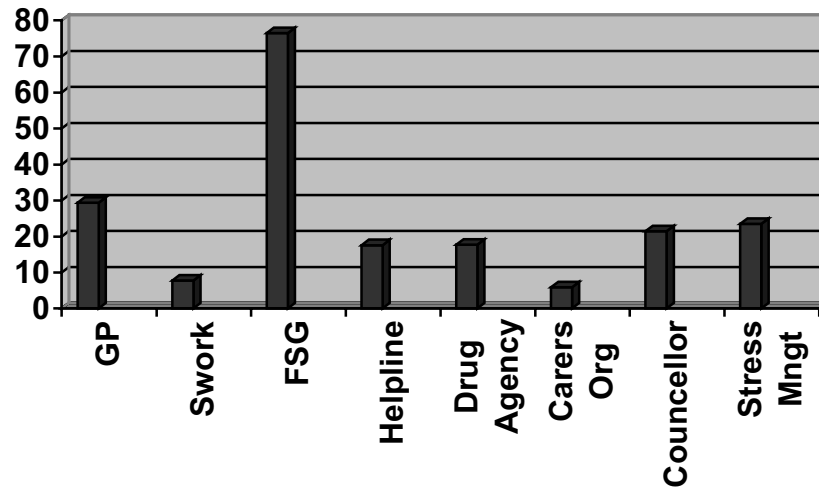
### SUPPORT VERY UNHELPFUL/UNHELPFUL



### NEITHER HELPFUL/UNHELPFUL



### SUPPORT HELPFUL/VERY HELPFUL



#### Useful skills and knowledge

Respondents prioritised what skills / knowledge they perceived as being useful for family members. The top four areas identified by respondents were

- 1 - drug treatments & services
- 2 - drugs & effects
- 3 - addiction & relapse
- 4 - support services within your area

#### Practical Support:

Respondents prioritised what practical support would be most useful to family members. The top five areas identified by respondents were

- 1 - advocacy
- 2 - befriending
- 3 - child care assistance
- 4 - alternative therapies
- 5 - respite

#### Emotional Support:

Respondents prioritised what emotional support would be most useful to family members. The top three areas were

- 1 - support group
- 2 - counselling
- 3 - helpline



## Appendix 6

### References

This list includes what is termed 'grey literature'. This includes unpublished literature and information taken from the Internet.

Aberlour Child Care Trust: Keeping it Quiet; Children and families in Greater Govan affected by parental drug use (2002)

ADFAM: A Guide to Setting Up a Family/Friends Support Group (2000)

ADFAM: Families in focus - Wales (2002)

Ayrshire and Arran NHS Trust: A Needs Assessment of Families and Carers of Drug and Alcohol Misusers in Ayrshire and Arran (2002)

Bancroft A, Carty A, Cunningham-Burley S, Backett-Millburn K: Support for the Families of Drug Users: A review of the literature (2002)

Effective Interventions Unit: Drug treatment services for young people (2002)

Effective Interventions Unit: Integrated Care for drug users; principles and practice (2002)

Family Support Scotland National Conference Report (2002)

Flemen K: Familiar drugs - working inclusively with families about drugs (2001)  
<http://www.release.org.uk/>

Hay, G., McKeganey, N., Hutchinson, S. Estimating the national and local prevalence of problem drug misuse in Scotland. Glasgow. University of Glasgow (2001)  
<http://www.drugmisuse.isdscotland.org/publications/local/Prevalence.pdf>

Kenny, Steve: There but for fortune: An investigation into the current role and working practices of community based parent and family substance misuse support groups (2000)

Labour force survey (1999)

C:\temp\Equality in Scotland Ethnic Minorities page 1.htm

Lockley, Paul: Working with drug family support groups (1995)

Ministerial Drugs Task Force: Meeting the Challenge (1994)

Orford J, Guillermina N, Davies J, Nava A, Mora J, Rigby K, Bradbury C, Bowie N, Copella A, Velleman R: Tolerate, engage or withdraw: a study of the structure of families coping with alcohol and drug problems in South West England and Mexico City; Research Report; Addiction (1998)

Orford J: Mental Health Foundation – Working with the Families of People with Alcohol and Drug Problems. Updates volume 1, issue 11 (1999)

Royal College of Psychiatrists: Changing minds (2001)  
<http://www.tcpsych.ac.uk>

Scottish Drugs Forum: Survey of community engagement (2001)

Scottish Drugs Forum: Where to get help – A directory of specialist drug services in Scotland (1999)

Scottish Executive: Communities and Drugs Taking Effective Action Conference (2001)

Scottish Executive: Getting our priorities right - Consultation Document (2001)

Scottish Health Advisory Service: Advocacy; A guide to good practice (1997)

Scottish Office: Tackling Drugs in Scotland - Action in Partnership (1999)

The University of Birmingham: Responding to alcohol and drug problems in the family; A guide for Primary Health Care Professionals Using a Five Step Approach (2000)

Velleman R: Family Interventions in Substance Misuse (2002)