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# Supporting adult family members of people with drug problems in Scotland

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- Action on Addiction
- SPODA, Derbyshire
- Families, Partners and Friends Service, CASA, Islington
- The Princess Royal Trust for Carers
- DrugScope
- Centre for Drug Misuse Research, University of Glasgow
- Scottish Government
- Welsh Assembly Government
- National Treatment Agency for Substance Misuse

# **Summary**

This report highlights some of the key issues that have emerged from a study commissioned by the UK Drug Policy Commission (UKDPC) to look at the extent and nature of support currently provided for adult family members affected by a relative's drug problem. This mapping exercise was part of a UK-wide project, but the findings presented here focus solely on the data collected relating to Scotland.

#### Why are adult family members important?

Problematic drug use affects many people besides the person using the drugs. Family members and close friends, for example, can experience significant stress and health problems as a result of being close to and concerned about the person with the drug problem. The impact can also spread more widely, for example affecting their employment, their social lives and relationships, and their finances.

But adult family members also often provide support to their drug-using relative and this has been shown to be important in three distinct but related ways:

- Preventing and/or influencing the course of the substance misuse problem;
- Improving substance-related outcomes (such as reduced substance misuse and relapse) for their drug-using relative, as well as promoting better engagement with treatment;
- Helping to reduce the negative effects of substance misuse problems on other family members.

Thus adult family members need services to meet their own needs but also to assist them to provide effective support to promote the recovery of their drug-using relative and to other family members.

However, adult family members affected by a relative's substance misuse have been largely hidden, partly due to concerns about stigma but also because their focus and that of much of policy has been first and foremost on helping the person with the drug problem. Nevertheless, earlier research for UKDPC estimated that in 2008 in Scotland, at the very least:

- 134,000 adults were significantly affected by a relative's drug use (including about 6,500 adult relatives of people in drug treatment);
- the cost of the harms they experienced was about £229 million per year; and
- the value of support they provided would cost about £95 million per year (at 2008 prices) if it was to be provided by health and social care providers.

This second phase of the research was carried out between March 2011 and January 2012 and aimed to describe the extent and nature of support provision for adult family members / carers of people experiencing drug problems to highlight gaps and good practice to help improve provision. It used a multi-method approach that included a review of 13 policy and guidance documents and eight ADP treatment plans; an on-line survey of service provision to which 72 services responded; and in-depth interviews with co-ordinators and providers in eight areas.<sup>1</sup>

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<sup>&</sup>lt;sup>1</sup> More details of the methodology and findings will be available in the full report.

#### Recognition of the support needs of adult family members

Over the last decade Scottish policy has clearly acknowledged the significant impact of substance misuse on children and families. *The Road to Recovery* includes over 100 mentions of 'families'. The impact on families is mentioned early on in the document and grandparent carers are specifically mentioned as a group of adult family members in need. This increased recognition of families is very welcome but there are still a number of ways that this can be improved.

For example, it is clear that 'families' usually refers to children of substance-using parents or what are often described as 'troubled families'. Clearly these are very important groups but recognition of the needs of and potential contribution of adult family members is also important. Similarly, there is little discussion of different sub-groups of family members who will have different needs, such as parents, spouses and siblings, nor of, for example, different ethnic groups. Where adult family members are mentioned this is more often in terms of involving them in treatment, with less recognition of their needs in their own right, and with little detail on what specifically should be provided. There is also little consideration of monitoring quality and the extent of provision. There is also a need for greater recognition of adults affected by a relative's substance misuse in strategies in related policy areas, eg criminal justice or domestic violence.

#### What support is being provided?

Of the 72 services that responded to the web survey:

- almost half (60%) were from the non-statutory sector, while NHS and social services each made up 14% of respondents;
- a third (66%) were part of a service for people with substance misuse problems, 13% a service solely for adult family members, 9% were part of a generic carers service;
- the majority (86%) worked with people affected by drug and/or alcohol problems;
- almost three quarters (71%) worked with families alongside their relative's with drug problems with 29% reporting that they worked with adult family members alone.

Further questions asked services that worked with families alongside drug users about the amount of time they spent working with family members alone and also with family members alongside drug users. In both cases, over half said they spent less than 10% of their time on both of these activities.

All services were asked about the number of staff including volunteers that they had and a quarter had less than five and a further quarter had five to nine employees.

The previous UKDPC research identified the need for five different types of support to adult family members, which were:

- Responses in non-specialist settings recognition of need, information, signposting, referral by GPs, prisons, carers services, on-line, leaflets etc.;
- Assessment of needs routine assessment of family relationships (including adults) in treatment services and carers assessments;

- Services to adult family members in their own right individual support (eg advice, respite, complementary therapies, OD training), group support and therapeutic interventions (such as counselling and specific evidence-based interventions like 5step);
- Engaging family members in services for drug users information provision, mediation
   advocacy, care planning/case conferences; and
- Intensive family-based therapeutic interventions, eg Behavioural Couples Therapy; Social Behaviour & Network Therapy; Family therapy etc.

The web survey asked about the types of interventions services provided both for adult members on their own and for family members and their drug-using relative together.

With respect to support for family members, information and signposting was common (93% of services reported providing it) with other general support, such as crisis support, advocacy, mentoring, social events and trips, also provided by over half the services (61%). However, there was less availability of therapeutic interventions, in particular structured interventions that have been shown to have an impact on family members' well-being, such as the 5-step method; only 17% of services said they provided these. Counselling was reported to be available at 47% of services and group support at 43%. Formal carers assessments, although not specifically prompted for in the question, were rarely mentioned (by only 1% of respondents) and this was also the case for overdose prevention or naloxone training (3%) and respite provision (1%).

There was greater use of therapeutic interventions within support for family members alongside their drug-using relative (47% of services reported that this was available) but a lot of this was unspecified family therapy (24%), with less mention of evidence-based interventions such as Social Behaviour and Network Therapy (14%) and Behavioural Couples Therapy (mentioned by only 6% of services).

Group work was reported by 18% of services with information and signposting and relationship counselling each mentioned by 12% of the sample. Other joint working support such as mediation, case conferencing, and involvement in care planning were mentioned by 7% of services.

#### **Improving service provision**

The in-depth look at eight Alcohol and Drug Partnership (ADP) areas identified a number of issues relating to provision for adult family members.

- 1. While ADP co-ordinators were concerned about adult family members they did not always recognise the need for both involvement in treatment and recovery of drug-using relatives <u>and</u> support for family members in their own right.
- 2. They did not always identify the need to provide a full range of services from identification and assessment; through support and advice; to therapies.
- 3. A number of barriers were identified
  - (a) Families don't come forward for a number of reasons, eg they do not see themselves as carers, they are concerned about stigma, and often they do not recognise their own needs.
  - (b) ADP co-ordinators may not prioritise adult family members because:
    - a lack of data on prevalence means the adequacy of provision is difficult to assess;

- they may be unclear about the range of services needed;
- there is no, or very limited, collection of data on numbers using services or outcomes against which to assess provision.
- (c) Specialist and generic workforce may not be aware of the needs of adult family members or feel that they have the skills to address them.
- (d) Treatment services may have concerns about service users' feelings about involving relatives in treatment.

There are a number of things that might help overcome some of these barriers and improve the provision available to family members. These include:

- **Promoting the evidence** both for what is needed and what works. Organisations such as SFAD have a role to play here. A more specific recognition of adult family members and their needs and contribution to recovery in policy and guidance documents across a range of areas would also contribute to this.
- Improving needs assessment. ADP strategies and action plans need to reflect the different sub-groups of adult family members, the range of different needs, and basic prevalence information. Involving family members in identifying needs and making use of available data eg information on the Scottish Drug Misuse Database (on living situation) and from the UKDPC estimates would assist this process. To identify 'hidden' groups of adults affected by a relative's drug problem specific data collection, eg a module on a household survey, could be considered.
- Developing targets and outcome assessment would provide a focus for evaluating levels of provision as well as demonstrating the value of these services and building the evidence base. The work of the Scottish Government on outcome indicators could be valuable in this respect.
- **Promoting the issues and services** to address stigma and lack of knowledge among affected family members. This might involve public events and the use of a wide range of media for delivering information and signposting.
- Workforce development, both specialist and generic, should aim to raise awareness
  of the needs of adult family members and provide training in evidence-based
  interventions to increase provision.
- **Integrating specialist and generic services** to increase the identification and assessment of adult family members and provide access to the full range of services through clear pathways and linkages.

In summary, there has been a welcome increase in attention to families affected by drug use, which has been facilitated by the *Road to Recovery* strategy. Considerable numbers of adult family members are affected by a relative's drug use; the impact on them is great and they also have an important role to play in supporting their relative's recovery. This study suggests that while there are good examples of service provision for adult family members affected by a relative's drug use in Scotland the quantity and range of provision is insufficient when considered alongside the numbers affected. However, it was clear from the interviews conducted that there is an interest in and appetite for improving provision and we hope that these research findings will help that process.

# 1. Background and methods used

Problematic drug use affects many people besides the person using the drugs. Family members and close friends, for example, can experience significant stress and health problems as a result of being close to and concerned about the person with the drug problem (e.g Ray et al, 2007; Orford et al, 2005). The ripple effect of a drug problem on others is significant. This work is concerned with adult family members of people with drug problems. This group includes anyone in a family relationship with the person using drugs, including partners, parents, siblings, grandparents and other adult relationships, such as uncles, aunts etc. Very close friends can often be similarly affected. Commonly, adult family members are concerned about the person using drugs and affected by the ripple effects and consequences resulting when drug use becomes a problem. This group is the focus of this report.

The impact of drug using parents on their children is, of course, also very great and potentially damaging. This is a very significant area of need, which recently has received much welcome attention in drug policy and services. The present work therefore aims to complement this by helping to identify the needs and experiences of adults affected by the drug problem of somebody else in the family setting, rather than to children similarly affected. In addition, given the focus of the work, less attention is given throughout the report to discussion of the people with the drug problem themselves. When a drug problem develops, a range of people are seriously affected and there is a need to develop ways of understanding the different impacts and experiences including those on the person using the drugs, on the adult family members as well as on the children within the family setting. The developments in 'recovery' focused treatment emphasise consideration of individuals in their social context as well as the role of social and recovery capital as central to the recovery process (e.g. Best et al, 2010) and hence increased understanding of the experiences of adult family members affected can help and enhance this work.

Whilst the harmful impact of drug (and alcohol) misuse on families is now recognised and accepted, less is known about the extent and nature of what is available to support adult family members (Copello and Orford, 2002; Barnard, 2007).

#### WHY IS IT IMPORTANT TO SUPPORT AND INVOLVE ADULT FAMILY MEMBERS?

While reducing the harms experienced by family members is reason enough for providing support services, there can be additional benefits to both the drug using relative, in supporting recovery, and to other family members. The role of close adult family members affected by a relative's drug use has been shown to be important in three distinct but related ways (e.g. Copello, Templeton and Velleman, 2006; Velleman et al, 2005; Best et al., 2010):

- Preventing and/or influencing the course of the substance misuse problem
- Improving substance-related outcomes (such as reduced drug use and relapse) for the drug using relative
- Helping to reduce the negative effects of substance misuse problems on other family members.

However, to realise this potential they need to be involved and supported. Therefore a comprehensive service response should address both this potential for helping the person who is using drugs as well as providing support to reduce harm for the family as a whole.

Strategies need to be developed with two aspects: firstly, ensuring treatment services are able to involve and support family members appropriately to maximise their contribution to recovery; and secondly providing a range of support options to meet the needs of the family members in their own right that are widely accessible and are not dependent on their relative accessing drug treatment.

#### How common is the experience? Prevalence and costs

The first phase of the UKDPC project sought to estimate the number of adult family members with a relative with an illegal drug problem in the UK and the cost of the harms experienced by these family members (Copello et al, 2009; UKDPC, 2009). Estimating the number of adult family members affected by someone with a drug problem in the family poses a number of challenges. Using available data from various sources and based on secondary analyses of these data, a method for estimating the prevalence of adult family members of people with drug problems in the treatment and general populations was developed. Applying this method across the UK suggested that in 2008 there were a minimum of 140,000 adult family members of drug users in treatment that were significantly affected and in need of support and that this figure increases tenfold when family members within the wider population of people with severe drug problems is considered across the UK.

More specifically in Scotland it was estimated that there is a minimum of 6,500 family members affected related to drug users in treatment services and the number increases to over 134,000 when the wider population of those with drug problems (including those not in treatment) are considered. This highlights the significant extent of the problem and, considering both drugs and alcohol, one can conclude that the chronic on-going stress resulting from having a relative with a substance misuse problem is one of the most common forms that adults are likely to experience (Caswell et al., 2011; Orford et al., 2005).

The costs involved are also significant and were explored as part of the UKDPC first phase work. Two types of costs were considered:

- costs relating to the health impact of drug use in the family on family members other than the person using drugs and the associated healthcare demands made by affected family members along with costs of lost employment, and of crime; and
- ii. information on the time and resources used by family members to support the relative using drugs.

Using these data, a model was developed in order to estimate: (a) the costs of the harms experienced by family members; and (b) the value of the support provided if this same level of support had to be provided by the NHS or local authorities.

Applying this model, it was estimated that in Scotland the costs of the harms experienced by adult family members affected by a relative's drug problems was about £229 million pounds per year while the value of the support they provided was about £95 million pounds per year (at 2008 prices).

#### METHODS USED IN THIS PHASE OF THE RESEARCH

In the light of the number of people affected and the extent of the harms they experience and the value of the contribution they can make, a second phase of work was undertaken to explore in more depth the way in which both policy and practice are recognising and providing a response to these highly prevalent needs. The overall aim of this phase was to describe the extent and nature of support provision for adult family members / carers of people experiencing drug problems to highlight gaps and good practice to help improve provision.

The approach taken was to go from national to local policy and provision, first exploring the extent to which specifically adult family members were identified in national policies and then whether this recognition of need was making an impact at the local level both in terms of local strategies and also service provision. Whilst this work was conducted across the UK, the contents of this report are focused on the results from Scotland.<sup>2</sup> A multi-method approach was used including:

- A review of policy and guidance. Thirteen documents from Scotland from six areas of policy were thematically reviewed.
- A web survey across the United Kingdom including 72 responses from Scottish services.
- An in-depth mapping exercise of current support provision in 8 areas in Scotland. This
  involved 37 interviews (8 Alcohol and Drug Partnership [ADP] coordinators and 29
  service providers and other key informants from those eight partnership areas).

This report presents the results in Scotland.

#### Review of policies and strategies

The approach taken by this review was informed by a paper which explored how drug and alcohol policy across the UK considers the needs of families (Velleman, 2010). The current review built on Velleman's work by, first, focusing on adult family members and illegal drugs and, secondly, by considering other areas of policy which most closely overlap with substance misuse. **The following six areas of policy were therefore considered**:

- Illegal drugs
- 2. Families and Carers
- 3. Children and Safeguarding
- 4. Domestic Abuse
- 5. Mental Health
- 6. Criminal Justice

The documents included in the review (listed in Appendix 1) were identified in a number of ways including: (i) documents identified through Velleman's review (Velleman, 2010); (ii) knowledge of members of the project research team; (iii) Google searches to check for the most recent documents in the policy areas and (iv) input from experts in each country, usually from individuals who were members of the Project Advisory Group.

<sup>&</sup>lt;sup>2</sup> The overall results for the UK from this second UKDPC phase can be found in three separate reports: Templeton and Copello (2012); Copello and Templeton (2012); and Copello, Templeton, Chohan and McCarthy (2012).

All documents included were collated using Excel. Hard copies and/or electronic copies of all documents were obtained for review. Analysis was broad and thematic. For electronic documents the search function was used to gauge the extent to which the issues were covered in each document and, for longer documents, to identify where exactly the issues were mentioned. So, for example, a document in the area of domestic abuse or mental health was searched to identify the extent to which issues of drugs/alcohol and/or families/carers were mentioned, while a drugs policy or strategy document was searched to identify the extent to which families/carers/children were mentioned<sup>3</sup>. Many of the shorter documents, or those which were obviously directly relevant, were read in more detail.

While a great deal of policy attention in Scotland has focused on the important issue of children affected by parental substance misuse, and on the role of parents in this regard, the focus of this review of policy was on the extent to which the needs of a wide range of **adult** family members have been considered.

#### Web survey of service provision

An online survey questionnaire<sup>4</sup> was developed by the Research Team in consultation with the UKDPC (with additional expert input from other members of the UK Alcohol, Drugs and the Family Research Group), and was piloted with two services known to the Research Team. The survey tool was designed and tested in February-March 2011 and the survey ran until July 2011, with a reminder circulated in June 2011. A copy of the survey questionnaire is shown in Appendix 2. In the absence of any comprehensive listing of services to act as a sampling frame the survey was advertised across the UK through a range of channels to try and reach as many different types of service as possible; by e-mail but also other forms of communication such as newsletters. Thus, the project was advertised through:

- DS Daily
- Adfam
- SFAD (Scottish Families Affected by Drugs)
- Scottish Drugs Forum
- Princess Royal Trust for Carers
- Professional networks of the UKDPC and the Research Team
- By members of the Project Advisory Group and their networks.

#### Qualitative study of eight Alcohol and Drug Partnership areas

Eight Alcohol and Drug Partnership (ADP) areas were the focus of a qualitative exploration of service provision. Areas for this in-depth study were selected, as far as it was feasible within the resources of the project, in order to represent a wide geographical spread as well as to include city, rural and semi-rural areas in Scotland.

A number of areas were identified in consultation with key informants from the Project Advisory Group and chosen to represent a range of different types of area. The final sample included: three cities, two semi-rural and three rural areas. The initial key informant for each

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<sup>&</sup>lt;sup>3</sup> The search strategy varied across the documents but these were the most common search terms used - families, carer(s), child(ren), drug(s), addiction, substance misuse/use/abuse, alcohol.

<sup>&</sup>lt;sup>4</sup> Using SurveyMonkey.

area in Scotland was the Alcohol and Drug Partnership (ADP) coordinator. For each area the ADP coordinator was identified, approached and interviewed by telephone. Towards the end of the interview, the ADP coordinator was asked to identify key informants from the service providers in the area and contacts for these were obtained. Service providers were then contacted and telephone interviews were organised. All eight ADP coordinators were interviewed. A total of 29 service provider interviews were conducted, which represented all but three of the services identified.

Therefore, the full interview set for each area included (i) the ADP coordinator and (ii) the service providers identified.

Given the absence of any definitive listing of services for family members of people with drug problems, it was not possible to establish whether we managed to elicit a full coverage of all services that came into contact or provided support for adult family members for each area. However, our interviews sought to prompt the ADP key informants in such a way as to elicit all of the range of services for adult family members within each area known to that key informant and also where possible we looked at web survey responses to identify any services that had not been identified through key informant interviews in the areas. In some instances, additional services were identified as part of the service provider interview process but this varied between areas. It is a fair assumption that the main services were covered with this method and difficulty identifying other services may reflect the fact that the latter may not be clearly visible also for people potentially needing access to these services in the area.

#### Interview content and procedure

Two interview schedules were developed one for coordinators and one for service providers. The full semi-structured interview schedules for coordinators and service providers can be seen in Appendix 3 of this report respectively. Once an area was selected the initial contact was made by a member of the study team with the ADP coordinator. Initial contact was made via e-mail which was followed-up after a day or two with a telephone call. ADP coordinators were sent the interview schedule in advance to the actual telephone interview. ADP coordinator interviews were transcribed in full whilst service provider interviews were written up in report form. Reports were produced shortly after the interview was conducted and followed a set of rules/parameters that involved the inclusion of verbatim quotes as well as a comprehensive description of the contents of the discussion.

#### **STRUCTURE OF THE REPORT**

The next chapter in this report outlines the findings of the reviews of national policies and local strategies. First national policies are explored and the extent to which adult family members are covered is discussed. Secondly local Alcohol and Drug Partnership (ADP) strategies of the eight areas selected for qualitative interview were are also reviewed in order to establish the extent of the influence of national on local strategies in relation to adult family members. Chapter 3 then discusses the perception and recognition of the problem and challenges associated with delivering support for adult family members from findings of qualitative interviews with the eight ADP coordinators. Chapter 4 then focuses specifically on the extent and nature of service provision by integrating findings from the web survey of service providers and qualitative interview sets in the eight ADP areas (including those with ADP coordinators and service providers). Finally conclusions and recommendations are presented as well as examples of positive approaches to the provision of support for family members that emerged from this work.

# 2. Coverage in policy and guidance

The aim of this part of the work was to review national and local policy and other guidance in order to assess the extent to which adult family members affected by a relative's drug use were identified, included, and the nature of the responses to their needs considered. As discussed earlier, the focus was on **adult family members or carers**, rather than children affected by a parent's substance use who have been the subject of other reviews such as Hidden Harm (ACMD, 2003), and on illegal drugs.

Thematic analysis considered three main issues, informed by the approach taken by Velleman (2010):

- Recognition-Acknowledgement of the issue, and of the impact of drug/substance misuse on families (and children).
- 2. **Involvement** Involvement, planning and delivery of families/carers in services, focusing on the engagement of family members alongside the drug misuser's treatment.
- 3. **Support** Treatment and support, with a particular focus on supporting adult family members in their own right.

In Scotland documents from both the previous Scottish Executive and the current Scottish Government were reviewed. In total 13 documents were included and are listed in Appendix 1. Many documents covered both drugs and alcohol; documents which considered alcohol only have not been included. Documents related to the Hidden Harm agenda were reviewed in less detail as their focus is towards children and their drug or alcohol using parents.

#### **NATIONAL DOCUMENTS**

Over the last decade or so Scottish policy has clearly acknowledged the significant impact of substance misuse on children and families. A considerable amount of attention has focused on the children of substance misusers and on the response needed in terms of child protection, safeguarding, and supporting these children and their parents – and this valuable work has made an important contribution to recognising and responding to the needs of these children. Scotland's response to Hidden Harm (Scottish Executive, 2004; 2006) and documents such as Getting our Priorities Right (GOPR - Scottish Executive, undated<sup>5</sup>), It's everyone's job to make sure I'm alright (Scottish Executive, 2002 – report of the Children Protection and Audit Review), and the Getting it Right for Every Child (GIRFEC) agenda have been central to progress in this area in Scotland. Acknowledgement of young carers and grandparent (or kinship) carers has been given but perhaps there has been limited broadening of policy to consider the needs of adult family members as a specific group. Table 1 summarises the key Scottish policies in this area and rates the extent to which each of the three main issues outlined above are considered using a three point scale where three indicates the highest level on each factor.

<sup>&</sup>lt;sup>5</sup> GOPR is currently being updated but no more information about this is available as yet.

Table 1: Coverage\* of adult family members within Scottish Policy documents

	Recognition	Involvement	Support
Caring Together (Scottish Govt, 2010)	<b>///</b>	<b>√√</b>	√√
Safer Lives (Scottish Govt, 2009)	<b>√</b> √	<b>√</b>	✓
Towards a Mentally Flourishing Scotland (Scottish Govt, 2009)	<b>√</b>	<b>√</b>	✓
Road to Recovery (Scottish Govt, 2008) & progress report	<b>/ / /</b>	<b>///</b>	<b>///</b>
National DA Delivery Plan (Scottish Govt, 2008)	<b>√</b> √	<b>√</b>	✓
Early Years Framework (Scottish Govt, 2008)	<b>√</b> √	✓	✓
Getting our Priorities Right (Scottish Exec, undated)	<b>√</b> √	<b>√</b>	<b>√</b>
It's everyone's job (Scottish Exec, 2002)	<b>√</b> √	<b>√</b>	✓
Crime Prevention Strategy for Scotland (ACPOS, undated)	<b>√</b>	<b>√</b>	✓

<sup>\*</sup>One tick indicates minimal or no coverage ( $\checkmark$ ); two ticks indicates some coverage but little detail ( $\checkmark\checkmark$ ); three ticks indicates a high level of coverage and/or specific detail about the issues ( $\checkmark\checkmark\checkmark$ ).

More recently there are indications that further progress is being made to give greater policy recognition to adult family members. The three key documents which are leading this development are *The Road to Recovery- a New Approach to Tackling Scotland's Drug Problem* (Scottish Government, 2008), *The Road to Recovery – One Year On* (Scottish Government, 2009a) and *Caring Together – The Carer's Strategy for Scotland 2010-2015* (Scottish Government, 2010).

The Road to Recovery (Scottish Government, 2008) includes over 100 mentions of 'families'. The impact on families is mentioned early on in the document and grandparent carers are specifically mentioned as a group of adult family members in need. One of the priority areas of the strategy is "supporting families affected by drug use" (page 8). Chapter 5 of the policy focuses on 'Getting it Right for Children in Substance Misusing Families', where the two following statements are given:

"build capacity, availability and quality of support services for children and families affected by parental substance misuse" (p49);

"strengthen the focus of adult substance misuse services on the needs of children and families by including relevant outcomes in the commissioning framework" (p52)

The document further promises to meet its aims in this area by continuing to support the Scottish Network for Families Affected by Drugs (SNFAD – now called Scottish Families Affected by Drugs or SFAD) and to support parents through the *Know the Score* campaign. There is limited detail beyond this as to how families will be supported, although it is important to recognise the limitations of a national document in terms of providing this level of detail as opposed to a more strategic statement of principle. However, the 2009 document on the progress (one year on) made with *The Road to Recovery* indicates that progress has been made and highlights six achievements which have been made in relation to families are listed:

- 1. Continuing to fund SNFAD;
- 2. Enhancing knowledge and awareness amongst BME families/communities;
- 3. Work in the area of overdose awareness and training for families;
- 4. Published a leaflet on overdose bereavement
- 5. Supporting kinship carers; and
- 6. Supporting young carers.

The document also indicates that there have been a number of other achievements in terms of supporting the children of substance misusing parents. It is encouraging that work in Scotland is considering specific groups of family members, such as families from black and minority ethnic groups and kinship carers, and particular issues with which families have to contend, such as overdose and bereavement. For example, in 2009 the Scottish Government published a booklet for the families and friends of someone who has died of a suspected overdose and is also supporting the roll-out of the National Naloxone Programme, which will include families, friends, carers and partners as well as drug users.<sup>6</sup>

There are several specific and important statements regarding carers of drug (and alcohol misusers) in Scotland's *Carer's Strategy* (Scottish Government, 2010). This document appears to go beyond the acknowledgement of the needs of this group of carers, and consider specific ways in which they could be supported. The particular role of Alcohol and Drug Partnerships is highlighted.

"There is scope for the Scottish Government to work with Alcohol and Drug Partnerships (ADPs) and with the new Scottish Drugs Recovery Consortium (SDRC) to promote the need for the identification of, and support to, carers of people with substance misuse problems. The Scottish Government expects ADPs to engage with all relevant aspects of community planning to help secure the best outcomes both for people with addiction problems and for their carers and families. The SDRC will be working closely with ADPs by assisting service user groups, family support networks and local communities. Carers of people with drug and alcohol problems can make an important contribution to the recovery of the people they are caring for, and the welfare of carers is an important part of this agenda" (p54-55)

The challenges of identifying and working with this group of carers are also recognised in this document (page 56), as are the needs of particular groups of carers such as grandparent carers and young carers (page 34). Currently, as far as the documents reviewed seem to indicate, it appears that other areas of policy in Scotland (e.g. mental health, domestic violence and generic child policy such as the Early Years Framework) are not as far advanced

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<sup>&</sup>lt;sup>6</sup> See: http://www.scotland.gov.uk/Topics/Justice/law/Drugs-Strategy/drugrelateddeaths/NationalNaloxone

in considering the needs of family members as the more specific drug focused policies. However, there is some evidence that domestic violence policy is starting to recognise the need to consider addictions as one of a number of areas where there is overlap and where collaboration is needed. Safer Lives: Changed Lives. A Shared Approach to Tackling Violence Against Women in Scotland (Scottish Government, 2009) includes one mention of acting on the link between domestic violence and addictions in terms of making more detailed enquiries of victims. This Strategy talks about a 'shared approach' (for example, page 14-15) but this does not highlight areas of policy which might more closely match with drugs and alcohol and/or families and carers. The National Domestic Abuse Delivery Plan for Children & Young People (Scottish Government, 2008b) includes a small number of statements which acknowledge that addiction services are one of a number of places where women who have experienced domestic abuse will disproportionately present. Addictions services are later highlighted as area where attention is needed as part of improving the NHS response to domestic violence, and there are some statements about how this will be achieved. Priority Area 9 of this Plan focuses on developing a skilled workforce to better respond to domestic violence and there is a statement in this section which mentions addictions (p52).

In 2012, there has been an important development in terms of implementing policy at a local level across Scotland. Seven core outcomes have been agreed, outcomes against which all Alcohol and Drug Partnerships (there are 30 of them) will be expected to deliver. ADPs will be required to develop plans of how they will use the funding available to them (from both earmarked and core budgets) to deliver both improved core outcomes. Outcome 4 is focused on children and families and, at the time of this research,<sup>7</sup> states:

"CAPSM: Children and family members of people misusing alcohol and drugs are safe, well-supported and have improved life-chances: this will include reducing the risks and impact of drug and alcohol misuse on users' children and other family members; supporting the social, educational and economic potential of children and other family members; and helping family members support the recovery of their parents, children and significant others"

other members of the family).

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<sup>&</sup>lt;sup>7</sup> Following consultation it is possible that the first word in this outcome will change from CAPSM to Families to reflect a more holistic focus in terms of the impact which alcohol and drug problems can have on both children and

# Key Points – National Policy Review □ Considering children, adult and other family members affected by substance misuse has been an important part of Scottish policy for over a decade. Supporting families is a priority area of Road to Recovery, with a progress report indicating that progress has been made in several areas. □ National policy in Scotland also includes some consideration of specific groups of family members, such as families from black and minority ethnic groups and kinship carers, and particular issues with which families have to contend, such as overdose and bereavement. □ The development of a core outcome that is focused on the reduction of risk and impact on families and children is a positive step towards further development this agenda □ The extent to which families of substance misusers are considered in other areas of policy is varied. The issue is given greater attention through the Carer's Strategy, and some recognition through domestic violence policy, but less attention in other

#### From National to Local Strategies: Analysis of ADP Strategies

areas such as mental health and criminal justice.

Strategies for Alcohol and Drug Partnerships in eight areas selected for in-depth study were reviewed. The methodology adopted involved using the 'find' function to establish the number of times the words 'carer'(s) and 'fam' (family, families, family members, familial) were used. The plans were then scrutinised more closely to consider the extent to which they considered adult family members of people with drug problems.

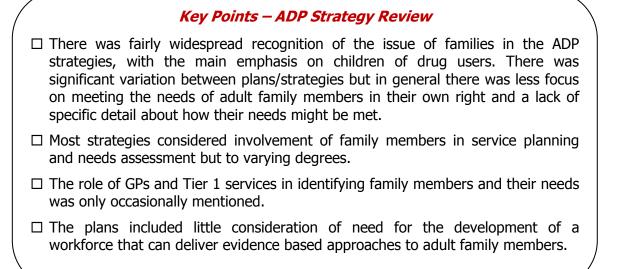
Some discussion of the key points that arose from this review is included below but more detailed information in the form of a brief summary review of each strategy is included as Appendix 4 of this report.

Overall, the vision set out in the majority of the local ADP strategies reflected national outcomes outlined in the *Road to Recovery* (Scottish Government, 2008) and *Changing Scotland's Relationship with Alcohol* (Scottish Government, 2009c) where there is recognition of the need to support and improve the outcomes of families affected by substance misuse. However, perhaps reflecting the fact that the strategies concentrated on general principles, only limited detail was provided in most cases on the level or type of support to be provided, e.g. will adult family members receive services in their own right? If so, where will this be delivered? Furthermore, no strategies identified specific services (for affected family members) which existed in their area.

Most strategies expressed a commitment to improve identification, assessment and monitoring outcomes of affected adult family members, however, only a few provided or referred to a detailed action plan of how this would be achieved. In most areas there was a clear commitment to work with Scottish Families Affected by Drugs to help establish or improve accessibility (in cases where groups are already available) to self-help or recovery groups. At this local level, which in some cases had been informed through a local needs assessment, there was strong recognition of the importance of engaging with family members; having

family member representatives or forums to better develop services and inform future priorities of the ADP. Furthermore, some strategies mentioned delivering overdose prevention training to family members.

In summary, the overall picture was one of recognition of the issue of families with the main emphasis on children of drug users. There was variation between plans and strategies with lack of consistent approaches in terms of identifying need, specific identification of adult family members as a group and discussion of a range of responses including General Practice and Tier 1 responses. Little consideration is given to the development of a workforce that can deliver evidence based approaches to adult family members. It is likely that some of the increased recognition evident from the review of the national documents is making some impact at the local level.



# 3. Identification, recognition of need and commissioning

As part of the mapping of service provision, qualitative interviews were conducted with Alcohol and Drug Partnership (ADP) coordinators and service providers in each of the eight areas. First, the coordinator interviews were used for a broad thematic analysis in order to identify key issues that coordinators described facing in terms of services for family members. This analysis was therefore concerned with coordinators' views and how these may impact on the development, commissioning and delivery of services as a first stage of analysis before proceeding to look at the full interview sets (coordinators and service providers) for the eight areas in order to investigate the range of provision in all areas as well as discrepancies. The details of the full analysis can be found in Copello, Templeton, Chohan and McCarthy (2012). Insight into how coordinators are responding to guidance and seeking to engage and support adult family members revealed responses at a range of levels that are discussed below with examples of quotes from what coordinators said in the interviews. All quotes included in this section are from interview transcripts with ADP coordinators and aim to illustrate the points discussed. Quotes were selected from across the full sample of coordinators.

# THE IDENTIFICATION OF ADULT FAMILY MEMBERS AS A TARGET GROUP WITH SPECIFIC NEEDS IN THEIR OWN RIGHT

Perception of the needs of family members were mixed and varied across areas. In some areas, there was acknowledgement that whilst families were important, services still mainly focused on the person using drugs and not the wider family needs.

'The way our services are delivered currently our main services focus on individuals and their treatment...not kind of wider role of family'.

In contrast, the *Road to Recovery* strategy was quoted in terms of the acknowledgement and recognition it provides to families as important in the support of the recovery of drug users. The focus of the strategy brings the role of families into the recovery process in a way that was not so evident before.

'...there's been a huge national political drive over the past couple of years....our services are predominantly focused on the problem drug and alcohol user themselves.'

'moving to a greater focus on recovery and development of recovery capital, services are beginning to recognise the family as a source of support....it's in its early days.'

It also was clear that there needs to be recognition that adult family members have two related but distinct needs as previously discussed. These include receiving help and support in their 'own right' as well as, where appropriate, supporting the drug user's recovery. Sometimes one of the latter two needs was only identified. These two needs are complementary and not mutually exclusive.

The picture that emerged suggests that there is some room for improvement in terms of clarity in identifying adult family members, for example partners, parents, grandparents, as a specific group of people with needs in their own right. This is an important first step in the planning process.

#### **E**NSURING ADULT FAMILY MEMBERS' NEEDS ARE PART OF THE COMMISSIONING AGENDA

The second gap (partly linked to the lack of clear identification) involves a lack of prevalence data and the findings show that the problem of adult family members affected by drug use of a relative is still very much underestimated. Most coordinator interviews acknowledged families and their needs but failed to provide precise details of estimates of the extent and nature of the problem for adult family members at a local level. This is essential in order to guide decisions about service responses.

'we've no idea what people want....I think we have identified the need but not done the work yet.'

There was a tendency in some areas to use demand as a form of establishing the level of need of adult family members. The limitation of planning provision based on 'demand' is that the problem is hidden partly resulting from stigma and this makes it likely that demand is much lower than real need.

'At the moment, mostly demand... We've just done a needs assessment, well about a year and a half ago and it didn't really pick up on the issue of carers as much as we'd hoped and I guess for us it's an area we need to look at in the future in terms of needs assessment work. At the moment really it's demand that impacts on the range of provision that is available.'

'But at the moment we don't know. I know the services are quite popular and certainly there's demand for them but I don't know how many overall.'

There was much acknowledgement here that since *Road to Recovery* and in the past few years there has been increased recognition of families. Interviewees stated that commissioning processes should support the maintenance and development of adult family member services at the local level but that in order to achieve this, adult family members' needs should be clearly identified within the commissioning agenda.

"...my sense is that the level of provision we have got is much lower than the need out there. The issue we have is that particularly the needs of adult carers aren't picked up particularly well by treatment services...'I think for us it's really starting with our treatment services and changing the culture of our treatment services so that they are much more family friendly'

# ENGAGEMENT OF ADULT FAMILY MEMBERS IN THE COMMISSIONING CYCLE AND REVIEW OF SERVICES

There were examples of successful involvement of family members in the commissioning and service review process but these varied. The results suggest that consideration should be given to developing guidance on better ways in which family members can engage further with these processes across all areas. Below are two contrasting examples from two different areas.

'We don't have any sort of forum for carers to come together and influence strategy so that's a gap for us as well.'

'We held seven community consultation events... we have very direct community members, I meet with them directly every six to eight weeks within community forums...they speak very directly to me about any changes or any concerns and they also very directly tell me what I should do.'

One area described successful engagement with a particular group of adult family members.

'..we are engaging with grandparents in a way that we never engaged before; so that's very successful.'

#### PROMOTING AND IMPROVING ACCESS TO SERVICES

The challenges faced when attempting to engage adult family members were also articulated by those interviewed who talked about the importance to consider the impact of 'shame' and 'stigma' in preventing adult family members coming forward and requesting help.

'...we have found in the past it difficult to engage people in group work because of the stigma that is attached to it.'

In addition it was remarked that the terminology used to describe adult family members, such as 'carers', can sometimes prevent self-identification and recognition by this group and prevent access to valuable services e.g. carer services. The availability of the latter services to this group needs to be promoted more clearly.

'I think the challenge that has been recognised by Scottish government around you know carers in terms of alcohol and drug use is that carers of adults with substance misuse issues, because of the stigma around alcohol and drug use tend not to identify themselves as a carer.'

It also appears that the services for adult family members, where available, need to be promoted actively through other more generic services, including primary care. There are challenges in more rural areas to achieve engagement of adult family members in services.

'family members do not readily report or present in rural communities'

Yearly events described in some areas are a useful way to bring adult family members together, promote the help that is available and to de-stigmatise the experience. In one area, a yearly service has been running successfully for eighteen years.

"... each year we have a remembrance service... which is attended in excess of two hundred people and that's for those who have died of drug or alcohol problems."

'We also have a weeklong community based event across the city with about 60 events with a whole range of issues, some of which are family related, to engage with and capture what are the current needs for people that attended those events.'

#### FURTHER THEMES DISCUSSED BY ADP COORDINATORS

As described, the analysis was conducted on all commissioner and ADP coordinator interviews and the framework and findings emerged from both Scotland and England. There were however, a number of issues that were more prominent in Scotland from interviews with ADP coordinators.

**Self-help groups** were mentioned by all interviewees, either, in some areas, where these were quite successful and working well with support from services, or in other cases, difficult to maintain or develop. Whilst it is not possible to know whether the use of self-help groups is not present to the same extent in England, it was noticeable that the Scottish interviews made more mention of this form of help and of organisations devoted to the support of group activity including promoting, setting up and maintaining support groups. An example of an association of adult family member groups provided by Family Addiction Support Services (FASS) can be seen in Box 2 on page 35.

The document **Road to Recovery** was mentioned by all interviewees as being influential in the thinking about families and development of services (there was no similar English document that was so consistently mentioned by DAT commissioners). Having said this, as discussed earlier, the emphasis in that document was more geared towards involving families in the recovery process with less detail of family member needs in their own right.

In some of the Scottish areas, the **extremely rural** nature of the area posed in the coordinators' views a number of significant challenges; with difficulties for family members accessing services and stigma also acting as a potential barrier in these areas, where the risk of other people in the area (e.g. neighbours, people from the same community) finding out about the problem appeared to be prominent and perceived as a greater barrier in the smaller communities. The impact of 'stigma' and 'shame' was also present in urban areas. Also, self-help groups had often failed in some of these areas and alternative forms of help such as those that could be accessed anonymously over the web were mentioned as potentially helpful.

The interviews with the Scottish ADP coordinators all included references to **generic carer services** and in some cases the relationship between specialist and generic services appeared to be robust. There were also areas where the uptake of generic carers' assessments was low however and this was linked to some of the issues identified in terms of stigma, awareness for family members of the fact that these services are available to them.

The role of the Scottish Families Affected by Drugs (SFAD) was mentioned in a number of the interviews as providing support and guidance and valuable help setting up groups. An example is included below from one of the coordinators:

"We are using SFAD, they are showing us how to set things up. They give us brochures, they give us information"

Whilst there was recognition of the influence of the 'Road to Recovery' document, there were also references in some areas that services pre-dated the strategy and hence were not so much influenced by policy but local needs and influential family members.

Finally, there appeared to be recognition that the children affected by substance misuse agenda had made a significant impact in Scotland and services for children were more robust and developed than those for adult family members. As one coordinator described:

"I think I am holding my hands up because it's not something we have done a lot of work on [working with adults affected by substance use]. The real focus has been on children."

# 4. Extent and nature of provision

At this stage, the aim was to explore service provision, both across Scotland and in each of the eight areas selected for in-depth study. Two different but complementary strategies were used in order to explore current levels of provision. First the web based survey across Scotland (this was part of a UK wide survey but results here are focused on the Scottish responses) and secondly the full sets of qualitative in-depth interviews with ADP coordinators and service providers across the eight selected areas, chosen to represent a range of urban, semi-rural and rural areas. The survey results are discussed first before the analysis of area interview sets.

#### **NATIONAL WEB-BASED SURVEY OF PROVISION**

The method used was described earlier and full details of the methodology used are described, along with the full results for the UK, in a separate report of the survey (Copello and Templeton, 2012). The questionnaire covered a range of issues such as the type of service, what they provided for adult family members, the modes of delivery (e.g. face to face; telephone; web) and the perception of funding for the future.

In total there were 72 responses from Scotland, the largest number of responses after England and proportionately larger than might have been expected considering the relative size of the countries. However, given the nature of the survey method it is not possible to conclude whether this proportionately larger number of responses was due to better level of provision or a better response rate. However, to some extent, it suggests a higher level of engagement of Scottish services with the survey than other countries in the UK.

The larger proportion of services that responded to the survey in Scotland were from the non-statutory sector (60%) followed by NHS and social services (14% each). The proportion of responses from social services was more than twice that found across the UK as a whole. About half of the responses in Scotland were from services that had 10 or less members of staff (about one quarter less than 5 and another quarter less than 10). About one third of the responding services (31%) said that they were working in partnership and the large majority of respondents were from services primarily for people with the substance misuse problem (66%). Services for family members only made up 13% of Scottish responses, which is in contrast to, for example England and Wales (with 30 and 35% respectively). Most services were delivered for both drug and alcohol use and the largest proportion of the help offered to family members took place alongside the drug users in treatment. In those services that worked with family members alongside their drug-using relative, more than half of the services reported that work with family members either on their own or alongside the drug users took up less than 10% of the service workload.

#### What was on offer for adult family members in Scotland?

The survey explored the types of support that was offered to adult family members in their own right as well as that offered when working together with adult family members and the person with drug use problems.

Table 2: Interventions offered to family members on their own

(N=72) [Note: people could provide more than one response]

Form of support or intervention	No., % of responses
Information and signposting (includes helpline, website, info provided through education & training, housing support, legal support, referral for carer assessment, health support & advice, relapse advice and information)	67, 93%
Group Support (includes peer support)	31, 43%
Other General Support	44, 61%
Crisis support	29, 40%
Advocacy support	31, 43%
Individual mentoring	13, 18%
Support to grandparents & kinship carers	1, 1%
Social events, activities & trips	2, 3%
General support (includes support to parents, family group conferencing, self-help, and non-specified family sessions/support)	7, 10%
Counselling	34, 47%
Counselling	30, 42%
Bereavement support/counselling	17, 24%
Structured Intervention for Family Members	12, 17%
Co-dependency based interventions	8, 11%
5-Step Method	4, 6%
12-step support	3, 4%
Complementary or alternative therapies	5, 7%
Respite	3, 4%
Intensive support (i.e. Residential support)	1, 1%
Overdose prevention or naloxone training	2, 3%
Carers assessment	1, 1%

Table 2 shows the support which respondents said they provided to adult family members on their own (respondents could give multiple options as well as free text responses). In order to aid interpretation, the responses were coded under higher order categories that are shown in bold. It can be seen that the majority of services offered basic information and signposting to family members. This was followed by other forms of general support, a category that included a range of services; some more specific to dealing with crises, some with advocacy and mentoring and some with specific family member groups e.g. grandparents. Crisis support and advocacy were the most common interventions within this category, being offered by about 40% of respondents.

Counselling was delivered by nearly half of the services and bereavement support by a quarter, the latter perhaps reflecting the growing recognition of this as a specific area where attention and support are needed. However, provision of more structured interventions to help family members in their own right was limited, being provided by less than a fifth of services and of these co-dependency-based interventions were most commonly reported while named, evidence-based interventions such as the 5-Step Method, were delivered to a much lower extent (6%).

The types of support that less than 10% of services mentioned were all ones that were not specified within the question and were reported in the other category. Nevertheless, it does suggest that the provision of carer's assessments is not widespread. The number of services offering overdose prevention and naloxone training might be expected to increase in the future as the national naloxone programme is rolled out and this would be welcomed by family members.

Table3. Interventions offered to family members alongside their drug-using relative (N=72) [Note: people could provide more than one response]

Form of support or intervention	No., % of responses
Information, education, advice, signposting, & general support	9, 12%
Group work	13, 18%
Structured interventions	34, 47%
Family therapy	17, 24%
Social Behaviour & Network Therapy (SBNT)	10, 14%
Behaviour Couples Therapy/other couples therapies	4, 6%
Psychological interventions	4, 6%
Brief interventions and counselling	5, 7%
Relationship counselling	9, 12%
Other joint working support	5, 7%
Mediation and advocacy support	3, 4%
Care planning and care conferences	2, 3%
Does not apply (only work with family members)	22, 31%

Table 3 summarises the support which respondents said was available when they were working with adult family members alongside their drug using relative (respondents could give multiple options as well as free text responses). Again, for this section we grouped responses into higher order categories that are indicated in bold within the table. Here it appears that information and signposting does not frequently occur with family members and drug users together (but this was not a specific category within the question). However, more structured interventions of one sort or another were provided by almost half of the services in the survey. Family therapy was the most common of these, being reported by about a quarter of

the respondents. There appears to be lower implementation and offer of a range of named, evidence-based interventions, although SBNT (Social Behaviour and Network Therapy – Copello et al., 2002) and BCT (Behavioural Couples Therapy – O'Farrell and Fals-Stewart, 2006) were mentioned by a number of services. Group work was reported by 18% of the sample. Relationship counselling was on offer less frequently (12%). Although not specifically prompted for within the question a few services mentioned various ways of working jointly, including mediation and care planning and care conferences.

Two further issues that were explored as part of the survey included the mode of delivery of the support to family members and the perception of the future in terms of funding.

In relation to delivery, the most common forms of delivery included face to face (96%) and telephone contact (81%) with the use of the internet (32%) and written materials (8%) reported less frequently.

In terms of the future provision of services in Scotland, 40% of respondents thought that their level of activity would stay roughly the same over the next 12 months whilst 43% thought that it would increase and a much smaller proportion (7%) thought that their level of provision would decrease whilst no services felt that they would cease work altogether.

#### **ANALYSIS OF QUALITATIVE INTERVIEW SETS FOR EIGHT ADP AREAS**

In order to explore the service provision in more depth further qualitative analyses were conducted by looking at sets of interviews within the eight areas in Scotland. Initially a coding framework was produced after an initial preliminary analysis of two interviews. The framework comprised three main categories namely 'Understanding, strategy and vision'; 'Implementation' and 'Treatment systems'. Each category included a number of themes. As a second step, this framework was used in the analysis of the full sets of interviews in the eight areas in Scotland. To some extent there is some overlap between the initial category, 'Understanding, strategy and vision', and some of the issues already described in the coordinator interview analysis. This second analysis however was focused on contrasting the eight areas as opposed to the overall perceptions of coordinators in order to see the extent to which the themes varied and in order to obtain a full description of each area. The second and third categories were focused on service provision and the findings complement some of those obtained from the broader web survey. The main findings from the analysis by area are summarised in the next sections under headings for each category. The summary analysis for each area is illustrated in Appendix 5, Tables A5.1, A5.2 and A5.3. The eight areas included three cities, two semi-rural and three rural areas. Overall, the analysis involved eight ADP coordinators and 29 service provider interviews. Details of the sample are shown in Table 4.

Table 4: Breakdown of Service Provider Interviews in Scotland

Area Region	Family service	Carers service	Drug tr	Drug treatment	Other (details)
			Statutory/NHS	Non-statutory	
S		1	1	1	
S	2	2		1	
S	1	$(1)^{1}$	1		
S	1	2			1 (Generic counselling)
S	1	1	1		
S				3 (1) <sup>1</sup>	
S	1	$1 (1)^1$		2	1 (Generic counselling)
S			1	1	<ol> <li>(relationship counselling)</li> <li>(women's service)</li> </ol>
Totals interviews completed 29 (3)	9	7 (2)	4	8 (1)	4

<sup>&</sup>lt;sup>1</sup> Numbers in brackets indicate services that were identified but were not interviewed. Most common reasons were lack of available contact details or in some areas contact had not been established by the time field work had to be completed.

In qualitative research the aim is to describe the full range of responses rather than to cover a representative sample from which it would be possible to state with certainty how the findings relate to the total level of provision across the country. The sample aimed to represent a range of situations, higher and lower levels of provision, urban and rural, in order to identify the different types of challenges and issues faced. It is possible that we missed some extreme examples (e.g. extremely poor provision or excellent comprehensive provision areas) but the consistency of the results across the whole project and the various components increases confidence in the findings and indicates considerable variability of provision across the areas covered. It is also a first attempt to explore in depth provision of responses to adult family members across areas and services and future work could build on and improve the current findings.

#### Understanding, strategy and vision

The level of understanding, strategy and vision appeared to vary between the eight areas considered. A summary can be seen in Table A5.1. Some areas, e.g. 6S, had robust knowledge and awareness of the problem and reported that this had been the case for a number of years, predating recent developments in recognition of the importance of families through policy (e.g. *Road to Recovery*). Other areas recognised the needs of family members but felt that more work needed to be done in terms of identification and service provision, whilst a minority of areas reported that the adult family members' agenda was not a priority, mentioning services for drug users, alcohol users or children as higher in the priority list. Area 1S also perceived that there was a range of needs within the broad group of 'families' and attempts were made to respond to these through various services both generic and specialist and also including the delivery of an intensive family prevention programme for whole families. In the case of Area 2S, the commissioner was relatively new to the post and whilst recognising that family members were important, felt that their area was at the very early stages of having an adequate response to the needs of adult family members.

Overall, there was a general perception that, while the needs of children with drug-using parents are being addressed, there was still further work to be done in relation to the identification of adult family members affected by a relative's drug use and providing support to them. In two areas, the extremely rural characteristics of the area posed significant challenges in terms of accessibility and stigma, although references to stigma were also made in urban areas.

There was considerable variation between areas in respect to the extent to which there was a clear vision of what is necessary to meet need. There appeared to be a stronger more developed vision in areas where there was greater communication between the coordinator and family members and family member groups. It is fair to say that most areas had made some mention of adult family members in their strategies but that at present there is not always clear evidence that the aims identified in the strategies are being operationalised.

Overall, the findings suggest that whilst families in general, and children in particular, are perceived as being significantly affected and having needs that it is important to address, further developments in provision could be achieved by identifying adult family members more specifically and then developing estimates of prevalence of this group. This would give a greater focus to planning of service provision to meet their needs.

#### **Implementation**

This theme was concerned with what services were on offer in each area and what influenced level of provision. A summary of the results are included in Table A5.2 in Appendix 5. All the areas reported provision of advice, support, information and signposting for family members. This is in concordance with the findings from the web-survey which found that 93% of services that responded were providing these types of support. Whilst reported in all areas, it is not possible to gauge the extent to which these services are easily available across the area and, as discussed later, the volume of some of these services is unclear. In some areas the challenges of accessing services, particularly in some of the rural areas, were mentioned.

Counselling was also reported to be available in all areas, mostly generic in nature not specific to families and drug use. A number of areas reported the presence of support groups for family members but that the success and use of these is mixed, mostly due to the difficulty engaging family members in the available groups. Area 6S for example reports a group programme with 18 active groups whilst area 7S reported low uptake of groups. This would suggest that areas can benefit from learning the active ingredients to support successful group programmes. The role of Scottish Families Affected by Drugs was noted as important in supporting the development of support groups in some areas.

Carers' assessments were offered through generic services but uptake was reported to be mixed and this was perceived to be due to lack of awareness in family members. In Area 2S however, one of the carer organisations had 3 workers specifically to work with family members affected by substance misuse.

Kinship carer support was mentioned in some areas, whilst Naloxone training was also available. Kinship support was delivered through parenting programmes in a number of areas. There were also references to specialist counselling and bereavement support.

One area (1S) described a more intensive family prevention programme, although limited to 6 weeks with no follow-up support and focused on young people, and one area (6S) had a parenting programme. There were other parenting programmes mentioned focused on helping young people affected by drug using parents. However, it was of note that some of the parenting programmes were quite active in supporting kinship carers.

#### Support structures for treatment system development

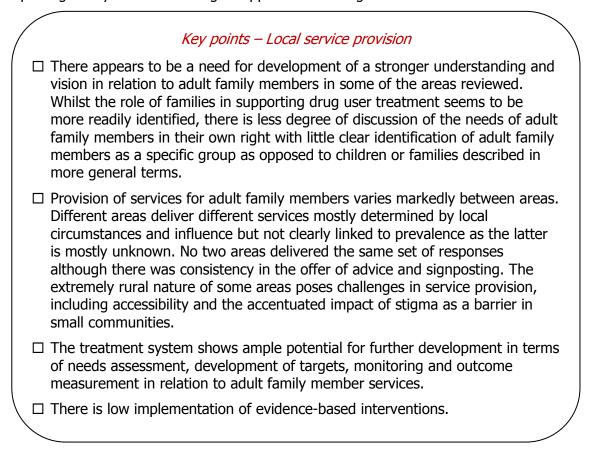
This theme considered a number of specific aspects and structures within the treatment system in each area which might facilitate the development of an integrated system of support for family members, such as targets, monitoring, outcome measurement. A summary of the results relating to this area is included in Table A5.3 in Appendix 5. The overall picture of the system across the 8 areas is varied and shows potential for further development. No area had an overall target for family members although in some areas, there were identified targets for specific services, e.g. 6S and 8S.

Monitoring of provision was patchy, mostly centred on the treatment activity for the person using drugs, and not so much on family member services or contacts. Some areas reported that they were currently developing more robust systems to monitor and identify adult family focused activity. In some cases, coordinators had figures of adult family member contacts but these did not appear to be systematically collected and used for monitoring. One coordinator remarked that they were not required to monitor or report these figures. An

exception was area 6S where the monitoring system appeared more robust and there appeared to be more integration across services. In this area, the commissioner was more familiar with the range of responses available and the need to monitor activity across all these systems.

In terms of outcome measurement, this mostly appeared to take place within specific treatment programmes rather than more widely. Pathways between services and communication varied. One example (3S) illustrated a more integrated pathway where all services had a clear referral pathway to one service that coordinated future care and support and signposting where necessary. The importance of carer events to promote services, particularly within urban areas, was also noted. One area described a yearly memorial service that had been organised for a number of years and has been very successful attracting family members affected by drug use.

There were some workforce training initiatives being undertaken, with half of the areas reporting family focused training as opposed to more generic initiatives.



# COMPARISON OF SERVICE PROVISION WITH A TEMPLATE FOR COMPREHENSIVE SERVICE PROVISION

A comprehensive service response needs to be both accessible and to include the delivery of help and support to adult family members at different levels, given that family members may come into contact with services in a range of different ways e.g. to social services, in primary care, in specialist settings. As well as providing support to meet the needs of adult family members such a response, it could be argued, also needs to maximise the potential to engage adult family members in supporting the recovery of the person using drugs. In order to attempt to further enhance our understanding of current provision and gaps, the picture of provision obtained from the interview material has been compared with the five levels of provision recommended on the basis of the evidence review conducted as part of the Phase 1 UKDPC research (Copello, Templeton and Powell, 2009). Although the questions about provision of services were not couched in terms of these levels, the qualitative interviews with service providers gave us information that allowed exploration of this issue based on post-hoc classification of services according to the different levels proposed in UKDPC phase 1 report. While the potential limitation of this approach does need to be borne in mind when considering the findings, we re-contacted 6 of the key informants after conducting the analysis and checked our classification with their perception of provision in each level and they considered them to be accurate. A summary table of the results for the eight areas can be seen in table 5 below.

Each level of provision it outlined briefly (from Copello, Templeton and Powell, 2009) followed by a summary of the observations from the qualitative interviews.

#### Level 1: Responses to family members in non-specialist settings

'Family members may approach the whole range of services and agencies requesting advice, information or direction towards sources of help. This requires training of staff so that the impact of drug problems on families is understood and basic information or signposting can be provided. In addition, good quality leaflets, access to web based information and signposting should be available.' (Copello, Templeton and Powell, 2009, p.40)

The extent to which responses of this nature that involve recognition and assessment in non-specialist settings are provided appears inconsistent. In most areas we found awareness of the importance of carers' assessments but in most cases the volume appeared low compared to the level of prevalence one would predict. Out of the 8 areas, we found clear statements about carer assessments in 5 and reference to other generic services including housing and financial advice in 3. Some areas, acknowledged the need to work more closely with General Practitioners and increase awareness and identification at the primary care level. Most of these areas, however, recognise this as work in progress. A case example of a generic carer service with good levels of engagement of adult family members is illustrated in Box 1.

#### Box 1: Voice of Carers Across Lothian (VOCAL)

An example of a generic service that appears to be successful in engaging adult family members is VOCAL in Edinburgh.

"the organisation is called VOCAL, that's an acronym for Voice of Carers Across Lothian. VOCAL works predominately in Edinburgh and Mid Lothian. We are a generic carer support organisation, carers we define as informal or unpaid carers, not those in a paid role."

The organisation has 25 staff and 60 volunteers that offer a number of services including counselling, an advocacy service, carer training programme that benefits over 500 people a year. One of the services offered includes a project that has three trained staff members that specifically work with individuals affected by someone else's addition:

"As part of our generic carer support work, we have one project with three staff which we call the family support addiction service. Those three staff work exclusively with family members who live with someone or support someone who has an addiction. They are usually relatives or close friends, often parents who support somebody with an addiction to alcohol or drugs. What we provide is information, advice, emotional support, peer support groups, campaigning for carer recognition and that's often with carers involved. We also have a campaign for the carer recognition in the recovery process, which is the new focus of addiction services here, we provide advocacy and counselling."

The information provided included: "information about services – what services are available, the whole process of getting into any form of rehabilitation, of getting a community care assessment, we provide information on prison services where relevant. We explore with the carer what the key issues are...the issues with which they come to us, the issues that are affecting them, we provide information on anything we uncover as being of interest or benefit to the carer."

#### Level 2: Assessment of support needs: Best practice is not only related to interventions.

'The existing evidence, for example on the influence of family relationships and stability on outcome, strongly supports the need to assess family relationships when people enter treatment, a practice that is not widespread within treatment services.' (Copello, Templeton and Powell, 2009, p40)

Level 2 relates to the assessment of family needs when users approach treatment services. In general there appears to be a lack of any systematic and comprehensive way of implementing an assessment in relation to affected adult family members, although some areas described work in progress and recognised this as an important issue to develop. Across all other areas, despite some good examples of assessments in specific services that had family member components, there did not appear to be any clear action plans in place to increase this level of provision or robust ways of monitoring this work.

#### Box 2: Family Addiction Support Services (FASS)

An example of an organisation that is focused on adult family member needs and attempts to respond to the **range** of needs of this group in a **comprehensive** and **flexible** way is the Family Addiction Support Services (FASS) in Glasgow. In the words of the service provider interviewed:

"Were driven by what their need is. We are a holistic service...the best example I can give you is the counsellor...say you have a distraught mother on the phone...we give that person an option, the counsellor may engage with the person for a few sessions and she will also let them know of support groups in or outside their area. Sometimes people don't want to go to a support group on their doorstep. What you might find is someone being happy with seeing the counsellor a couple of times to be then referred onto a support group and they feel that is enough for them. Indeed there are some people that feel groups are not for them and they will engage on a longer basis with the counsellor... We don't give people a particular number of sessions because you might get somebody when things are particularly chaotic in the household they are looking for quite a bit of support with us and then you might not hear from them for a couple of months, things are ok and they getting on with things. If things flare up they get back in touch....we are flexible to the needs of the client.

The services offered include providing support to families affected by drugs through counselling, offering respite services, parenting training courses and alternative therapies. Offering support to all family groups established in Glasgow (e.g., offering their premises to hold groups), but also helping new groups to set up "and get their feet off the ground." Within Glasgow we have a total of 18 family support and kinship groups across the city and they're affiliated with our organisation..." we have a counsellor; we also have a link worker, now that post works in conjunction with a partnership organisation called 'Geeza Break' (that provides respite services). What the link worker does, she basically supports kinship carers throughout Glasgow. Support includes providing practical support and advice on childcare issues, respite services, welfare rights, information about local kinship groups and connecting carers to mainstream childcare services and other agencies.

..."in our main reception area, as quite a few people drop in, we have quite a variety of literature available whether it's for somebody looking for fellowship groups such as NA or AA, whether its statutory services; community mental health teams...we have a lot of leaflets depending on the information they are looking for."

"Another kind of service that we run, every year we have a remembrance service in Glasgow which is attended in excess of 200 people and that's for those who have died through drug or alcohol problems. It's been running for eighteen years now."

### Level 3: Services specifically focused on providing help and support to family members in their own right.

'The provision of these services is patchy across the UK and can be improved. Some evidence based interventions such as the 5-step intervention (Copello et al., 2009) can be delivered in family focused services and provide a useful framework for workers.' (Copello, Templeton and Powell, 2009, p40)

There was more provision within Level 3 and here is where most of the eight areas interviewed have concentrated. All areas described some provision for family members including information, general support, advice and signposting. Counselling was available in all areas with the majority offering generic counselling in contrast to approaches specifically developed for and focused on the impact of drug addiction upon the family member. This was also found in the results of the web survey.

In a minority of areas, reference was made to more evidence based interventions. One of the limitations here is the absence of clear and robust monitoring systems, without which it is difficult to know the volume of the service provision. In most cases, there was recognition that services were not likely to meet real need. An example of a positive service response specifically developed for adult family members and taking into account the varied range of needs and presentations is illustrated in Box 2.

#### Level 4: Response to family members delivered as part of services for drug users.

'It is important that a response to family members is delivered as part of services for drug users.' (Copello, Templeton and Powell, 2009, p41)

This is an issue that was recognised in the majority of areas, yet provision was patchy and perceived as a challenge. Out of the eight areas, six described attempting to involve family members in the treatment of the drug user. This posed a number of challenges, including how to manage working together in a positive way, how to engage families in this process and how to deal with worries from drug users when considering involving family members. No specific approaches were mentioned. It is also worth considering that as part of the web survey it was found that this type of work was not done frequently with most services reporting that working with adult family members made up less than ten percent of the services workload. There was little mention of the offer of more structured approaches for family members within treatment services for drug users, unless they were 'ad hoc' or there was a family service component attached to the drug service.

#### Level 5: Intensive family-based therapeutic interventions

'Some services will have the capacity and capability to deliver some of the more intensive interventions reviewed. Behavioural Couple Therapy has been recommended as part of the NICE guideline and can be used with drug users who have non-drug using partners. In addition there are a number of interventions that show promise and together cater for the needs of the whole range of family relationships. These include Multimodal Family Therapy; Community Reinforcement Approach and social network approaches. These will require a higher level of training and supervision for staff that will not be available in all services.' (Copello, Templeton and Powell, 2009, p41)

#### Supporting adult family members of people with drug problems in Scotland

The overall picture here was again varied and the delivery of intensive family interventions or programmes focused on helping adult family members was low. Out of the eight areas, only one described some form of intensive family prevention programme. Whilst there were references to parenting programmes to support drug-using parents, the availability of programmes focused on the adult family members was very low.

The comparison lends further support to what is evident so far from the analysis of the other components that the level of provision for family members affected by substance misuse is generally underdeveloped although in most areas there is interest in doing more.

Table 5: Assessment of level of provision by area

Level of Provision	Area 1S	Area 2S	Area 3S	Area 4S	Area 5S	Area 6S	Area 7S	Area 8S
Level 1: Responses to family members in non- specialist settings	Carer services provide assessments and have communications team to promote service	Some evidence of good response through carers' services Some GP referral	Carer's assessment. Central focal point for family member assessments. Identified need to work with GPs, A&E, police. Identified as 'challenge'	Carer support plans. No clear pathways	Some carers' assessment. Otherwise knowledge in other areas weak.	Some good examples of links with generic services	Some generic service provision	Some integration work with housing and finances
Level 2: Assessment of family needs when users enter treatment	Not clear	No evidence of a systematic approach across services	Takes place at single shared assessment	Not widespread. Anticipate developing in the future	Assessments of relationships but user focused	Some activity but mostly focused on children	Some activity	Some activity
Level 3: Services providing help and support to family members in their own	Range of responses. Face to face, self- help.	Some provision including self-help	Range of response, mostly generic and some specialist	Range of responses through mainly one service	Range through generic services	Range including individual help as well as active support groups and other activities	Yes, range of services	Counselling as well as 'ad hoc' support

Supporting adult family members of people with drug problems in Scotland

Level of Provision	Area 1S	Area 2S	Area 3S	Area 4S	Area 5S	Area 6S	Area 7S	Area 8S
Level 4: Response to family members delivered as part of services for drug users	Work in progress attempting to involve family members in drug user treatment	Recognition but limited work so far Varies between services	Built into standard practice	Not standard but identified for future development	Option available. Can be developed further	Some involvement of family members in users' treatment. Issue recognised	Not evident from interviews	Some involvement of family members in users' treatment
Level 5: Intensive family-based therapeutic interventions	Some through family prevention programme	Not evident from interviews	Not evident for adult family members	Not evident from interviews	Not evident from interviews	Support for kinship carers	Not evident from interviews	Not evident from interviews

# 5. Conclusions and implications for policy and practice

Adult family members of people who use drugs have been increasingly recognised in research and practice as a group who have significant needs as a result of the stress of living and caring for someone with problem drug use. Policy has reflected this increased recognition to an extent, but there is still lack of clarity in the identification of this specific group of adult family members, that include a number of different relationships such as parents, partners, grandparents and adult siblings. There is a welcome increased recognition of the needs of children affected by parental substance misuse and the general impact of drug use on families, as well as the potential contribution that adult family members can make to the recovery process.

However, the lack of clear identification of adult family members as a distinct group in need of support, and of sub-groups within this broader grouping, has been exacerbated by a lack of data sources in which they are identified. This makes robust estimation of prevalence very difficult (as was highlighted in the research for phase 1 of this project) which may have hampered the development and implementation of an adequate level of service provision at the local level. As part of the UKDPC phase 1 work a method for estimating prevalence of adult family members was developed (Copello, Templeton and Powell, 2009) using the data available at the time. The method can be used with different sources of data and could be adapted for local use.

When the method was used to estimate prevalence of parents, partners and other adult family members affected by the impact of having a relative who experiences problems with drug use the results suggested that across Scotland there is a minimum of 6,500 adult family members affected of those people in treatment for drug use and the number increases to 134,000 when the wider population of people who have developed a problem with drug use but are not in contact with services is considered. There are two possible strategies that can be used as a first estimate approximation for local areas. Firstly, if data is available the same method could be used substituting local data and population estimates to provide estimates for the local area (Copello, Templeton and Powell, 2009). Alternatively, it could simply be assumed that the national prevalence applied so that a number representing 64% of the total number of people in treatment for drug use in the area and 77% if you consider the prevalence of drug use problems in general would yield an estimated number of significantly affected family members in a particular area. Such simple estimates could at least provide a starting point for a needs assessment. The development of more robust systems for monitoring, coordinating and delivering a range of services to respond to the range of need could follow.

Organisations, such as Scottish Families Affected by Drugs (SFAD (see Box 3), can play an important role in raising awareness of the needs of this group, promoting the evidence about good practice and supporting services.

#### Box 3: Scottish Families Affected by Drugs (SFAD)

Scottish Families Affected by Drugs (SFAD) is a national organisation formally established in 2003 in order to support families across Scotland that are affected by drug misuse and to help and support those agencies that in turn represent and support such families.

The role and function of SFAD is extremely valuable in terms of supporting groups across Scotland, advising Alcohol and Drug Partnerships (ADPs) and local service providers about how to set up groups as well as how to reach and engage with families. In addition, SFAD support's functioning family support groups to maintain themselves by using a capacity building approach when working with facilitator's and members. Most ADPs have a good working relationship with the organisation and acknowledged the importance and support received from SFAD.

In addition, SFAD provides a voice to adult family members and family support groups who often feel isolated and forgotten by representing families at local and national level, raising awareness of the issues associated with drug misuse and campaigning at a national level on their behalf. The importance of a national organisation is also related to ensuring equity of provision across different areas of Scotland, an issue highlighted by some of the reviews of the different areas

The potential value of having a greater focus on adult family members affected by a relative's substance misuse and recognising their own needs was also evident in a recent review of the evidence relating to the role of social work in substance misuse (Galvani, Forrester et al., 2011). This is of particular relevance in Scotland since, as demonstrated by our web survey, social services provide a significant proportion of services for families. As that review states "Social workers are best placed to work with people with a range of addictions due to the profession's holistic theoretical frameworks and flexible approaches to practice; in particular their ability to coordinate care across a range of services is important to people with complex needs." (p45-46) However, as well as developing the ability of these services to work with family members to help their relative achieve and sustain recovery it is important that attention is also given to the needs of the family members in their own right and their own need for 'recovery'.

What emerges from the review of current service delivery is a picture of somewhat inconsistent provision across different geographical areas. While ADP co-ordinators were concerned about adult family members they did not always recognise the need for both involvement in treatment and recovery of drug-using relatives and support for family members in their own right.

They also did not always identify the need to provide a full range of services from identification and assessment; through support and advice; to therapies. Whilst most of the eight areas studied offer advice, support and signposting it is difficult to establish with any degree of certainty, whether the level of provision is commensurate with the level of need because information on the numbers receiving services is rarely available. However some coordinators remarked that their perception suggested to them that the provision did not match real demand.

Beyond the provision of advice and signposting, more intensive forms of support were offered to a lesser degree. Whilst counselling appeared to be delivered across most areas, named evidence based family focused interventions such as the 5-Step Method (Copello, Templeton et al., 2009; Copello, Templeton et al., 2010) or Behavioural Couples Therapy (O'Farrell and Fals-Stewart, 2007) were delivered to a much lesser extent and there were no clear plans articulated to develop and train the workforce in order to increase the delivery of these approaches.

There were some examples of successful practice in terms of services that managed to engage adult family members in receiving support in their own right, taking into account the range of needs, having a high volume of carer assessments and recognising this group as a genuine group of carers. Some of the areas had more robust communication and monitoring systems, engaging family members at various levels of the development, review and monitoring of services and organising consultation events.

A number of barriers to providing services to adult family members were identified:

- (a) Families don't come forward for a number of reasons, eg they do not see themselves as carers, they are concerned about stigma, and often they do not recognise their own needs.
- (b) ADP co-ordinators may not prioritise adult family members because:
  - a lack of data on prevalence means the adequacy of provision is difficult to assess;
  - they may be unclear about the range of services needed;
  - there is no, or very limited, collection of data on numbers using services or outcomes against which to assess provision.
- (c) Specialist and generic workforce may not be aware of the needs of adult family members or feel that they have the skills to address them.
- (d) Treatment services may have concerns about service users' feelings about involving relatives in treatment.

There are a number of things that might help overcome some of these barriers and improve the provision available to family members. These include:

- Promoting the evidence both for what is needed and what works. The need for advice
  on what should be provided and for examples of good practice was highlighted by some
  interviewees. Organisations such as SFAD could have a role to play here but a more
  specific recognition of adult family members and their needs and contribution to recovery
  in policy and guidance documents across a range of areas should also contribute to this.
- Improving needs assessment. ADP strategies and action plans need to reflect the different sub-groups of adult family members, the range of different needs, and basic prevalence information. Involving family members in identifying needs and making use of available data eg information on the Scottish Drug Misuse Database (on living situation) and from the UKDPC estimates would assist this process. To identify 'hidden' groups of adults affected by a relative's drug problem specific data collection, eg a module on a household survey, could be considered.
- Developing targets and outcome assessment would provide a focus for evaluating levels of provision as well as demonstrating the value of these services and building the

evidence base. The work of the Scottish Government on outcome indicators could be valuable in this respect.

- Promoting the issues and services to address stigma and lack of knowledge among
  affected family members. This might involve public events and the use of a wide range of
  media for delivering information and signposting.
- Integrating specialist and generic services to increase the identification and assessment of adult family members and provide access to the full range of services through clear pathways and linkages. This should include promoting identification and recognition of adult's affected by a relative's drug use in a range of non-specialist settings, such as GPs, Police, Accident & Emergency.
- Workforce development, both specialist and generic, should aim to raise awareness of the needs of adult family members and provide training in evidence-based interventions to increase provision.

In terms of funding, it appears that the current level of provision is likely to be lower than the need, so funding needs to increase to deliver appropriate services.

In summary, there has been a welcome increase in attention to families affected by drug use, which has been facilitated by the *Road to Recovery* strategy. Considerable numbers of adult family members are affected by a relative's drug use; the impact on them is great and they also have an important role to play in supporting their relative's recovery. This study suggests that while there are good examples of service provision for adult family members affected by a relative's drug use in Scotland the quantity and range of provision is insufficient when considered alongside the numbers affected. However, it was clear from the interviews conducted that there is an interest in and appetite for improving provision and we hope that these research findings will help that process.

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## **Appendix 1: Policy Documents included in the review**

#### Scotland – 13 documents

The Road to Recovery - a New Approach to Tackling Scotland's Drug Problem

The Road to Recovery - One Year On

Caring Together - The Carers Strategy for Scotland 2010-2015

Safer Lives: Changed Lives. A Shared Approach to Tackling Violence Against Women in Scotland

National Domestic Abuse Delivery Plan for Children and Young People

Towards a Mentally Flourishing Scotland: Policy and Action Plan 2009-2011

The Early Years Framework

Getting our priorities right - policy and practice guidelines for working with children and families affected by problem drug use

Hidden Harm - Next Steps - Supporting Children: Working with Parents

It's everyone's job to make sure I'm alright report of the Children Protection Audit and Review

A Crime Prevention Strategy for Scotland 2006-2009

Alcohol and Drug Strategy: A framework for partnership action 2011-2014

Protecting children living in families with problem substance use - guidelines for agencies in Edinburgh and the Lothians

Scottish Government (2008) - 95 pages

Scottish Government (2009) - 19 pages

Scottish Government (2010) - 153 pages

Scottish Government (2009) - 30 pages

Scottish Government (2008) - 89 pages

Scottish Government (2009) - 56 pages

Scottish Government (2008) - 44 pages

Scottish Executive (undated) - 77 pages.

Scottish Executive (2006) - 35 pages

Scottish Executive (2002) - 211 pages

Association of Chief Police Officers in Scotland (undated) - 15 pages

Edinburgh Alcohol and Drug Partnership (2011) - 18 pages

Unauthored (2005) - 78 pages. There is also a guidelines leaflet (6 pages) and a guidelines summary (6 pages)

## **Appendix 2: Survey questionnaire**

## Supporting the Supporters: mapping services for adult family members of people with drug problems

This is the second stage of a project looking at the help available to ADULT FAMILY MEMBERS\* affected by a relative's drug problem, which is funded by the Pilgrim Trust, Scottish Families Affected by Drugs and Adfam. The aim of this phase is to map the extent and nature of current provision of support for this group to identify gaps and highlight good practice. We want to look at all types of provision throughout the UK.

If you are a service that provides support to adult family members and/or carers of people with drug problems, whether to the families/carers only or alongside or as part of treatment provision to their drug-using relative, we would be very grateful if you would complete this short questionnaire. It should not take more than about 10 minutes.

As we want to map provision we would like a separate questionnaire completed for each local service so if you are a service provider with services in a number of different localities we would be grateful if this could be sent to the managers of each service.

If you have any queries about the survey or who should complete it please contact Professor Alex Copello at a.g.copello@bham.ac.uk. Many thanks

for your help.

\* We use the term 'family members and carers' throughout to denote people who are family members of someone with a drug problem or, in some cases, people who are not part of the family but who are very close and concerned about someone with a drug problem and provide support and care to them on a consistent basis.

1	Do voi	ı provide	services f	for adu	ilt family	/ members	/carers of	drug u	sers.
Ι.		a pi ovide	3CI VICC3 I	oi aut	ait rairiii	/ 1110111111111111111111111111111111111	/ Cal Cl 3 Oi	uruy u	<b>3CI3.</b>

- as part of a generic carers service (supporting people caring for individual's with a variety of conditions)?
- as part of a service for substance users?
- as a service solely targeted at adult family members of substance users?
- To Other (please specify)

#### 2. Is your service for family members/carers of people who have problems with:

- Drugs only
- Drugs and alcohol
- Alcohol only (→ Exit questionnaire)

#### 3. Who does your service provide help for? Is it: 🖈

- $_{\overline{\hspace{-0.05cm}}}$  only for the adult family members/carers affected by a relative's drug use  $( o\!$ Go to O5)
- or is help provided alongside other services for the drug using relative?

	Less than	10-25%	26-50%	51-75%	76%-90%	Over 90%
	10%	10-25%	20-30-70	31-73-70	7070-3070	Over 90%
seeing family members/carers on their own (whether or not the drug-using relative is involved with your	j	j	j	j	j	j
ervice)?						
seeing family members/carers alongside their drug-	j	Ď	j	j	j	j
ising relative?						
5. What types of support or interventions do	you provide fo	or family	members/ca	rers? (Tic	k all that a	pply)
■ Information provision & signposting		€ 5-s	tep intervention			
Advocacy support		€ Co-	dependence bas	sed intervention	ons	
Individual mentoring service		<b>e</b> 12-	step intervention	าร		
Counselling		<b>€</b> Gro	oups (including p	eer support)		
Bereavement support/counselling		e Cris	sis support			
Other (please specify)						
5. What interventions do you use when you cogether?	work with drug	j users a	nd family m	iembers/ca	arers	
Tick all that apply)						
Does not apply (family/carers service only)		e Rel	ationship Couns	elling		
Behavioural Couple Therapy		Far	nily Therapy			
Group work		€ Soc	cial Behaviour ar	nd Network Th	nerapy	
Other (please specify)						
_	_		-	-	-	-
7. Do you provide adult family member/care	r services as pa	irt of a p	artnership	arrangen	nent?	
Yes						
■ N- ( ) C- +- OO)						
No (→ Go to Q9)						
NO (→ GO tO Q9)						
NO (→ GO tO Q9)	_					
NO ( <del>-&gt;</del> GO to Q9)						

	What methods do you use to provide your services.  k all that apply)
e	Face-to-face
ē	Telephone
e	Internet
e	Other (please specify)
	10. Is your service:
Ď	NHS
ij	Voluntary/Non-statutory
Ď	Private
Ó	Social Services
Ď	Other (please specify)
	Thinking about the services that you currently provide for adult family members/carers. Do you think to over the next 12 months the level of services that you are able to provide will:
	you are unsure can you please make a 'best guess')
jji	Increase substantially  Increase a little
ji 	Stay roughly the same
ji *	Decrease a little
ji ij	Decrease a lot
er Nj	Cease altogether

12.	How many staff (including volunteers) work in the service	e. (	Please give your answer in full-time
	uivalents)	•	<b>5</b> ,
ji	Less than 5		
Ď	5 to 9		
Ď	10 to 14		
j	15 to 19		
jji E	20 or more		
Ď	Don't know		
12	In what part of the United Kingdom is your consist locat	tod?	
13. j	In what part of the United Kingdom is your service locat Scotland	teu:	West Midlands
ij	Wales	ij	East Midlands
m	Northern Ireland	j	East Anglia
j j	North East England North West England		Greater London South East England
j	Yorkshire & Humberside	j	South West England
14.	For services in Scotland only: Are you happy for us to pa	ss th	ne details of your service, eg address and
oth	er contact information, to Scottish Families Affected by I	Drug	s (SFAD) so that they can keep you informed
of	relevant activities?		
_	v		
j	Yes		
Ď	No		
15.	Asked of all: Would you be willing to help with a more in-	-der	th survey conducted in the future?
	, , , , , , , , , , , , , , , , , , , ,	-	•
-	ease note that we will not be contacting everyone who ticked if we do contact you?	KS T	es and you will be at liberty to change your
	nd if we do contact you).		
ń	Yes		
ń	No		

	y aspects of your work with family members that you would like to highlight as a model
here or alternatively	ovation? If so, please tell us about them if you prefer to contact us directly with information and documents describing mail us at: a.g.copello@bham.ac.uk or send them to:
Professor Alex Cope School of Psycholo The University of Bir Edgbaston	ello gy
B15 2TT	
form. This will help ι	provide the address of your service and the name of the person completing this us map the service provision across the country. We will not use this to contact you for unless you granted permission at question 15. (Please ensure you give us your
Very many thanks for your	help with this survey.
If you want any more info nsingleton@ukdpc.org.uk	rmation about the research preogramme more generally please contact Nicola Singleton at or phone 020 7812 3794.
the impact this had on the	nase of the study, which investigated the number of adults in the UK affected by a relative's drug problems, ir lives and the ways in which they could be supported were published in 2009.

## Appendix 3: In-depth interview schedules

#### ADP co-ordinators interview schedule

This is a mapping exercise surveying the provision of services to meet the needs of adults affected by a family member's substance misuse problems

- 1. What services are you aware of in your area?
  - a. Are there any services that you specifically commission?
- 2. Can you describe what is specifically provided for family members?
- 3. Are there national or local policies that have influenced the range of provision?
  - a. How well do you think the services available reflect policy and guidance?
- 4. What factors influence the range of provision available?
- 5. How many families or individual family members receive services?
  - a. How does the extent of services delivered reflect local prevalence?
- 6. What are the arrangements for data collection and monitoring?
  - a. How does data inform planning and commissioning for family members?
- 7. What requirements are there for the levels of expertise and training for those providing services to family members?
- 8. Are there any developments in provision for family members that you would like to see in your area?
- 9. What would help to improve the services for family members in general?
- 10. Anything else you would like to say?
- 11. Please can you provide us with the following contact information for:
  - a. Family services: specialist substance use agencies or generic carer agencies
  - b. Specialist treatment services (Tiers II & III)
  - c. Affected Family member services

#### Semi structured questionnaire for service providers

- 1. Please describe briefly your organisation and the services you provide?
- 2. Do you deliver any services to adults affected by a family member's substance use? If yes, can you describe what they are.
- 3. Is there a model or theory underpinning the services you deliver? Please describe.
- 4. How do people hear about and get referred to your services?
- 5. How many family members do you help each year (if available ask for figures or estimates for last year)?
- 6. Are the services for family members being evaluated?
- 7. Have the people providing these services received specific training? What are the supervision arrangements?
- 8. What are the key policies, if any that guide this work (confidentiality, safety)?
- 9. What other organisations can you refer family members to for help and support?
- 10. Are there any other services you know about in your area that are provided for family members of people with substance use problems?
- 11. Where do you get your funding from? What is your annual turnover? Are you experiencing/anticipating any funding difficulties? What are the funding arrangements for the family member components of your service?
- 12. Are there any developments in provision for family members that you would like to see in your area?
- 13. What would help to improve the services for family members in general?

# **Appendix 4: Review of ADP strategies for in-depth study areas**

Area		Consideration of Families and Carers
		Scotland
	No. of mentions	Review
Scotland (S)	23	The ADP vision states that they are committed to supporting and achieving better outcomes for individuals or families affected by substance misuse. The focus on family members is linked to a local needs assessment that was conducted in 2010; this identified a significant gap in services available for family members and that "more support was needed for families and carers." The strategy has seven core outcomes that need to be achieved by 2014; commissioned partners will be expected to develop their services to achieve these outcomes. One outcome specifically addresses the needs of family members: "Children and family member of people misusing alcohol and drugs are safe, well supported and have improved life chances." Furthermore, in line with the Scottish Executive document 'National Quality Standards for Substance Misuse Services' (NQS) there is recognition of the importance of service user involvement in the development of services. Having carried out a pilot project on this last year the ADP is committed to involving both "service users and their families" so "they are at the centre of the services offered to them." No additional details are provided as to how the ADP will ensure these outcomes are achieved.
S	26	Outlines several key priorities over 2010-2012 which includes several references to family members; the main focus is however on safeguarding children and young people affected by substance misuse. Aims to deliver and evaluate more parenting programmes, particularly to kinship carers. Recognition of the importance of community engagement; a key priority includes working "in partnership with the local Substance Misuse Forum representing the views and experiences of service users, their families, community groups and service providers" so that they can inform future priorities and actions of the ADP. Furthermore another community engagement priority includes offering support and information to families by working "with the Scottish Association for Families Affected by Drugs." Part of the action plan for 2011 includes delivering overdose prevention training to both service users and carers. A plan of action is summarised alongside each priority, outcomes are measured against set performance indicators but it is not clear how this information will be collected and timescales.
S	49	The executive summary states that from both national and local data available it is apparent that "positive work is taking place protecting vulnerable children and adults from the impact of alcohol and drugs, but we recognise the need for continuous improvement." A large part of the vision for 2011-2015 responds to this and outlines a number of priorities to ensure services meet the needs of families. This includes a work stream that focuses on "prevention and early intervention," identifying and providing support to family members as early as possible "to reduce the negative impact this behaviour has." A core outcome for this work stream is stated as ensuring that children and adults are "well supported and have improved life chances;" little detail is provided as to how this will be measured. Part of the ADP's strategy recognises the importance of using families' experiences and feedback "to the on-going process of services improving" and they are committed to using this knowledge to inform their approach. Section at the end outlines an action plan to provide "overdose awareness and training sessions for families and concerned significant others;" with a target of training 20 individuals a year. Two national documents ('The Road to Recovery' and 'Changing Scotland's Relationship with Alcohol') have significantly contributed to the vision outlined in this strategy and the local and national outcomes they have set and hope to achieve.

S	8	The strategy for 2011-2016 is heavily influenced by the national document 'The Road to Recovery,' which sees a greater emphasis on moving treatment services to "placing a clear focus on recovery." As part of this the ADP plan to have an integrated treatment service that will enable "family support services within treatment services." No details are provided as to how or when this will be achieved. Furthermore, it is not clear whether these services will include support that family members can access in their own right. The role of families and service users in developing services is recognised and identified as being important; a key short term outcome to be achieved over the next two years includes "increased involvement of service users and their families in service delivery and design." Again, no details are provided in relation to how or when the ADP hopes to achieve these outcomes. A key priority and vision outlined in the strategy is to make "individuals and communities affected by substance misuse safer" however in reviewing how this outcome will be achieved there is a greater focus on children; no reference is made to families or adults: "collect relevant data on the extent and nature of the impact of parental substance use and the impact on children."
S	6/14	The strategy for 2011-2014 is structured around three main priorities, one of which focuses on "protecting vulnerable groups" which includes both children and adults affected by substance misuse. A comprehensive action plan provides details of set objectives to "reduce the harm caused by drug addiction" by (1) working towards improving the capacity of universal services to "identify the needs" of vulnerable adults affected by substance misuse, (2) "improve practice, assessment and risk management," and (3) improve "responses and outcomes." The rationale for each objective, how it will be measured and who is responsible is provided; the objectives are shaped by both national and local documents including the city ADP Strategy Consultation feedback process (2011) and the Scottish Governments Core Outcome indicators for ADPs (2011). The document indicates that work has started to achieve set objectives however" more is still required" which will be the focus over the next three years. Furthermore, the ADP recognises the importance of joint working between services to inform service development and recovery of service users: "Continue to improve joint working between community forums, family support groups and the Recovery Network of the city."
S	54	The strategy for 2011 is informed by a local needs assessment that was conducted over 2010-11 to establish met and unmet needs, and national outcomes outlined in two key government policies 'Road to Recovery' and 'Changing Scotland's relationship with alcohol.' The ADP is committed to supporting children and families; there are family support groups available for "families affected by someone's drinking" but not those affected by drugs. There is a focus on developing such groups by working with "Scottish Families Affected by Drugs." Another priority area identified is to develop "more formal family support interventions" and "information systems to gather more robust local data regarding family support." Although an action plan is attached detailing actions and expected outputs to meet each priority little indication is provided as to how they will be measured. There is recognition of the importance and need to engage service users, carers and their families "in the ongoing planning and decision making for future service provision." The local needs assessment identified this as an area that needed to be improved.
S	53	Supporting children and families affected by substance misuse is identified as one of the key priorities set out by the ADP for 2009-2011. The vision set out is heavily influenced by national documents including 'The Road to Recovery,' 'Changing Scotland's relationship with Alcohol' and 'Audit Scotland: drug and alcohol services in Scotland.' The focus is on developing "networks of support for families and carers" by working with the Scottish Network for Families Affected by Drugs (SFAD) to "develop self-help and recovery groups" and continue to provide "one to one support through those services commissioned through health, social work and the third sector." There is a focus on keeping family members better informed and supported in local services, developing improved assessments and outcomes. There is also recognition of the challenges faced in engaging family members and the need to work with SFAD and the Scottish Drugs Forum to identify ways to "engage with those not already accessing services and look at how we can meet their needs." Details are provided in an appendix on the lead officers responsible for meeting each outcome, their targets and the resources that can be used, however there is no information as to how these outcomes will be achieved.

services will be developed.
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# Appendix 5: Summary of the findings from the qualitative analysis by ADP area

Table A5.1: Understanding, strategy and vision

	Area 1S	Area 2S	Area 3S	Area 4S	Area 5S	Area 6S	Area 7S	Area 8S
Knowledge and	Good knowledge	There is an	Awareness of the	Some	The way our	Robust	Perception at	Good grasp of
Understanding	and recognition	awareness of	problem and	acknowledgement	services are	knowledge,	commissioning	the problem
of the problem	of the problem.	the needs of	needs of family	although the	delivered,	awareness and	level that	and contact
	High level of	family	members. There	emphasis is more	currently our	recognition of the	families affected	with family
	focus on	members.	have been	on children rather	main services	problem. Focus on	by drug use are	members but
	children and	"the level of	attempts to	than adults	focus on	family members	not an area of	more on an
	kinship care.	provision is	develop support	affected and drug	individuals and	has been on the	priority. More	informal basis.
	Identification of	much lower	groups that have	users themselves.	their	agenda for a	focus locally on	Main emphasis
	the need for a	than the need	not always been	'Our services are	treatmentnot	number of	alcohol than	on supporting
	range of	out there. The	successful.	predominantly	kind of the wider	years. One family	drugs overall	groups.
	services: carer	issue we have is	Perceived	focused on the	role of family'.	support service	and sense that	Identified a
	generic services;	that particularly	problems with	alcohol and drug	Recognition that	set up in 1984.	the number of	need for the
	specialist carer	the needs of	stigma and rural	users themselves'.	national policy	Ample	families affected	ADP to have
	services and	adult carers are	area spread.	Adult family	perceives	involvement and	is low.	someone with
	involvement in	not picked up	Focus more on	Adult Idilliily	families as	consultation with	Perception that	a specific remit
	the treatment of	by treatment	alcohol but	nerreived sc	important but	fms about extent	there is no	to work with
	the person using	providers. 'Need	perception that	perceived as	not seen as a	of services	evidence from	family
	drugs. Emphasis	to change	carer services are	idontif,	priority. 'We've	delivered,	services that	members.
	on supporting	culture of	strong	ומבוותו .	no idea what	development of	large numbers	More services
	the whole	treatment			people want'	future services	of family	for young
	family. 'We are	services to be			Identified local	and service	members are	people.
	at an early	more family			need in general	improvements -	seen	
	stage.'	friendly'			but no specific	cited as example		
					prevalence work	of good practice in		
						the Road to		
						Recovery		

A UK-wide survey of services for adult family members

	Area 1S	Area 2S	Area 3S	Area 4S	Area 5S	Area 6S	Area 7S	Area 8S
Strategy and	Recognition of	Not evident	Family members	Strategy identifies	No clear vision	Recognition of the	-	Recognition of
Vision	the importance	from interviews.	seen as	need to focus on	or strategy	importance of	'services' for	the needs of
	of families and	Appears	important and	family members	articulated	families and the	families affected	family
	the need to	underdeveloped	needs	but barriers are	locally. Not	need to involve	by drug	members.
	consider families	. Need to	recognised.	perceived i.e.	perceived as a	fms in order to	problems not	Aims to
	when a drug	improve fm		stigma,	priority.	inform service	perceived as	continue to
	problem is	services.		identification and		delivery and	priority or	support fms
	present.			rural spread.		development.	significant	but funding is
							problem locally.	limited.

Note: the abbreviation fm or fms is used to indicate 'family member/s'

Adult family members affected by a relative's substance misuse

Table A5.2: Implementation

	Area 1S	Area 2S	Area 3S	Area 4S	Area 5S	Area 6S	Area 7S	Area 8S
Services	-Carer service provides emotional and practical support -Counselling -Short breaks -Alternative Therapies -Telephone support -Self -help groups -Intensive Family Prevention Programme -Support for kinship carers	-Information -Advice -Signposting -Emotional support -Counselling in their own right -Courses for fms -Joint work with fms and users -Some respite -Some respite -Some self-help but patchy -Support for kinship carers	-Practical support, information and signposting -Family support groups -Carers assessment -Counselling, telephone or face to face -Specialist counselling support	Mostly delivered by one service -Signposting -Face to face support -Counselling -Respite -Alternative therapies -Naloxone training -Self help groups	-Information and advice -Emotional and practical support -Signposting -Counselling -Alternative Therapies -Attempts to support through treatment for users but limited success	-Practical and emotional support -Signposting -Counselling -Respite -Parenting training (some geared at kinship carers) -Alternative therapies -Bereavement groups -Yearly remembrance service -Kinship services -Involvement in users' treatment -Naloxone training -Community events	Most provision through more generic services apart from specific addiction advisory service that offers 1 to 1 counselling -Signposting -Support -Emotional support -Counselling -Group support was available but no uptake	-'ad hoc' support -Support groups - Alternative therapies -Counselling -Helpline -Support with housing -home support -Involvement in user treatment -Naloxone training
Developme nts influenced by:	'Road to recovery' Local needs and fm representation	Developme influenced         'Road to recovery'.         Local strategy and recovery' Local consultation linfluenced needs and fm carried out but representation carers'         Local consultation documents. 'Road consideration carers'         In Recovery' and documents. 'Road documents.' Road consideration limited.' Demand'         'National strategy and documents.' Road consideration limited.' Demand'         'National strategy limited.' Demand'	Local strategy and National documents. 'Road to Recovery' and 'National strategy for carers and young carers'	National policy	National policies focused on carers and on recovery. 'Ad hoc' developments influenced by experience and knowledge at a local level	National strategy, 'Road to Recovery' also local strategy focused on supporting vulnerable children and adults. A lot has been developed out of need	'Road to recovery' quoted as influential. Also national domestic abuse delivery plan.	'Road to Recovery' quoted as influential. Also 'Changing Scotland's relationship with alcohol'

Note: the abbreviation fm or fms is used to indicate 'family member/s'

Table A5.3: Treatment systems

A UK-wide survey of services for adult family members

	Area 1S	Area 2S	Area 3S	Area 4S	Area 5S	Area 6S	Area 7S	Area 8S
Overall adult family member target	Not evident	Not evident	Not evident	Not evident	Not evident	Not evident – some for separate services	Not evident	Not evident – some for separate services
Assessment of adult family members	Through the various service components	Mostly through the different services	All services refer to one carer service as first point of call for assessment	Within fm service. Carers assessments available but limited uptake	Mainly generic. Some fm involvement in treatment services for drug use but low volume	Within fm services and also treatment services for drug use – generic carers centre offers assessments	Within each separate service	Within separate services
Outcomes	Only within individual programmes e.g. Family prevention programme.	Mostly for drug users. `in our monitoring of services we don't put in outcomes for carers at all'	Some outcome evaluation through commissioning. ADP has set of outcomes services have to meet.	Robust measurement of outcomes within the main fm service – not reported to ADP	It's a kind of grey area with carers because there are no specific outcomes; it is something that is being developed	Some examples of robust outcome measurement	Some measurement within services	Some process measurement
Monitoring	No robust system at present. Developing substance misuse information system that will allow recording of fm activity in the future. Risk of 'Double counting' 'Services for fms are popular'	System in development. Quarterly reports but emphasis on users and not fms. Perceived as challenging process	Some fm services appear to have robust recording systems. Patchy across the whole system.  Developing different ways of recording.	Robust monitoring system within the main service provider – both phone calls and visits –not reported to ADP	Generic carer services – low volume Drug user treatment services: 'It is not something we are required to monitor'	High volume of work through the various services. Robust monitoring systems.	Some monitoring of individual services but no robust family member focused system	No robust system for family members although some figures are available

Adult family members affected by a relative's substance misuse

N N	Not clear	Not clear, Some signposting and cross referral from separate service provider organisations	Various services trying to improve pathways and awareness of services for fms	Pathways between the two main services appear pretty clear. Some feeling that support to Fm and their drug-using relative should be delivered in the same place: "More joined up." Need more 'joined up' working.	Predominantly self- referral of fms. Some signposting between services	There appear to be clear links between the different services- this has been helped by community events	Mostly self-referral into services	Not clear
	ADP coordinator has good grasp of all service components. Communication patchy between services	Appears patchy	Good communication between services. Carer strategy development officer.	Unclear from interviews how robust communication is. Uncertainty of funding of main service provider for fms	Appears to be patchy – services make little mention of other services	Robust communication between services	Appears to be robust knowledge of different services	Appears to be good between services
	Involved in various groups	Not at present. Felt to be a gap	Some representation but not formalised	Not evident	Currently user rep. 'Including family members is the next step'	Good communication between commissioning and family members. Fmsinvolved in various service management committees	Not evident	Not evident Some more 'ad hoc' communication
	Some family specific within treatment components e.g. Family prevention programme	Not family specific	Mostly focused on carers assessments and counselling. Current work on training carers	Within the fm service	Generic training for thise conducting assessments. Some specific family training planned for the future	Current work to develop training programme addressing working with families affected by drugs	Some family and addiction focused training through STRADA	Addiction focused, some delivered by SFAD and STRADA