

# The Forgotten Carers: Support for adult family members affected by a relative's drug problems

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This briefing provides an overview of the key findings and implications of a study investigating the extent and nature of support provided to adult family members affected by a relative's drug problems. It brings together the findings from three pieces of work, the full reports of which are available at: [www.ukdpc.org.uk/reports.html](http://www.ukdpc.org.uk/reports.html).

## **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 family members' employment, their social lives and relationships, and the family finances.

The work described in this overview was concerned with adults who have a relative with drug problems. This group includes people in family relationships with the person using drugs, including partners, parents, siblings, grandparents and other adult relationships such as uncles, aunts etc. Commonly, adult family members are concerned about the person using drugs and affected by the ripple effects and consequences when drug use becomes a problem.

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 for their drug-using relative, i.e. reduced substance misuse, 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 may need help to meet their own pressing needs but also to assist them to provide effective support to 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 drug treatment services has been first and foremost towards helping the person with the drug problem. To put this in perspective, earlier research for UKDPC estimated that in 2008 in the United Kingdom, at the very least:

- 1.4 million adults were significantly affected by a relative's drug use (including about 140,000 adult relatives of people in drug treatment);
- the cost of the harms they experienced was about £1.8 billion per year; and
- the value of support they provide would cost about £747 million per year (at 2008 prices) if it was to be delivered by health and social care providers.

Clearly, families and the support they give are a crucial asset to the individuals needing their backing and for the wider community. But we know little about their needs and what services are available to help them. This study sets out to provide information about this.

This second phase of the UKDPC programme of work 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 in order to help improve provision. It used a multi-method approach that included a review of policy and guidance documents, a national web-based survey of provision and an in-depth qualitative study of twenty areas in England and eight Alcohol and Drug Partnerships (ADPs) in Scotland. The aim of this work was to drill down from national to local policy and provision, exploring where possible the extent to which adult family members were identified specifically in national policies and whether this recognition of need was making an impact at the local level both in terms of local strategies and also service provision.

## **OVERVIEW OF METHODS USED**

The second phase of the project involved three tasks:

- A review of policy and guidance. Over 50 documents from six areas of social policy from across the four countries of the UK were reviewed thematically.
- A web survey of 253 services across the United Kingdom.
- An in-depth mapping exercise of current support provision. This involved 100 qualitative interviews across England and Scotland. In England 63 interviews (20 commissioners of drug treatment and 43 treatment service providers and other key informants) were conducted across 20 areas from five regions (North East, West Midlands, East Midlands, London and the South West). In Scotland 37 interviews (8 Alcohol and Drug Partnership [ADP] coordinators and 29 service providers and other key informants) were conducted.

A summary of the methods used is given below. Full details for each of the three project components can be found in the separate reports of each element.<sup>1</sup>

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<sup>1</sup> Templeton and Copello (2012) *Adult Family Members Affected by a Relative's Substance Misuse: A Review of Policy and Guidance Across the UK*. London: UKDPC;  
Copello and Templeton (2012) *Adult Family Members Affected by a Relative's Substance Misuse: A UK-wide survey of services for adult family members of drug misusers*. London: UKDPC; and

## REVIEW OF POLICIES AND STRATEGIES

The approach taken by this review was informed by a paper by Velleman<sup>2</sup> which explored how drug and alcohol policy across the UK considers the needs of families. 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:**

1. 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 were identified in a number of ways including: (i) documents identified through Velleman's review; (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 representatives in each country, usually from individuals who were members of the expert Project Advisory Group.

Hard copies and/or electronic versions of all documents were obtained for review. Analysis was broad and thematic. Where appropriate electronic 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<sup>3</sup>. Shorter documents, or those which were obviously directly relevant, were read in more detail.

## WEB SURVEY OF SERVICE PROVISION

An online survey<sup>4</sup> questionnaire was developed by the Research Team in consultation with 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. The survey was advertised across the UK through a range of channels: by e-mail but also other forms of communication such as newsletters.

## QUALITATIVE MAPPING EXERCISE OF TWENTY EIGHT AREAS ACROSS ENGLAND AND SCOTLAND

Areas for 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 inner city, city, town, rural and semi rural areas in both England and Scotland.

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Copello, Templeton, Chohan and McCarthy (2012) *Adult Family Members Affected by a Relative's Substance Misuse: Qualitative interviews with Commissioners and Service Providers in England and Scotland*. London: UKDPC Available at [www.ukdpc.org.uk](http://www.ukdpc.org.uk)

<sup>2</sup> Velleman R (2010) "The policy context: Reversing a state of neglect." *Drugs: Education, Prevention & Policy* 17(S1): 8-35.

<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>4</sup> Using SurveyMonkey.

The areas that were surveyed in England were selected from five regions that included: East Midlands; West Midlands; London; South West and North East. Four Drug (and Alcohol) Action Team areas were selected at random from each of the five regions, giving a total of 20 areas for inclusion in the study.

The main drug service commissioner was identified for each of the 20 areas and a semi-structured qualitative interview was arranged and conducted. All interviews except for one were conducted by telephone and recorded with the interviewees' consent. Towards the end of each interview, the key commissioner was asked to identify key informants from all the services in their area that provided support to adult family members/carers of people with drug problems and contacts for these were obtained. Service providers were then contacted and telephone interviews were arranged. In some cases interviews were also conducted with carers and/or service user representatives. A total of 43 interviews with service providers were completed. In most areas all services identified were interviewed but in a few cases it was not possible to make contact with the service within the project timescale and, as a result, in three areas no service provider interviews were carried out.

In Scotland eight areas were identified in consultation with key informants 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 area in Scotland was the Alcohol and Drug Partnership (ADP) coordinator. For each area the ADP coordinator was identified, approached and interviewed by telephone. As in England, 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.

Drawing from the findings of the three components, the remainder of this overview begins with a section focused on national policy and guidance. It then considers the level of local recognition of needs of this group before considering the extent and nature of service responses across the UK and at a local level. Recommendations are put forward at the end of each section.

## **ADULT FAMILY MEMBERS IN NATIONAL POLICY AND GUIDANCE**

To what extent are the needs of adult family members recognised in national policy and strategy documents?

Over 50 documents were reviewed. The documents included policy documents (about one third) with the rest consultation documents, guidance to support the implementation of national policy, or 'manifesto' type documents intended to influence the direction and development of policy. Some key points emerged from this review:

- There is a welcome more overt recognition than had been the case in previous years, of how substance misuse affects families and some mention of the support needs of such families within national drug strategies (which often now incorporate alcohol).
- For the most part, the focus has been on risky/vulnerable families and/or children affected by parental substance misuse, while other groups of affected family members, including adult family members, have been less prominent. Much of the

progress which has been made appears to stem from the ACMD 'Hidden Harm' and DfE 'Every Child Matters' and the Social Exclusion Task Force 'Think Family' policy agendas.<sup>5</sup>

- In general, few policies or strategies provided detail on exactly how to support adult family members, and how to involve them. Nevertheless, there are some examples of good practice and of some progress which has been made to carefully consider how to support adult family members affected by drug misuse.
- Policy and supporting guidance tends to take a broad approach to dealing with the issues of families. It is unusual for sub-groups of family members, or those with particular needs, to be considered.

In addition, documents from a range of other related policy areas, such as Carers, Children and Families, Domestic Violence and Offender management, were reviewed to see the extent to which they recognised the issues of adult family members/carers affected by a relative's drug problems. In terms of generic carers' strategies, and generic child & family policy, there is indication that family members of substance misusers are being recognised as one of a number of specific groups with particular needs and where more specific attention and investment was identified. However, references were general with little detail on what support these groups might need.

There is some evidence that drug policy is alert to the need to work closely with domestic violence policies and programmes. However, there is little evidence from domestic violence policy, or from mental health or criminal justice, of the recognition of families affected by substance misuse. It can be concluded that there are missed opportunities for more integration and to dovetail policy and guidance as well as to cross refer between policies where areas such as adult family members overlap or similar recommendations can be made e.g. domestic violence and mental health and substance misuse. In a period of austerity, greater integration and efficiency is sought across the board and there is clear potential to do this here, at the same time benefiting families by improving pathways and access to services.

Although within substance misuse strategies across the UK there is increasing recognition of the needs of adult family members, as shown in Box A, the lack of specific identification of this group and detail of what needs to be done practically towards supporting them is an important gap. The kinds of practice issues that need to be covered include:

- Identification and assessment processes;
- Service delivery models and development;
- Workforce development opportunities;
- Monitoring of interventions including evaluation; and
- Delivery and implementation issues.

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<sup>5</sup> Advisory Council on the Misuse of Drugs (2003) *Hidden Harms*. Home Office  
*Every Child Matters* (2003) Cm 5860 The Station  
Families at Risk Review (2007) *Reaching Out: Think Family*, Cabinet Office Social Exclusion Task Force.

### **Box A: Examples of increasing recognition of adult family members in substance misuse policies across the UK**

The *Road to Recovery* strategy in **Scotland** identifies supporting families as a priority. It includes over 100 mentions of 'families'. The impact on families is mentioned early on in the document and grandparent carers are specifically identified as a group of adult family members in need. Two specific issues identified include the need to "*build capacity, availability and quality of support services for children and families affected by parental substance misuse*" and to "*strengthen the focus of adult substance misuse services on the needs of children and families by including relevant outcomes in the commissioning framework*".

The Coalition Government's *2010 Drug Strategy* includes the commitment 'to consider the provision of support services for families and carers in their own right'. This is the first time that the specific needs of family members have been quoted within a national policy document in **England**. In 2008 the National Treatment Agency published its guide, for both commissioners and providers, on supporting and involving carers. The guidance considers both help to carers *in their own right* as well as how include carers in their relative's drug treatment.

A key development in **Wales** has been the publication of the Substance Misuse Treatment Framework. *Carers and Families of Substance Misusers. A Framework for the Provision of Support and Involvement* (undated). This is the only specific policy (rather than guidance) document in the UK which considers families and carers of substance misusers. The Framework is useful for a number of reasons. It seeks to involve carers in a range of ways, highlights that organisational responsibility for these issues should be shared, summarises the key steps to take and issues to consider when developing services for families, lists five quality standards for delivering quality services, and emphasises the need to provide dedicated support to carers as well as recognising the role they may play in supporting the misusers.

**Northern Ireland's** *New Strategic Direction for Alcohol and Drugs* (both Phase 1 2006-2011 and Phase 2 2011-2016) emphasises 'children, young people and families' as central to the strategy. Additionally, the Phase 2 Strategy recommends that "*....where appropriate, family-based interventions should be encouraged*", and has two (of seven) categories of outcomes which specifically consider children and families.

An example of a document that covers these issues more comprehensively than most is **The Isle of Man Implementation Plan: 'Supporting affected others living with substance misuse: a National Implementation Plan for the Isle of Man'** which contains the level of detail necessary to move beyond general discussion and point towards more specific action.

More specific mention of adult family member needs and recommendations is included in recent NICE guidelines. Two sets of NICE guidance both make (slightly different) specific recommendations relating to families. Guidance CG51 on psychosocial interventions<sup>6</sup> focuses on asking clients about family involvement and how families can be supported, as well as recommending BCT (Behavioural Couples Therapy) as an intervention; the 5-Step Method is also indicated although it is not referred to by name (see Box B). Guidance CG52 on Opioid detoxification<sup>7</sup> focuses on involving families and on assessment. However, as can

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<sup>6</sup> NICE (2008) *Drug misuse: psychosocial interventions: full guidelines*, Guidance CG51. BPS & RCPsych.

<sup>7</sup> NICE (2008) *Drug misuse: opioid detoxification: full guidelines*. Guidance CG52. BPS & RCPsych.



be seen from the findings of the web survey described below, there is a relatively low level implementation of Behavioural Couples Therapy across the UK. Furthermore, very low numbers of interviewees who participated in the qualitative study made reference to the NICE guidance as informing commissioning or service delivery in their areas.

**Box B: Excerpts from NICE Guidance CG51 relating to Adult Family Members**

1.1.2 Supporting families and carers

1.1.2.1 Staff should ask families and carers about, and discuss concerns regarding, the impact of drug misuse on themselves and other family members, including children. Staff should also:

- offer family members and carers an assessment of their personal, social and mental health needs
- provide verbal and written information and advice on the impact of drug misuse on service users, families and carers.

1.1.2.2 Where the needs of families and carers of people who misuse drugs have been identified, staff should:

- offer guided self-help, typically consisting of a single session with the provision of written material
- provide information about, and facilitate contact with, support groups, such as self-help groups specifically focused on addressing families' and carers' needs.

1.1.2.3 Where the families of people who misuse drugs have not benefited, or are not likely to benefit, from guided self-help and/or support groups and continue to have significant problems, staff should consider offering individual family meetings. These should:

- provide information and education about drug misuse
- help to identify sources of stress related to drug misuse
- explore and promote effective coping behaviours
- normally consist of at least five weekly sessions.

1.4.4 Behavioural couples therapy

1.4.4.1 Behavioural couples therapy should be considered for people who are in close contact with a non-drug-misusing partner and who present for treatment of stimulant or opioid misuse (including those who continue to use illicit drugs while receiving opioid maintenance treatment or after completing opioid detoxification). The intervention should:

- focus on the service user's drug misuse
- consist of at least 12 weekly sessions."

Source: Drug misuse: psychosocial interventions, Guidance CG51, NICE 2008

Overall the review of national policy and strategy shows that the needs of family members of people with drug problems are increasingly identified, recognised and considered. There was, however, only limited recognition of adult family members as a group with needs in their own right. The need to support drug users' recovery and the use the family as a vehicle to support drug user treatment features more often in recent strategies. Adult family members (i.e. partners, parents, kinship carers) as a specific group of people with significant needs, although included as part of general references to families, are rarely identified specifically.

### **Implications: Policy and guidance**

- Future policy documents should recognise and make specific reference to the importance of supporting adults who have a relative with drug problems (e.g. parents, partners, kinship carers) and the role they can play in supporting their drug-using relative in achieving recovery.
- Policy documents should reflect the need for services that provide support to family members both in their own right as well as in supporting their drug-using relative through treatment and recovery.
- There should be a way of monitoring the impact of national policy at the local level and the extent to which recommendations help develop a response commensurate with need.

## **FROM NATIONAL GUIDANCE TO LOCAL PLANS AND STRATEGIES**

However good national strategies are, unless these are translated into action at the local level, they will struggle to have an impact on the lives of families affected by drug problems. One Governmental region in England, the East Midlands region, had a specific Family and Carer Strategy (published in 2009)<sup>8</sup> that aimed to '*support the ongoing improvement agenda for drug treatment services across the region and promote the need for developments in family focused provision*'. In recognition of this priority afforded to families, the local adult drug treatment plans for the East Midlands region were reviewed, alongside those from the areas included the in-depth mapping exercise, to see if this regional strategy had been reflected in the consideration of families and carers in local plans. The snapshot of local treatment plans over two years (2009-2010 and 2010-2011 either side of the publication of the Family and Carer Strategy) in the East Midlands however, indicated that detail in relation to adult family members is still, with a few exceptions, a largely under-developed area and there was little or no reference to the regional 'Family and Carer Strategy' in the local policy documents.

Looking across the whole set of local treatment plans and strategies<sup>9</sup> suggested that:

- While there was fairly widespread recognition of the issue of families in the area treatment plans/strategies, the emphasis was mostly on children of drug users rather than on adult family members.
- Most plans/strategies considered involvement of family members in service planning and needs assessment but to varying degrees. The role of GPs and Tier 1 services<sup>10</sup> in identifying family members and their needs was only occasionally mentioned.

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<sup>8</sup> East Midlands Regional Family & Carer Forum (2009) *East Midlands Family and Carer Strategy*. London: NTA

<sup>9</sup> As well as the East Midlands treatment plans, 20 English DA(A)T treatment plans and eight Scottish Alcohol and Drug Partnerships (ADP) strategies from the in-depth mapping exercise were included.

<sup>10</sup> Tier 1 drug services are usually defined as interventions comprising drug-related information and advice, screening, assessment, and referral to specialised drug treatment services.



- There was significant variation between plans/strategies but in general there was less focus on meeting the needs of adult family members in their own right and a lack of specific detail about how their needs might be met.

In general, local policy appears to mirror the national documents in that there is some lack of specificity about the adult family member groups that are in need of help and support and this leads to lack of clarity about what range of service responses are needed in local areas. Whilst the children's policy agenda has progressed more from policy to action, the adult family member response has some way to go and is still hampered by the lack of clear and specific focus on the adult family members as a target group needing help in their own right.

### **LEVEL OF LOCAL RECOGNITION OF NEED AND COMMISSIONING PROCESSES**

Thematic analysis of qualitative interviews with all commissioners and coordinators (N=28) provided insight into how those in key local commissioning roles are responding to guidance and seeking to engage with and support adult family members. These themes are illustrated in the quotes from interviews with commissioners/coordinators shown below. The following key issues emerged.

#### ➤ ***Identifying adult family members as a target group with specific needs in their own right.***

The picture that emerged consistently suggests that there needs to be much more clarity in terms of identification of adult family members as a specific group of people with needs in their own right for example as partners, parents, grandparents. This is an important first step in the planning process.

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

#### ➤ ***Establishing estimates of prevalence***

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 commissioner/coordinator interviews acknowledged families and their needs but failed to provide more precise details or estimates of the extent and nature of local need. This is essential in order to guide more informed decisions about service responses.

*"We have prevalence data in terms of drug problems – we know something about our penetration rate in terms of that. In terms of the number of families we don't know an exact figure"*

*"we've yet to be able to get that data anywhere....there's huge gaps in terms of planning around family needs".*

*"...we go very much with what's being presented and what we hear from service users..."*

➤ ***Developing robust methods (and consistent across areas) for engagement of adult family members in the full 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 and promoting good practice information on better ways in which family members can engage further with these processes across all areas.

It was evident that there needs to be increased recognition of adult family member needs in their '**own right**' both at local and national policy/strategy/plans.

*"...part of that treatment spec is to put carers and service users right at the middle of the treatment system...we've viewed for some time the carers and family members as being one of the key stakeholder groups.....to have family members as "partners" in treatment services."*

➤ ***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 of considering the impact of 'shame' and 'stigma' in preventing adult family members coming forward and requesting help. Strategies should be adopted to minimise this impact.

The terminology used to describe adult family members, such as 'carers', can sometimes prevent self-identification by this group and prevent access to valuable services e.g. carer services. These services should be promoted more clearly in relation to this group.

*"...because of the stigma around alcohol and drug use tend not to identify themselves as a carer. Also the person with care needs, the actual drug user, may deny that they need or are getting support. So in effect they say they don't have a carer, so there's a two way thing here."*

*"....I think it's fair to say that there is a greater recognition but I still think we've got a lot to do....[for all that] there's a lot of activity. I think it can be piecemeal, I don't think we have necessarily advertised and have a robust referral and collective pathway, so obviously some families can fall into a void ...we need to get our act together and....we're trying to work closer with social care to integrate our services more effectively..."*

*"What would help family members access services?" - "Knowing what's available; how to access it and when to access it."*

In general there appeared to be a need to more actively promote services for adult family members. Where available, these should be promoted not just to the target recipients of the services but also to other more generic services, including primary care, which may provide an alternative access gateway. Commissioners/coordinators will need to develop links, and where necessary strategies, for engaging with these services and also with existing adult family member support networks in the area so that provision can be integrated.

The interviews also highlighted the particular challenges in more rural areas to achieving engagement of adult family members in services. In these cases different ways of engaging with family members, such as more use of the internet and telephone support or utilisation of self-help booklets, need to be explored.

➤ ***Prioritising family members within the commissioning agenda***

The interviews showed that there was considerable variation in the extent to which adult family members affected by a relative's drug problems were prioritised within the service commissioning agenda. A number of issues were highlighted, some of which, such as a lack of knowledge about numbers affected and the reluctance of this group to come forward, have already been highlighted. It was also clear that some commissioners were uncertain about what services should be provided and how this can be achieved.

*"There is always competing priorities and that's why carers is never number one and makes it to the top of the list"*

*"...but I suppose personally in terms of carer services we haven't really probably put as much money in to those services..."*

*"I don't think ... traditional commissioning processes are well placed to provide the services that this cohort of individuals requires. Or if they are, I haven't found a way of doing it yet. And what would be really helpful would be if there were a national advisory service who could offer support to commissioners to develop a service of this nature, based upon a collection of good practice examples"*

However, some areas have taken steps to improve provision for this group and two examples are given in Box C.

➤ ***Developing systems to improve and support provision***

As part of the qualitative exploration with commissioners/coordinators and providers, we aimed to establish how robust the commissioning and monitoring systems were in supporting the delivery of a response to the needs of family members. For example, were there any targets for number of individuals supported or any way of measuring activity or outcomes for this group?

It is clear that this is a weakness in many areas that, to some extent, stems from the already identified lack of clear identification and prevalence for this group. This leads to lack of clarity in terms of 'targets' with most areas not having an identified overall target for this activity. Where targets were mentioned (this was the exception rather than the rule) they tended to be for a specific service and not across the range of responses. This to some extent is also a reflection of the fact the responses to adult family members take place across different services within different delivery systems e.g. primary care, social care, specialist drug treatment. All these services will be coming into contact with family members but it is difficult to coordinate provision and still harder to develop ways of monitoring and reporting the work in a comprehensive, integrated and coordinated manner. The system of support for adult family members as a result appears to be underdeveloped. Monitoring is inconsistent and weak, and outcome measurement is mostly absent or in its infancy apart from in specific treatment programmes, mostly focused on whole-family approaches.

One interesting development is the inclusion in the outcomes under development in Scotland against which ADPs will be required to demonstrate progress of an outcome specific to family members. Originally this outcome was:

*"Outcome 4: 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".

Having such an outcome is very valuable. Although it is currently 'badged' as relating to Children Affected by Parental Substance Misuse (CAPSM) it does cover other family members as well. There is a consultation process underway (as of March 2012) on the basis of which it is likely that this broader coverage will be made more explicit.

**Box C: Positive approaches to adult family members**

Solihull – Involving adult family members and monitoring activity

"...we developed a user and carer agenda and the carer representatives that we managed to support and develop have done an awfully good job for us and brought to our attention the needs of families in this area and that has very much been a local development. Our carer representative..... has played a very important part and we've been happy to have him on things like Needs – Annual Needs Assessment Expert Groups, so he's raised the issue there. He's been a member of our annual Planning Forum for our annual planning exercise and he's obviously raised the issues there and we've been very happy for him to do so."

"The data collection is done by SIAS (Solihull Integrated Addiction Services – a statutory non-statutory treatment partnership) and SIAS has the responsibility to collate data on what it's doing and report it to us: and the number of people – the number of family members who they are individually supporting i.e. the people – the number of cases of care planned support to family members is one of the items and the amount of general contact say at group meetings or whatever, the number of people attending group meetings, the number of family members are also all a set of items we require SIAS to collect and report to ourselves. More importantly they have to report them to our carer representative who happens to be very fierce on checking this data very helpfully. Pushing services to be very accountable for how well they are delivering this agenda."

Bournemouth – Involving adult family members and coordinating services

".....well we just wanted to make sure that we got best value for our money and people weren't going to the wrong level of intervention.... we did a mapping exercise you know and social services do a little bit and other people do a bit, so we kind of said let's go round the table, let's map what we've got, let's put them into a hierarchy, so low level, medium level or high level, cos we don't want people to go straight to high level if their needs could be met [with] a lower level intervention, it's about getting best value for money with what we've got in the area....."

"...we had a big carers day in a hotel where people could just come in and give us their views....we got about a couple of hundred carers through on the day and they gave us all their views of what they wanted and then based on that that's what we re-commissioned...."

### ***Implications: Local commissioning***

- Local areas should identify clearly and specifically adult family members as a target group for services and develop some estimate of prevalence and specific needs in their area against which to measure provision.
- Consideration could be given to a national advisory service to advise commissioners about good practice in terms of adult family member services.
- Local areas need to identify some form of target for adult family member activity against which provision should be regularly reviewed.
- More robust systems for monitoring adult family member services should be developed at the local level including measurement of activity across the different types of service responses as well as outcome measurement.
- Services need to be promoted assertively in the local areas, although with sensitivity, to address the barrier that may be posed by the 'stigma' and 'shame' experienced by families.
- Consideration needs to be given to the development of a workforce that has the capacity and capability to deliver evidence based help to adult family members in all areas. This should form part of local treatment strategies and plans.
- Given the contribution family members can make to the recovery agenda and the extent of their need for support in their own right it is important that this group is prioritised in services development at both national and local level.

## **EXTENT AND NATURE OF SERVICE PROVISION**

The national survey and in-depth qualitative interviews provided a snapshot of the extent and nature of service provision.

### **WHERE IS SUPPORT FOR ADULT FAMILY MEMBERS BEING PROVIDED?**

As can be seen from Box D, the web survey showed that most of the work attempting to respond to adult family members in their own right is delivered in non-statutory services that tend to consist of staff teams of fewer than 10 members. A large proportion of services reported working with adult family members alongside the treatment for drug users and this occurs mainly in NHS or local authority run services. The amount of this type of joint work however, appears to be low with the most common reports of services indicating that this work takes up 10% or less of the overall service caseload.

As well as supporting their drug-using relative in treatment, adult family members need help in their own right and this is helped by clear pathways between or integration of the different types of provision. Just over a third of respondents stated that they delivered their service in partnership with one or more other service(s). Despite some examples of integration and partnership working, overall there is still much room for improvement in terms of well-developed methods for joint working and monitoring both between substance misuse services but also importantly across substance misuse and wider services.

**Box D: Key Findings from Web Survey (N=253 unless otherwise stated)**

- There were 145 responses from England, with variation across the nine English regions. In addition, there were 72 responses from Scotland (25% of all responses), 19 from Northern Ireland and 17 from Wales.
- Just over half of respondents (58%) supported adult family members (AFMs) as part of a service for substance misusers, while another 10% were part of a generic carers service and 8% covered a range of other services (such as working with children or criminal justice).
- 61 (24%) respondents said that they worked in a service that worked solely with AFMs. Such services were more common in Wales (35%) and England (30%) than in Northern Ireland (16%) and Scotland (13%). The 43 responses from England came from eight of the nine regions.
- Respondents from non-statutory services were the most likely to report that they provided services specifically for AFMs of people with drug problems.
- Nearly three quarters (70%) of responses were from non-statutory services, increasing to 90% of the services who worked solely with AFMs. Responses from non-statutory services were common in England and Northern Ireland, while 18% of responses from Wales and 14% from Scotland were from social services, and 17% of responses from England came from NHS services.
- Just over a third of respondents (38%) delivered their service in partnership with one or more other service(s) - roughly the same for services that worked solely with AFMs and for other services.
- In England and Wales respondents were roughly as likely to work with AFMs alone as with AFMs alongside drug misusers. In Northern Ireland and Scotland respondents were much more likely to work with AFMs alongside drug misusers.
- Over half (N=142, 56%) of all respondents said that their services had less than 10 members of staff. This increased to nearly three quarters (N=45, 73%) for respondents from services who worked solely with AFMs. Smaller services were more likely to be from the non-statutory sector.
- Approximately half of services (70% in Wales) who worked with AFMs as part of a service for drug users said that working with AFMs on their own was less than 10% of their workload. Non-statutory services tended to spend more time working with AFMs alone. Working with AFMs alongside drug misusers tended to take up to 25% of workload.

**WHAT TYPES OF SUPPORT ARE BEING OFFERED TO ADULT FAMILY MEMBERS?**

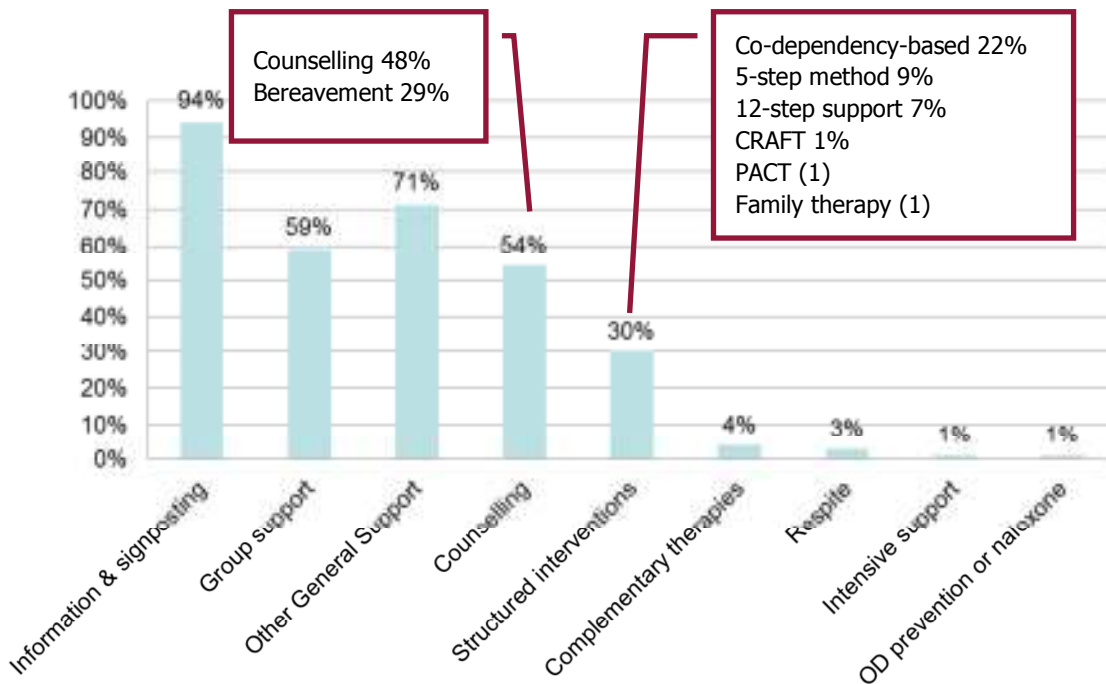
Almost all respondents reported offering information and signposting to family members in their own right (see Figure 1). Group support was reported to be offered in nearly 60% of services for family members with other forms of general support including advocacy, crisis support and mentoring delivered to a lesser degree. There was low delivery of named evidence-based interventions both to family members on their own or as part of joint working with family members and drug users.

Working jointly with drug users and family members (see Figure 2) usually involved more structured interventions such as family, couple or social therapies although the level of this work was relatively low. There is little implementation of Behavioural Couples Therapy which, as previously highlighted, was a recommendation from the National Institute of Clinical Excellence (NICE) guideline on Drug Misuse: Psychosocial Interventions (2008).



**Figure 1. Support to family members in their own right**

(N=274) [Note: Respondents could provide more than one answer]

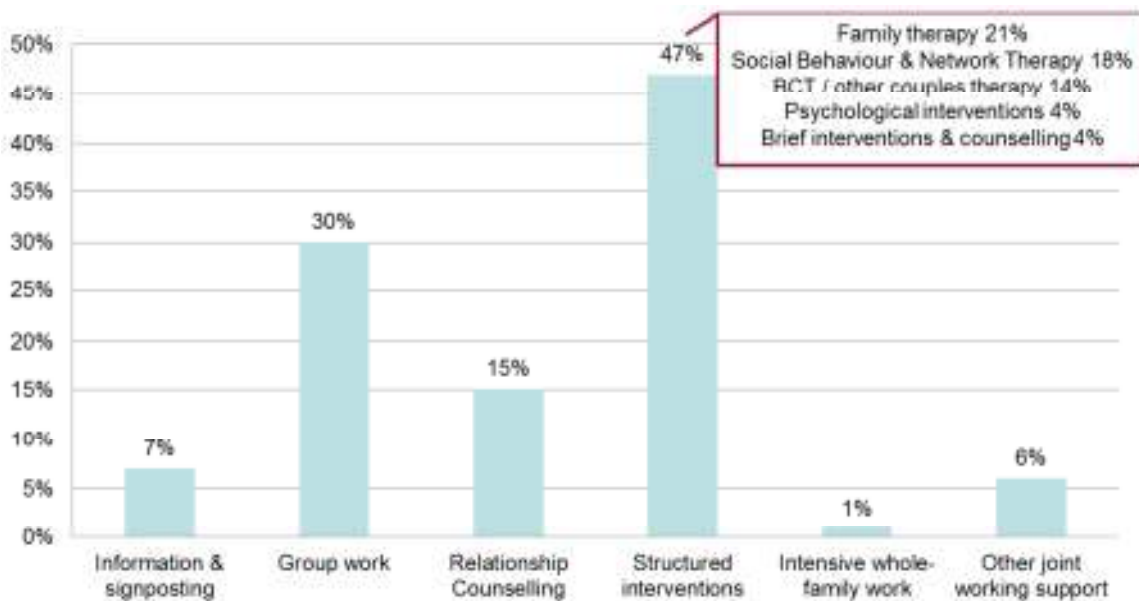


The survey also found that most forms of help and support were offered to a larger extent in family member focused services when compared to those services working with family members and users together.

When considering the current response to family members, most of the services for family members in their own right are from the third sector. There is some work conducted in supporting family members by working alongside the drug user (mostly in NHS/Local authority services) but this takes place at a relatively low volume and it is at a very early stage of development.

**Figure 2: Support for family members drug users together**

(N=274) [Note: Respondents could provide more than one answer]



The main gap is the extent to which current provision levels reported match existing need. From attempts at estimating the number of family members significantly affected by drug problems in phase 1 of this project<sup>11</sup> we know that likely prevalence is higher than that perceived at the local level by those interviewed (estimates were usually general and vague and not based on any robust method). Some interviewees reported no knowledge of likely estimates in their area. Whilst all areas can outline some response to adult family members in their own right, this is not commensurate with estimates of levels of need.

The perception of most services is that funding will remain stable over the current year (2011-12) and in some cases increase. There were however, a number of services concerned about future funding. Considering the fact that current level of provision appears much lower than estimated need, it would appear that funding for family services ought to be at least maintained at the current level.

### **HOW COMPREHENSIVE ARE THE LOCAL SERVICE RESPONSES?**

The information gained from qualitative interview sets in the 16 areas used for in-depth qualitative analysis was compared with a template for comprehensive service provision taken from the evidence review as part of phase 1 of the project.<sup>12</sup> Full details of this analysis can be seen in the full report of this component of the study<sup>13</sup>.

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

- 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 5-Step Method);
- Engaging family members in services for drug users - information provision, mediation & advocacy, care planning/case conferences; support for family members using 5-Step Method and
- Intensive family-based therapeutic interventions, eg Behavioural Couples Therapy; Social Behaviour & Network Therapy; Family therapy etc.

The interviews with commissioners and service providers in the 28 areas indicated that all areas had some gaps in service responses when compared to the 'ideal' planning template above.

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<sup>11</sup> See UKDPC (2009) *Supporting the Supporters: families of drug misusers*. London: UKDPC. Available at: [http://www.ukdpc.org.uk/publications.shtml#Families\\_report](http://www.ukdpc.org.uk/publications.shtml#Families_report)

<sup>12</sup> Copello, Templeton and Powell (2009) *Adult family members and carers of dependent drug users: prevalence, social cost, resource savings and treatment responses*. London: UKDPC.

<sup>13</sup> Copello et al. (2012) *Adult Family Members Affected by a Relative's Substance Misuse: Qualitative Interviews with Commissioners and Service Providers in England and Scotland*. London: UKDPC. Available at: [http://www.ukdpc.org.uk/publications.shtml#Families\\_report](http://www.ukdpc.org.uk/publications.shtml#Families_report)

The provision of service responses to adult family members in non-specialist settings were varied and inconsistent. Whilst some areas showed recognition and plans to enhance the identification and response to adult family members in **non-specialist settings** e.g. General Practice, Accident and Emergency, Police; in all areas there was much room for development and improvement. Two areas appeared to have a strategy that recognised the need to increase identification and the provision of a response at a range of non-specialist settings but this level of focus was unusual. However, an example of a non-specialist service that successfully promoted the needs of and engaged adult family members as carers is illustrated in Box E.

### **Box E: Voice of Carers Across Lothian (VOCAL)**

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

"VOCAL works predominately in Edinburgh and Midlothian. We are a generic carer support organisation, and define carers as informal, unpaid or family 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, and carer training programmes that benefit over 500 people a year. One of the specific services offered provides support to individuals affected by someone else's drug or alcohol problem. It employs three trained staff members:

"As part of our generic carer support work, we have one project we call the Family Support Addiction service. 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 an adult child with an addiction to alcohol or drugs. We provide information, advice, emotional support, training courses and peer support groups. We also support carers campaigning for carer recognition, and support their involvement in a campaign for carer recognition in the recovery process, which is the new focus of addiction services in Scotland."

The information provided includes: "information about addiction, the impact on families, services – what services are available, the whole process of accessing support and getting into any form of rehabilitation, and of getting a community care assessment. We provide much emotional support, helping carers to build their own strength and confidence in supporting the family, and we provide information on police and prison services where relevant. We explore with carers what the key issues are in their lives and support them to address these issues and find solutions and help. ... we provide information on anything we uncover as being of interest or benefit to the carer."

VOCAL Family Support Addictions, 8-13 Johnston Terrace, Edinburgh EH1 2PW. Tel 0131 622 62626, [www.vocal.org.uk/addictions.html](http://www.vocal.org.uk/addictions.html)

The **assessment and identification of adult family members** when a drug user enters treatment is recognised but not consistently implemented. Assessment of the impact of the problem on adult family members as part of the initial drug user assessment is patchy. Where it occurs, it tends to focus on supporting the drug user as opposed to identification of adult family member needs. Uptake of carers assessments was suggested within a number of interviews as being generally poor and, although it was not specifically prompted for, it was rarely mentioned as being provided in the web survey suggesting this problem is widespread.

There was greater provision of services for **family members in their own right**, but this mostly involved the provision of information and advice as well as some generic counselling. These were available in most areas but, as noted earlier, provision is not based on a robust assessment of prevalence or need. Without this it is hard to know the extent to which this is adequate to meet the volume of need. However, in most areas it was felt that it was likely that current levels of provision were not adequate to fully meet the level of need.

In many areas, particularly in England, the difficulties in providing support to people whose drug-using relative is not in treatment was mentioned, which links back to the issue of identification in non-specialist settings.

Two examples of services focused on the needs of family members in their own right as well as helping adult family members support the treatment and recovery of the person with the drug problems can be seen in Boxes F and G. Both services have experience of providing adult family member services over a long time, and recognise and work with the whole range of needs presented.

**Adult family member involvement in drug user treatment** is an issue identified in most areas, partly as a result of the recognition of the role of families in recovery in recent policy and drug 'recovery' models, but this is still at an early stage with patchy implementation with some services lacking confidence and strategies to conduct this work.

Implementation of **evidence-based structured interventions** to help adult family members were mentioned in a few areas, but these are not widespread (as also indicated in the web survey).

So overall, the results of this comparison showed that there are gaps at every level of provision in all areas. There appears to be a need for workforce development, in both specialist and non-specialist services if a more integrated and evidence-based approach to provision is to be achieved.

### ***Implications: Service Response***

- To support family members a comprehensive range of responses is required including generic responses in non-specialist services as well as family involvement in drug treatment and specific services for family members in their own right. At the moment this is rarely provided.
- To ensure support is provided to family members early and irrespective of whether or not their drug-using relative is in treatment there is a need to improve identification and recognition of adult family members affected by drug use and the provision of responses in non-specialist settings e.g. General Practitioners, Police, Accident and Emergency.
- Coordination of services within drug treatment and with other generic services should be strengthened at the local level to provide access to the full range of services.
- There is a need for workforce development, both specialist and non-specialist to raise awareness of the needs and contribution of adult family members affected by a relative's substance misuse as well as more training in specific therapeutic interventions.

### **Box F: 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:

"We're 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."

F.A.S.S. (Family Addiction Support Service): 123 West Street, Glasgow. G5 8BA  
<http://www.fassglasgow.org>

**Box G: SPODA: Support for families, friends and carers of drug users**

SPODA has been supporting families for over 11 years. "Over the years, the service has helped over 1000 families to cope with a wide range of extremely difficult, disabling and distressing circumstances. SPODA provides a flexible and family member focused approach to meet the varied and often complex needs that the impacts of having a relative who experience drug problems create.

"The service delivered is in line with all relevant guidance and best practice relating to the provision of family support. We provide information advice and support to concern others who are adversely affected by someone else's substance use. The different modalities of service provision available are telephone support, triage assessment of need, some clients may only need brief interventions or information to assist with their presenting circumstance, whilst others may require the high intensity service provision allowing them to be allocated their own named key worker to plan face to face key working sessions, educational sessions including overdose management training, group support, and the provision of advocacy.

"The support provision is tailored to the service users' own needs, we assist our clients to set realistic and achievable goals, to hopefully improve their life options, reduce stress and improve family harmony in the face of substance use. We also provide immediate support to allow families to work through periods of crisis. One of the aims of the service is to challenge stigma and discrimination and to improve social acceptance for the families affected by another's substance use.

"We work with many other local agencies to ensure that we as an agency can be part of a wrap around service improving outcomes for clients that present within their own right or within the partnership we have with the local treatment provider to improve outcomes for successful completions from drug treatment and to enhance recovery for user, carer and the extended family, our motto is that "recovery is a family affair". We also provide support, information and advice to grandparents and kin carers.

"The project constantly monitors the evidence for the need for any further areas of specialist support necessary. SPODA staff ensure that they provide a service with pride, compassion and commitment ensuring that they deliver a service that they would want to use for themselves and their own family members."

**SPODA:** 104 Saltergate, Chesterfield, Derbyshire, S40 1NE

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



## **OVERALL CONCLUSIONS**

In summary, adults who have a relative with drug problems have been increasingly recognised as a group with significant needs as a result of the stress of living and caring for someone with such problems. Policy has reflected this increased recognition to an extent, but there is still lack of clarity in the identification of this specific group of family members. Children affected by parental drug misuse have been increasingly recognised in policy and provision. Families in general have also been identified as a useful source of support for treatment and recovery of the person with the drug problem. However, apart from a few exceptions, adult family members as a specific group are not yet clearly identified in policy and guidance.

The lack of routine data sources providing information on the numbers affected continues to hamper the development of services to meet the full range of needs of adult family members. Therefore adult family members need to be identified as a specific group in national and local policies, accompanied by data collection to provide estimates of need at local level followed by robust systems for monitoring, coordinating and delivering a range of services to respond to the range of need.

The study has identified a number of strategies that might help overcome some of the challenges identified and improve the provision available to adult family members. These include:

- **Promoting the evidence** both for what is needed and what works. Organisations such as Adfam and SFAD have a valuable intermediary 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.** National strategies and local treatment and recovery 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 as well as making use of 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 evidence base. The work of the Scottish Government on outcome indicators could be valuable in this respect and could be used as a model.
- **Promote 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.

Whilst there has been welcome development in terms of acknowledgement of the importance of adult family members affected by a relative's drug problems, there is still a significant challenge in terms of identifying this specific group and developing a robust and integrated service response commensurate with need and with the potential to reduce significant harm. The study suggests that while there are good examples of service provision in some areas of the UK 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 interest in and appetite for improving provision and we hope these findings will help that process.

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