

Supporting the Supporters: families of drug misusers

This briefing highlights the key findings and implications of the study *Family members and carers of dependent drug users: prevalence, social cost, resource savings and treatment responses*. The full research report is available at www.ukdpc.org.uk/reports.shtml.

This study has estimated that in the UK, at the very least:

- nearly 1.5 million adults will be significantly affected by a relative's drug use¹;
- the cost of the harms they experience as a result amounts to about £1.8 billion per year; and
- the support they provide would cost the NHS or local authorities about £750 million to provide if it were not available.

These figures are *minimum* estimates, but nevertheless demonstrate the enormous impact of drug use on adult family members and the value derived from the support they provide and highlight the importance of identifying and supporting this often unrecognised group. To build on the welcome increase in focus on families of drug users in national drug policies across the UK and the guidance that has been produced, action is required in the following areas to deliver the desired benefits to families:

1. The level and quality of direct support to help families in their own right need to be improved.
2. The stigma associated with drug dependency needs to be challenged.
3. The drug treatment system needs to be made more supportive and inclusive for families.
4. Leadership – responsibility for driving forward an agenda to enhance support for families needs to be placed with an identified champion at national and local levels.
5. Information/knowledge development is essential for ensuring the adequacy and appropriateness of service provision – currently even the most basic data are lacking.

THE IMPORTANCE OF FAMILIES

People with drug problems,² however isolated, will have networks of families and friends who will feel the impact of the drug problems, whether they have become estranged or continue to provide vital support.

Adult family members of people with drug problems, such as spouses, partners, parents, grandparents, adult children and siblings, often suffer a wide range of negative consequences – emotional, financial and physical (see examples in Box A³). They are frequently an unrecognised, unappreciated and unpaid resource providing economic and other forms of support to their drug using relatives. The shame and stigma they often feel can lead to isolation and make them reluctant to seek help.

In addition, families are increasingly being recognised as a significant factor in addressing challenging social and behavioural problems. Hence, in drug (and alcohol) use and misuse, families may play an important role within a person's drug using career, especially in the achievement and maintenance of recovery, both within and outside drug treatment. They can play a critical role in two essential ways:

- by providing a bedrock of support for those using and recovering from problematic drug use; and
- as a resource to help prevent use and misuse of drugs among children and young people.

1 Problematic use or dependence on heroin, crack, powder cocaine and cannabis.

2 This report focuses on family members of people with drug problems, but many of the issues highlighted also apply to families of people with alcohol problems, and it should be noted that many drug users will also misuse alcohol.

3 We are very grateful to the family members who shared their stories with us, despite the pain this often involved. However, please note that, within this briefing, all names have been changed to protect the identities of the families involved.

The Advisory Council on the Misuse of Drugs (ACMD) report *Hidden Harm*⁴ turned a welcome spotlight on the impact of illicit drug use on the children of drug users and their needs. However, the impacts of a relative's drug use on other concerned and affected adult family members have received less attention. This project, therefore, focuses on this group. The hidden nature of drug use and the stigma associated with it means that the evidence available about families is limited. The findings of this review should therefore be seen as a starting point for further work, including consideration of the cost-effectiveness of supporting families and involving them in treatment services. We hope that it will raise the profile of this neglected group. As such, it provides a 'call to action' by highlighting the numbers affected and the extent of their contribution and support needs as well as providing a framework for assessing the adequacy of current service provision.

BOX A: EXAMPLES OF THE HARMS EXPERIENCED BY FAMILY MEMBERS

Mary, now aged 63, had a daughter, Paula, who began using drugs – cannabis and then crack cocaine – in 1992. The impact of this on Mary and her family has been wide-ranging. Not only has Mary had to give up her job, she has also lost hundreds of pounds as Paula has stolen from her and she has had to take responsibility for Paula's two children. Mary said: "The family has been torn apart in many ways. Both my sons have had to stay with friends to protect them from what was going on and Paula's daughter Sally [16] has faced stigma at school."

For Simon and Louisa, the impact on their family of their son Brian's addiction to heroin, which led to his death from overdose, has been devastating. As Simon says: "When Brian became the centre of attention because of his problems, our other girls suffered. They were scared of Brian, because he was violent, and the emotional stress meant they missed important periods at school. There have been some really bleak times when the strain has been unbearable. We've had to deal with drug dealers demanding money at the house and had to pay back thousands of pounds in drug debts."

Ben was the eldest of four children whose parents used heroin and cocaine throughout their childhood. Now they are grown up the effects continue: "The constant fear I had about protecting the family meant I used to smash people and things up. I stopped going to school and my brothers and sisters didn't really ever go to school properly. They can't read and write now, which is tragic. My brother can't even take his own children out for the day because he can't read and is too frightened to use the tube."

The role of the family in preventing early onset of drug use related problems – or in some circumstances as a negative influence, by inadvertently contributing to an increased risk of developing or prolonging drug using careers – is also very important but is outside of the scope of the project. Much work on this has been done by the ACMD and subsequently by government departments across the UK; for example, as part of the cross-departmental 'Think Family' initiative and the subsequent protocol between DCSF and the NTA⁵ in England.

ESTIMATING THE NUMBER OF FAMILY MEMBERS AFFECTED

Family members of drug users are a largely hidden group so estimating the numbers affected is extremely difficult. Most of the available information focuses on the drug users themselves. However, a recent DrugScope poll⁶ found that almost 1 in 5 adults in the UK (19%) had personal experience of drug addiction either directly or through family or friends, and that 1 in 20 had experienced addiction in their family. However, the extent and nature of this experience was not investigated – for some there may have been little impact, while for others the experience may have been devastating. There will also be people affected by illicit drug use below the level of addiction.

4 Advisory Council on the Misuse of Drugs (2003). *Hidden Harm*. London: ACMD; <http://drugs.homeoffice.gov.uk/publication-search/acmd/hidden-harm?view=Standard&pubID=173822>

5 DCSF, DH and NTA (2009). *Joint Guidance on Development of Local Protocols between Drug and Alcohol Treatment Services and Local Safeguarding and Family Services*. London: NTA.

6 DrugScope (2009). Closer to home than you think. *Druglink* July/August.

Given this, the project sought to produce a robust *minimum* estimate using a process that made data sources and assumptions explicit, and to provide a model that can be updated as better data become available.⁷ The focus has been on levels of drug use at the severe end of the spectrum (heroin or crack use or signs of dependence on cocaine powder or cannabis) and on those living with a person with this level of drug problem, as the impact on this group is likely to be greatest. However, we know that many people who do not live with their drug using relative may provide them with substantial amounts of support and care and that their levels of worry and concern will be considerable. Similarly, lower levels of use may also have a considerable impact on families. Therefore, the estimates we have generated (shown in Box B) will considerably understate both the number of people affected by a relative's drug use and the impact of this use, and so should be viewed as being the tip of the iceberg. It is also worth noting that the number of people affected by a relative's alcohol misuse will be even greater.⁸

Our estimates of numbers of people affected include people living with individuals who report signs of cannabis and cocaine dependence. As use of these drugs is more common than opiates and crack, the number of affected family members is considerable. We know less about the impact on family members of use of these drugs. However, it is likely to be less than for opiate and crack use, so we have not included them in the economic estimates. Nevertheless, the stresses and strains these family members experience should not be ignored. It is also worth noting that primary cocaine and cannabis users are making up an increasing proportion of users in treatment, particularly among younger age groups.

Box B: ESTIMATED MINIMUM NUMBER OF FAMILY MEMBERS AFFECTED BY A RELATIVE'S DRUG MISUSE

This project has estimated that in the UK:

- at the very least nearly 1.5 million adults are affected by a relative's drug use;
 - over 250,000 are seriously affected by a relative's problematic use of opiates or crack;
 - nearly 130,000 have a relative who shows signs of dependence on cocaine powder; and
 - over 1 million have a relative who shows signs of dependence on cannabis;
- about 575,000 of those affected are spouses, 610,000 are parents and 250,000 are other family members, such as grandparents or siblings;
- there are over 140,000 family members living with someone who is receiving treatment for illicit drug use.

COSTING THE IMPACT OF OPIATE/CRACK USE ON FAMILIES AND THE VALUE OF FAMILIES' SUPPORT

The impact of a person's drug problem on the different adult members of their family can be wide ranging, including for example:

- psychological distress, which can also result in both mental and physical ill-health;
- harm resulting from the domestic violence that can accompany drug use;
- negative financial impact resulting from direct or indirect support of the drug user or as a result of being victims of acquisitive crime;
- impact on employment, either as a result of stress or the need to provide care or support to the drug user or their children;

⁷ Details of how these figures were reached and the data sources used can be found in the background research report (www.ukdpc.org.uk/reports.shtml), and we hope this will stimulate the collection of information so that better estimates can be made in the future.

⁸ Also, the estimates only include adults; estimates of the number of children affected by parental drug use have recently been published in: Manning V., Best D., Faulkner N. and Titherington E. (2009). New estimates of the number of children living with substance misusing parents: results from UK national household surveys. *BMC Public Health* 9; 377.

- strain on family relationships, both with the drug user and among the other family members; and
- a negative impact on their social life, leading to increasing isolation, which may be exacerbated by the feelings of guilt and shame that families often feel.

The precise impact will vary between individuals and is dependent on their circumstances and their relationship to the drug user. For example, parents of problem drug users may have to bring up their grandchildren on a temporary or permanent basis.⁹ Siblings of problem drug users will share the impact of the chaotic behaviour, and may also feel neglected by their parents, whose attention is focused on their drug using sibling. Spouses of problem drug users may have to take sole responsibility for all aspects of family life, and on top of the worry about the drug user, they may feel guilt and concern about the impact on their children. Sometimes, families may feel they must disengage with the drug user, which can also pose problems and have considerable psychological impact. Whether or not families remain engaged, the damage to relationships is likely to be profound.

In addition to the support with day-to-day living they provide, families may provide important motivation and financial help to get a relative into a drug treatment programme. Research shows that there may also be benefits in involving families in that treatment. In some cases families provide the support and encouragement that enable some people to undertake detoxification and recovery outside of the formal treatment sector.

Putting a notional financial value on the support provided by families and the impacts on those families is not an easy task. Some impacts will be very variable and the information on which to base estimates is limited or non-existent. Indeed, some might question the whole idea of putting a cost on this suffering. However, as with other areas of caring, we believe that expressing the harms in economic terms helps to bring home the magnitude of the problems in comparison to the amounts spent in dealing with them.

Box C: ESTIMATED COSTS TO FAMILY MEMBERS AND THE VALUE OF CARE THEY PROVIDE

Costs borne by family members of problem opiate/crack users

- The average annual financial cost per affected family member/carer was estimated to be £9,741 (2008 prices).
- The average excess healthcare cost for families of drug users was estimated to be £450 per family member per annum.
- This equates to an estimated overall total cost of about £1.8 billion per annum in the UK.

Value of the care they provide

- The value of the care and support provided to problem drug users by family members is estimated to be £3,935 per family member per annum.
- Therefore, the total annual saving to statutory services for the UK as a whole is estimated to be about £750 million.

Within this project we have identified some costs data from the USA and sought to apply this to the UK context, recognising the obvious limitations. We have sought to identify a minimum cost,¹⁰ although the figures should still be viewed with a degree of caution. In essence, we have sought to identify the average cost per affected family member for some key types of harms created through a family member's problem drug use and then applied this to our estimates of numbers involved¹¹ (see Box C).

⁹ The difficulties that this brings are described more fully in: Adfam and Grandparents Plus (2006). *Forgotten Families*; <http://www.adfam.org.uk/docets/Forgotten%20Families%20Full%20Report.pdf.pdf>

¹⁰ Hence we have only attributed costs to heroin and crack users, who are at the more severe end of the spectrum of problematic drug use, and to partners and parents who in many cases probably provide the bulk of care.

¹¹ Full details of the approach taken, the source of the information and the assumptions made in applying these to the UK can be found in the background research report (www.ukdpc.org.uk/reports.shtml).

At a minimum, we estimate that across the UK as a whole the cost of harms to family members from a relative's misuse of opiates or crack cocaine amounts to about £1.8 billion per year.

Importantly, the estimates do not factor in the costs of mental distress experienced by families of problem drug users or the enormous impact this can have on their quality of life. The data do not yet exist to allow robust estimates of these costs and so we have set them to one side for this analysis. However, existing evidence suggests that these costs could be considerable.

Another way of looking at the value of the support that carers provide is to consider how much it would cost the NHS or local authorities to provide if it were not available. Our minimum estimate suggests this would be about £750 million. Most families are probably 'content' to provide support and would not ask for financial compensation for the care they give. However, in the case of a breakdown in that care it will be the NHS, social services or the criminal justice sector that will be left facing the costs and consequences.

DELIVERING IMPROVED SUPPORT FOR FAMILIES OF PROBLEM DRUG USERS

Our research also reviewed the evidence for both how family members can be supported and how they may be more effectively involved in the treatment of drug using family members.

Many of the needs of family members/carers of people with drug problems are similar to those for carers more generally. However, they are different in two important respects. First, the types of support that families provide to their drug dependent relatives may be different. Second, families have the added burden of coping not only with that the stresses that drug dependency brings, but also with the widespread stigma and shame associated with drug use.

BOX D: EXAMPLES OF THE NEED FOR AND BENEFITS OF SUPPORT FOR FAMILIES/CARERS

Mary has struggled to find support. She said: "Apart from the help from social services because I have to take care of Paula's children, I didn't know where to go. When things were really bad, when Paula was stealing from the house and all she wanted to do was attack me, there was no one to talk to, and nowhere to go for help. You just had to do your best to muddle through. It is only since Paula had Billy, now 11 months, that I've come realise a lot of Paula's behaviour was down to drugs. This is because people have sat down with me from a specialist family support group and explained how drugs affect people. Back in the 80s and 90s no one really spoke about drugs and if I knew then, what I know now, things might have been different for Paula."

As Simon says: "If there's one thing that could have helped my family it's talking to parents going through similar experiences. But not once, over the last twelve years, did anyone say 'you are not alone – there are others going through the same thing who you can talk to'." Simon had felt frustrated that he didn't know enough about what was happening with Brian's treatment services. Simon says: "We knew we couldn't ask any questions because whenever we tried, we were totally ignored, especially by his drug worker. We felt invisible and never really felt we could get involved."

Rose, whose son William has used heroin for over ten years, initially struggled to get help from services. However, over the years things have improved. She says: "It was when I found SPODA [support agency] that things changed dramatically. Both me and my husband can speak to someone now, separately and as a couple. We can speak to someone who understands what we are going through, and they've helped us find other support too. They've given us advice and I can even go with William to the clinic now, when he's getting treatment services, which never would have happened before. So I can make sure he's attending sessions and that I'm there in a positive way give support."

The range of types of services and interventions needed to support families includes the following:

1. Advice and information provided through non-specialist settings, such as NHS Direct, Carers Direct or third sector carers services, which can provide direction towards sources of help.
2. Dedicated family and carer support services providing help and support to family members in their own right; for example, peer support groups, specialist support groups and services, help from mainstream carers organisations, and GPs.
3. Proper assessment of family relationships at the point when a drug user enters a treatment programme. This does not appear to be done systematically at present.
4. Providing support and recognising the contribution of family members within treatment programmes for drug users, including residential recovery programmes. This could typically include the provision of information and education about drug misuse, the identification of sources of stress, handling relapses and the promotion of coping skills.
5. For some people there will be a need for more intensive and specialist support, provided through such interventions as intensive family-based therapy, Behavioural Couples Therapy, Multidimensional Family Therapy and social network approaches.

The benefits of providing these types of support, to both the families and the drug users, are highlighted in the examples shown in Box D.

The estimate of 1.5 million adults in the UK significantly affected by a relative's drug use, despite being a minimum estimate, clearly shows the scale of the issue. The minimum estimates of the costs borne by these families and the value of the support they give, over and above what families would normally provide, derived in this study are substantial. Increasing and improving the support available for families, both in their own right and to assist their contribution to their relative's recovery, is clearly imperative both from a moral or civic duty perspective and from a simple economic standpoint.

The challenge now is to turn the increased focus on families of drug users in national drug policies and the range of guidance that has been produced into reality (recent key publications are shown in Box E). We hope the estimates produced will add impetus to the work in this area and will provide a firmer basis for service development. To achieve the necessary improvements in support and service provision, we suggest there is a need for action in the following areas:

1. IMPROVING THE LEVEL AND QUALITY OF DIRECT SUPPORT TO FAMILIES IN THEIR OWN RIGHT

The number of people potentially needing support is large, and in many cases those people are hidden. Families/carers of drug misusers are not a homogeneous group and the extent and nature of the impact on them will vary. Therefore, there is a need for a range of services focusing on the needs of the family members themselves. This study was undertaken with advice from stakeholders and experts in the field,¹² as well as from family members, and our discussions highlighted some issues that need to be addressed to improve the delivery quality of this support:

- 1.1 ***Sustaining or increasing expenditure on both national and local support and services for families is important.*** The investment should be targeted and evaluated systematically to improve the evidence base and ensure value for money.
- 1.2 ***Local commissioners should ensure the full range of support and therapeutic interventions are provided in each area.*** It is important that the increased focus on families within specialist services is not seen as a substitute for self-help or peer-support groups, which may be the first (and perhaps only) source of help for families looking for support.
- 1.3 ***The Care Quality Commission (in England) and its counterparts in other parts of the UK should prioritise regular reviews of the adequacy of support provision for the families of those with drug (and alcohol) dependency problems.***

12 We are very grateful to the many groups whose participation and support has greatly enhanced the study. A list of those organisations involved in the advisory group can be found in the Acknowledgements section in the main report.

1.4 ***Training and workforce development is needed to equip staff in mainstream services to respond better to the needs of family members.*** Families/carers of drug users need the same access to mainstream services as other carer groups. Services such as social services, teachers, health staff and domestic violence teams need to be able to identify and respond to the needs of family members of drug users seeking their help.

1.5 ***A continuing education programme for GPs, to raise awareness of the needs of families of drug misusers and how they can respond to them, should be developed by the Department of Health in conjunction with national carer organisations.*** GPs and other primary care practitioners could play an important role, both in provision of therapeutic interventions to family members/carers presenting with stress and other health problems, and in signposting them to other services. They need to be aware of the considerable proportion of people within the population who may be suffering from the impact of drug use within their family.

2. CHALLENGING THE STIGMA ASSOCIATED WITH DRUG DEPENDENCY

2.1 ***A major programme to raise awareness of the numbers of families affected, the support available to them, and to challenge the guilt-inducing stereotypes associated with drug dependency and recovery is needed.*** People with addiction and dependency problems and their families encounter very real negative attitudes. This challenges and undermines efforts to help reintegrate people into their community and acts as a barrier to families seeking help. Government departments (e.g. the Department of Health) or bodies that are seeking to promote recovery (e.g. the new Scottish Drug Recovery Consortium) are ideally placed to undertake such work.

2.2 ***The passage of the Equalities Bill ought to be used as an opportunity to remove some of the obstacles that families face in caring for those recovering from dependency and addictions.*** Currently, employment protection for carers is dependent on the person being cared for being considered disabled within the definitions of the current Disability Discrimination Act. However, 'addiction' is specifically excluded from the Act (unless caused through prescribed medications), so family members caring for a drug dependent relative are not protected unless the relative has some other condition covered by the act.

3. MAKING THE DRUG TREATMENT SYSTEM MORE SUPPORTIVE AND INCLUSIVE OF FAMILIES

3.1 ***A far-reaching workforce development programme to deliver a culture change within all drug treatment services is required to ensure that families are given proper consideration.*** Professional attitudes among those delivering care and support for those recovering from dependency and addiction can be implicitly or explicitly negative towards family members. Family members frequently feel excluded and struggle to obtain any information on the treatment that their relative may be receiving. At the same time, family members may be expected to assume responsibility for their relative when discharged from services or custody.¹³

4. LEADERSHIP

4.1 ***Responsibility for driving forward an agenda to enhance support for families of those in recovery should be placed with an identified champion or advocate at both national and local levels.*** The needs of families/carers of drug misusers and their contribution to drug treatment and recovery cut across many national and local departmental responsibilities and interests. There is thus a danger that the needs of families as carers may fall into a gap.

5. INFORMATION/KNOWLEDGE DEVELOPMENT

Our findings show that the number of people requiring support in dealing with the impact of a relative's drug use is large, yet we know that our figure is an underestimate and that this is very much a hidden group. The lack of detailed and timely information on the numbers affected and the problems they experience not only

13 DrugScope and Adfam (2009). *Recovery and Drug Dependency: A new deal for families*; <http://www.drugscope.org.uk/Resources/Drugscope/Documents/PDF/Policy/Adfamrecovery.pdf>

hampers provision of support services for them in their own right, but also results in a potential source of recovery capital for improving outcomes for their drug using family members remaining untapped. Therefore, in addition to the collection and analysis of information on family members by drug treatment services mentioned at 3.2 above, we recommend a programme of research and data collection is instituted, which should include the following:

- 5.1 ***A national survey looking at the number of people affected by a relative or close friend's drug use, the impact on them and the nature of the support they provide should be commissioned by Department of Health in conjunction with the relevant departments within the devolved administrations.*** This should provide information on support provided by families for problem drug users not in touch with services and who may recover without external help, as well as those affected by a relative's problematic use of cannabis and cocaine, currently a considerable knowledge gap.
- 5.2 ***An audit of current service provision for families/carers of drug misusers needs to be conducted in order to highlight gaps and priority areas for improved provision and to identify models of good practice.***
- 5.3 ***The new Recovery Academy and other bodies, such as the National Drug Evidence Group in Scotland, should include research examining recovery from the perspective of families within their work programmes.***
- 5.4 ***It is essential that the full range of models of service provision for families/carers of drug misusers are evaluated properly to identify who benefits from what types of intervention and also whether interventions are cost-effective.***
- 5.5 ***NICE (the National Institute for Health and Clinical Excellence) should consider including the impact of treatment on family members/carers in assessments of the cost-effectiveness of drug treatment.*** Our research has highlighted the considerable costs borne by families of problem drug users. However, the methods employed by NICE for assessing the cost-effectiveness of interventions focus entirely on the individual being treated and do not include the value of any impacts on family members.

BOX E: GUIDANCE AND INFORMATION FOR COMMISSIONERS AND PROVIDERS OF SERVICES FOR FAMILIES/CARERS OF DRUG MISUSERS

- ***Carers at the Heart of 21st-Century Families and Communities***, HM Government (2008)
- ***Recovery and Drug Dependency: A new deal for families***, DrugScope/Adfam (2009)
- ***Carers and Families of Substance Misusers: A framework for the provision of support and involvement***, Welsh Assembly Government (2009)
- ***Around Arrest, Beyond Release – The experiences and needs of families in relation to arrest and release of drug using offenders***, Home Office (2007)
- ***Around Arrest, Beyond Release 2 – Moving forward – identifying and promoting practice to meet the needs of families in relation to the arrest and release of drug misusing offenders***, Home Office (2009)
- ***Supporting Families and Carers of Drug Users: A review***, Effective Interventions Unit, Scottish Executive (2002)
- ***We Count Too: Good Practice Guide and Quality Standards for work with family members affected by someone else's drug use*** (2nd edition), Adfam (2009)
- ***Supporting and Involving Carers: A guide for commissioners and providers***, NTA (2008)
- ***Supplementary Advice on Treatment Planning in Relation to Families and Carers***, NTA (2009).