Adult family members and carers of dependent drug users: prevalence, social cost, resource savings and treatment responses

November 2009

Prof. Alex Copello, Lorna Templeton and Dr Jane Powell
Published by:
The UK Drug Policy Commission (UKDPC)
Kings Place
90 York Way
London N1 9AG
Tel: +44 (0)20 7812 3790
Email: info@ukdpc.org.uk
Web: www.ukdpc.org.uk

This publication is available online at www.ukdpc.org.uk/reports.shtml

ISBN 978-1-906246-14-3

© UKDPC November 2009

The UK Drug Policy Commission (UKDPC) is an independent body providing objective analysis of evidence related to UK drug policy. It aims to improve political, media and public understanding of drug policy issues and the options for achieving an effective, evidence-led response to the problems caused by illegal drugs.

UKDPC is a company limited by guarantee registered in England and Wales No. 5823583 and is a charity registered in England No. 1118203. The UKDPC is grateful to the Esmée Fairbairn Foundation for its support.

The views, interpretations and conclusions set out in this publication are those of the authors and are not necessarily those of the UK Drug Policy Commission.
## Contents

<table>
<thead>
<tr>
<th>Acknowledgements</th>
<th>iii</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Introduction</td>
<td>5</td>
</tr>
<tr>
<td>Familial Ties are Not Easily Broken</td>
<td>5</td>
</tr>
<tr>
<td>The Importance of Family Members and Carers in Care and Support</td>
<td>5</td>
</tr>
<tr>
<td>Hidden Harm and Its Social Costs</td>
<td>6</td>
</tr>
<tr>
<td>The Number of Family Members and Carers Affected in This Way is Unknown</td>
<td>6</td>
</tr>
<tr>
<td>The Importance of This Study</td>
<td>6</td>
</tr>
<tr>
<td>The Structure of This Report</td>
<td>7</td>
</tr>
<tr>
<td>2. Estimating the Number of People Affected</td>
<td>8</td>
</tr>
<tr>
<td>Aims</td>
<td>8</td>
</tr>
<tr>
<td>Process</td>
<td>8</td>
</tr>
<tr>
<td>The Application of the Model to Treatment/Population Estimates</td>
<td>9</td>
</tr>
<tr>
<td>Limitation of the Prevalence Estimates of Family Members and Carers</td>
<td>10</td>
</tr>
<tr>
<td>Estimate 1: Adult Family Members of Drug Misusers in Drug Treatment</td>
<td>10</td>
</tr>
<tr>
<td>Estimate 2: Estimating the Numbers of Adult Family Members of Drug Misusers in the General Population</td>
<td>13</td>
</tr>
<tr>
<td>Discussion of Prevalence Model and Estimates</td>
<td>17</td>
</tr>
<tr>
<td>3. Social Costs and Resource Savings</td>
<td>21</td>
</tr>
<tr>
<td>Introduction</td>
<td>21</td>
</tr>
<tr>
<td>The Costs to Family Members and Carers</td>
<td>22</td>
</tr>
<tr>
<td>The Evidence Base and Economic Estimates</td>
<td>24</td>
</tr>
<tr>
<td>Unhappiness Experienced by Family Members and Carers</td>
<td>27</td>
</tr>
</tbody>
</table>
Acknowledgements

The authors would like to acknowledge the UK Drug Policy Commission for the financial support that made this work possible. In addition, Nicola Singleton of UKDPC provided expert comment on various drafts, a substantial input into the methodology for the prevalence estimation and steered and co-ordinated the process of production of this report. Professor Alan Maynard expertly chaired the advisory group meetings. The members of the advisory group were very supportive and made substantial comments on the draft contents of this report. Organisations represented on the advisory group included:

- Adfam
- Scottish Network for Families Affected by Drugs (SNFAD)
- Action on Addiction
- SPODA, Derbyshire
- Families, Partners and Friends Service, CASA, Islington
- Carers UK
- The Princess Royal Trust for Carers
- Drugscope
- Centre for Drug Misuse Research, University of Glasgow
- Scottish Government
- Welsh Assembly Government
- National Treatment Agency for Substance Misuse
- DHSSPS, Northern Ireland
- National Audit Office

The authors would also like to acknowledge the expert comments on early drafts of the report by Professor Jim Orford, University of Birmingham and Professor Richard Velleman, the Mental Health Research and Development Unit, University of Bath and the Avon and Wiltshire Mental Health Partnership NHS Trust (AWP).

Thanks are also due to Professor Howard Meltzer, University of Leicester for assistance with the access to and analysis of the 2007 Adult Psychiatric Morbidity Survey data.
1. Introduction

**Familial ties are not easily broken**

The impact of problem drug use on the family members and carers of drug users is profound and can take many forms. A comprehensive discussion of the nature of this impact, based on findings from an international programme of research, can be seen in Orford et al. (2005). The experience often involves the family member worrying about the financial impact that the drug problem is having on the family, being concerned about the drug user’s state of physical and mental health as well as his or her behaviour, the reduction of social life for the family and the negative impact on communication between family members. The feelings often associated with these experiences include anxiety, worry, depression, helplessness, anger and guilt (Orford et al., 2005).

Because of the stigma associated with drug use the problem is often hidden, which not only exacerbates the family’s stressful experience but may also prevent the potentially useful contribution that families can make to the recovery of the drug user. In addition to the hidden nature of family harm associated with drug use that may result to some extent from the stigma discussed, services for drug problems on the whole tend to focus on the drug users, with the needs of family members often seen as peripheral and not central to the treatment process (Copello and Orford, 2002). A number of research studies, however, have shown that support can be offered to family members while maintaining good practice in relation to confidentiality and responding to difficult situations. These studies are discussed later in this report.

**The importance of family members and carers in care and support**

Over the past three decades there has been increased recognition by researchers in the field of the important role that families of drug users can play, both in terms of influencing the course of the substance related problem and in contributing to the achievement of positive outcomes when drug users are attempting to change their problematic behaviour, either within or outside the treatment system. Recently, the needs of family members that arise from the stress that they experience as well as the role and potential contribution that adult family members can make to treatment intervention for drug problems have been recognised in the research, clinical and policy arenas. This has been noted, for example, in the UK National Drug Strategy (HM Government, 2008), the recent National Treatment Agency for Substance Misuse guidelines for commissioning families and carer services (NTA, 2008) and the National Institute for Health and Clinical Excellence (NICE) guidance on psychosocial interventions for drug misuse (NICE, 2007).

More specifically, in terms of the contribution of family members, research has supported the notion that the family members of people with substance misuse
problems can be highly influential in terms of helping those people to initiate treatment (e.g. Barber and Crisp, 1995; Meyers et al., 1996; Miller et al., 1999; Meyers and Smith, 1995), in affecting the course and outcome of interventions (e.g. McCrady et al., 1986; Stout et al., 1987; Stanton and Shadish, 1997) and also influencing the likelihood of relapse and supporting long-term maintenance of change (e.g. McCrady et al., 1999; Marlatt and Gordon, 1985; O’Farrell et al., 1993). Furthermore, there is a growing library of evidence to support the need to offer support to family members in their own right regardless of whether the user is or is not in treatment. For example, studies using the 5-Step intervention for family members (Copello et al, 2009a) have shown that symptoms of stress commonly experienced by family members can be significantly reduced after a relatively brief and systematic psychosocial intervention. This is delivered to family members in their own right and has the potential to reduce family harm that emerges from drug use in the family context.

Hidden Harm and Its Social Costs

How are family members and carers affected by the drug misuse of a close relative? As well as experiencing harm and much stigma, families of drug users – as is the case in other fields such as mental health and disability – are frequently an unpaid and unconsidered resource providing economic and other forms of support to their drug using relatives and carrying a large burden in terms of costs, which are often to some extent forced upon them. As mentioned, it is widely recognised that a person with an illegal drug problem can have a significant impact on their family members in terms of physical and psychological stress and that those stresses can be severe and long lasting. Research across the UK has articulated the experiences of such family members; for example, for family members generally (Barnard, 2007; Orford et al., 2005), siblings (Barnard, 2005), parents (Mentor UK, 2007) and children (Aberlour Child Care Trust, 2002; Barnard and McKeeganey, 2004; Forrester et al., 2008; Gorin, 2004; Kroll, 2004).

The Number of Family Members and Carers Affected in This Way Is Unknown

However, while the Hidden Harm report published by the Advisory Council on the Misuse of Drugs (ACMD, 2003) significantly raised the profile of children affected by parental drug misuse, and work has been done to estimate the numbers of these children (Aberlour Child Care Trust, 2002; ACMD, 2003; Manning et al, 2009; Hay et al., 2005; McNeill, 1998), there has to date been no comprehensive effort to accurately calculate or estimate the numbers of adult family members affected by a relative’s drug misuse. Given the increased emphasis on the importance of families in drugs policy across the UK (DHSSPS, 2006; HM Government, 2008; NTA, 2008; Scottish Government, 2008; Welsh Assembly Government, 2008), such work is vital to ensure that services are appropriately developed to meet the needs of all family members affected.

The Importance of This Study

A study commissioned by Carers UK estimated the total economic value of the contribution made by carers in the UK to be £87 billion a year (Buckner and Yeandle, 2007). However, this covers all carers and does not distinguish those caring for
problem drug users. Indeed, it is probable that many family members of problem drug users, although providing much support, may not perceive themselves as carers and so will not be included within these estimates, which are based on responses to a question about caring included within the population census undertaken in 2001. However, there is a cost to ‘free’ care in terms of increased unhappiness, lower levels of well-being and increased hospital and other health service use by adult carers of drug users as a result of associated ill health (Clark and Oswald, 2002 Oswald, 2007; Svenson et al., 1995; Ray et al., 2007) as well as loss of employment opportunities and reduced productivity.

Most of the economic evidence in this area comes from US studies that contain some economic estimates of elements of social costs incurred by family members and carers – partners, spouses or parents – across a range of drugs. Currently, there is no UK study in which a complete economic estimate of the social cost of dependent drug use on family members and carers has been derived, but such a study is needed. Therefore, this study is significant because it constitutes as far as we are aware the first attempt in the UK at both estimating the numbers of adult family members with a drug-using relative and calculating the levels of cost and cost saving brought about by the impact of the problem on families and the care that they provide to their relatives. Work of this nature has implications for government policy, service planning and delivery to family members and carers.

**THE STRUCTURE OF THIS REPORT**

The main part of this report is divided into three chapters. In Chapter 2, a model for estimating the prevalence of adult family members affected by drug use is presented. It is then applied to existing data and the findings are discussed. In Chapter 3, a model is presented for estimating the total social costs and resource savings to the NHS and local authorities that emerge from the care and support that family members provide to drug using relatives. Chapter 4 provides a summary of effective interventions for family members. Throughout this report the terms ‘family members’ and ‘carers’ are used to denote adult family members affected by the drug problem of a close relative and who do not themselves have a drug problem.
2. Estimating the number of people affected

**AIMS**

This element of the project aimed to:

- design a model (a template) for estimating the numbers of affected adult family members of illegal drug misusers; and

- demonstrate how this model can be used, by providing two estimates on the numbers of affected adult family members of illegal drug misusers – one within the drug treatment population and one within the general population.

**PROCESS**

The model presented was developed following discussions and consensus of experts and representatives of family members’ services and a review of the possible data sources that could be used for the development and testing of the model. The starting point for the model had to be survey data on drug misuse itself as there are no UK general population surveys that include questions about family members or carers of drug users. The model was therefore specified as encompassing:

- four groupings of drugs (heroin and crack; cocaine; cannabis; and ‘other’); and
- three groupings of affected adult family members (spouses and partners; parents; and ‘other’).

Groupings were driven by the availability of data and agreed with the project’s advisory group. Given that there is very little quantitative data available across the UK on families who live with or are affected by the illegal drug misuse of a relative, certain assumptions had to be made before we could proceed with the work. Components of the model and assumptions are presented in Figure 1. In many cases, the data sources used represented the only data currently available. We were aware, for example, that siblings and grandparents of people with drug problems are important groups, but we were unable to find data on which to base separate estimates of the numbers involved in these groups.

The main calculation involved multiplying the estimates of drug problem prevalence (EDPP) (expressed in terms of the estimated number of people in the UK) for each of the drug groupings by the estimates of the number of family members (EFM) deemed to be affected by each type of drug within each family member grouping. However, in selecting the underlying estimates we applied a number of criteria or assumptions. In
relation to the EDPP, for example, we required the level of severity of the drug problem to be high enough to be almost certain to lead to a significant impact on family members; therefore, we looked for estimates of dependence or estimates of users in treatment as these were assumed to be associated with higher levels of severity. In relation to family members, we required that family members lived with the drug user (indicating high frequency of contact) and had no drug problems themselves. The latter two assumptions were made in order to maximise the likelihood of a significant impact. Throughout the work, we took a cautious stance, and therefore the estimates are likely to represent the lowest possible numbers of family members affected. This is further discussed later within this chapter.

**Figure 1: Components of estimated prevalence of affected family members, including assumptions and indices used**

<table>
<thead>
<tr>
<th>Main estimate based on EDPP × EFM</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Estimate of drug problem prevalence (EDPP)</strong></td>
</tr>
<tr>
<td>Estimate of the number of people with drug problems defined at a level judged to be sufficient to lead to family impact</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Assumptions about the problem</th>
<th>Criteria for family members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of severity of the drug problem has to be significant</td>
<td>High frequency of contact between drug user and family member</td>
</tr>
<tr>
<td></td>
<td>Family member should not have a drug problem</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Some indices used</th>
<th>Some indices used</th>
</tr>
</thead>
<tbody>
<tr>
<td>User in treatment</td>
<td>Living with user</td>
</tr>
<tr>
<td>Diagnosis of dependence</td>
<td>Absence of drug problem for family member</td>
</tr>
<tr>
<td>Problem use of substance</td>
<td>Data on family composition</td>
</tr>
</tbody>
</table>

**The application of the model to treatment/population estimates**

Two examples of how the model can be used are presented. Table 1 estimates the numbers of adult family members related to the group of drug misusers who are in drug treatment. Table 2 estimates the numbers of adult family members of drug misusers in the population as a whole. Separate estimates for each of the four UK administrations are given within each estimate (using data sources which were, as far as possible, compatible across the four UK countries), alongside overall totals for the UK.

It should be highlighted that Tables 1 and 2 are examples of how the model can be used to estimate the numbers of affected family members of illegal drug misusers. Different estimates could be calculated by using different data sources, definitions and assumptions. This will be discussed later in this report.
By illustrating here two ways in which the model can be used – one focused on the treatment population and one focused on the general population – we hope to demonstrate a range of ways in which such a model can be useful. The estimates in Tables 1 and 2 are useful in different ways. For example, the estimate of the number of family members of those drug users who are in treatment is useful for those planning and providing drug services as it gives an idea of how many family members could potentially be involved in family-based treatment. The larger population estimate is useful for broader level strategic planning of services for family members.

**LIMITATION OF THE PREVALENCE ESTIMATES OF FAMILY MEMBERS AND CARERS**

As mentioned before, in the light of available data and assumptions made, the calculations presented here should be seen as *minimum* estimates. In other words, we can be confident that the estimates reported represent the lowest possible number of affected family members within each category.

**ESTIMATE 1: ADULT FAMILY MEMBERS OF DRUG MISUSERS IN DRUG TREATMENT**

Recent data from the national drug misuse databases for England (DH & NTA, 2008), Scotland (ISD, 2008), Wales (WAG, 2009) and Northern Ireland (DHSSPS, 2009) (see Table 1 and references for details) were used to provide the numbers of drug users in treatment that form the basis for the estimate presented here. When dividing drug users according to type of drug, we used the primary drug for which users were recorded as being in treatment so that individuals would not be double counted. Data from national surveys and other research studies were then used to estimate the numbers of family members likely to be living with these users. The data and assumptions used were as follows.

**Partners**

The English Drug Treatment Outcomes Research Study (DTORS) (Jones et al., 2007) asked respondents (who were a random sample of drug misusers entering treatment across England, \( n = 1,794 \)) whether they had a partner and whether that partner was also a drug user. Separate data were available for opiate users (39% had a partner, 56% of whom did not take drugs), crack cocaine users (34% partner, 62% of whom did not take drugs) and another drug (not specified) (35% partner, 74% of whom did not take drugs). These percentages were applied to the numbers of drug misusers obtained from the annual treatment statistics to estimate the number of partners of those illegal drug misusers in treatment.\(^1\) The assumption was made that the DTORS data could be generalised to a larger English treatment sample and, further, it was assumed that the data for England could be applied to Scotland, Wales and Northern Ireland (where no equivalent information is currently available).

For example, the number of affected partners of heroin users in treatment in England was estimated as follows:

\(^1\) However it should be noted that in Scotland, Wales and Northern Ireland the statistics relate to new entrants to treatment only and so will underestimate the numbers in treatment.
Number of heroin users in treatment = 139,081
Proportion who have a non-drug using partner living with them = 0.39 \times 0.56 = 0.2184
Therefore estimated number of affected partners = 139,081 \times 0.2184 = 30,375

Parents
Data from the Scottish Drug Misuse Database (ISD, 2008) suggest that 24% of drug misusers were living with at least one parent. Similar data from the Northern Ireland Drug Misuse Database (DHSSPS, 2009) suggest that 26% of drug misusers were living with a parent. Therefore, the mid-point of these two figures (25%) was used to estimate the number of drug misusers living with a parent. In the absence of any data on the number of parents users were living with, the estimate assumed only one parent per drug user. The figure of 25% was applied to users of all types of drugs.

Other family members
Data from the Drug Outcome Research in Scotland (DORIS) study (M Barnard, 2009, pers.comm., 9 March) reported that 10% of the sample lived with siblings and 6% with other family members. Therefore, the figure of 16% was used to estimate the number of drug misusers living with siblings or other family members (this again assumes only one sibling and only one other family member per user). The assumption was made that the data for Scotland could be applied to England, Wales and Northern Ireland (where no equivalent information was available). Further, the assumption was made that the figures for a sample of primarily opiate misusers could be applied to groups of other drug misusers. While it is recognised that there will be differences in the profiles of family members affected by different drugs, a lack of data necessitated this assumption.
Table 1: An estimate of the numbers of adult family members of drug users who are in drug treatment

<table>
<thead>
<tr>
<th>Primary problem drug</th>
<th>Users</th>
<th>Family members</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Partner</td>
</tr>
<tr>
<td><strong>England</strong>&lt;sup&gt;1&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opiates</td>
<td>139,081</td>
<td>30,375</td>
</tr>
<tr>
<td>Crack</td>
<td>10,994</td>
<td>2,318</td>
</tr>
<tr>
<td>Cocaine</td>
<td>12,613</td>
<td>3,267</td>
</tr>
<tr>
<td>Cannabis</td>
<td>26,287</td>
<td>6,808</td>
</tr>
<tr>
<td>Other</td>
<td>13,691</td>
<td>3,546</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td>202,666</td>
<td>46,314</td>
</tr>
<tr>
<td><strong>Scotland</strong>&lt;sup&gt;2&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opiates</td>
<td>7,035</td>
<td>1,536</td>
</tr>
<tr>
<td>Crack</td>
<td>111</td>
<td>23</td>
</tr>
<tr>
<td>Cocaine</td>
<td>625</td>
<td>162</td>
</tr>
<tr>
<td>Cannabis</td>
<td>1,388</td>
<td>359</td>
</tr>
<tr>
<td>Other</td>
<td>1,089</td>
<td>282</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td>10,248</td>
<td>2,362</td>
</tr>
<tr>
<td><strong>Wales</strong>&lt;sup&gt;3&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opiates</td>
<td>3,338</td>
<td>729</td>
</tr>
<tr>
<td>Crack</td>
<td>73</td>
<td>15</td>
</tr>
<tr>
<td>Cocaine</td>
<td>299</td>
<td>77</td>
</tr>
<tr>
<td>Cannabis</td>
<td>915</td>
<td>237</td>
</tr>
<tr>
<td>Other</td>
<td>749</td>
<td>194</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td>5,374</td>
<td>1,252</td>
</tr>
<tr>
<td><strong>Northern Ireland</strong>&lt;sup&gt;4&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opiates</td>
<td>222</td>
<td>48</td>
</tr>
<tr>
<td>Crack</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Cocaine</td>
<td>195</td>
<td>51</td>
</tr>
<tr>
<td>Cannabis</td>
<td>685</td>
<td>177</td>
</tr>
<tr>
<td>Other</td>
<td>653</td>
<td>169</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td>1,755</td>
<td>445</td>
</tr>
<tr>
<td><strong>United Kingdom</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opiates</td>
<td>149,676</td>
<td>32,688</td>
</tr>
<tr>
<td>Crack</td>
<td>11,178</td>
<td>2,356</td>
</tr>
<tr>
<td>Cocaine</td>
<td>13,732</td>
<td>3,557</td>
</tr>
<tr>
<td>Cannabis</td>
<td>29,275</td>
<td>7,581</td>
</tr>
<tr>
<td>Other</td>
<td>16,182</td>
<td>4,191</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td>220,043</td>
<td>50,373</td>
</tr>
</tbody>
</table>

1. Number of users based on all users in treatment in 2007/08 classified by primary drug of use at triage, obtained from Table 4.3.1 in DH & NTA (2008).
2. Number of users based on new individual patients/clients only in 2007/08 by main illicit drug, obtained from Table A1.9 in ISD (2008).
3. Number of users obtained by multiplying the number of referrals by main substance in 2008/09 by 51.5%, which is the figure for individuals as percentage of all referrals (data shown in WAG, 2009: Table 4 & Table 6).
4. Number of users based on new referrals to treatment in 2008/09 classified by main drug of use obtained from DHSSPS (2009): Table 9. Cocaine figures include crack cocaine.
**Estimate 2: Estimating the Numbers of Adult Family Members of Drug Misusers in the General Population**

Across the UK there is a very wide range of data sources that could be used, and which have wide variation in, for example, age ranges considered, severity of use and time-frame. Therefore, a range of sources were consulted and those with the most relevant data were used to produce the estimates in Table 2, including data for the UK submitted to the European Monitoring Centre for Drugs and Drug Addiction (Eaton et al, 2008) and the Adult Psychiatric Morbidity Survey for 2007 (McManus et al, 2009). Data sources were selected which were the most comparable across the UK, which presented the most recent data available and which provided specific data on severity of use (e.g. dependence) as this was believed most likely to correlate with more problematic use which would affect family members. However, due to wide variation in the data available on the misuse of drugs other than heroin, crack, cocaine and cannabis, estimates relating to groups of other drugs were not possible.

**Heroin/crack and cocaine**

For data on prevalence, estimates of problem drug use obtained using indirect estimation techniques were used for heroin and crack cocaine since household surveys do not provide robust estimates of these most complex users. Although the nature of the estimation process means that these estimates are quite old, where information on trends is available (i.e. in England and Scotland) it appears that prevalence rates are generally stable or decreasing very slightly. The exact definition of problem drug use varies by country:

- in England, the problem drug use estimates cover heroin and/or crack cocaine users aged 15–64 years in 2005/06 (Hay et al., 2007);
- in Scotland, they cover opiate and benzodiazepine users aged 15 to 54 years in 2003 (Hay et al., 2005);
- in Northern Ireland they cover opiates and both crack and powder cocaine users aged 16–64 in 2004 (Centre for Drug Misuse Research, 2006);
- for Wales, in the absence of finalised estimates covering their population\(^2\), the problem drug use prevalence rates for England were applied to population estimates for Wales (Eaton et al, 2008).

The number of people with cocaine and cannabis dependence was, in general, obtained by applying the prevalence rates for signs of dependence on these drugs found in the 2007 Adult Psychiatric Morbidity Survey for England (APMS) (McManus et al., 2009) to the 2007 population estimates aged 16 and over for each country obtained from the Office for National Statistics (ONS, 2008) The prevalence rates used

---

\(^2\) Interim estimates have recently been published (WAG, 2009) but these may be subject to change so were not used in this study. However, it should be noted that they are quite similar to the figures used here.
were 0.4% for signs of cocaine powder dependence and 2.5% for signs of cannabis dependence. The exception to this was for cocaine powder in Northern Ireland, since problematic cocaine powder use was included in their estimates of problem drug use.

To estimate the number of adult family members affected by opiates, crack and cocaine, the same assumptions as for Estimate 1 were employed (with the same limitations therefore associated with these estimates). The assumptions used are:

- for partners, using DTORS data, separate data were available for heroin users (39% had a partner, 56% of whom do not take drugs), crack cocaine users (34% partner, 62% of whom do not take drugs) and another drug (not specified) (35% partner, 74% of whom do not take drugs);

- for parents, the figure of 25% was used to estimate the number of drug misusers living with at least one parent; and

- for other family members, the figure of 16% was used to estimate the number of drug misusers living with siblings or other family members.

**Cannabis**

It is recognised that the age profile of cannabis misusers in the general population is different from the profile of the misusers of other drugs (e.g. heroin, crack), given that cannabis use generally begins at an earlier age (Chivite-Matthews et al., 2005), and that this will affect the make-up of the families in which they live. We therefore subdivided the cannabis group into two categories, one focused on young people aged 16–24 years and one focused on adults aged 25 years and above.

Data from the 2007 APMS (McManus et al., 2009), weighted to be representative of the general population, indicate that 2.5% of the population aged 16 years and over report symptoms of cannabis dependence alone (i.e. without signs of dependence on any other illicit drugs). We used results from this survey to estimate the number of people with cannabis dependence. This required an assumption that the estimates for England would be equivalent to those for Wales, Scotland and Northern Ireland, an assumption adopted given the lack of comparable data.

We applied the estimate of 2.5% to the 2007 UK mid-year population estimates (ONS, 2009) for each of the four countries (England, Wales, Scotland and Northern Ireland) for people aged 16 years and over. Secondary analysis of the data from the APMS further suggests that 46% of people with signs of cannabis dependence only are aged 16–24 years, with 54% being aged 25 and above. Therefore, this percentage split was used to estimate the numbers of people with cannabis dependence in each of the two age bands for each country. These calculations provided us the estimated numbers of people in each group (‘16–24’ and ‘25 and above’) with cannabis dependence that are reported in Table 2.
Family members of younger cannabis misusers (aged 16–24)

Secondary analysis of the data on people with signs of cannabis dependence in the APMS to look at their marital status and the number of people in the household (see table in Appendix 2) shows that among those aged 16–24:

- only 19% were married or cohabiting, and the vast majority of these only had one adult living with them and the remainder had three other adults in the household;
- 6% were the sole adult in the household;
- 23% were not married or cohabiting and were living with one other adult;
- 37% were not married or cohabiting and were living with two other adults;
- 12% were living with three other adults (including 2% who were married or cohabiting); and
- 5% were not married or cohabiting and were living with four other adults.

For each country we extrapolated from the figures above to estimate the potential number of affected family members in each group, as follows.

- For partners, we assumed that all those who described themselves as married/cohabiting and living with at least one person had a partner living with them, hence 19% of the estimated number of 16–24-year-old users was used as the number of partners.
- For parents, the APMS figures show that 23% are not married and live with one adult and 37% live with two adults. We assumed that each one of those people living with one or two adults but not married/cohabiting, i.e. 60%, was living with one parent.
- For other family members, we estimated one affected other family member for the 12% and 5% living with three and four other adults, respectively, hence 17% of the estimated number of 16–24-year-old people with signs of cannabis dependence.

We applied these estimates to each country; the results are reported in Table 2.

Family members of older cannabis misusers (aged 25 and above)

Secondary analysis of the data for people with signs of cannabis dependence over the age of 25 in the APMS indicates that:

- 31% were living as sole adults in the household;
- 49% were married/cohabiting and living with at least one other adult;
- 11% were without a partner and living with one other adult;
- 7% were without a partner and living with two other adults; and
- overall, 10% were living with three or more other adults (including 8% who were married or cohabiting).
Table 2: An estimate of the numbers of adult family members of problem drug users in the general population

<table>
<thead>
<tr>
<th>Problem drug/age</th>
<th>Users</th>
<th>Family members</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Partner</td>
</tr>
<tr>
<td><strong>England</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opiates &amp;/or crack</td>
<td>332,090</td>
<td>72,528</td>
</tr>
<tr>
<td>Cocaine</td>
<td>165,745</td>
<td>42,928</td>
</tr>
</tbody>
</table>
| Cannabis
| 16 to 24 years | 476,516 | 90,538 | 285,910 | 81,008 | 457,456 |
| 25+ years        | 559,389 | 274,101 | 100,690 | 55,939 | 430,730 |
| **Totals**       | 1,533,740 | 480,095 | 511,059 | 216,600 | 1,207,754 |
| **Scotland**     |       |         |        |       |               |
| Opiates &/or crack | 51582 | 11,266 | 12,896 | 8,253 | 32,415 |
| Cocaine          | 16,909 | 4,379 | 4,227 | 2,705 | 11,311 |
| Cannabis
| 16 to 24 years | 48,614 | 9,237 | 29,168 | 8,264 | 46,669 |
| 25+ years        | 57,069 | 27,964 | 10,272 | 5,707 | 43,943 |
| **Totals**       | 174,174 | 52,846 | 56,563 | 24,929 | 134,338 |
| **Wales**        |       |         |        |       |               |
| Opiates &/or crack | 18,480 | 4,036 | 4,620 | 2,957 | 11,613 |
| Cocaine          | 9,694 | 2,511 | 2,424 | 1,551 | 6,486 |
| Cannabis
| 16 to 24 years | 27,870 | 5,295 | 16,722 | 4,738 | 26,755 |
| 25+ years        | 32,717 | 16,031 | 5,889 | 3,272 | 25,192 |
| **Totals**       | 88,761 | 27,873 | 29,655 | 12,518 | 70,046 |
| **Northern Ireland** | 3,030 | 721 | 826 | 528 | 2,075 |
| Cocaine          | (included in the opiates/crack estimates above) | | | | |
| Cannabis
| 16 to 24 years | 15,860 | 3,013 | 9,516 | 2,696 | 15,225 |
| 25+ years        | 18,618 | 9,123 | 3,351 | 1,862 | 14,336 |
| **Totals**       | 37,781 | 12,857 | 13,693 | 5,086 | 31,636 |
| **United Kingdom** | 405,455 | 88,551 | 101,365 | 64,872 | 254,788 |
| Cocaine          | 192,348 | 49,818 | 48,087 | 30,775 | 128,680 |
| Cannabis
| 16 to 24 years | 568,860 | 108,083 | 341,316 | 96,706 | 546,105 |
| 25+ years        | 667,793 | 327,219 | 120,202 | 66,780 | 514,201 |
| **Totals**       | 1,834,486 | 573,671 | 610,970 | 259,133 | 1,443,774 |

1 Opiates &/or crack estimates are based on the Problem Drug Use estimates for each country. For England, the estimate refers to opiate and/or crack use (Hay et al, 2007); the estimate for Wales is extrapolated from the English estimate (Eaton et al., 2005) (an interim PDU estimate for Wales has since been published (WAG, 2009)). The estimate for Northern Ireland includes opiates and/or cocaine (including both crack and cocaine powder) (Centre for Drug Misuse Research, 2006). The estimates for Scotland include opiate and/or benzodiazepine use (Hay et al, 2005).

Cocaine estimates for England, Scotland and Wales were based on the figure of 0.4% of the population with signs of cocaine dependence reported in the 2007 APMS.

Estimates for cannabis were based on the prevalence of users with signs of cannabis dependence from the 2007 APMS in England that was applied to population estimates for England, Scotland, Wales and Northern Ireland.
For each country we used the figures above from the APMS to estimate the potential number of affected family members in each group, as follows.

- For partners, 49% of people with signs of cannabis dependence in this age group were married/cohabiting and living with at least one other adult, hence the figure of 49% of the number of users aged 25 and over was used to estimate the number of partners.

- For parents, the APMS figures show that 11% live with one adult and 7% live with two adults. It was assumed that each one of those living with one or two adults but not married/cohabiting was living with one parent.

- For other family members, we estimated one affected other family member for the 10% living with three or more other adults.

We conducted these estimates for each country; the results are reported in Table 2.

**DISCUSSION OF PREVALENCE MODEL AND ESTIMATES**

Figure 2 summarises the overall estimates calculated using the model developed.

*Figure 2: Summary of estimates of the minimum number of adults/carers affected by a relative’s drug use*

<table>
<thead>
<tr>
<th>Drug users in treatment</th>
<th>General population¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>50,373 partners</td>
<td>573,671 partners</td>
</tr>
<tr>
<td>55,012 parents</td>
<td>610,970 parents</td>
</tr>
<tr>
<td>35,208 ‘other’ family members</td>
<td>259,133 ‘other’ family members</td>
</tr>
<tr>
<td>Total = 140,593</td>
<td>Total = 1,443,774</td>
</tr>
</tbody>
</table>

¹The estimates presented in the general population group include the treatment population group.

The model that has been developed and presented here is a useful template for the development of work that is urgently needed to provide better estimates of the numbers of adult family members affected by illegal drug misuse. Two estimates have been presented to demonstrate how the model might be used. Other estimates are possible, using alternative data sources, different predefined assumptions or different levels within the assumptions. Hence, the two estimates that have been presented are examples of how the model may be applied and should be seen as guides or a first approximation, rather than a definitive answer to how many adult family members might be affected by illegal drug misuse. A more detailed model could be produced which could further develop the estimates by, for example, profiling family members by gender, age, geographical region or minority ethnic status. Such detailed models and estimates are outside the scope of this piece of work. Moreover, the data to move in this direction are currently unavailable.
The limitations of the data available, and the assumptions that had to be made, mean that the estimates are minimum estimates of the numbers of adult family members of illegal drug misusers, in drug treatment or in the general population, who are significantly affected by their family member’s drug use, across the UK. Increasing the number of assumptions made would have increased the fragility of the estimates.

**Figure 3: Summary of the ways in which the estimates under-estimate the number of family members affected**

1. Only family members living with a drug misuser are included in the estimates, although it is known that family members not living with the user may also be significantly affected.

2. Family members who were also classified as drug misusers are excluded from the calculations. While it is known that some family members will themselves use drugs or alcohol as a means of coping with their relative’s misuse and may themselves subsequently also develop a problem with drugs or alcohol, this assumption was made so that we did not count individuals twice, i.e. as drug users and as family members.

3. For parents of drug users, we have only included parents living with the drug user and assumed only one parent in each case. This is because the available data relating to parents of drug users do not provide information as to whether the drug misuser lives with one or two parents. Nor do we have information about parents who are not living with the drug user, although they are also likely to be affected.

4. In terms of siblings and ‘other’ family members, the calculations conducted do not consider multiple siblings or types of other family members (e.g. grandparents).

5. As the focus of the report is on adult family members/carers, the estimates do not include children who have a parent or other family member with a drug problem.

6. Due to the nature of the available data, and to provide some consistency and focus to the estimates which are presented, narrow definitions of dependence and problematic use have been adopted. It is of course the case that many family members will also be affected by much lower levels of the use and misuse of a range of illegal drugs.

7. Due to availability of data, young people under 16 years of age who might be problematic users of, or dependent on, cannabis or other drugs are not included in the general population estimates presented.

8. The focus of data collection in the UK is on opiates, cannabis and crack/cocaine, meaning that some of the estimates are limited to these groups of drugs.
Hence, while the two estimates presented might be limited in scope (because, for example, they are based on drug misusers who live with specified family members), this limited scope increases confidence that at least as many people as estimated by the model are significantly affected by a family member’s drug use.

Figure 3 summarises some of the ways in which the results obtained may represent under-estimates.

Despite being only minimum estimates, this is the first time such calculations have been presented and, therefore, this work is a significant step forward in identifying more accurately the numbers of family members who may need support. Furthermore, the work also highlights significant gaps in knowledge in this area, and thus it provides a basis for improving the evidence base and developing better estimates in the future based on the collection of accurate new data.

Other data sources can also be used to explore the results further and to stimulate debate and future refinement of the estimates. The DORIS study, for example, reported that 88% of respondents (n = 1,007) had a living mother and 78% had a living father, suggesting that the numbers of affected parents presented here are considerable under-estimates (Neale, 2002).

Some data on family size and size of support networks offer an additional perspective on the estimates presented in this report. For example, the 2000 national Psychiatric Morbidity Survey (Coulthard et al., 2002) found that 7% of those who were defined as drug dependent said they had a primary support group comprising three people or fewer, 28% a group of four to eight people and 65% a group of nine or more people (a primary support group was defined as ‘close friends and relatives’ and includes people residing elsewhere – the proportions were similar for groups of respondents who reported illicit drug use in the past month, in the past year and a year or more ago). Qualitative interview data (Barnard, 2007; Orford et al., 2005, 2009; Templeton et al., 2007) also demonstrate the ripple effect, both within and external to a household where there is a drug misuse problem, showing how many other people can be affected by someone who has a drug problem and the range of relationships they may have. Some examples are given in Appendix 1 (Copello et al., 2009a; Templeton et al., 2007). Such data give a useful, albeit only indicative, picture of the many individuals that might be affected by the problem drug use of any one person.

A further issue to highlight is that the data presented here are intentionally focused on adult family members of drug misusers, and therefore exclude children affected by familial (usually parental) drug misuse. It has been estimated that there are in the region of 250,000 children of problem drug misusers in England and Wales and in the region of 50,000 children of problem drug misusers in Scotland (ACMD, 2003).

Finally, on a methodological level, the models do not take into account the possible overlap in the groups of drug misusers (for example, individuals who may misuse heroin and an ‘other’ drug). Further, more complex statistical refinement to the models would be needed to deal with this. Thus, in this one respect the models may include a small element of over-estimation in terms of affected family members. However, as far
as possible, the data sources used counted according to the main problem drug and hence the potential for this problem to arise was minimised. Furthermore, the sources of under-estimation far outweigh any over-estimation.
3. Social costs and resource savings

INTRODUCTION

Rationale

Families of drug users are frequently an unpaid and unconsidered resource, providing health and social care to their drug misusing relatives. Family members and carers may also carry a large burden in terms of costs linked with the drug use of a relative, which are to some extent forced upon them through loyalty and familial ties. Families and carers agree that the hidden costs of this public health problem are significant, but in the face of stigma and the illegality of drug related activity, they are not systematically recorded in public datasets or in research studies. In addition, economic evaluations of treatment services conducted by NICE take an NHS or state perspective that does not include (social) costs to individual family members that arise from the drug misuse of a relative.

The role that family members and carers play in the care and support of drug misusing relatives and the hidden costs they bear are not recognised or acknowledged by a range of public bodies or government. Generally, the users themselves and the drug treatment services are the focus of attention. This study marks the first attempt to throw light on this issue in the UK and to quantify with a conservative economic estimate the costs to family members associated with illicit drug misuse by a relative that are largely hidden to society. The arguments presented do not address the issue of the broader costs associated with drug misuse or the cost-effectiveness of drug treatment services, so the costings presented in this report should not viewed or applied in that way. The costs to society of drug misuse are not included in this report, but readers are referred to the following articles, which consider the societal benefits of drug treatment services: Godfrey et al. (2004) and Cartwright (2008).

The nature and definition of costs

The basic approach taken in this report is first to calculate economic estimates of annual unit or average costs per family member. These are then applied to the prevalence estimates of the number of family members and carers obtained in Chapter 2 to arrive at an annual total cost for the UK and its individual countries. The costs presented should be viewed as a first step in establishing a costing process. The cost estimates do not claim to be definitive or complete and should not be viewed in this way.

Costs are commonly understood to be the amounts of money spent buying goods or services. However, economists are interested in opportunity costs, or the value of the opportunity foregone by using resources in one way rather than another way. This view of costs means that all resources changing hands have an opportunity cost, even when money does not change hands. For example, family members do not get paid
when they help a drug using relative with a home detoxification or nurse them through an illness, but there is an opportunity cost in that they sacrifice employment opportunities or time they could have spent doing something else. In this example, opportunity costs are also resource savings, in the sense that the NHS is not involved in providing healthcare.

**The approach to cost estimation**

The approach to economic unit cost estimation applied in this research has been as follows.

1. Identify the main areas of resource use and costs to family members and carers.
2. Find robust evidence on these identified elements from large, controlled studies.
3. Translate mostly US evidence into a UK resource use and costs context, making all assumptions explicit.
4. Build UK estimates of resource use and prices/costs to family members and carers, making all assumptions explicit.
5. Develop a model that might be adjusted to apply the estimates of unit costs to the prevalence estimates for family members and carers, to create final economic estimates of the costs to and resources saved by family members and carers.

**THE COSTS TO FAMILY MEMBERS AND CARERS**

Economic costs to family members and carers may take the form of direct monetary expenditure, contributions in kind or time spent assisting a relative with a disorganised and complex lifestyle. Contributions include the need to engage with service agencies, transport to appointments, home care, purchase of food and rent. In addition to time, money and goods given in support of a drug using relative, which can all be measured directly, other indirect and intangible costs might arise to family members and carers that are not necessarily represented by money changing hands. A range of costs are included in the cost estimates for family members and carers in the UK, along with the cost savings to the NHS and local authorities arising from the care provided to drug using relatives (Figure 4). The cost estimates include the costs arising from witting and unwitting monetary expenditure in alleviation or support of the drug use of a relative. Family members typically experience costs arising from stolen money, property and assets (Drugscope, 2004; Home Office, 2005), taken by drug dependent relatives in their drive to secure drugs. This is particularly the case for heroin and crack users, but family members may experience crime from any other drug dependent relative in this way.

Figure 4 illustrates the items of cost and resource saving included in the unit cost estimates. The domains of social cost or resource saving are described along with the basis for estimation of each cost dimension in the section headed “The evidence base and economic estimates”.
Definition of cost dimensions

The dimensions below are those for which costs are presented in Table 3.

**Day-to-day costs**

Families are often a major source of support for people with substance problems severe enough to disrupt their lives. Clark and Drake demonstrated that family members provide financial support from their own resources (Clark and Drake, 1995). These costs are termed 'day-to-day costs' in this report.

**Drug incidental costs**

Drug incidental costs are those costs that reflect the money that family members may innocently or unwillingly give to relatives and which help them to obtain drugs. Other financial costs might arise from protecting drug misusing relatives from dealers, such as where a dealer makes threatening demands for payment of sums of money (probably inflated) and family members make payment to protect their relative from violence.

**Costs of crime on carers**

As mentioned earlier, family members are very likely to experience the theft of money and individual personal property by their drug dependent relatives, which is captured by the 'cost of crime on carer'.
Lost carer employment opportunities

Adult family members and carers may need to put their lives on hold in order to help a drug misusing family member or because of stress related problems, which can lead to lost employment opportunities or reduced productivity for that individual.

Healthcare costs

Family members and carers can experience ill-health arising from the stressful environment created by the presence of a drug problem within the family context. Psychological ill-health may also manifest itself in an increase in physical health problems and so excess demand for medical services is created. These costs have been designated 'healthcare costs' in this report.

Resource savings from nursing and home help care

As major partners in the treatment and support of those who have problems with drug use, family members and carers often provide informal care for which they are not remunerated. These costs would otherwise or might otherwise be picked up by the NHS (nursing care) or local authorities (home care) and so form part of the estimation of costs to family members and carers. Resource savings to the NHS and local authorities included here arise from the time spent by family members and carers on the health and social care of drug dependent relatives, which is on average over and above the time that would be committed to the care of any other family member.

The evidence base and economic estimates

Translation of economic evidence between contexts

A requirement for building economic costing estimates was to have evidence from large randomised controlled trials or cohort studies. The only available evidence that fitted this requirement was from the USA. The evidence was translated from the US to the UK context directly, which presented some limitations in its use as a basis for UK estimates. However, this approach can be justified as UK evidence was not available. In terms of financing, health systems in the UK and the USA are not similar, but both countries have advanced healthcare systems. There are limitations to the explicit assumptions that have been applied in the analysis of additional healthcare costs. For example, patterns of ethnicity, access to healthcare and patterns of deprivation are different between the two countries, and this should not be overlooked. However, there were no robust UK studies on which to base estimation of the unit costs arising from care and support of a drug dependent relative. The rigour and robustness of the quantitative research design utilised as the basis for the economic estimations made the translation of findings across contexts justifiable. Without these compromises, the economic estimation process would not have been possible in this study.

Table 3 presents a profile of annual UK unit costs to family members and carers of a relative’s problem opiate/crack use and the potential resource savings to the NHS and local authorities resulting from the care they provide.
Financial costs to family members and carers

Day-to-day costs

A randomised controlled trial from the USA by Clark and Drake (1995) and Clark (1994) collected detailed data on the support provided by 169 family members to people diagnosed with both mental health and substance misuse problems living with and living away from their family. Of those family members, 119 (70%) were parents, 30 (18%) were siblings and the remainder were spouses, grandparents, children or other relatives. The majority of family members interviewed were women (82%). Estimated family income averaged $26,829 (1992 prices). Time spent caring for relatives with dual diagnoses (mental health and substance misuse problems) by family members and carers was recorded. Time spent caring for relatives without these same dual diagnoses by family members was also collected for comparison purposes (Clark, 1994). Clark reasoned that time spent helping a relative is not always seen as economic assistance because money does not change hands in this sort of exchange transaction. Moreover, family members, especially parents, often give time and monetary resources to their adult children because they want to. Therefore, the Clark study establishes the additional day-to-day cost to family members of drug using relatives over and above that of family members without drug using relatives.

The papers from the Clark and Drake study provide a robust basis for estimating the ‘excess’ time and money devoted to informal care of drug using relatives by family members because the estimates come from a large randomised controlled trial. However, the limitation of the study as a basis for day-to-day cost estimates of drug misusers in the UK needs to be made clear. The study population in the Clark and Drake study had differences from the population that is the subject of this report: in the US study, 82% (139/169) were alcohol dependent, with a spread of mental health diagnoses, including schizophrenia, across the sample. Nevertheless, the estimates in the Clark and Drake study are all that we have on which to form the basis of an estimate of time devoted to day-to-day tasks. Therefore, that study is used as a basis for estimation of day-to-day costs in the UK. However, it is likely that the data in that study are representative of the most severe end of the spectrum of drug users, such as crack and heroin users rather than cannabis and cocaine users. Consequently, we have only applied the economic estimation to the estimation of prevalence of family members of heroin and crack cocaine users and not to numbers in other drug using groups. Thus, once again, the estimates presented in this report can be viewed as minimum estimates.

Excess annual day-to-day costs were estimated from Clark’s paper (Clark, 1994) and converted to pounds sterling at $1.77 = £1 from US dollars (1992 average exchange rates) and uprated to 2008 prices (Office for National Statistics, 2009a). This gives an excess average annual day-to-day care cost for each family member or carer of £2,330 (at 2008 prices).

Drug incidental costs

This has been estimated as half the excess annual day-to-day costs of families, or £1,165 per family member. It was felt reasonable to make the assumption that these
costs would be half the additional day-to-day costs as families report this element is a key feature of their experience with drug using relatives.

**Costs of crime on carers**

In addition to the costs above, family members report that they are often victims of acquisitive crime from drug misusers within their own family. The annual unit cost of crime on carers has been captured and represented as the personal victim cost of a single burglary at a dwelling based on Home Office estimates (Home Office, 2005:9): £2,626, uprated to 2008 prices = £2,840. The cost for a burglary is used as being indicative of the type of crime that family members and carers might experience, and does not include costs incurred through the criminal justice system.

**Lost carer employment opportunities**

The time family members sacrifice to the care of drug users 226 hours per annum (Clark, 1994), was costed at the average UK earnings rate of £12 per hour (April 2008 prices) (Office for National Statistics, 2009b). This assumed that employment opportunities would be at the average hourly earnings rate for a 40-hour week.

**Health cost of hidden harm to carers**

**Healthcare utilisation costs**

A study funded in the USA by the National Institute of Alcohol Abuse and Alcoholism and conducted by Ray and colleagues estimated the excess medical costs and health problems of family members of persons diagnosed with alcohol or drug dependence (AOD) using a large case-control study. Through secondary analysis of the database of a large health plan, the excess medical costs and prevalence of health conditions were compared for family members of people up to 65 years diagnosed with AOD (n = 21,740) and family members of similar people without AOD (n = 71,151) to calculate additional costs. The time period considered was the two years prior to the diagnosis of their family member’s AOD and the same respective time-frame for the control group. The estimated additional medical costs for adult family members were $710 per annum (range $583–$837) for the two years before the index date (2004 prices). Excess medical costs two years before the index date were much higher if the family member with AOD was female ($648; range $498–$799, 2004 prices) rather than male ($388; range $267–$509, 2004 prices) (Ray et al., 2007).

These annual unit excess cost of healthcare for family members and carers were assumed to apply to people in the UK with a drug dependent relative. Costs were uprated to 2008 dollar prices using retail prices indices (Bureau of Labor Statistics, 2009). The resultant figure was then converted to pounds using an exchange rate of £1 = $1.77. This gives an annual excess healthcare cost of £450 per family member.

Family treatment services may need to consider the differential impact of gender in family interactions in the face of a drug problem, in terms of the services they provide to support the male partners and other family members of drug dependent women.
Resources saved by the NHS and local authorities

Nursing care and home help care

The studies by Clark and Drake demonstrated that the time devoted by families to informal care giving for relatives with dual diagnoses was intensive and was substantially greater than in families in which relatives did not have either diagnosis. Annual average hourly estimates of additional time devoted to care and support of a dual diagnosed relative (substance abuse and mental health) was 226 hours per annum for both relatives living with and apart from family respectively (there was no significant difference in care support time between these groups). Time was devoted to providing transport, talking with mental health and substance abuse workers, talking with police and lawyers, general care giving, cooking, assisting with medications, crisis intervention, structured leisure activities (excluding television watching), shopping, childcare and attending support groups (Clark, 1994).

Annual estimates of additional carer time devoted to assisting with illness related tasks medications, crisis management, co-ordinating treatment services was estimated at 29 hours per annum by Clark (Clark, 1994). An alcohol and drugs worker in a hospital A&E department would have been paid £27 per hour at 2007/08 prices for the same tasks (Curtis, 2008:63). This produced an estimate of £783 per annum (2008 prices) in resource savings to the NHS. Carer time devoted to home help-type tasks (social care) was 197 hours per annum (Clark, 1994). An annual estimate of resource savings to UK local authorities was £3,152 per annum, derived from the product of the hourly cost of a local authority home care worker – £16 at 2007/08 prices (Curtis, 2008:117) – and 197 hours per annum.

Unhappiness experienced by family members and carers

The complex drug use of an individual and all that that entails has a big impact on the happiness, well-being and quality of life of their close relatives. Most people working in drug treatment services would identify unhappiness as one of the biggest impacts on family members in this situation. However, unhappiness is intangible, and so difficult to measure and value. Economists Clark and Oswald (2002; Oswald, 2007) have developed methods to measure the magnitude of life events on well-being using happiness regression equations derived from large random samples of people in the British Household Panel Survey. These methods allow an intangible cost such as ‘unhappiness’ to be reflected in monetary terms, so that it can take its place with other direct costs that are easier to express as sums of money.

Using these established methods, it is possible to estimate the level of compensation that would be required to compensate for the intangible cost of unhappiness caused by the drug misuse of a close relative, if such a market existed (Oswald, 2007). Such a market does not exist, but monetary compensation of a family member would amount to as much as £186,108 per annum using these estimation techniques. This value has not been included in the costing of this report, as these estimates are not strictly comparable with unit costs. However, the amount is large and the prevalence estimates of the number of people affected in this way is great.
Table 3: Annual unit costs and resource savings to NHS and local authorities

<table>
<thead>
<tr>
<th>Type of cost</th>
<th>Costs: £ (2008 prices)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Unit costs per annum per family member of a problem drug user</strong>¹</td>
<td></td>
</tr>
<tr>
<td>Day-to-day costs²</td>
<td>2,330</td>
</tr>
<tr>
<td>Drug incidental costs³</td>
<td>1,165</td>
</tr>
<tr>
<td>Cost of crime on carer⁴</td>
<td>2,840</td>
</tr>
<tr>
<td>Lost carer employment opportunities⁵</td>
<td>2,712</td>
</tr>
<tr>
<td>Healthcare costs⁶</td>
<td>450</td>
</tr>
<tr>
<td><strong>Annual total unit cost</strong>⁷</td>
<td><strong>9,497</strong></td>
</tr>
<tr>
<td><strong>Resource savings</strong></td>
<td></td>
</tr>
<tr>
<td>Resources saved: NHS⁸</td>
<td>783</td>
</tr>
<tr>
<td>Resources saved: local authority⁹</td>
<td>3,152</td>
</tr>
<tr>
<td><strong>Annual savings to NHS/local authority</strong>¹⁰</td>
<td><strong>3,935</strong></td>
</tr>
</tbody>
</table>

Notes:

1. Problem drug user = heroin or crack user in England and Wales, opiate or benzodiazepine user in Scotland and heroin or cocaine user in Northern Ireland.
3. Assumes half the excess day-to-day costs (Clark, 1994).
6. Annuited estimates of the excess cost of healthcare for family members and carers with a drug dependent relative (Ray et al., 2007). Upgraded for inflation to 2008 dollar prices (Bureau of Labor statistics, 2009) and converted to sterling at £1 = $1.77.
7. Sum of excess day-day costs, drug incidental costs, cost crime on carer, excess lost carer employment and excess healthcare (range: £8,612–£11,770).
10. Sum of resources saved by NHS and resources saved by the local authority over and above those committed to other free care of relatives (range: £3,613–£4,257).

These facts all point to the need for an expansion of family support and treatment services, so that families can get the help that they need. These services would pay for themselves when the cost of provision is compared with the huge economic cost imposed on the family members and carers of drug dependent relatives demonstrated in this report. Family members can make a very big difference to successful treatment outcomes of drug misusing relatives – it makes sense to include families in treatment. However, as more money is put into family support and treatment services, this investment should be evaluated within an appropriate framework to establish cost-effectiveness.
ESTIMATES OF ANNUAL UNIT COSTS AND THE RESOURCES SAVED

Annual total unit costs per family member and carer were estimated by summing day-to-day costs, drug incidental costs, costs of crime on carer, lost carer employment opportunities and healthcare costs. This gave a base economic cost estimate of £9,497 per annum (2008 prices). The confidence intervals around the annual unit cost were estimated to be in the range £7,918–£11,076.

Annual resource savings to the NHS and local authorities per family member over and above those committed to other free care of relatives was £3,935 (range £3,613–£4,257). Overall, the total estimated annual unit cost per family member was £13,432 (range £11,531–£15,333).

The economic estimation model: total costs and resource savings

The general models below might be used to construct economic estimates using alternative data for prevalence estimates and economic costs.

The general economic models are:

\[
ATC = N \times AC \\
ARS = N \times RS
\]

where:

- \(ATC\) = annual total cost, UK or member country
- \(ARS\) = annual resource saving, UK or member country
- \(N\) = estimated prevalence of affected family members (partners, parents, other relatives)
- \(AC\) = annual family member unit costs
- \(RS\) = annual unit resource savings to the NHS and local authorities from each family member.

The specific economic models below were used to create costing estimates for family members affected by heroin and crack cocaine in the UK and its member countries (see Table 4):

\[
ATC = N \times AC \\
ARS = N \times RS
\]

where:

- \(ATC\) = annual total cost, UK or member country
- \(ARS\) = annual resource saving, UK or member country
N = estimated prevalence of partners and parents as affected family members (other relatives have not been included in the estimates for Table 4) for drug misusers (mainly opiate and/or crack users)

AC = annual family member unit costs

RS = annual unit resource savings to the NHS and local authorities from each family member.

These models can be adapted to accommodate different assumptions. For example, in this report the prevalence estimates of partners and parents as family members affected by the crack cocaine and/or heroin use of a relative are applied to create a total cost estimate. Different economic estimates might be created by using different base assumptions to form estimates. The costs to the family members and carers of cannabis and cocaine misusers have not been included in the economic estimates presented in this report. This was a decision made as a result of the difficulties in attributing this type of drug use to the costs and resource savings of family members directly. However, readers of this report could use the data presented to make assumptions and produce different estimates of economic costs that might reflect other information or evidence about the impacts of different types of drug misuse on families.

The sum unit cost estimates were applied to the prevalence data for the four UK countries to give overall annual estimates of the social costs and resource savings for family members and carers. It was assumed that all parents and partners were equally and fully affected by the misuse of the estimated number of heroin and crack misusers overall in the UK and in the individual countries. It has been assumed that ‘other relatives’ are not affected at all by any category of drug misuse of a relative. The estimates for the four countries and the total estimates for the UK are given in Table 4.

**Table 4: Estimated cost and resource savings of family members and carers of problem drug users for each UK country and for the UK as a whole, 2008 prices**

<table>
<thead>
<tr>
<th>Per family member: £ per annum</th>
<th>Number affected</th>
<th>All family members and carers: £ million per annum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual unit cost</td>
<td>Resource savings NHS/local authority</td>
<td>Partners</td>
</tr>
<tr>
<td>England</td>
<td>9,497</td>
<td>3,935</td>
</tr>
<tr>
<td>Scotland</td>
<td>9,497</td>
<td>3,935</td>
</tr>
<tr>
<td>Wales</td>
<td>9,497</td>
<td>3,935</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>9,497</td>
<td>3,935</td>
</tr>
<tr>
<td><strong>Total for UK</strong></td>
<td><strong>9,497</strong></td>
<td><strong>3,935</strong></td>
</tr>
</tbody>
</table>
DISCUSSION OF ECONOMIC ESTIMATES

The annual cost estimate for the UK comprises an annual family members and carers total cost of £1.8 billion and resource savings to the NHS and local authorities from the care that family members provide to drug using relatives of £747 million (2008 prices). Prices are based upon bold assumptions using the poor sources of data available.

Many assumptions have been made to create the economic estimates of the annual cost of drug dependence of relatives for family members and carers. The evidence presented here demonstrates the specific impact on parents and partners of heroin and crack use. The number of assumptions used to create estimates produces uncertainty in the estimates, which has been captured with confidence intervals around the estimates in the studies that contribute to the unit costing (see Table 3).

The base evidence from which the economic estimates are developed is robust. It comes from large randomised controlled studies and large surveys. However, two of the main studies are US-based, as it was not possible to use UK studies of the same research design – they were just not available. Also, the studies were of people with mental health as well as substance misuse problems, and it was not possible to disentangle the differential effect of each condition. However, we know that a number of the more complex drug users also experience mental health problems and it was felt important to base estimates on quantitative research designs. Qualitative evidence has not been used as the basis of any of the economic estimates of cost.

This work raises a number of questions. This study provides, for the first time, estimates that demonstrate that the hidden costs on individual family members of the heroin and crack use of a relative is significant. Carers of relatives with drug dependence are not recognised in the same way as other carers; for example, those who care for older people. Should the state intervene?, and if so, at what level and with what magnitude of resources? Are the families of drug misusers less deserving than other families and carers? Families need support and treatment in their own right. However, support of family members of drug misusers should mean more than resources for NHS treatment services on their own. Families can and do contribute to routine care and support of drug misusers, and in some cases provide detoxification services at home – relieving the pressure on NHS services as well as providing accommodation, support and day-to-day care that might otherwise need to be provided by the state. Other family services that respond to the needs of family members, irrespective of whether the user is in treatment, need to be developed through voluntary groups and social enterprises to back up the family and support treatment services and to ensure that families are able to continue providing this support. A variety of services could be envisaged, but it is important that when resources are committed they are evaluated and that the cost-effectiveness of a service is established. Chapter 4 highlights the evidence currently available on the types of support and treatment that have so far been shown to be effective.
**Conclusions**

The UK evidence base for prevalence of family members and associated family costs is fragile and better evidence on which to base both family prevalence and economic estimates is urgently required. Large, well-designed studies with control groups are required to enable the nature and extent of the costs that family members experience to be identified. Such studies need to record the considerable hours of care, the unhappiness and the crime that family members and carers are exposed to, their lost opportunities and the way they support drug using relatives in treatment and home detoxification. This would not only help make the case for support provision but also help to identify the areas in which support is required.

Families are a largely untapped treatment resource and a force for achieving good treatment outcomes in their drug misusing relatives. The evidence in this report suggests that policymakers need to reframe and reflect upon the negative aspects of the hidden economic costs and consider how this could be turned to advantage by embracing family treatment much more fully.
4. An overview of effective interventions to help family members and users

Family members report two separate, yet related, needs when interviewed about their experience of living with someone with a substance problem (Orford et al., 2005). First, they need to understand the problem that they are facing and to receive support in their own right in order to reduce the experience of stress and to be able to provide what may constitute positive responses that support change or improvement of the drug problem. Part of understanding the problem involves receiving accurate information about drug problems and effects. Second, family members express a wish to contribute to the treatment of their relative.

A number of intervention approaches have been developed which involve family members in drug treatment but which also focus on family members’ own needs. An overview of the best known and most widely researched approaches is the focus of this section of the report. The term ‘family member’ is used to denote spouses/partners, parents, grandparents and siblings of people with drug problems.

This section of the report is based on a review of the academic literature on family-based approaches to the treatment of drug problems. Two of the most recent published reviews (Copello et al., 2005, 2006) summarised treatments across three broad categories: (1) entry and engagement of the user in treatment through work with concerned family members; (2) joint working with family members and the substance user; and (3) interventions for family members in their own right. Interventions of the latter type have been delivered to family members whether or not the drug misuser is in treatment. These categorisations have been used to structure this section of the report. This is helpful both in guiding a service response to meet the expressed needs of family members affected by drug use and in serving as a template against which to assess the current delivery of appropriate services for this group across the UK.

The work for this section involved considering the existing reviews in the area as well as identifying and critiquing more recent studies. A large proportion of the literature on families and addiction focuses on alcohol interventions, or covers both alcohol and drugs. This review covers all of these, thereby including alcohol, given that alcohol focused interventions will have potential application to other drug problems. Indeed, in some cases, interventions originally tested with alcohol problems were later adapted and tested with drug related problems (e.g. Behavioural Couples Therapy, Social Behaviour and Network Therapy). For further detailed knowledge information about the components of each intervention, the reader is referred to the academic references or treatment manuals where available.
RESPONDING TO THE NEEDS OF FAMILY MEMBERS IN THEIR OWN RIGHT

As already described, interventions can be delivered to family members affected by a drug problem irrespective of whether the user of drugs is in treatment or not. On close inspection, these interventions appear to fall into two types. Some are focused on responding to the needs of family members in their own right in terms of the provision of information and support and aim to reduce the experience of stress by the family member. The second type involves interventions where the main aim is to work with the concerned and affected family members in order to bring the drug user into treatment.

Interventions focused on responding to the needs of family members in their own right

Interventions based on the stress-strain-coping-support theoretical model: The 5-Step Intervention

Perhaps the most well-known of these interventions in the UK is the 5-Step intervention for family members affected by alcohol and drug problems (Copello et al., 2000a). This intervention is based on a stress-strain-coping-support model of addiction and the family (Orford et al., 2005) that emphasises the interaction between the stress that emerges when a family member is affected by the drug problem of a relative and the family member's response to the stressful situation. Informed by research, this intervention was developed originally to work with family members affected by drug and alcohol problems within the primary care setting. The intervention consists of the delivery of five different components, which comprise: listening to and reassuring the family member; providing targeted information; discussing ways in which the family member interacts with the user; exploring social support available; and finally identifying any further needs for support or access to services.

The 5-Step intervention has been subjected to a series of studies in both English primary care (Copello et al, 2000b; 2009a) and specialist settings (Howells and Orford, 2006; Templeton et al., 2007; Templeton, 2009) as well as in the Italian healthcare system (Velleman et al., 2006). The results of these research studies consistently show that the intervention appears to be effective in reducing stress symptoms and improving family member coping responses. The latest reported study (Copello et al., 2009b) showed that, in primary care, a relatively brief version of the intervention supported by a self-help manual was as effective as a more intensive one (one session versus up to five sessions). Overall, there appears to be good evidence that the 5-Step intervention can be used to help family members in their own right. Further work has been done to demonstrate how the 5-Step model, alongside the network approach of Social Behaviour and Network Therapy (SBNT – see below), can be implemented with statutory and non-statutory alcohol and drug teams in order to develop an overall team family focused response to addiction treatment (Orford et al., 2009).

Training family members (particularly parents) in coping skills

An approach with a different emphasis has focused on training family members in order to equip them with behaviours that are seen to be helpful in interactions with drug users. Two examples of these interventions evaluated in the research literature
involve Behavioural Exchange Systems Training (BEST) (Tombourou et al., 1997, 2001) and Parents Coping Skills Training (McGillicuddy et al., 2001). Both approaches consist of eight sessions with parents where the focus is on improving coping skills (particularly assertive coping skills) in response to adolescents’ substance misuse.

BEST has been subjected to a quasi-experimental evaluation, which showed that it was associated with greater reductions in mental health symptoms in parents and a higher frequency of more assertive coping behaviours when those receiving the intervention were compared with controls. Parents Coping Skills Training was subjected to a small randomised trial that showed improvements in the parents’ coping skills and enhanced family communication following the intervention. These approaches are useful in terms of focusing on the development of skills that can enhance the repertoire of responses that family members can use in what usually is a challenging interaction with adolescent drug users.

**Mutual-help groups**

Mutual-help groups are available for family members, who can meet for support. These are available for problem drinking or drug taking, although availability in the UK is limited, particularly for drug problems. Most of the research has focused on alcohol groups (Gorman and Rooney, 1979; Miller et al., 1999; Humphreys, 2004). There is some evidence that men with drinking problems have relatively good outcomes when their partners attend Al-Anon a self help group for family members affected by alcohol problems of a relative. There is also some evidence that family members attending Al-Anon become more independent. Overall, there is some evidence of benefit to family members, but there is limited availability of this type of group in the UK.

**Interventions focused on supporting family members in order to facilitate treatment entry of the drug user**

*Community Reinforcement and Family Training and ‘Pressures to Change’*

A number of interventions have focused on working with family members in order to engage the user in treatment. These have mainly been used in the USA and Australia. The interventions that have been more robustly evaluated include the Community Reinforcement and Family Training (CRAFT) (Meyers et al., 1996; Sisson and Azrin, 1986) and the Pressures to Change approach (Barber and Crisp, 1995). There are some overlaps in the methods used, which often include providing support to the family member in the initial stages and later discussing ways to influence the user’s behaviour in a way that it is hoped would lead to the user of substances entering treatment. The evaluations of these interventions show that the user of substances is more likely to enter treatment (even those resistant and difficult to engage) when family members receive the intervention, either in individual or group format. The evidence also suggests that there is a reduction in physical and psychological symptoms for the non-misusing family member (Miller et al., 1999).

*Unilateral Family Therapy*

An interesting approach that has been reported in the literature involves Unilateral Family Therapy (UFT). UFT uses a systemic model that suggests it is possible to alter
the ways that a family behaves without all members of the family being present in sessions. The approach has been used to work with the concerned family member alone, aiming to effect change through working with a spouse in the absence of a person with alcohol problems (Thomas et al., 1987). In line with the studies in the previous section, this approach has produced greater rates of subsequent treatment entry on the part of the person with the substance problem.

**INTERVENTIONS WORKING WITH FAMILY MEMBERS AND USERS TOGETHER**

There are a range of interventions that are designed to work with a user of substances and members of his or her family jointly. Some focus on the immediate family, while others also tend to involve wider social and community networks. The interventions with the most robust evidence, and hence are discussed below, include Behavioural Couples Therapy (BCT), family therapy, and community and wider network interventions.

*Behavioural Couples Therapy*

BCT involves working with couples where one of the members has an alcohol or other drug problem. Particularly in the USA, BCT has been subjected to a number of well-designed research studies (O’Farrell and Fals-Stewart, 2006) and there is good evidence of its effectiveness, in terms of improvements in both substance related outcomes and relationship functioning. There are three central aims to BCT: (1) to strengthen and improve the marital relationship; (2) to eliminate abusive drug use and drinking; and (3) to engage the family’s support for the client’s effort to change. The overall aim is to change couple and family interaction patterns in a way that leads to a more stable relationship supporting stable abstinence. The intervention involves a number of cognitive and behavioural procedures, and is described in the most recent treatment manual produced by the originators of the approach (O’Farrell and Fals-Stewart, 2006).

BCT produces more abstinence, happy relationships and fewer separations when compared with individually based treatment. There is also evidence that domestic violence is reduced after BCT, and that BCT with a couple can indirectly benefit their children. A meta-analysis of 12 randomised controlled trials involving BCT (Powers et al., 2008) showed that better outcomes were achieved with this approach when compared with more typical individually based treatment for married and cohabiting individuals who seek help for alcohol or drug dependence. The benefits were seen at long-term follow-up in terms of reductions in frequency of substance use and improvements in relationships satisfaction and consequences of use.

The benefit-to-cost ratio for BCT is reported to be greater than 5 to 1. Finally, BCT can improve compliance with recovery medications (e.g. disulfiram, naltrexone). Recent NICE guidelines (NICE, 2007) produced in the UK have recommended wider implementation of BCT in drug treatments, based on the available evidence.

*Family therapy*

There has been a great deal of interest in a range of types of family therapy for drug problems, including Structural-strategic therapy, ‘Bowen’ Type therapy and contextual...
family therapy (Szapocznik et al., 1988; Stanton et al., 1982; Gacic, 1978; Bernal et al., 1987). Controlled trials have shown that family therapy is more effective than control interventions, mostly involving individually focused treatments, in terms of engaging drug users and is superior at follow-up in terms of drug use for family functioning.

Family-based treatments aimed at adolescent substance misusers have been shown to lead to improved rates of school attendance and performance, improved family functioning and reduced behavioural problems associated with the substance use (Liddle, 2004). More recently, Multidimensional Family Therapy (MDFT) has been shown to be effective with adolescent drug users (e.g. Liddle et al., 2008). MDFT contains four interdependent treatment domains: adolescents, parents and other family members, family interactional patterns and extra-familial systems of influence, and the therapist works simultaneously in each domain according to a profile for each adolescent and family.

There is also a growing number of services in the UK for whole families, usually including children and sometimes also including the misusing parent. While there is a dearth of research in this area, evaluation reports and pilot studies give indications that this is a growing and beneficial area of treatment delivery for families. Examples of family focused services include the Moving Parents and Children Together (M-PACT) model developed by Action on Addiction, Option 2, the Family Alcohol Service in London, CoreKids in London and the Addaction Breaking the Cycle service.

**Social network approaches**

While family interventions utilise close (and sometimes wider) family members, other approaches follow the idea that better success in treatment of substance misuse can occur if positive social networks are involved. There is an accumulating body of positive evidence showing that network approaches have promise not only in terms of substance related outcomes but also in terms of family functioning, improved relationships and reductions in stress for family and network members. Social Behaviour and Network Therapy (SBNT), (Copello et al., 2002, 2009b) is one approach that was developed by integrating a number of the family and social network strategies that were proven effective in previous research. It is based on the premise that to give the best chance of a good outcome, people with serious alcohol or drug problems need to develop positive social network support for change. The treatment has been evaluated and found to be as effective as Motivational and Enhancement Therapy when used with alcohol problems (UKATT Research Team, 2005) and has also been tested with drug users in routine services. SBNT has been produced in manual form (Copello et al., 2009b) and has been quoted as part of the orange guidelines on Clinical Management of Drug Misuse and Dependence (DH England and the devolved administrations, 2007). The powerful notion underlying these interventions is that the social environments (families and friends) of users can be activated and used in a positive way to enhance recovery from drugs and alcohol. Network therapy was originally developed and tested by Galanter (1993a, 1993b) and two further recent studies have shown network interventions to be promising and feasible with alcohol users (Litt et al., 2007) and drug problems (Kidorf et al., 2005).
The Community Reinforcement Approach

The Community Reinforcement Approach (CRA) has been examined in several studies and found to be efficacious for the treatment of alcohol and drug problems. The essence of the CRA involves restructuring the social, family and vocational aspects of the lives of people with alcohol or drug problems, so that abstinence from these substances is selectively reinforced. Part of this process involves influencing the user’s social environment, including family members. The work, however, is mostly conducted through the individual drug user. The CRA has been described in detail in a treatment manual (Meyers and Smith, 1995). There have been a number of studies with alcohol and other drug problems providing a strong evidence base for this approach (e.g. Higgins et al., 1993; Abbott et al, 1998; Gruber et al, 2000). A review published by Smith et al (2001) confirms the positive outcomes for this approach across a range of clients and problem substances.
5. Conclusions and recommendations

THE SHEER SCALE OF THE NUMBERS

This report makes the first attempt in the UK to estimate the numbers of family members of adult illegal drug misusers, and to further estimate costs associated with that group of family members. What has been presented here highlights that there are very large numbers of family members of adult illegal drug misusers, the vast majority of whom will need help and support, either in their own right or as part of the package of care offered to the individual with the drug problem (Copello and Orford, 2002; NTA, 2008). The fact that the figures outlined here can be considered under-estimates only serves to further emphasise the scale of the problem.

THE POLICY RESPONSE

A changing policy climate, alongside accumulating evidence about what can be helpful to family members, on their own and/or with other family members and/or the drug misuser, is ensuring that the needs of family members can be more appropriately and effectively met. It is clear that there is no one intervention that should be made available to families; rather, as with drug treatment, a toolbox of interventions and services should be considered. Brief interventions for family members, self-help approaches, support groups, online materials, treatments involving the users and family members, and sometimes a wider network, as well as broader family oriented approaches all have their place. What seems to be clear from the evidence is that family members need and value the space to talk about their problems and to receive guided support to explore solutions. Information about drugs and effects, coping responses, enhancing social support and relapse management is required. Also, attention should be paid to other problems which are commonly present in such families; for example, domestic violence or domestic abuse (Galvani, 2007), mental health problems, financial difficulties, unemployment, deprivation and social exclusion. There is great potential for family members to also facilitate the entry and retention of a drug misuser into treatment.

THE SCALE OF THE HIDDEN COSTS SHOULD NOT BE IGNORED

This report has drawn attention to the significant gaps in data collected about family members of drug misusers, gaps which if filled could drive forward the planning and delivery of services in this area. While there have been some recent changes to recording mechanisms (for example, to the English National Drug Treatment Monitoring System and the Scottish Drug Misuse Database reporting framework), which will enable more data to be collected about family members, there remain large gaps, and differences in approach across the four UK administrations, in terms of data.
collected about the family members and carers of drug dependent users. The UK evidence base for prevalence of family members and associated family social costs is fragile and better evidence on which to base both family prevalence and economic estimates is urgently required. Families are a largely untapped treatment resource and force for good treatment outcomes to be achieved in their drug misusing relatives. The evidence in this report suggests that policymakers need to reframe and reflect upon the negative aspects of the hidden economic costs and consider how this could be turned to advantage by embracing family interventions and family support much more fully.

**Family treatment and support — the way forward**

The research literature on family interventions shows that there is a range of approaches that can be used to help people with drug problems and their families. We conclude that there is an increasingly robust evidence base that supports family focused interventions in substance misuse, as demonstrated by the recognition of such approaches in clinical and policy guidance, such as that produced by NICE (2008) and the National Treatment Agency for Substance Misuse (NTA, 2008). The research studies, in which there is careful control of the intervention, confirm that families can play a central role in the treatment of addiction problems, and recent studies have shown that family approaches either match or improve outcomes when compared with individual approaches. Where more work is needed is in the implementation of these interventions and services, beyond the confines of research studies, in routine clinical practice (O'Farrell et al., 2007; Orford et al., 2009).

The research reviewed suggests that there should be a range of responses available to family members affected by drug problems. It is possible to develop a template including levels of responses that could be used to monitor the extent of services provision across different areas of the UK.

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

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

**Level 2: Assessment: best practice is not only related to interventions**

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

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

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

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

It is important that a response for family members is delivered as part of services for drug users. This is in line with clinical practice recommendations from NICE (2008) that state:

‘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’

*(clinical practice recommendation 8.10.7.1)*

And in addition:

‘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’

*(clinical practice recommendation 8.10.7.2)*

Level 5: Intensive family-based therapeutic interventions

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

A key principle is that there should be a range of flexible services of different intensities that can respond to the varied and complex needs of families affected by drug problems. These levels should not be seen as a hierarchy in which level 5 is in someway ‘better’ than level 4. All types of intervention should be available in order to
meet the differing needs of family members. Finally, families and carers should be involved in the planning and commissioning of services as this will improve the effectiveness of services and the drug treatments system.

**RESEARCH AND INFORMATION NEEDS**

Implications for the research agenda emerge from this work.

There is an urgent need for robust, well-designed surveys and studies to inform future accurate prevalence estimates. This includes, for example, the inclusion of detailed data on affected family members in routine monitoring systems.

In addition, there is a need for further detailed understanding of the day-to-day impacts of drug use on families. This includes accurate estimates of economic costs in a range of areas, including: excess day-to-day costs; drug incidental costs; loss of property, money or assets; excess health costs; excess service utilisation costs; and cost savings to the NHS and local authorities.

Finally, there is a need to implement research findings about family intervention in routine practice and to evaluate such research implementation. Orford et al. (2009) provides an example of this work in specialist addiction teams.


Appendix 1: Examples of the wide reaching impact of drug misuse within families

The examples below, taken from research by the authors (Copello et al., 2009a;; Templeton et al., 2007) illustrate how many different family members can be affected by a person’s drug problems. Interviewees, from families affected by drug problems, were asked about other people in the family who were also affected.

1. A woman with a drug misusing partner mentioned two children, one of whom is a baby, and her mother who lives close by. The family member also alluded to other family members who live close by.

2. A family member with a drug misusing son (who has a partner who is also on methadone and who is currently expecting their baby) talked about his partner, who has herself had an alcohol problem, three other children, who have families of their own, and his sisters. The family member had two other children but they both died a few years ago (one was killed in a car accident and the other was murdered); the family member’s mother has also recently died.

3. A Pakistani woman with a drug misusing husband mentioned their three children as well as her own family and her husband’s parents.

4. A woman with a son who misuses drugs and a husband with an alcohol problem mentioned her elderly father, who is 80 years old, lives next door and needs a lot of assistance, two other sons who are currently living with her, and a daughter with two children of her own.

5. Another woman with a drug misusing partner mentioned her three children and her mother.

6. A father with a drug misusing daughter mentioned his wife and his other daughter.

7. A mother with a drug misusing son talked about her other children, at least one of whom has a family of their own, as well as her brother and sister-in-law.

8. An Indian woman with a drug misusing husband talked about her young son, her mother, her husband’s parents and an aunt.

9. A sister with a drug misusing brother mentioned his brother’s child, her own husband, their children, her husband’s family and her mother.

10. A mother with a drug misusing son mentioned her husband, daughter and three grandchildren as well as her mother and sister.
Appendix 2: Secondary analysis of the 2007 Adult Psychiatric Morbidity Survey data

To obtain information on the number of family members who may be affected by an individual’s problem cannabis use, many of whom may not be in contact with services, secondary analysis of the data from the 2007 Adult Psychiatric Morbidity Survey (APMS) for England was carried out. Details of the content and coverage of the survey can be found in the main survey report (McManus et al, 2009).

Individuals with problematic cannabis use were identified as those who reported symptoms of cannabis dependence (2.4% of the population). Because use of cannabis starts earlier than drugs such as opiates, crack and cocaine powder, it is likely that the family members affected would be different, at least among the younger age groups. Analysis was therefore undertaken to investigate the likely number and types of family members affected by looking at the number of adults living in the household and the de facto marital status of the problem cannabis users. The findings are shown in Table A1 below and it is clear from this that younger cannabis users are less likely to be married or cohabiting than their older counterparts.

Table A.1: Breakdown of the de facto marital status and number of other adults in the household for people reporting signs of cannabis dependence in two age groups.

<table>
<thead>
<tr>
<th>Age group (years)</th>
<th>Defacto Marital status</th>
<th>Number of other adults in household</th>
<th>Percentage of total in age group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>16-24</td>
<td>Married/cohabiting</td>
<td>0</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>6</td>
<td>23</td>
</tr>
<tr>
<td>All 16-24s</td>
<td></td>
<td>6</td>
<td>40</td>
</tr>
<tr>
<td>Base (unweighted)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25+</td>
<td>Married/cohabiting</td>
<td>2</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>29</td>
<td>11</td>
</tr>
<tr>
<td>All 25+s</td>
<td></td>
<td>31</td>
<td>45</td>
</tr>
<tr>
<td>Base (unweighted)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The numbers of individuals on which the figures are based are small, 46 people aged 16 to 24 and 93 people aged 25 or over, but the differences between the groups was
sufficiently marked that it was felt that it was important to use differentiate between them within the estimate. The way in which these figures have been used in the estimation of the number of family members affected by a relative’s problem cannabis use is described in the main body of the report on pages 16-17.