Guidance Notes

Support for families and carers affected by someone else’s drug or alcohol use:
Why Invest?

This document is intended to complement and expand on the presentation Support for families and carers affected by someone else’s drug or alcohol use: why invest?, developed to help organisations make a strong case to commissioners and other funders as to why investment in family support is crucial. It can be used to provide anyone delivering the presentation with the background knowledge, references and further information to explain the content of the presentation slides and explore the points raised.

A note on definitions
In this presentation, the terms ‘carer’ and ‘family member’ are used interchangeably. Carers are defined as ‘a person who provides, or intends to provide, care for another adult’; and given the nature of drug addiction, it is not uncommon for family members to fulfil a ‘carer’ role. However, a carer could also be a friend, neighbour or any concerned other.

Slides 1, 2 & 3: Who is affected?

Main argument: you don’t have to use drugs and alcohol to be affected by them. Millions of families and children are living with the impact of a loved one’s substance use, and this has ripple effects throughout our society.

References:

When a person uses drugs or alcohol, it is not only that person who is affected – the impact can be far-reaching and multi-faceted. Close family, friends, children and significant others are all particularly affected, but extended family and friends, neighbours, colleagues and the community at large can all experience negative impacts too. This has knock-on effects throughout society.

1 The Care Act 2014
The UK Drug Policy Commission’s claim that 1.5million adults are ‘significantly affected’ by a relative’s drug use is in fact a minimum estimate, as it only includes families who are living with their drug using relative and where their drug use falls at the most severe end of the spectrum. Therefore, there are many other families below these thresholds who, for example, do not live with their loved one, or whose relatives use other drugs or alcohol. A poll conducted by DrugScope determined that 1 in 5 respondents had either direct or indirect experience of addiction, with 1 in 20 having experienced it within their family. The ACMD’s estimate that 250-350,000 children are affected by parental drug use only covers heroin and crack users, and the NTA’s prediction that 120,000 children were living with a parent in treatment does not represent the full extent of the problem. The true picture is uncertain, and the stigma and secrecy surrounding addiction also makes accurate estimates hard to come by.

The number of family members affected by someone else’s drinking is also difficult to ascertain with any real accuracy. Alcohol misuse is far more prevalent than drug addiction, and it is safe to assume that the number of family members affected is much higher than corresponding figures for those affected by a relative’s drug use. Whilst some have indicated that 1 million children are affected by parental alcohol use, others suggest a figure closer to 3.5 million. Manning et. al. has estimated that 705,000 children in the UK were living with dependent drinkers in 2009. This is further complicated by the difficulty of defining ‘acceptable’ levels of drinking or when it becomes a ‘problem’.

Slides 4 & 5: Impacts of drug and alcohol use on adult family members and costs of harm

Main argument: addiction is a journey taken by the whole family. When an individual uses substances, the impacts on families are destructive and wide-ranging.

References:
6 – UKDPC (2009) Supporting the supporters: Families of drug misusers

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2 UKDPC (2009) Adult family members and carers of dependent drug users: prevalence, social cost, resource savings and treatment responses
3 DrugScope/ICM (2009) What does the public really think about addiction and its treatment?
4 National Treatment Agency (2009) Moves to provide greater protection for children living with drug addicts (media release)
6 Ibid
Much of the research into the impacts on family members has focused on their health and wellbeing. Studies have found, for example, that family members:

- are more likely to be diagnosed with their own medical conditions than non-drug using families, to levels of seriousness comparable with psychiatric outpatients.\(^8\)
- suffer stress-related physical and psychological symptoms that can be severe and long-lasting, which are associated with high use of primary care services.\(^9\)
- are at a similar or higher risk of disease, emotional issues and behavioural problems to families with a relative suffering from a chronic health condition.\(^10\)

Common complaints attributed to familial substance use include sleep problems, weight changes, an increase in psychological symptoms of anxiety and depression, and physical symptoms such as hypertension, pains and migraines.\(^11\) Exposure to heavy drinkers has been shown to reduce personal wellbeing and utility health scores, particularly in relation to areas such as reduction in usual activities, increased pain and discomfort and higher levels of anxiety and depression.\(^12\) One piece of research found that families consistently reported higher health service-related costs and use than comparison groups – mental health care, substance use services and presentations at the hospital emergency department being especially relevant\(^13\) – whilst another found ‘greater rates of a variety of health conditions.’\(^14\)

Impacts may also vary between different family members, for example:

- siblings may be affected by the user’s chaotic behaviour and can feel neglected by the parents if their focus is drawn to managing the user

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8 Adfam, Supporting families affected by drug and alcohol use: Adfam evidence pack
10 Thomas et. al. (2009) ‘Family members of persons with alcohol or drug dependence: Health problems and medical cost compared to family members of persons with diabetes and asthma: Family members of persons with AODD,’ 104(2) Addiction 203
11 Copello & Walsh (in press) Families, friends and addiction: Impacts, psychological models and interventions, in Addiction Psychology and Treatment
13 Ray et. al. (2009) ‘Family members of people with alcohol or drug dependence: Health problems and medical cost compared to family members of people with diabetes and asthma,’ 104 Addiction 203
14 Thomas et. al. (2007) ‘The excess medical cost and health problems of family members with persons diagnosed with alcohol or drug problems,’ 45(2) Medical Care 116
• partners may have to assume sole responsibility for running family life, in addition to coping with the stress, worry and possibly guilt about the impact on any children
• parents can experience an overwhelming sense of self-blame and guilt and feel stigmatised due to the prejudices surrounding drug use and ideas of ‘bad families’
• other family members – particularly grandparents – may assume care for substance users’ children, with all the emotional, financial and legal complications this entails.

Families will often feel ashamed, embarrassed and stigmatised. Consequently, they may try and conceal or minimise the problem out of fear of judgement, blame or criticism from other relatives, their social network and wider society. This represents a negative feedback loop in which families lose the social support that could help address the build-up of problems, which then feeds back into psychological distress. These interlacing and mutually reinforcing factors ultimately amount to considerable negative impact on all aspects of family members’ lives.

Whilst it is extremely difficult to ascribe a notional financial value to the impacts, the harm caused to those families as a result of a loved one’s drug use has been estimated at a cost of £1.8 billion per year. The figure was based on the following:

• £9,741 per annum = the average cost per affected family member/carer (at 2008 prices)
• £450 per annum = average healthcare costs per affected family member (at 2008 prices)

As before, this amount was limited to the costs borne by family members of crack cocaine and heroin users only; therefore, the real cost to families whose relatives use all types of substances (including alcohol) is substantially higher. Impacts such as mental distress and quality of life were not considered in the estimate; however, research suggests that these costs are extensive. For example, criminality can be extremely costly to family members; most obviously due to the theft of property and money so that the user can buy drugs or alcohol. The UKDPC estimated the cost of crime to family members at £2,840 per annum, not including costs incurred by the criminal justice system. Further associations between substance use and, for instance, domestic violence, child neglect or abuse, and even sexual abuse, have been substantiated. The connection between alcohol and domestic violence is fraught with controversy, and alcohol does not cause domestic violence: still, victim and perpetrator reports clearly evidence a correlation, and where domestic violence does exist, alcohol is often present, with 73% of perpetrators in one study reporting that they had been drinking at the time of the assault. Substance use in and of itself can have tremendous impacts, but when we consider the associated behaviours that can come with it, we can then begin to appreciate the true cost to families.

15 Ibid
16 UKDPC (2009) Adult family members and carers of dependent drug users: prevalence, social cost, resource savings and treatment responses
Kinship carers such as grandparents, who take on the care of children because their substance using parents cannot, are particularly noteworthy, as they commonly sacrifice their employment and are often insufficiently supported to fulfil their caring responsibilities. Kinship carers have reported a lack of financial support for the children they look after and difficulty in accessing help and information. Only a third of participants in one Grandparents Plus survey received an allowance from their Local Authority to help look after the child, and 57% reported having had to give up work or reduce their hours. Research by Mentor yielded similar results: the majority of grandparents had financial difficulties and many had to give up work or take lower paid jobs; Mentor therefore recommended that grandparents be urgently provided with information and advice on accessing financial support and the benefits available to them. Furthermore, payments to kinship carers were found to be wholly inadequate in comparison to the financial assistance provided to, for instance, foster carers. Grandparents also reported experiencing health and emotional issues, such as stress and depression, and social isolation linked to the stigma surrounding drug and alcohol use.

Slide 6: Impacts on children

Main argument: parental substance use has a number of detrimental impacts on children, thereby increasing the likelihood of negative outcomes as they grow older.

References:
9 - ACMD (2003) Hidden Harm: Responding to the needs of children of problem drug users

The 2003 Hidden Harm report estimated that there were 250,000-350,000 children of problem drug users in the UK, while in 2008 the Princess Royal Trust for Carers and Alcohol Concern said that there were up to 1 million children affected by parental alcohol problems. It has been suggested that there are up to 5 times more children affected by parental alcohol use than drug use, and that parental substance use ‘can and does cause serious harm to children at every age from conception to adulthood.

Adverse effects on children encompass a wide range of emotional, cognitive, behavioural and other psychological problems, and they are potentially exposed to many sustained and intermittent hazards as a result of parental substance use, including:

- inadequate supervision
- inappropriate parenting practices

17 Mentor (2007) Mind the Gap
18 Ibid
20 ACMD (2003) Hidden Harm: Responding to the needs of children of problem drug users
• separation
• inadequate accommodation or instability of residence
• dangerous substances in the home
• interrupted or otherwise unsatisfactory education and socialisation
• exposure to criminal or inappropriate behaviour
• social isolation
• increased likelihood of early substance misuse and offending behaviour
• poor educational attainment.

One study found that mothers with drug dependencies, whilst trying to manage their own difficulties, are not always aware of the child’s needs. As a result, they can tend to focus on ‘functional parenting’ – whereby being a mother is seen as a simply functional role in their life – and believe that by merely fulfilling the child’s basic needs, their responsibilities are satisfied. However, this means that mothers can be less engaged with the child, commonly arousing issues of neglect. The impact of substance use on parenting is illustrated in its prevalence in referrals to social services and its common citation in care proceedings.

Slide 7: The value of support which family members provide

Main argument: the value of support that families and carers provide is substantial and needs to be sufficiently recognised.

References:
10 - UKDPC (2012) The Forgotten Carers

Families are frequently an unpaid and unconsidered resource in providing health and social care services to their relatives. Were this support provided by the health and social care sector, it would come at a cost of £747 million a year; again this is an underestimate as it only covers the parents and partners of heroin and crack users. Families provide ‘services’ like routine care and support, home detox, accommodation and day-to-day care, all of which would otherwise have to be provided by the state at considerable cost.

One study which looked specifically at dual diagnosis – the coexistence of mental health and substance use problems – found that, on average, family members (both living with and apart from the drug using relative) devoted 226 hours every year to the care and support of a dual diagnosis relative. Another study found that carers spent 29 hours a year dealing with a number of presenting issues, including

21 Silva et. al. (2012) ‘Balancing motherhood and drug addiction: The transition to parenthood of addicted mothers,’ 18(3) JHP 359
illness, medications, crisis management and treatment services (which would have cost a professional £783 to provide) and 197 hours a year on home help tasks (a saving to the state of £3,152). Considering the financial burden being relieved by these carers, taken with the gravity of harms they experience financially, socially, emotionally and physically, the need to invest in their support is clear.

When family members receive support for their own needs...

Slides 9 & 10: The benefits to adult family members

Main argument: supporting families for their own unique needs results in a number of benefits across the spectrum of health and wellbeing.

References:
11 – Adfam (2009) We count too, 2nd ed.

A considerable number of studies have revealed the positive outcomes associated with providing support to family members in their own right (i.e. as an individual, rather than as an ‘add-on’ to their relative’s substance use treatment). Where family members are supported, a number of improvements are observable in:

- self-esteem
- ability to set boundaries
- coping skills
- relationships with friends and other family relations
- levels of independence
- psychological stress
- overall family functioning.

One study which examined the effectiveness of intensive interventions for families found that once family members had undergone the intervention, they were often described as being happier, more confident, more assertive, less anxious and depressed and/or eating better or smoking less. Adfam’s study of one family support service also found that significant outcomes were being achieved for family members, with the service generating £145,000 worth of value specifically for the family members

22 Copello et. al. (2009) ‘The relative efficacy of two levels of a primary care intervention for family members affected by the addiction problem of a close relative: a randomized trial,’ 104 Addiction 49
attending. This figure was reached after considering the resulting benefits to their health and wellbeing, their regaining of independence, bettering of their relationships with others and improvements in their financial situations.

One of the most pervasive effects of drug use on family members is damage to, and reduction of, social relationships because of stress, anxiety, stigma and isolation. A study that looked at the interplay between social relationships and mortality found that individuals with strong social relationships have a 50% greater likelihood of survival compared to those with weak social relationships. The magnitude of this effect is actually comparable with stopping smoking and exceeds many well-known risk factors for mortality, such as obesity, thus epitomising the extent of damage that familial drug use can have on people close to the substance user. Further research suggests that providing support to families helps combat stigma and prejudice in the wider community and the media.

Of relevance here is the government’s carer’s strategy, which encourages the tailoring of support to fit the individual’s needs and circumstances, enabling carers to reach their full educational and employment potential, so that they are able to have a family and community life whilst being supported to remain physically and mentally well.

Secondary effects arising from improved relationships, health and wellbeing are plentiful, including an improvement in work-life balance or education. When individuals are supported to feel better in themselves this can positively reflect on all aspects of their life.

**Slide 11: The benefits to children**

**Main argument:** when families and children are supported, children can benefit in a number of ways and their life chances can be improved.

**References:**
13 - ACMD (2003) *Hidden Harm: Responding to the needs of children of problem drug users*

Children affected by parental substance use are vulnerable to a wide range of risks, from threats to physical safety, to the psychological and practical results of poor parenting. Given that children are still developing, there are a number of risk factors that are unique to them: issues encountered during childhood can have severe and lifelong effects. For example, educational disruption can have an impact on their life chances, ability to form positive relationships, their aspirations and self-esteem. Research shows that children of dependent drug users are seven times more likely to go on to misuse substances.

23 Adfam (2012) *Social Return on Investment of Drug and Alcohol Family Support Services*
25 HM Government (2010) *Recognised, valued and supported: next steps for the carer’s strategy*
themselves, and similar patterns of intergenerational transmission have also been highlighted with behaviours such as offending and antisocial activity.

When family support is in place children will see many of the same benefits to their physical and psychological health and wellbeing as adult family members, with negative impacts, including the risk of involvement in substance use themselves in later life, potentially prevented or reversed. The provision of family support acts as a protective factor for the child, saving the state a huge amount long-term, when considering all those children who do not go on to burden the criminal justice, welfare and healthcare systems.

**Slide 12: The benefits to the user**

**Main argument:** positive outcomes for substance users are more likely when their families and carers are receiving support for their own needs.

It is now widely recognised that family support positively influences outcomes for substance users in a number of ways, with an increasing amount of evidence to support this. In one study, 74% of significant others successfully managed to engage their ‘previously treatment-resistant drug-using relative’ into treatment; as well as supporting users to *enter* treatment, family support can also make drug and alcohol users more likely to *remain* in treatment, and successfully recover.

When families are supported themselves, they are more able and better equipped to support and encourage the user’s recovery journey. The government’s drug strategy explicitly recognised that ‘treatment is likely to be more effective, and recovery to be sustained, where families, partners and carers are closely involved,’ and NICE guidance also recommends the involvement of families and carers in decisions around the treatment and care of the user. The Carer’s Trust’s ‘Triangle of Care’ guide also emphasises the importance of ensuring that carers receive the support they require, whilst also promoting the involvement of families in their relative’s recovery. As such, it is considered good practice that families are both supported themselves and involved in their relative’s treatment. Navigating the treatment system can be extremely challenging for families, and family support can

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27 Dick & Agrawal (2008) ‘The genetics of alcohol and other drug dependence,’ 31(2) Alcohol research and health
enable family members to better understand the treatment system, and act as a bridge between the family member and the treatment system. Support for families themselves and their involvement in treatment have far-reaching positive repercussions for the user.

**Slides 13 & 14: The benefits to the community and State**

**Main argument:** Family support benefits the state both in social and economic terms.

**References:**

Adfam’s Social Return on Investment study found that because supporting family members improves outcomes for the user; there is a marked reduction in use of the criminal justice system and the NHS. The reduced impact on the NHS is mostly attributable to the user’s reduction in use of healthcare services (26%), and whilst there is only a small level of change in use by families (2%), this is mainly because most had not been accessing those services in the first place.

In the same study, Adfam looked at a sample family support service and found that the value created by the service amounted to over £240,000, with investment in the service totalling £52,000. Therefore, for every £1 invested, £4.70 of social value\(^{30}\) was created, mostly for the clients themselves. The return to the state alone, at £69,000, was greater than the investment in the service, meaning it provided good value for money even prior to accounting for the health and wellbeing benefits to clients themselves. Even brief interventions for family members have been found to reduce ‘both stress-related psychological and physical symptoms…and as a result costs associated with health and welfare service demands made by affected family members.’\(^{31}\)

With regards to crime, according to the NTA, drug treatment and recovery systems in 2010-11 prevented 4.9 million crimes, with estimated savings valued at a staggering £960million.\(^{32}\) Evidence has come to light that local crime rates have an effect on the mental wellbeing of residents, mostly associated with anxiety and depression; therefore, decreases in crime will result in happier, healthier and safer communities. The potential for the state to make great savings through the provision of family support is highlighted by these findings.

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\(^{30}\) The social return on investment analysis conducted looked at the various types of social benefits (e.g. health and wellbeing and improvements in social relationships) resulting from investment into a family support service, and ascribes a value to these benefits, based on an accepted model.

\(^{31}\) Copello et.al. (2009) ’The relative efficacy of two levels of a primary care intervention for family members affected by the addiction problem of a close relative: a randomised trial,’ *Addiction* 104

\(^{32}\) NTA (2012) *Estimating the crime reduction benefits of drug treatment and recovery*
Slide 15: What are the costs of not providing family support?

**Main argument:** an area without sufficient family support provision is likely to experience a variety of negative impacts on the local population, and increased burdens on local statutory services.

**References:**
17 - Demos (2010) In loco parentis

The benefits of providing families with support have already been addressed: improvements in the health and wellbeing of substance users and families, better outcomes for children, an increase in the number of users entering and completing treatment, and all the results of these: reductions in crime, reduced burden on the criminal justice system, health services and welfare system, and associated cost savings to the state. It follows, then, that without family support, the burden on public services increases, population health and wellbeing suffers, successful treatment outcomes are reduced and children are at risk of poorer outcomes. Essentially, the substantial benefits of family support are absent or reversed. The cost of failing to provide family support is great and spans across a number of interconnected fields.

Slide 16: So, why invest in family support?

**Main argument:** investment in family support services is necessary, desirable and justifiable.

- To reduce crime and criminal justice expenditure

  Crime is often a priority for local communities and their residents. When family members are supported, crime is reduced and savings to the public purse made, since more drug users are in treatment and less are involved in criminal behaviour. Reduced local crime rates will also have a positive effect on the psychological wellbeing of residents.

- To improve public health

  The improvements to family members’ physical and mental health and wellbeing have been evidenced. We know that this group are associated with high usage of public health services, and the burden on public health and social care systems is significantly reduced when families receive support for their own needs. A decrease in social isolation also has great public health benefits, and feeds back into the reduction in use of public health services.
• To improve outcomes for substance users and ensure the potential of drug treatment is maximised

Families are an important source of recovery capital. We need to ensure that families and carers receive support for themselves, in order to increase the likelihood that their substance using relatives enter treatment, continue to engage with it and finally achieve successful outcomes. Simply put, families receiving support are better able to support the user.

• To improve outcomes for children

Family support provides certain protective factors for children. It increases their resilience and ability to cope with adversity and helps prevent intergenerational transmission of substance misuse and associated behaviours, bettering outcomes for children across the board. Support should enable families to exert positive influences on the child, and to build resilience in children: resilience and parenting practices are both highly influential factors when considering how risks to children and the adverse impacts of parental substance use can be mitigated.

Slide 17: What can effective investment in family support give you?

Main argument: dedicated family support is needed to ensure families’ support needs are met and provides opportunities to carry out innovative and effective work with families.

References:
18 – Adfam (2009) We count too, 2nd Ed.

Although families may be able to receive elements of support from services elsewhere, this is insufficient and falls short of addressing the extent of the families’ needs for support, particularly those family members whose loved one is not receiving treatment. Universal services, for example generic carers’ services, can provide valuable opportunities to enhance family support, but they do not have the specialist knowledge of the unique circumstances and needs of the families, or the capacity to respond to and support them appropriately. Without dedicated family support sitting in the forefront, the barriers and stigma that families face also continue to prevent their take up of services.

Effective investment in dedicated support for families in their own right, together with a service that encourages and enables referral pathways, is needed in order to capitalise on the potential benefits to adult and child family members, substance users, and the state. Different service models may be suited to the needs identified in different local areas; however, when local commissioning decisions are taken and implemented with consultation and good practice in mind, commissioners can expect to receive a service that provides the right support and space to enable family members to recover from the harms
they are experiencing, regain their independence and ability to support themselves, and better link in with the treatment system where appropriate.

Slides 18 & 19: The importance of partnership working: Everyone has a part to play

Main argument: family support spans across a number of fields and cannot work in isolation. Effective family support requires investment and strategic support from a range of local leaders and service providers.

Substance using families are associated with high use of primary care services, and are often known to the police, housing professionals, social services and a host of other local organisations: these services must work collaboratively with these families to ensure they receive the support they need. The relationship between substance use and mental health, for example, is a strong one, and is receiving increasing attention from policymakers and professionals in the sector. Councillors and local Directors of Public Health need to be made aware of these facts to be able to commission and direct service provision efficiently.

Partnership working and information sharing have been lauded as the key principles for effective working in the public sector – and the realm of family support is no exception. Indeed, it is impossible to look at family support in isolation, as there are many overlapping and interlinking issues in problem substance-using families. The research conducted into ‘troubled families’, as part of the government’s national programme of interventions for these families, concluded that ‘perhaps the starkest message...is the extent to which the problems of these families are linked and reinforcing.’ The programme, intended to tackle families whose problems and needs are complex, overlapping and interlinked, recognised that this can only be accomplished through joining up local services, as well as the adoption of a holistic, whole-family approach. A more effective approach will enable systemic working across agencies, linking the NHS, GPs, prescribers and family support services to create a coordinated approach to care, with information sharing across all agencies.

In securing family support, different agencies and individuals will have different roles, but everyone has a part to play in improving the situation for family members affected by a relative’s substance use, and in ensuring that these families are appropriately supported.

Conclusion
Families are often the unheard and unseen victims when a loved one uses drugs or alcohol, and on top of the physical and psychological strains, they must struggle to get the support they need, whilst all the while grappling with the stigma and shame from wider society. The sheer number of families, friends and concerned others who are affected is in itself a justification for the provision of sufficient support. However, the multitude and severity of the impacts on their health, wellbeing and finances make this even more critical.

The benefits of family support are huge, far-reaching and span across a number of different spheres, substantially bettering the lives of families themselves (including children) and their communities. Advantages include improving treatment rates, retention and outcomes for users; reducing the burden on the NHS, criminal justice system and welfare system; and creating significant savings to the state. Furthermore, investment in family support services could help improve links between relevant agencies and encourage partnership working. Without it, we overlook the needs of a large proportion of the population, fail to maximise potential in terms of reducing drug and alcohol misuse and offending, and incur great and needless cost to the taxpayer.

Following the reform of health and social care structures, an opportunity to develop drug and alcohol and family support services within the public health framework is presented. The reforms are also conducive to the development of a dialogue with local communities, which then opens the door to the creation of a framework which truly reflects local concerns and priorities. Drug and alcohol services, along with family support services, can make a strong, evidence-based case for the work they do, with benefits delivered to users, their families and their communities – not to mention their cost-effectiveness. The potential to diversify and develop the sector is clear, and the contribution that drug and alcohol family support services can make to everything from the housing sector, employment, mental health and even sexual health, should be highlighted. Local Directors of Public Health and the new Health and Wellbeing Boards are therefore ideally placed to build cross-cutting and holistic recovery in their communities.