ALICE RAP Policy Paper Series

Policy Brief 6.

Addiction in the Family

Adult and child family members affected by their relatives' excessive substance use or gambling

AR Policy Paper 6

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ALICE RAP (Addictions and Lifestyles in Contemporary Europe – Reframing Addictions Project) is the first major Europe-wide project studying addictions as a whole and their influence on health and wealth. The aim of this five-year €10-million co-financed EU project is to stimulate and feed scientific evidence into a comprehensive public policy dialogue and debate on current and alternative approaches to addictions and to inform the development of more effective and efficient interventions.

The ALICE RAP Policy Paper series aims to provide concise evidence briefs for decision-makers and advocates working on key addiction-related issues. This sixth paper in the series focuses on the impact of alcohol and gambling on family members and policy directions to protect this group.

This paper, based on the work of Jim Orford, as part of Work Package 2 of ALICE RAP, Stakeholders in Addiction, is divided into three parts: The first summarises the stressors experienced by *adult* family members of close relatives with alcohol, drug or gambling problems, the coping dilemmas they face, their needs for information and support, and their heightened risks for ill-health. The second part looks again at these themes, but, specifically, for children and young people who are affected by living with parents or carers with such problems. In the third part of the paper, some of the difficulties and barriers to routinely providing help for affected family members, whether children or adults, are considered.

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Summary

This paper is in three parts. The first summarises the stressors experienced by adult family members of close relatives with alcohol, drug or gambling problems, the coping dilemmas they face, their needs for information and support, and their heightened risks for ill-health. The second part does the same, but specifically for children and young people who are affected by living with parents or carers with substance or gambling problems. In the third part of the paper are considered some of the difficulties in the way of routinely providing help for affected family members, whether children or adults. For convenience 'affected family members' (AFMs) will be used as a collective term to denote the people this paper is concerned with.

1. The ways adult family members are affected

Adult AFMs experience multiple stressors involving worry, disruption and loss. Worry for the drinking, drug-taking or gambling relative is often at the forefront. A second facet is more actively disruptive involving a decline in the quality of family relationships ranging from diminished communication to emotional abuse, 'coercive control' and physical violence. Loss of trust is a significant factor. One feature of a gambling problem is the absence of obvious physical signs rendering it relatively easy to hide from family members, and the discovery of the problem often sudden and traumatic. Severe negative financial consequences are often a more central part of the experience in the case of problem gambling and sometimes with problem drug use.

AFMs face difficult coping dilemmas: They may have to put up with their relatives' problematic consumption; they often struggle to refocus attention on their own rights and needs, and to take what is happening less personally. Nevertheless, they find many ways to stand up to their relatives' behaviour. With a gambling problem, coping dilemmas often revolve around money; AFMs frequently make the difficult decision to take up the role of managing family finances and controlling their relatives' access to money.

AFMs are often left uninformed or are misled by their relatives about what is happening. There are also a number of barriers that stand in the way of AFMs receiving the support they find most helpful. Others who might provide support are often perceived as unsupportive or critical. Professionals are often perceived by AFMs as lacking in knowledge, awareness, and even sympathetic understanding.

Adult AFMs constitute a group which is at high risk of ill-health. A consistent finding is that AFMs obtain high mean scores on standard measures of general ill-health and show increased odds of having a clinical level psychiatric disorder, especially depression. AFMs bear personal and household or family-wide 'costs', often substantial, of living with addiction. Some of those costs would otherwise be borne by governments.

2. The ways child family members are affected

Child AFMs feel worry, hurt and confusion, and often experience neglect. They experience many of the same stresses, dilemmas and strains as do adult AFMs. Children are often first exposed to a parental alcohol or drug problem at a young age and exposure can continue for much of the childhood years. How to cope with these circumstances is as much a dilemma for children as it is for adult AFMs. Children go to great lengths to find their own solutions and ways to be resilient.

Child AFMs often experience role conflicts, for example being caught in the middle of family tensions, and not uncommonly, children take on a caring or protective role towards a parent. However young people can be ambivalent about being given the label of 'young carer', finding it of little relevance to their situation.

Child AFMs are at heightened risk for: 'internalising' problems such as being withdrawn, concentration difficulties at school, and depression; 'externalising' or 'anti-social behaviour' problems, such as aggressiveness and delinquency; as well for friendship problems.

Risks to children are greater if there is exposure to multiple problems. The child AFM experience is often complicated by other problems such as witnessing conflict and violence; experiencing direct violence, additional chronic parental mental or physical ill-health, or parental criminality; social disadvantage, such as parental unemployment or family housing problems; or instability associated with accommodation moves, changes of carer, or bereavement.

Concern for child AFMs is a major motivating factor for their parents, both for adult AFMs and for the excessive substance using or gambling parents themselves.

3. What affected children and adults need

Policy regarding AFMs has been overshadowed by the importance of the children and families agenda. Compared to child AFMs, adult AFMs have been neglected. One of the best ways of protecting children is to support the adult members of the family, especially those members who do not themselves have addiction

problems, who are often in the best position to protect the children. It is still too often the case that an exclusive focus on children's welfare encourages an unhelpful separation of adult and child services.

A second feature which overshadows policy is the importance of drugs policy. There is comparatively little focus specifically around parental *alcohol* misuse and its impact on families. The situation with regard to gambling is even worse. It is even unclear which government departments should take the lead with these issues.

There is no clear picture of how many services there are which wholly or partly work with children affected by parental alcohol or drug misuse or gambling problems. The size of the problem remains unknown and estimates are currently only very approximate. In the UK, for example, a 2009 study estimated there to be over 700,000 under 16s living with a dependent drinker. The picture is even less clear when it comes to adult AFMs, although a 2008 study in the UK estimated there to be at least 1.4 million adults significantly affected by a relative's drug use (alcohol was not included).

Social work services focusing on child care is one principal location for the identification of harmful effects of adult alcohol and drug problems on children. There is a high incidence of parental alcohol misuse in childcare social work. However there is still insufficient pre- and post-qualification training for social workers around substance misuse issues. The social work profession has been almost silent on the issue of problem gambling.

It is equally important that professionals in specialist and general services such as primary care, education and generic youth services, receive training in both understanding and working with parental substance misuse and problem gambling. Services for people with mental health problems, particularly anxiety and depression, constitute another location where AFMs might be identified but currently remain largely hidden.

There are a number of problems in the responses of services to these issues. One is poor communication and co-ordinated activity between children's services and adult services. The links between universal and specialist services, and between adult services and child and adolescent and family services, are crucial. Partnership working is widely recognised as an area where further progress continues to be needed.

When asked what they want from services, child AFMs say they want a patient, empathetic and sensitive approach, based on trust, in which someone who is helpful, caring and encouraging recognises their circumstances and takes the time to get to know them. They have said they do not want to be patronised and seen as victims; and that they do not want to have an identity that is based on being, for example, the 'child of an alcoholic' or compulsive gambler.

A number of positive factors are associated with resilience for child AFMs, including positive experiences of education, the experience of success more generally and positive friendships. Child AFMs have often talked of the importance of support from their schools where much more needs to be done in terms of alcohol

education and awareness. The same can be said about gambling problems for which understanding and recognition lags even further behind.

Policy has understandably focused largely on young children. However for many growing up with parental substance misuse, or excessive gambling, problems will continue into young adult life. Services for children experiencing these parental difficulties need to extend beyond childhood and to support young adults.

The greatest volume of harm associated with drinking and gambling is not associated with the most severe problems –the 'prevention paradox'. This is likely to apply to family harms. There remains a need for a greater understanding of how services are able to engage child and adult AFMs who may be in need of help but who are not currently known to services. Policy should not take a narrow focus only on family members of relatives who are, for example, the most dependent drinkers or heaviest gamblers.

Scarcely any intervention methods for AFMs in their own right have been thoroughly researched and none has been adopted routinely or even widely (there has been a greater number which engage AFMs as allies in treatment for their addicted relatives). However, a number of promising methods for responding to the needs of AFMs have been reported.

There is probably no one best way of offering the help that is necessary. More important is the availability of approaches that are helpful and effective, and which are accessibility to sufficiently large numbers of AFMs. For example, services need to provide easy routes to accessing services, to be creative and flexible, offering a range of options for affected children, adults and families.

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Introduction

The term 'affected family members' (AFMs) will be used as a collective term to denote the people this paper is concerned with. It should be noted that the majority of adult AFMs who have taken part in research are women, mostly wives, partners and mothers. Male AFMs have appeared in research in the largest numbers as fathers. However, other adult AFMs, such as siblings, grandparents, and grown-up children, are also affected in many similar ways. The term 'child AFMs' will be used when referring specifically to those who are not yet adult; for convenience, it will be used to embrace those sometimes described as young children, adolescents and young people.

'AFMs' will be taken to include those affected by their relatives' excessive alcohol consumption, those affected by their relatives' problem drug use, and those affected by their relatives' excessive gambling. There has been least study of gambling, so when there are special features relating to gambling this will be noted.

This paper has largely drawn on English-language reports, and, particularly in Section 3, largely those that have considered British policy and practice. It has been assumed that the conclusions that can be drawn are likely to be as relevant in other parts of Europe, but that remains an assumption.

Sources of information referenced are given at the start of each section.

1 The ways adult family members are affected

This section draws on the following sources: Adfam, 2014; Barnard, 2007; Caswell et al., 2011; Copello et al., 2009, 2010; Krishnan & Orford, 2002; Orford, 2012; Orford et al., 2005, 2014; Ray et al., 2009; Shepherd, 2014; Tepperman, 2009; Valentine & Hughes, 2010; Velleman et al., 2014; Walter et al., 2015; Weisner et al., 2010.

Stress on family members: worry, disruption and loss

> Once [my partner] starts gambling, I don't feel a part of this relationship anymore. I find it's very selfish behaviour. Then I try to analyse it and then I wonder, is it an addiction.
>
> I get visions of hitting him or stabbing him or destroying his possessions, something to make him feel what I've felt (partner of a drinker).

There are many overlapping facets to the stress experienced by AFMs. *Worry for the relative* is often at the forefront; including worry about the relative's physical and mental health, self-care, educational, work or other performance, finances, the company the relative is keeping, and his/her future. But it usually also includes concern about the functioning of the whole family, the maintenance of good quality relationships both within the family and with others and concern about the ability of the family to function well now and in the future for the sake of all its members.

A second very broad facet is more actively disruptive in nature; it always involves a *decline in the quality of family relationships*. At the very least good communication is diminished. Usually there is some element of open conflict and very often, but by no means always, there is aggressiveness and physical violence. When partners of people with substance or gambling problems are asked about this directly, rates of reported violence are found to be high: 50% physical violence from partners, 83% emotional abuse and 91% 'coercive control' in one recent study. The latter is particularly interesting because 'coercive control' is a concept that is now being used a lot when domestic abuse is discussed generally and we know that coercive control in different ways plays a large part in the effects of addiction problems in the family.

AFMs often talk of their feelings of loss of the good quality relationships they once had with their now-addicted children, partners, parents or siblings, along with altered feelings towards the substance misusing relatives. Such feelings usually contain negative elements such as feelings of hurt, bitterness, being let down, anger or hatred, but in total are almost invariably highly ambivalent, containing positive references to good qualities the relative showed in the past, or which are on display when substances are not being used, or positive hopes for the future. Loss of trust is a significant factor within relationships affected by problem drinking, drug misuse or gambling.

Special features of gambling

One feature of a gambling problem, compared to other addictive behaviour problems, is the absence of obvious physical signs and symptoms, rendering it relatively easy to hide from family members. Even if family members notice changes in their relatives (such as irritability, decrease in sleep, less time at home), without full information changes may be attributed to other difficulties. Additionally, the general population may still be relatively unfamiliar with the nature and extent of gambling problems. All of these factors combine to make it much more likely that the disclosure or discovery of a gambling problem is 'sudden, devastating and traumatic' for a family member.

Although there can be severe negative financial consequences for family members affected by excessive alcohol use, and sometimes extremely negative financial complications involving threats and violence from dealers in the case of drug misuse, in the case of gambling problems involving money are a central part of the family experience. Nor is it always a matter of debts accumulating over a period of time, since the loss of very large sums of money can happen in a matter of hours or minutes when gambling. One well-known, early study of 'compulsive gamblers' referred to the 'exploitative' financial relationship those with gambling problems had with their families. This included using money earmarked for family needs, 'borrowing' from relations, lying about the true extent of earnings, and selling or pawning own or family members' possessions. Family members may be put at serious financial risk. They may have to cope with large credit card and other debts, and can be at risk from loan sharks and other creditors.

Family members' coping dilemmas

One of the most stressful aspects is the difficulty of knowing how to cope with these circumstances. Nearly all accounts of how AFMs cope include examples of the ways in which they appear *to put up with* their relatives' problematic consumption. This is a large category of coping actions, including acceptance of things as they are, self-sacrifices made by restricting oneself or putting oneself out in some way to accommodate the relative's substance use or gambling, uncritical support for the relative's behaviour, or simply inaction and resignation.

The ubiquity of such ways of acting is an indication of the very difficult and fraught *coping dilemmas* which otherwise ordinary family members find themselves caught up in, placed as they are in circumstances which provoke a complicated mix of strong feelings towards the relative and the relative's excessive behaviour, and which involve a complex set of obligations towards the relative and other family members. Some of the constraints affecting their actions are material, others to do with the need to maintain stability for children and oneself, and others to do with the AFM's own reduced self-confidence or health. Other constraints are related to coercion by the relative, and often they derive from the AFM's own feelings of care, concern and obligation towards the relative.

A contrast that is often drawn is between ways of putting up with a relative's addictive behaviour and ways family members find for *withdrawing and gaining independence* – for example: not worrying, doing what

the family member wants to do, getting involved in other activities, escaping or getting away, sorting oneself out, and getting a new and better life for oneself and other members of the family. A number of authors have described the struggle which AFMs undergo in trying to achieve such independence, to refocus attention on their own rights, obligations and needs, and to take what is happening less personally.

There is also recognition of the many ways AFMs find to *stand up* to their relatives' drinking, drug use or gambling. At least three separate facets can be distinguished. One group (emotional and controlling), about which few AFMs have much positive to say in the light of their own experience, consists of getting aggressive or otherwise emotional with their relatives or interfering in their relatives' drinking, drug use or gambling in an effort to control it. A second sub-group (protecting self, family and home) embraces those ways of coping which have the 'harm minimisation' aim of protecting the family member, the home, and particularly children, from the harmful effects of the problem, rather than the aim of controlling the excessive behaviour itself. The third group (assertive and supportive) covers ways of asserting the AFM's own understanding of the seriousness of the problem, what is acceptable and unacceptable behaviour, and supporting the relative in efforts to control use of substances or gambling and/or to seek treatment.

Special features of gambling

> She [her sister] said she'd had some debts; she was very sorry she'd gone on the gambling again. She needed so much to bail herself out… would I be willing to do it?… So I spoke to my mother. I spoke to my husband and we all came to the conclusion that she needed a loan. I'd get her the loan but it had to be, you know, there had to be certain regulations or conditions to getting the loan. And I made her wait for a week before I told her. And then another condition was she had to tell her husband because her husband had no idea what she had been doing… I took the loan out from my bank and made sure it was a secured loan for £5,000… I'm not best pleased… I took the loan out because I thought it's not fair on her daughter to have to suffer and go without (from Valentine & Hughes, 2010).

When there is a close relative with a gambling problem, 'coping dilemmas' often revolve around money. AFMs may have to decide whether to cut back on their spending, impacting on lifestyle including social life. They frequently make the difficult decision to take up the role of managing family finances and controlling their relatives' access to money, adding considerable stress. In one study parents of sons or daughters with gambling problems talked about watching money very carefully. Despite contrary advice by Gamblers Anonymous and others, parents had lent their gambling children money although they believed there was little chance of being repaid, worrying that otherwise their offspring would suffer, perhaps even starve, or that they would start stealing and getting into trouble. Some had covered their children's debts or rent, sometimes to the tune of several thousand pounds. Some had successfully taken over their children's finances, only handing out money for what were thought to be reasonable expenses. Again, although money is so central in the case of gambling, it can assume great importance in the case of substance problems, for example in the case of drug expenditure and debts.

Information and understanding

Closely related to ways of coping is the understanding an AFM has of what is taking place, her or his stance towards it, and the sense that is made of it. AFMs are often left uninformed or are deliberately misled by their relatives about what is happening. Part of gaining better understanding is receiving good, accurate information. Sometimes this is of a purely factual kind; for example information about the strength of different alcoholic beverages or the effects of different types of illicit drug or about different forms of gambling. AFMs also often find it useful to discuss the nature of addiction or dependence and the difficulties their relatives have in overcoming it. They also often find it useful to gain greater understanding and realisation of the links between their relatives' drinking, drug use or gambling and their own physical and mental health. At a different level, AFMs may benefit as much from reassurance about themselves as, for example, partners or parents.

Social support for family members

In view of the established importance of social support generally for good health, and particularly as a buffer in the face of stressful circumstances, AFMs might be thought of as a group in particular need of good social support. Yet the evidence is that social support for AFMs is highly problematic. One report described social support for wives as 'fragile' and research has found there to be a number of barriers that stand in the way of AFMs receiving the support they find most helpful. Family members themselves often express reluctance to talk about the problem to others, believing that problems should be dealt with in the family, that a good parent or a good wife should be able to cope, that knowledge of the problem might bring shame or dishonour, that the addicted relative would react badly if others knew, or simply that other people are too busy with their own affairs or would be unable to help.

Because addiction is associated with stigma and can evoke strong feelings in others, and because how to respond is problematic and debatable, others who might support an AFM in her coping efforts or in her way of understanding what is going on, are often perceived as unsupportive, critical or even overtly hostile to the AFM's position. Some AFMs are criticised by others for being too tough, others for not being firm enough. There are many examples of AFMs feeling pressure from others to put up with their relatives' addiction problems. AFMs have been described by others as 'hard', 'cold', or even 'cruel'. Some anticipate rebuke if they respond to relatives in ways that break with traditional family responsibilities, for example responsibilities as a wife. There are likely to be differences by social-cultural group in this respect as in other facets of the AFM experience.

Professional support for AFMs appears to be as problematic as is informal support. Even in countries with comparatively well-developed services, professionals are often perceived by AFMs as lacking in knowledge, awareness or even sympathetic understanding. If their relatives are receiving help from specialist agencies, AFMs often feel deprived of information, in part because professional models of treatment largely exclude them and prevent imparting information to them because of rigid and unimaginative rules of client confidentiality.

AFMs are themselves at heightened risk of ill-health

AFMs frequently describe themselves as feeling angry, frustrated, irritable and very shocked about the position their relatives have put them in, as well as guilty, believing that they may have in some way caused or contributed to the problem. AFMs are likely to describe being on high alert, watching their relatives and trying to ascertain whether consumption has continued, all of which leads them to feeling exhausted and overwrought. There may also be feelings of grief and resentment on account of a loss of 'the future' that the family member thought had been planned and agreed upon, or had hoped for. Those who have suffered the death of the substance using or gambling relative are likely to have had bereavement reactions that are specially complicated and stressful.
Adult AFMs constitute a group which is at high risk of ill-health. Data from many countries are full of references by AFMs to feelings of anxiety, depression, despair and fear, to general poor health, to disturbances of sleeping and eating, an increase or instability in their own use of substances including tobacco smoking and use of prescribed medication, as well as to physical symptoms such as headaches, back pain, hypertension, asthma, palpitations, migraines, diarrhoea, as well as exacerbation of long term illnesses they may have.

A consistent finding is that AFMs obtain high mean scores on standard measures of general ill-health and lower scores on 'happiness'. Significant correlations are found between poorer health and the degree of impact which AFMs report their relatives' problems having on their lives and that of their families, and ill-health scores are generally higher when AFMs and their relatives are living under the same roof.

Estimating the financial costs associated with the effects of addiction on family members

It is evident that AFMs bear personal and household or family-wide 'costs', often substantial, of living with addiction. Some of those costs would otherwise be borne by governments. In the UK a report for the Drugs Policy Commission attempted to estimate the cost of harm to adult AFMs of their relatives' illicit drug use (alcohol was therefore not included). A number of economic costs were considered: financial support to the relative from family resources; money innocently or unwillingly given to relatives which was used to fund their drug use; theft of money or property; lost opportunity for employment for AFMs; and costs of AFMs' ill-health. The cost per adult AFM was estimated to be £13,500 (2008 prices). The number of adults significantly affected was estimated to be at least 1.4 million, making a total UK cost of £1.8 billion annually of which £750 was estimated to be the value of support provided by AFMs if it was to be provided by health and social care providers. Studies in the USA have also attempted to estimate excess healthcare costs for AFMs (alcohol and drugs). One such study compared the healthcare costs of several thousand spouses and children of patients receiving treatment for an alcohol or other drug problem with a matched control group, using data from a private health plan. The former were found to have significantly higher average monthly healthcare costs (50% higher), with evidence of significantly higher prevalence of medical conditions such as heart failure, heart disease, diabetes, asthma and lower back pain, with much higher odds of having any psychiatric diagnosis, especially depression. Family members' average healthcare costs

reduced to control group levels in years when relatives had been abstinent, but remained high on average when relatives were non-abstinent. We are not aware of any similar work in the case of problem gambling.

Estimating the size of AFM costs in monetary terms is beset with conceptual and methodological problems. It is particularly difficult to estimate the 'cost' of the stresses, dilemmas and 'unhappiness' caused to a partner, parent or other AFM affected by alcohol or gambling problems. An Australian study used results from the national *Alcohol's Harm to Others* survey to estimate the intangible costs to AFMs of having a heavy drinker in their lives who was affecting them. Using a figure of AU$50,000 for the value of a quality adjusted life year (QALY), they estimated the cost per person to be $700 if affected 'a little' and $3800 if affected 'a lot'.

2 The ways child family members are affected

This section draws on the following sources: Adamson & Templeton, 2012; Cleaver et al., 1999, 2011; Manning et al., 2009; O'Connor et al., 2014; Prince-Embury & Saklofske, 2013; Templeton et al., 2009; Tunnard, 2002a, b; Turning Point, 2006; Velleman & Orford, 1999; Velleman & Templeton, 2007; Velleman et al., 2008; Velleman et al., 2014.

> It got to the point where I would hide the fact that it was sports day or some other event, otherwise he would turn up drunk.
>
> I'd get home from school, I'd watch TV and my Mum would be upstairs on the computer. She'd just be on the computer [gambling] like that all the time and then she'd make my tea and then she'd probably go back up again. Then she'd probably watch some TV and then I think before she went to bed she went on it. And then it just went like that.

Child AFMs experience worry, hurt and confusion, and can suffer neglect

Studies involving child AFMs have found that they experience many of the same stresses, dilemmas and strains as do adult AFMs. Children describe living with tension and worry and uncertainty and often with denial and secrecy, complicated by further uncertainty caused by cycles of relapse and recovery. Neglect of one kind or another is a common experience. They describe a mix of feelings including sadness, emotional hurt, depression, confusion, fear, anger, pity for their parents, hate, shame, helplessness, isolation, abandonment, and/or guilt. Although children often see and understand more than parents realise, the secrecy that is frequently associated with substance and gambling problems adds to their distress and confusion. Being worried about bringing friends home, or being embarrassed seeing your parent when with friends, are amongst the things that children with parents with alcohol problems often talk about. Notable is the young age at which children are first exposed to a parental alcohol or drug problem and the long span of childhood, quite commonly 5 to 10 years or longer, during which exposure continues.

A feature of gambling

The much larger amount of work has concerned children and parental substance misuse, but the more limited studies of the children of problem gamblers do suggest that the effects on children are very similar. In the case of gambling a feature that has been commented on is the neglect of children associated with the gambling parent's preoccupation with gambling which leads to promises being made to children which are then broken or to children being left unattended – for example there have been reports of children being found abandoned on casino premises or being locked in hot cars for hours while their caretakers gambled.

Coping dilemmas for children

How to cope with these circumstances is as much a dilemma for children as it is for adult AFMs. The comment has been made that affected children are not passive victims, despite 'living with a problem which they may not be able to name or understand, and which is often confusing, distressing and frightening'. Rather, they go to great lengths to find their own solutions, often combining practical, physical and emotional strategies. One typology of affected child coping actions was: avoidance and distraction; protection and inaction; confrontation, intervention and self-destruction; and help seeking and action. But 'children rarely adopt just one strategy and will most likely face coping as an on-going struggle to know what to do for the best'. Some coping strategies adopted by children - such as anger, aggression, truancy, anti-social behaviour or challenging authority - can make engagement with services harder. Furthermore studies have shown that children are often very careful and selective about whom to seek support from and it can often be a long time before they actively seek support. Research has also suggested a number of positive factors associated with resilience for children and young people, including positive experiences of education, the experience of success more generally, and positive friendships.

Child AFMs as 'carers'?

It is a common observation that children of parents with either substance or gambling problems often experience role conflicts, including taking on the role of peacemaker, being caught in the middle of family tensions, serving as scapegoat and/or taking the blame for family difficulties stemming from the problem. Not uncommonly role changes go further and children take on a caring or protective role towards a parent or a younger sibling. Sometimes a young person will even have a formal role as a young carer for a parent. It has been suggested that the 'expanse' of the caring role for children where there is parental alcohol misuse, for example, may be greater than in other types of care by children and young people, with children reporting responsibility for: emotional support, financial support, household tasks, safety and monitoring of drinking, arranging transport, personal care (e.g. giving medication, assisting with washing whilst intoxicated) and caring for siblings. One study reported that it was the emotional care which children spoke about 'most poignantly' but that what was involved was more than a simple reversal of the parent-child roles. Of particularly note was that young people were ambivalent about being given the label of 'young carer', finding it 'unusual or uncomfortable' and of 'little relevance' to them. It might be noted here that adult AFMs have also expressed ambivalence about being referred to as 'carers'.

Child AFMs are at heightened risk for ill-health

Child AFMs are at heightened risk as children. The risks include: 'internalising' problems such as being withdrawn, concentration difficulties at school, and depression; 'externalising' or 'anti-social behaviour' problems, such as aggressiveness and delinquency; as well as friendship problems. Problems that have commonly been described include: experiencing problems in school including erratic attendance, changes of school, bullying and behavioural difficulties; higher risk of smoking, excessive alcohol use, problematic

drug use and adolescent mental health problems; and emotional disorders, including depression and suicidal behaviour; describing home life as 'unhappy' or 'broken'.

The age of children is likely to be important. For example younger children may be more affected in terms of school attendance and developmental delays, with older children possibly being more affected because they have taken on caring responsibilities, being more isolated or themselves misusing substances. There is less clear evidence about the importance of gender, either that of the child or that of the parent who drinks, takes drugs or gambles excessively.

Complicating factors and greater risk associated with multiple problems

The child AFM experience is often complicated by other factors. It has been found that children who disclose that they are living with parental alcohol or drug misuse often have another major problem – often physical abuse, violence or family breakdown – which is the initial reason for making a contact. Research has clearly shown that risks to children are greater if the parental/family problem is more extensive; for example, if there is exposure to multiple problems, if the child is living with two parents with problems, where the problem is more severe or of longer standing, or where there is significant 'fallout' from the problem(s) in terms of family disharmony and disruption.

Witnessing conflict and violence and in some cases experiencing direct violence and hence living with fear is a very common part of the experience. How young people may be affected through living with co-existing domestic violence and parental alcohol misuse was explored in a study of 12-18 year-olds from five European countries. Many of the children were exposed to high, and often extreme, levels of violence between their parents.

Further common complications include additional chronic parental mental or physical ill-health, or parental criminality, as well as social disadvantages such as parental unemployment and family housing problems, and/or instability and insecurity associated with a considerable number of accommodation moves and frequent changes of carer. An important issue is that of contact between children and their parents particularly when they are temporarily or permanently removed from their families. Some of the research in this area has noted the strong bonds and attachments that many children retain with their parents, despite the latter's problems. This raises significant questions and challenges for those taking on the care of affected children, including grandparents or other kinship carers.

Among other sub-groups of child AFMs who may have specific experiences and needs are children who experience an alcohol, drug or gambling-related bereavement, children who have a parent who is also in prison, and children who are homeless. While it is outside the scope of this paper to consider children affected by foetal alcohol spectrum disorder (FASD), it is perhaps important to highlight that this is also an important group who may be identified/diagnosed late, more likely to be removed from their birth families, and who often have specific lifelong needs because of the damage they have experienced.

Although the risk to affected children as children is of most immediate concern, there is the further question of the longer-term impact of parental problems on offspring as they move into young adulthood and beyond. That is a more complicated longitudinal issue which is beyond the scope of this paper but it is likely that greater long-term risk is associated with greater extensity and impact of parental problems in childhood.

Finally it should be noted that concern for child AFMs is a major motivating factor for their parents. For adult AFMs the greatest weight of worry is often about possible effects on children: including concern that the children's health and happiness is being affected, the possibility of violence or neglect, more general worry about interference with good upbringing of the children, or concern that children might repeat the relative's behaviour. And there is evidence that the excessive substance using or gambling parents themselves often hold a high level of understanding about the range of ways in which their children are affected and the impact that their problems have on their parenting, and this often constitutes a major motivation for engaging in treatment.

3 What affected children and adults need

This section draws on the following sources: Adamson & Templeton, 2012; Advisory Committee on the Misuse of Drugs, 2003; Copello et al., 2010; Forrester & Harwin, 2006, 2011; Harwin et al., 2010, 2014; Hodgins et al., 2007; Kearney et al., 2003; Kroll & Taylor, 2003; Orford et al., 2005, 2014; Prince-Embury & Saklofske, 2013; Rogers, 2013; Rychtarik & McGillicuddy, 2006; Templeton, 2010, 2013, 2014; Templeton & Sipler, 2014; Tunnard, 2002b; Velleman, 2010; Velleman & Templeton, 2007.

> Alcohol misuse is frequently a family secret that remains undisclosed, and children's voices, all too often, go unheard.
>
> Alcoholism is hidden because it's legal – it's swept under the carpet.
>
> They think it's normal. They think it's happening to everybody. They don't know how bad it is. They just accept it. They have no one to turn to about it and they feel helpless.

Policy is overshadowed by the drugs and children and family agendas

Policy regarding AFMs, certainly in England, has been overshadowed by two issues. One is the importance of drugs policy – although even drugs policy documents have relatively little to say about AFMs, particularly child AFMs. Disappointingly there is comparatively even less focus specifically around parental *alcohol* misuse and its impact on families. One recent UK report has concluded that there have been improvements in policy in the last 10 to 15 years in terms of recognising and attempting to respond to children affected by parental substance misuse, but that there remain major limitations to the progress made in respect to alcohol.

The situation with regard to gambling is even worse: if the UK is anything to go by, there is little in the way of coordinated national or European gambling policies and nothing much of note regarding the impact of gambling problems on AFMs.

It is even unclear which Government department should take the lead with this issue, how Government departments should work together to develop the best response, or which areas of policy should be targeted in order to give the issues of family substance misuse and problem gambling greater policy attention.

The second feature which overshadows policy is the importance of the children and families agenda. As a result, compared to child AFMs, adult AFMs have been neglected. As one review of the relevant policy context concluded, adult family members have got, 'lost in the fog' on the policy landscape. Unlike most European policy documents which tend to ignore families altogether, the EU Alcohol Policy and Strategy 2006 did highlight family but mention of family was confined to protecting 'young people and children and the unborn child'. Impact on and needs of other family members are ignored. But the obvious point can be

made that children's and parents' needs are deeply interwoven. If children are the priority, '…one of the very best ways of protecting children, perhaps the best, is to support the adult members of the family who are in the best position to protect the children…'. Although 'whole family' policies are now being promoted by government in the UK, and there may be increasing recognition that parents' and children's needs overlap and are interdependent, it may still often be the case that too exclusive a focus on children's welfare encourages an unhelpful separation of adult and child services.

Social work services focusing on child care

No clear picture of how many services, specialist or general, there are in the UK or across the rest of Europe, which wholly or partly work with children affected by parental substance misuse or gambling problems. The picture is even less clear when it comes to adult AFMs. It is likely that the services which do exist do not match either the identified need let alone the larger submerged part of the iceberg, the 'hidden harm'.

Social work services focusing on child care is one principal location for the identification of harmful effects of adult substance problems on children. Several studies have highlighted the high incidence of parental substance misuse (of which alcohol misuse, often in combination with misuse of other substances, is recognised as the biggest problem) in childcare social work, and particularly amongst the most serious cases and those involving repeat care proceedings.

It has equally been recognised as an issue which is under-estimated and unrecognised. It is clear that the size of the problem remains hidden. Addressing the lack of prevalence data in this area may serve to give greater policy recognition to the issue of parental substance misuse and gambling problems. Estimates are currently only very approximate. In the UK for example, figures published in 2009, of the numbers of children, under 16 years, living with parental alcohol misuse in the UK, based on data from several UK household surveys, were that 6% were living with a dependent drinker (over 700,000 children), and 4% living with a problem drinker who had co-existing mental health problems (approximately 500,000 children) with yet greater numbers living with a parent whose drinking was risky or 'hazardous' (over 2.5 million children).

Reports have concluded that there is a lack of pre- and post-qualification training for social workers around substance misuse issues. Workforce development is a critical issue.

The social work profession, certainly in the UK at least, has been almost silent on the issue of problem gambling, perhaps because there are as yet very few statutory services for people with gambling problems. The issue does not feature in most social work training programmes, and few social workers ask about this issue when conducting assessments. It is important that action is taken so that both the training and practice of the social care workforce reflect knowledge and understanding of the seriousness of gambling related harm and its links to other personal and social problems.

Beyond social work

Inevitably there has been a focus on social workers. However, it is equally important that other professionals in specialist and general services such as primary care, education and generic youth services, receive training in both understanding and working with parental alcohol misuse and problem gambling. Although there are some good examples of specific workforce development alcohol and family training programmes, professionals from many groups would benefit from focused training on alcohol and drugs. The same can be said about gambling which is even more neglected.

Services for people with mental health problems, particularly anxiety and depression, constitute another location where family members affected by substance and gambling problems might be identified. It is likely, however, that the contribution those problems make to family members' psychological problems is largely hidden if and when they present to mental health services. An indication of the extent to which this is missed is provided by a small recent study of adult attenders at an Increasing Access to Psychological Therapies (IAPT) service in England, 17% of whom at the time of entering the IAPT service reported having a family member whose level of alcohol use concerned them (most of this group thought this was a factor in their seeking help).

Services need to be better co-ordinated

A number of problems in the responses of services to these issues have been highlighted in reports. One is a lack of communication and co-ordinated activity between the relevant services. Partnership working is widely recognised as an area where further progress continues to be needed. This applies to the links between universal or generic health and social services and specialist addiction-related services. The low number of referrals to social care which come from primary health care professionals and workers in substance misuse treatment services has been noted for example. But it also applies to the links between adult services which are likely to be dealing with parents with substance or gambling problems and those child and adolescent and family services which may be in contact with affected children. This is complicated by an often poor appreciation of the impact of substance misuse or gambling on children, leading to delays in taking appropriate action or a lack of action. It has been noted for example that concerns about alcohol misuse tend to lead to less, and later, intervention than concerns about drug misuse. .

What children say they need

It can be very hard for children to talk about parental substance misuse or gambling; however, children have told researchers about some of what they need in order to get help. They say they want a patient, empathetic and sensitive approach, based on trust, in which someone who is helpful, caring and encouraging recognises their circumstances and takes the time to get to know them. They also place importance on some things which professionals usually miss: such as, the role of play and humour– mainly

with siblings but also with friends and other family members; having a pet who they could care for, stroke and talk to; and having 'somewhere to go' when things were difficult at home. Children have said they do not want to be patronised and seen as victims; and that they do not want to have an identity that is based on being the 'child of an alcoholic'. Children can take great pride in 'surviving' their experiences, and this is linked to their wish not be patronised or seen as victims. The role of and support from other family members, particularly the 'other' parent and siblings, is important.

Child AFMs have often talked of the importance of support from their schools. The latter can offer praise and support to children, which might be missing at home; an escape from what is going on; and they offer the chance for adults to be proactive in identifying and offering support. There needs to be much more done generally by schools in terms of alcohol and gambling education and awareness, and to advertise services. Children do not necessarily want to be singled out for help. However, there is also a need for staff in school to have a better understanding of how parental alcohol or drug misuse can affect children and how they can respond. Once again the same can be said about gambling problems for which understanding and recognition lags even further behind.

Policy has understandably focused largely on young children. However for many growing up with parental substance misuse, or excessive gambling, problems may continue into young adult life. Services for children experiencing these parental difficulties need to extend beyond childhood and to support young adults, many of whom need additional support with issues after parents have received treatment and/or after they have left the family home.

Broadening the base of work with AFMs

Where child AFMs are identified by services this has largely been where a parent or child is already known to services, and more specifically where there is social care involvement. This has meant that there has been less progress in identifying and supporting the larger numbers of affected children who may be in need of help but who may not be known to, or engaged with, services. There remains a need for a greater understanding of how services are able to engage other groups of affected children and families, particularly in mainstream services such as primary care, education and generic youth services. The greatest volume of harm associated with drinking, drug and gambling is not necessarily associated with the most severe problems – a phenomenon which has been referred to as the 'prevention paradox'. This is as likely to apply to family harms as to other types of substance- and gambling-related harms. Policy should ensure that it does not take a narrow focus only on family members of relatives who are, for example, the most dependent drinkers or heaviest gamblers.

Promising interventions

Despite the evidence that AFMs are usually highly stressed and are at heightened risk of negative health and social outcomes themselves, help specifically for child and adult AFMs in their own right is a field still in

its infancy. Scarcely any intervention methods have been thoroughly researched and none has been adopted routinely or even widely. However, a number of promising methods for responding to the needs of AFMs have been reported. They include: some that take a more psycho-educational approach; others that provide counselling for partners in their own right, of which the 5-Step Method (a brief intervention for adult AFMs affected by a relative's alcohol or drug misuse, recently extended to a pilot with young people aged 12-18 years in Northern Ireland) is one of the better known; a not dissimilar programme known as Stepping Stones; Behavioural Exchange Systems Training; parent coping skills training; and the long established network of Al-Anon family groups. These methods have tended to be used in specialist settings but might have potential in generic family services such as SureStart, Children's Centres, youth services or the education sector, although appropriate training and support would be necessary.

Gambling examples include: an adaptation of the 5-Step Method; a coping skills training programme for AFMs with partners with gambling problems, a 'minimal treatment approach' for concerned and significant others of problem gamblers using a self-help workbook based on behavioural principles modified from the community reinforcement and family therapy (CRAFT) model; a form of couples based therapy for problem gamblers called Congruence Couple Therapy; and Gam Anon family groups.

There is probably no one best way of offering the help that is necessary. There are good examples of methods involving: individual support for affected adults; group support for affected adults; individual support to children; group support for children; couples therapy; whole family support; multiple family groups. Probably more important than the specific nature of an intervention is the availability of approaches that are helpful and effective for AFMs, and which are accessible to sufficiently large numbers of AFMs. For example, services need to provide easy routes to accessing services, including such methods as free and confidential helplines, and the use of mobile communication technology. Methods need to be creative and flexible – for example, not be time-limited, work in a range of ways, be prepared to offer support in the longer term, offer a range of things to children and families, and consider how to support adults or children separately as well as working with family units.

This paper has deliberately focused on the needs of adult and child AFMs in their own right since that is the area of greatest neglect. However AFMs, at least adult AFMs, express two broad needs – to receive understanding and support in their own right, and to be as helpfully involved as possible in the care and treatment of their problematically drinking, drug taking or gambling relatives. When it comes to professional interventions, there has been a greater number which respond to the second of those needs, either by engaging AFMs as allies in alcohol, drug or gambling treatment, or by using models of treatment that focus on couples or families. Examples of the latter include: the Recovery Coach model which involves an independent 'coach' who provides intensive assessment, advocacy, case management and direct work with parents when a mother is identified as using drugs during pregnancy and children are removed; Family Drug Treatment Courts (FDTCs) which include regular meetings with a designated judge who actively manages the case, a focus on recognizing and rewarding achievements, better coordination of services for families, and a specialist team that works with families to improve such coordination; and Option 2 based on the 'Homebuilders' model which is a crisis intervention model, providing relatively brief (6 weeks) but very intensive input.

Conclusions – what is needed now:

1. **A greater focus on family members affected by <u>substance</u> or <u>gambling</u> problems in the family.** The importance of drugs policy has meant there has been comparatively little focus specifically around parental *alcohol* misuse and its impact on families. The situation with regard to gambling is even worse.

2. **A greater focus on *both* adult and child affected family members (AFMs).** Compared to child AFMs, adult AFMs have been neglected; they are an at-risk group themselves and are also often in the best position to protect children living in the same families.

3. **Better data on incidence and services.** We need plentiful and accurate information on the numbers of adults and children affected by family alcohol misuse or gambling problems, and about the numbers of services wholly or partly working with them.

4. **More pre- and post-qualification training.** Education and training in parental and family alcohol misuse and problem gambling is needed for social workers and professionals in a range of other specialist and general services, such as primary care, mental health, education and generic youth services. All these professionals work in settings where AFMs might be identified but currently remain largely hidden.

5. **Better communication and coordination.** Because substance and gambling problems cut across services which have different remits, good coordination and communication between services is crucial. It is recognised that there is room for improvement, for example to improve communication and coordination between child and adolescent services and those that serve adults, and between generic services, and those that specialise in providing addiction services.

6. **Interventions**. Wider adoption of, and research into, intervention methods for AFMs in their own right, of which there are a number of promising examples. Probably more important than the exact form that the intervention takes is the availability of a range of approaches that are helpful and effective, which are accessible to sufficiently large numbers of AFMs, well-advertised, providing easy routes of access to services, and offering a range of creative and flexible options for affected children, adults and families.

7. **Better recognition of what child AFMs want**, particularly an empathetic and sensitive approach, where a helpful, caring and encouraging person recognises their circumstances and takes the time to get to know them. Qualitative research shows that they do not want to be patronised, seen as victims, or just as 'children of alcoholics' or compulsive gamblers for example. The term

'carer' is sometimes appropriate, but mostly not. Amongst the positive resilience factors which should be recognised are: support from other family members and school, positive experiences of education, the experience of success more generally, and positive friendships.

8. **Wide-reaching and long-term perspective**. A broader approach to try and engage child and adult AFMs who may be in need of help but who are not currently known to services. Policy should not take a narrow focus only on family members of relatives who are the most severely dependent or the heaviest consumers. There should also be recognition that for many growing up with parental substance misuse or excessive gambling, problems will continue and services need to extend beyond childhood.

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