Assessing the needs of families affected by substance misuse in Scottish Borders

March 2011

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The review of literature, analysis of data and writing of the final report was conducted by Andrew Rome, Myshi Mackenzie and Kirsty Elliot of Figure 8 Consultancy Services Ltd.
Acknowledgements

The authors would like to acknowledge the help, contributions and support of all those involved in supporting this study. In particular:

Carers
Specialist and front-line service providers
Napier University Borders Campus library staff
NHS Borders (Clinical Audit Team, Knowledge and Information Dept. and Healthy Working Lives Project)

‘Whatever the exact nature of these relationships and circumstances, the impact of problem drug use on families is profound, and often devastating. It can include anguish and unhappiness, experience of stigma and discrimination, isolation, poverty, mental health problems and social exclusion. Some families feel that their only option is to withdraw support and to break their ties with a family member with a substance misuse problem – but this is very difficult to cope with too. Many families struggle on, often on the margins of communities and with limited support’. ¹

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Abbreviated Terms

<table>
<thead>
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<th>Abbreviation</th>
<th>Meaning</th>
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<tbody>
<tr>
<td>BADP</td>
<td>Borders Alcohol and Drugs Partnership</td>
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<tr>
<td>BCAT</td>
<td>Borders Community Addiction Team</td>
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<td>EIU</td>
<td>Effective Interventions Unit</td>
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<td>GPs</td>
<td>General Practitioners</td>
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<td>NTA</td>
<td>National Treatment Agency</td>
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<td>UKDPC</td>
<td>UK Drug Policy Commission</td>
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CHAPTER 1: INTRODUCTION

1.1 Aims and Objectives

The Borders Alcohol & Drug Partnership (BADP) is a multi-agency group responsible for implementing national alcohol and drug strategies at local level. This includes assessing the needs of individuals, families and communities affected by substance misuse, and creating solutions for addressing these needs.

In recent years the Scottish Government has set out national strategies in relation to substance misuse; *The Road to Recovery: A new approach to tackling Scotland’s drug problem*⁵ (May 2008) and *Changing Scotland’s Relationship with Alcohol: A framework for action*³ (March 2009). Within these, the Scottish Government has set out the important role of families in the recovery of someone with a substance misuse problem, and underlined the fact that they, as individuals affected by these problems, have their own support needs.

Although the number of people with drug and alcohol problems is increasing, there is currently no dedicated service in the Borders for families affected by substance misuse, although informal support networks do exist. It is important to be able to accurately assess the nature and extent of needs in Scottish Borders in order to addressing this gap in services.

The aim of this study is to identify the needs of families, carers and friends affected by substance misuse in the Scottish Borders. Its remit does not include parental substance misuse affecting dependent children as this is currently being addressed through a range of separate initiatives.

The objectives of the study were to:-

1. Identify the needs of those affected by the substance misuse problems of someone close to them.
2. Examine what support systems are currently in place and how effective they are
3. Identify gaps in the provision of support.
4. Make recommendations as to how best to address unmet needs.

The cost of this needs assessment has been met by the Borders ADP.

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1.2 Methods

It was essential to engage as broad a range of stakeholders as possible in the process to ensure good representation of views across different groups (gender, age, geographical areas). A range of methods were employed to ensure that the necessary range and quality of data was collected and the objectives of the survey were achieved. Methods included:

- Publicity
- Literature review
- Visits to projects
- Survey of carers
- Survey of employers
- Interviews with service providers
- Interviews with GPs
- Feedback

1.2.1 Publicity

The study was promoted throughout Borders in order to raise awareness amongst potential stakeholders, to identify key contacts and to invite participation. This was done through a combination of letters, emails, telephone contact, and via local media and websites.

1.2.2 Review of research literature and good practice guidance

The objective of this stage is to seek to establish an overview of effective practice in Scotland, UK and abroad.

The analysis team sought to review current research, policy and good practice guidance in the provision of support to people affected by substance misuse. This was achieved by reviewing and analysing nationally available data as well as undertaking a limited review of key international literature.

By doing this, we aim to provide a background and context against which to place the report’s findings.
1.2.3 Visits to projects

Nine projects across Scotland were identified as potential sources of good practice in the provision of services for carers. Four of these were visited by the report author. The aims of the visits were to identify whether needs assessments had been carried out, what evaluation tools services were using, what services were being provided for families, and to establish the funding sources of each. A summary of each visit was written as a case study within the report.

1.2.4 Survey of carers and employers

Two surveys were conducted as part of the data collection process; one with carers and friends and the other with local employers. The surveys were conducted using questionnaires which were disseminated in paper and electronic format (using Survey Monkey via NHS Borders Intranet, BADP and Young Scot websites). The target groups were:

- carers, family members, and friends of substance misusers to identify support needs (self-completion)
- employers and staff within NHS Borders and Scottish Borders Council, and 29 small to medium sized organisations

The questionnaires were developed in consultation with NHS Borders Clinical Audit Department and key stakeholder groups. Draft questionnaires were then piloted with service providers, Dialogue Youth, Healthy Working Lives, and a local family support network (QUEST). These methods were adopted to ensure good representation of views across different groups and maximum participation.

The questionnaires were designed to provide a better understanding of a number of issues including:

- who was affected by substance misuse
- what geographical area they came from
- what substances were affecting families most
- what the main concerns and issues for families were
- what type of help people wanted
- where people sought support from
- Whether they felt that the service they received was effective
- what type of support would be useful for them in the future
1.2.5 Interviews with service providers

Interviews were conducted with representatives from 59 different service providers (generic and specialist) to identify and assess supports available. It was felt that interviews would generate greater understanding of the issues, increase participation, and elicit clearer responses.

Service providers were asked their views on the nature and extent of needs of carers and the extent to which services were available to meet these in Scottish Borders.

1.2.6 Interviews with general practitioners

General practitioners (GPs) across Borders were invited by email to participate in the study and to provide their views on service provision and gaps. Four GP’s responded and three of these were subsequently interviewed (two by telephone and 1 face-to-face). The other provided comments by email. Unfortunately because of the low number of responses these comments could not be regarded as representative of the views and experiences of GPs across Borders and are therefore not used as part of this report.

1.2.7 Feedback

To ensure accuracy of the findings the first draft of the report was shared with several of the key service providers who participated in the survey and also with Quest family support group.

1.3 Ethics

In 2007 the National Research Ethics Service (NRES) of the NHS National Patients Safety Agency issued guidance on the requirements for ethical approval differentiating audit, service evaluation and research.


This guidance indicates (pp.3 “Differentiating clinical audit, service evaluation, research and usual practice/surveillance work in public health”) that projects such as this are classed as ‘service evaluation’ –which does not require ethical approval and therefore no application is required to be made to the local research ethics committee or NHS R&D Committee.

After discussion with the Clinical Audit Support Team it was agreed that ethical approval was not required as it was patient opinions that were being collected and there would be no patient identifiable information contained in the final report.
1.4 Response

Seven responses were received from employers in Scottish Borders. Two described themselves as providing a ‘Borders-wide’ service; three were from Roxburghshire and two from Selkirkshire. The responses are summarised in chapter 6.

Completed questionnaires were received from 44 carers and friends and from 79 service providers in Scottish Borders.

1.4.1 Profile of carers responses

Most of the carers were either a parent (34%) or a partner (36%) of a person with a substance misuse problem. Two were siblings (5%) and six were caring for a parent (14%). Two respondents described themselves as friends.

Twenty five of the carers were from Selkirkshire (57%), 14 from Roxburghshire (32%), 3 from Berwickshire (7%) and 2 from Tweeddale (4%).

Almost two-thirds of respondents did not live with the person using drugs or alcohol (64%). One-third did live with the person (34%) and one person declined to state whether they did or did not.

Alcohol was most commonly cited as the substance used by the person they were caring for. Eighteen carers said alcohol alone (41%), 15 said alcohol and drugs (34%) and 10 said drugs only (23%). One person did not answer.

1.4.2 Perceptions of service providers

Half of the service providers (48%) stated that they operate across all areas of Scottish Borders. Other responses included Roxburghshire (23%), Berwickshire (15%), Selkirkshire (14%) and Tweeddale (9%).

Service providers stated that the carers that access their services are predominately female (70%) and described as adult (58%) or older adults (5%). Other responses included young adults (29%) and ‘all’ (5%). Two service providers did not respond to this question.

A third of service providers (33%) thought that issues relating to alcohol use took up most of their time, thirty (38%) thought that there was no difference between alcohol and drugs and nineteen (24%) thought that issues related to drug use took up more time. Four service providers did not make comments.
1.5 Analysis

The Clinical Audit support team, NHS Knowledge and Information Dept and Healthy Working Lives service all used Microsoft Excel and Survey monkey systems to support data collection.

Figure 8 Consultancy entered the quantitative data into SPSS (Version 17) for analysis and conducted a thematic analysis of the qualitative data contained in free text boxes of the questionnaires and interview schedules.
CHAPTER 2: REVIEW OF POLICY REGARDING CARERS

This chapter provides a summary of the policy in Scotland in relation to providing services for carers generally as well as those caring for a person with a substance misuse or mental health issues.

2.1 Carers - General

2.1.2 Scotland

In July 2010 the Scottish Government published their new strategy for carers.\(^4\)

The strategy defines what carers do as providing care to family members, other relatives, partners, friends and neighbours of any age affected by physical or mental illness (often long-term), disability, frailty or substance misuse or sometimes more than one of these. They can be caring short-term or long-term and they do not need to be living with the cared-for person.\(^5\) The strategy emphasises that due to social and demographic changes the number of carers will probably increase in the future.\(^6\)

The vision of the strategy is that in Scotland unpaid carers are ‘recognised and valued as equal partners in care; supported to manage their caring responsibilities; fully engaged in the planning and development of services; and not disadvantaged or discriminated against by virtue of caring’.\(^7\) There is also a focus on providing support on a ‘consistent and uniform basis’.\(^8\)

The main action points of the strategy are;

- A Carers’ Rights Charter will be developed,
- More measures will be taken to help professionals identify carers,
- Improve uptake and quality of carers’ assessments,
- Improve provision of information and advice to carers,
- Help with carer wellbeing and health,
- Investment in carer training and more respite care,
- Encouraging and promoting carer-friendly employment practices, and
- Ensure better strategic planning and collaborative working.\(^9\)

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\(^5\) Ibid, page 16
\(^6\) Ibid, page 19-20
\(^7\) Ibid, page 6
\(^8\) Ibid, page 4
\(^9\) Ibid, page 4-5
2.1.2 Scottish Borders

As required by the Community Care and Health (Scotland) Act 2002 NHS Borders has a Carer Information Strategy.\(^{10}\) It states that it ‘builds on the good work already being achieved in the Borders and seeks to further develop and support carers throughout the NHS service design and delivery process’.\(^{11}\)

Key aims of the strategy are:

- Identifying hidden carers,
- Providing carers will information at all stages, including about carers’ assessment,
- Providing carer awareness training for NHS staff, and
- Recognising young carers as a distinct group who are first and foremost children and young people.\(^{12}\)

2.2 Carers - Drugs and Alcohol

2.2.1 Drugs

The Road to Recovery\(^ {13}\) identifies supporting families affected by drug use as one of its key priorities.\(^ {14}\)

The strategy recognises that families play an important role in treatment, care and support for drug users but that such a level of intensive commitment can have a big impact on them; making the provision of support for the families vital.\(^ {15}\) The strategy identifies the Scottish Network for Families Affected by Drugs (now Scottish Families Affected by Drugs) as a group whose work in this area the Scottish Government supports.\(^ {16}\)

The National Treatment Agency (NTA) guidelines on clinical management of those who misuse or are dependent on drugs\(^ {17}\) recommends that carers of those with substance misuse problems should be offered specific information and advice on safe storage of medicines and on the risks from blood-borne viruses and overdose.


\(^{11}\) Ibid, page 8

\(^{12}\) Ibid, pages 9-10

\(^{13}\) Scottish Government (2010)

\(^{14}\) Ibid, page 8

\(^{15}\) Ibid, page 31

\(^{16}\) Ibid, page 32

\(^{17}\) National Treatment Agency (2007) *Drug misuse and dependence: UK guidelines on clinical management.*
and, if appropriate, should be offered vaccination against infection such as hepatitis B.\(^{18}\)

The guidelines recommend that clinicians;

- Make themselves accessible to family members and carers with the consent of the patient,
- Assess and take account of the needs of family members and carers, including the welfare of dependent children, siblings and vulnerable adults,
- Provide verbal and written information and advice on the impact of drug misuse and about treatment and the settings in which it may take place,
- Provide information about self-help, group and individual support for families and carers, and
- Consider family or couples-based interventions.\(^{19}\)

### 2.2.2 Alcohol

The Scottish Government Alcohol Strategy\(^{20}\) refers to the problem of parental substance misuse. The main focus is on identifying those children and improving assessment and communication between services where they are concerned. SIGN 74 is the clinical guideline for those in primary care in Scotland who are dealing with patients who may have an alcohol problem.\(^{21}\) The guideline recognises that the person's drinking can have an effect on the family and that, as a result, family members can suffer from anxiety, depression or alienation and reduced earnings and the extra cost of purchasing alcohol for the patient can impact on them financially. The guidance sets out a list of treatments that have proven effectiveness includes counselling and therapy for the family.\(^{22}\)

### 2.2.3 Drugs and Alcohol

The Scottish Government Carers strategy makes specific reference to carers of those who misuse substances. Action Point 8.1 of the strategy states that;

\textit{From 2010 onwards, the Scottish Government will promote this strategy with Alcohol and Drug Partnerships (ADPs) and with the Scottish Drugs Recovery Consortium.}

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\(^{18}\) NTA (2007) page 23  
\(^{19}\) Ibid, page 23  
\(^{20}\) Scottish Government (2009)  
\(^{22}\) Ibid, page 22
(SDRC) and will work with ADPs and with the SDRC to help identify and support
carers of people with substance misuse problems’.

Related to that action point the Government is looking to ADPs to engage with
community planning groups to secure the best outcomes for the substance misusers
and their carers and family. The Government recognises that these carers and
families can make an important contribution to the person’s recovery and so carers
are an important part of the recovery agenda.23 The strategy recognises that this
group may not self-identify because of the potential stigma attached to it.24

The National Quality Standards for Substance Misuse Services25 Standard
Statement 10 says that ‘services will recognise the needs of members of your family,
and those you live with and, where appropriate seek support for them’.26 This
requires services to provide the family with information on services where they can
get help or even, with the person’s permission, to arrange a referral to such a
service.27 Services are expected to meet these standards although there is no
national accountability process28

2.3 Carers - Mental Health

The Scottish Government’s mental health policy29 sets out aim to improve the quality
of life for the mentally ill and their carers and plan to campaign to improve social
attitudes towards these groups.30 It also states that improving support for carers is a
national priority of the Scottish Government.31

2.4 Key findings

• A commitment to identifying and addressing the needs of carers is contained in a
range of national and local strategies

______________________________
24 Ibid, page 56
26 Ibid, page 9
27 Ibid, page 21
28 Ibid, page 13
30 Ibid, page 41
31 Ibid, page 21
CHAPTER 3: PREVALENCE AND CARERS’ NEEDS

This chapter considers the information available on prevalence of carers and carers of those with substance misuse problems in Scotland. It also looks at the evidence to identify the particular needs of carers in relation to service provision. In order to do this it has been necessary to look at evidence from the whole of the UK. This report excludes evidence primarily focussed on parental substance misuse and child protection but does include evidence on information and involvement in treatment for the substance users insofar as it impacts on the carer’s own wellbeing.

3.1 Prevalence

The Scottish Government estimates that there are 657,300 carers in Scotland which is 1 in 8 of the population. It is also estimated that 110,000 of these carers provide over 50 hours of care per week. For Scottish Borders this is estimated by Scottish Government to be approximately 12502 people.

Carers UK estimates, based on 2001 census, that there are nearly 6 million carers in the UK, which is 12% of the adult population, and 1.25 million provide over 50 hours a week of care. It is estimated that 6% of these care for someone with a mental disability.

The NTA has estimated that as much as 17% of the UK population may be affected by another family member’s substance misuse.

A study in 2009 by the UK Drug Policy Commission (UKDPC) also devised a method for estimating the number of people affected by this issue. They found that there are 140,593 adult family members of drug users who are in drug treatment in the UK and 6,564 in Scotland. There were a number of methodological limitations of this study but three issues stand out. Firstly, obviously not all of these family members will be providing care for the substance user so it is not an estimate of carers.

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33 Ten Facts about Caring in Scotland, found at: http://www.carersscotland.org/Aboutus/AboutCarersScotland/TenfactsaboutcaringinScotland
34 Scottish Gov and CoSLA (2010), Appendix 6
36 Carers UK (2009),
38 Partners, parents, siblings and others.
Secondly, the data used for UK calculations were derived from total numbers of drug users in treatment in England. In Scotland, Wales and Northern Ireland the figures were derived from number of new notifications in 2007/08. In Scotland there were 10,248 new notifications in 2007/08 which is less than half of the total number of people in treatment. The number of family members of people with drug problems is more likely to be in excess of 14,000 (based on 22,000 people in treatment)\(^40\). In Borders there are approximately 200 people in drug treatment. Using the UKDPC calculation this would equate to approximately 130 family members. Furthermore, it does not include family members of those with alcohol problems. If a similar calculation were made with regard to the number of people in alcohol treatment in the Borders (n=535), the number of family members (alcohol) would be approximately 340.

The UKDPC report also estimates that there are 1,443,774 adult family members of problem drug users in the general population, 134,338 in Scotland.\(^41\) Across Scotland, carers of those with mental health problems provide 21 million hours of care per week, saving the Scottish Government £376 million per year.\(^42\)

### 3.2 Identifying the needs of carers

This section considers the needs of carers. An important point to note when considering this information is that the impact felt by carers is highly individualised; no two carers will experience exactly the same situations and emotions.\(^43\)

#### 3.2.1 Health

Caring can lead to physical and psychological problems, usually caused by the massive stress and strain carers are under.\(^44\) Specific conditions highlighted by the Effective Interventions Unit included depression, anxiety disorders, heart problems and stomach problems.\(^45\)

Three quarters of carers say their own health is worse because of their caring responsibilities.\(^46\) Carers UK’s analysis of 2001 census statistics showed that those

\(^{40}\) Reducing Harm, Promoting Recovery (2008) Scottish Government
\(^{41}\) UKDPC (2009) page 16
\(^{42}\) Audit Scotland (2009) *Overview of Mental Health Services*, page 29
\(^{43}\) Effective Interventions Unit (2002) *Supporting families and carers of drug users: A review*, page 12
\(^{44}\) EIU (2002), page 10 and Carers UK (2009), page 3
\(^{45}\) EIU (2002), page 10
\(^{46}\) *Ten facts about caring in Scotland*
caring for more than 50 hours a week are twice as likely to be in poor health (21% to 11%) and twice as likely to be ‘permanently sick or disabled’ as a result.\textsuperscript{47} 

The Scottish Borders carers strategy itself notes that one analysis of the health of Scottish carers had found the Scottish Borders had one of the largest gaps between the health of carers and non-carers.\textsuperscript{48} 

A study in America found that family members of people with an alcohol or drug dependence disorder were more likely to be diagnosed with depression, substance use disorders and trauma than family members of people with diabetes or asthma and to have higher healthcare costs but the study did not determine the reasons why this was and the authors admit there may be genetic and environmental contributory factors.\textsuperscript{49} 

\subsection*{3.2.2 Financial and other practical support}

Carers can often need a lot of help with financial and other practical issues, such as housing and employment.\textsuperscript{50} 

The financial impact can come about in a two main ways; lack of earnings and extra costs associated with caring. 

Trying to balance the role of carer with other responsibilities can make it difficult to work. Over 250,000 people in Scotland juggle caring with holding down a job.\textsuperscript{51} In the EIU study half of respondents said they had suffered problems at work such trying to keep it all secret, lack of concentration and having to take time off.\textsuperscript{52} One study quoted by Carers UK found that 1 in 5 carers had given up work or turned a job down because of their caring responsibilities.\textsuperscript{53} 

\begin{flushright}
\textsuperscript{47} Carers UK (2009), page 3  
\textsuperscript{48} Joint Scottish Borders Strategies Consultation Document, page 8  
\textsuperscript{50} ADFAM (2010), page 7  
\textsuperscript{51} Ten Facts about Caring in Scotland  
\textsuperscript{52} EIU (2002), page 11  
\textsuperscript{53} Carers UK (2009), page 4
\end{flushright}
Carers of substance misusers are not eligible for Carers’ Allowance unless the user has additional health problems or disability. Even when awarded the carers’ benefit is worth just £53.10 for a minimum of 35 hours - £1.52 per hour.

Three quarters of carers are struggling to pay utility bills and more than half are cutting back on food and heating to make ends meet. 72% are worse financially and 54% were in debt as a result of becoming a carer.

In terms of extra costs it can often be the family members who have to pay to get the person the treatment they should be getting under the NHS. Sometimes they will pay for the users’ drugs and drug debts as well as the additional costs of caring for dependents that arise.

### 3.2.3 Training and Information

Carers need good information to allow them to adequately care for the substance user and themselves, though this is of course subject to confidentiality between the patient and the treatment service. EIU interviews repeatedly found that a lack of information inhibited families from being able to best manage and cope with the circumstances.

There is a lack of awareness and recognition still amongst this group that they are carers, and about what services are available to help them.

There is also a need for training for carers. This training should comprise of drug/alcohol awareness as well as coping skills and strategies. Carers who have had training are able to manage their caring much better and feel less of a negative


55 Ten Facts about Caring in Scotland

56 Ten Facts about Caring in Scotland

57 Carers UK (2009), page 2

58 ADFAM and Drugscope (2009), page 4

59 EIU (2002) page 11 and UKDPC (2009), page 23

60 NTA (2008), page 11

61 NTA (2007), page 17

62 EIU (2002), page 43


64 Kelly (2007) page ix-x and EIU (2002) page 16
effect on their health.\textsuperscript{65} It is also mentioned by one study that training is also needed for health and social professionals to help them support carers better instead of contributing to an increase in their stress which can sometimes happen.\textsuperscript{66}

### 3.2.4 Family and Social impact

A caring situation can have a negative impact on family relationships. Almost all respondents to the EIU study felt that relationships with immediate family had been affected, resulting in arguments, tension and communications breaking down.\textsuperscript{67} This group of carers often experience problems around the issue of rights and responsibility for any children the substance misuser has which can make life more complicated for the carer.\textsuperscript{68}

There can be a massive social impact on the carer as well. They commonly suffer alienation by family and friends, are afraid to leave the drug user alone at home, have trouble coping with the demands of looking after dependants, feel like they are being talked about by others and have little energy to go out.\textsuperscript{69} They feel anger, shame, embarrassment\textsuperscript{70} and fear of social stigma.\textsuperscript{71} In one study staff in services identified unhappiness as one of the biggest impacts of familial drug misuse.\textsuperscript{72} Unless the user has additional health problems or disability the carer is not protected from discrimination by association as other carers are.\textsuperscript{73}

This stigma and discrimination can be exacerbated by other factors. Families can sometimes experience additional difficulties when the person they are caring for takes drugs as opposed to alcohol due to the element of illegality which leads to different levels of stigma and guilt.\textsuperscript{74} The situation can often be worse for those in


\textsuperscript{66} Kelly (2007), page x

\textsuperscript{67} EIU (2002), page 10

\textsuperscript{68} EIU (2002), page 19-21

\textsuperscript{69} EIU (2002), page 12

\textsuperscript{70} NTA (2008), page 12


\textsuperscript{72} UKDPC (2009), page 27

\textsuperscript{73} Blog by Drew Lindon, Substance Misuse Lead at Princess Royal Carers Trust on 24\textsuperscript{th} February 2010.

\textsuperscript{74} EIU (2002), page 14
Black and minority ethnic communities who can already feel exclusion from the community.\textsuperscript{75}

These factors strongly suggest that there is a need for different types of emotional support to this group.\textsuperscript{76}

\textbf{3.2.5 Service Provision}

In a report published in 2010 Adfam stated that there appears to be a lack of accessible services for carers to use.\textsuperscript{77} In one study quoted by Carers UK only a quarter of working carers felt they received adequate support and the majority said they needed at least one support service which they were not getting.\textsuperscript{78} The report noted that in some areas there were still no services which support the families specifically,\textsuperscript{79} as well as no mechanism for consistent review of family support services and their quality.\textsuperscript{80} Another study, conducted in Glasgow, found that in particular that there was not enough respite care.\textsuperscript{81} Adfam also questions the ‘approachability and effectiveness of a range of mainstream agencies and services’ (e.g. GPs, social services) in supporting these families.\textsuperscript{82}

Adfam’s consultation showed that families felt public services did not ‘Think Family’ – leading to them not recognising the needs of families and not sharing information intelligently.\textsuperscript{83} The Glasgow study also found that interventions provided by services for the carers were often not quick enough.\textsuperscript{84}

Adfam recognised that the services often have insecure funding which hampers their development of innovative and effective services.\textsuperscript{85}

\textsuperscript{75} ADFAM (2005) ‘We count too’ Good Practice Guide and Quality Standards for work with family members affected by someone else’s drug use, page 10-11
\textsuperscript{76} EIU (2002), page 16 and Kelly (2007), page ix
\textsuperscript{77} ADFAM (2010) ADFAM’s Manifesto for families: 5 key challenges for supporting families affected by drug and alcohol use, page 3 and Carers UK (2009), page 4
\textsuperscript{78} Carers UK (2009), page 4
\textsuperscript{79} ADFAM (2010), page 3
\textsuperscript{80} ADFAM(2010), page 5
\textsuperscript{81} Kelly, T (2007) Supported to Care? Carers’ views of services. Glasgow: Glasgow Caledonian University, page viii
\textsuperscript{82} ADFAM and Drugscope (2009) Recovery and Drug Dependency: a new deal for families, page 3
\textsuperscript{83} ADFAM(2010), page 6
\textsuperscript{84} Kelly (2007) page ix
\textsuperscript{85} ADFAM(2010), page 7
The report by EIU concluded that a range of appropriate support options is needed in recognition that all carers are different.86

3.3 Key findings

• The number of family members affected by drug and/or alcohol use in Borders is likely to be in excess of 400.

• There is consistent evidence from a range of sources in the UK and abroad that sets out the needs of carers
CHAPTER 4: GOOD PRACTICE IN CARER SUPPORT

This section sets out elements of good practice aimed at addressing the needs identified in chapter 3 above. Evidence is drawn from across the UK.

4.1 Provision of services

In 2008, the NTA set out what it believes a family and carer service should look like. It recommends a variety of interventions which include:

- Information and advice (substance misuse specific)
- Practical support (non-substance misuse specific e.g. housing, money)
- Support groups accessible to all kinds of carers
- One-to-one support (outreach and centre based)
- Services available for whole family to work through issues together
- Respite provision
- Training for carers (e.g. harm reduction, overdose).

Evidence suggests that single interventions are not really effective; what works is good quality mainstream services and professionals across those services that are sensitive and carer-aware. Also important is joint strategic planning between health, local government and voluntary organisations. The Scottish Recovery Network study suggests that carers don’t feel valued and recognised by formal services and that co-working between those two sources of support can assist the recovery from mental health problems.

Adfam suggests that if we want families to provide such a massive resource for those who are recovering we must also invest in services to support them too. Services for families are often linked to services for the drug user – it is important that this link is broken and family members get services in their own right which would continue even if they disengage from the drug user or vice versa, this is actually a situation when they most need help. NTA also suggests that assessments in family and carer services should minimise as much as possible the discussion of the user, and instead should focus in on the carer’s needs. They also

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87 NTA (2008), page 13
89 Parr (2009), page 19
90 Parr (2009), page 5
91 ADFAM and Drugscope (2009), page 7
92 ADFAM and Drugscope (2009), page 8
93 NTA (2008), page 14
say a key principle of carer services should be that they reflect and draw on family members and carers’ own experiences and expertise.\textsuperscript{94}

The EIU set out 3 principles for effective Family Support:

- The prime focus of family support should be to address the needs of the family and the carer.
- Family support services should be open, accessible and non-judgmental.
- Families and carers should be involved in assessing needs and designing services.\textsuperscript{95}

### 4.2 Information and Training

Adfam and Drugscope believe a valuable first step in the provision of information would be the production of resources just for carers.\textsuperscript{96}

For those who care for a person on opiates this may include training to avoid, recognise and deal with overdose situations.\textsuperscript{97} They also need health information adequate for them to protect themselves, for example if the user has a blood borne virus such as HIV or hepatitis.\textsuperscript{98}

Issues that should be addressed in any staff training and development are negative perceptions of carers, staff worries over workload, lack of knowledge on carer support and holistic family approaches.\textsuperscript{99}

There are also training needs for staff and carers around confidentiality, such as,

- Is the cared-for person capable of giving consent?
- What can professionals divulge to the carer?
- When does the carer’s need for support conflict with confidentiality?\textsuperscript{100}

Coping skills training has been found to be beneficial, particularly with parents, and has shown improvement in the parents’ coping skills, family communication and frequency of assertive coping behaviours.\textsuperscript{101}

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\textsuperscript{94} NTA (2008), page 13
\textsuperscript{95} EIU (2002), page 73
\textsuperscript{96} ADFAM and Drugscope (2009), page 5
\textsuperscript{97} NTA (2007), page 72
\textsuperscript{98} EIU (2002), page 17
\textsuperscript{99} NTA (2008), page 11
The EIU guidance stated that the ability to manage stress better and learning to be more assertive would assist the carers with coping and help their self confidence.\textsuperscript{102} NTA identifies a number of resilience processes and factors which can help a family’s response – e.g. planning and coping strategies, problem solving skills, ability to deal with change – NTA suggests that carers’ services should incorporate these sorts of measures to help increase resilience.\textsuperscript{103}

4.3 Emotional Support

Examples of the types of emotional support that carers would benefit from include local family support groups, counselling and telephone helpline services.\textsuperscript{104} Family support groups are ‘consistently highly valued by carers as a way of sharing experiences and providing mutual support’.\textsuperscript{105} How local the support is often important to carers as it suggests a greater awareness of what types of services and supports are available locally and provides a level of familiarity.\textsuperscript{106} Scottish Recovery Network found that carer support groups were an ‘an essential point of knowledge transfer and key to promoting recovery-based practice’.\textsuperscript{107} There is evidence that family members attending an Al-Anon group specifically for them became more independent.\textsuperscript{108}

In 2009 Adfam and Drugscope reported that ‘...availability and nature of [family support] services varies from place to place, but many of these local groups are becoming increasingly sophisticated, providing a robust evidence base that testifies to the demand for, and effectiveness of, family support’.\textsuperscript{109}

4.4 Practical Support

Suggestions of practical support which should be provided include advocacy, befriending, assistance with child care and stress management methods such as complementary therapies.\textsuperscript{110}

\textsuperscript{101} UKDPC (2009) page 35
\textsuperscript{102} EIU (2002) page 41
\textsuperscript{103} NTA (2008), page 12
\textsuperscript{104} EIU (2002), page 16
\textsuperscript{105} Support in Mind Scotland (2010) ‘It’s their job – it’s my life’, page 8
\textsuperscript{106} EIU (2002), page 37
\textsuperscript{107} Parr. H (2009), page 5
\textsuperscript{108} UKDPC (2009), page 35
\textsuperscript{109} ADFAM and Drugscope (2009), page 3
\textsuperscript{110} EIU (2002).page 16
Advocacy services, which help the carer access services and to understand their rights, can empower the carer and increase their self confidence. The advocacy work should be structured and set up to ensure good practice and consistency of support.\textsuperscript{111} The coalition of carers in Scotland states that access to an advocacy service is provided in only 3 areas in Scotland.\textsuperscript{112}

4.5 Respite

Carers UK reports that ‘research has found that those not receiving a break were far more likely to suffer from mental health problems, 36\% compared to 17\% of those carers getting a break’.\textsuperscript{113} Respite increasingly being recognised as useful for this group, especially where the carer has taken on care of children as well.\textsuperscript{114}

4.6 Five-Step intervention

UKDPC identified 5-step intervention as a way of reducing the family’s stress symptoms and improve their coping responses. A recent study has also shown a brief version of this along with a manual to be just as effective as the full intensive course.\textsuperscript{115} It is helpful for identifying carers and their needs because it is for use by primary care professionals who come into contact with family members for a range of other matters (see 3.2.1).\textsuperscript{116}

This intervention is comprised of 5 different components;

- Listening to and reassuring the family member,
- Providing targeted information,
- Discussing ways in which the family member interacts with the user,
- Exploring social support available and,
- Identifying any further needs for support or access to services.

Five-step is the main evaluated intervention model for families discussed in the UKDPC report.\textsuperscript{117}

\begin{thebibliography}{99}
\item \textsuperscript{111} EIU (2002), page 39
\item \textsuperscript{112} Coalition of Carers in Scotland (2010), page 3
\item \textsuperscript{113} Carers UK (2009), page 3
\item \textsuperscript{114} EIU (2002), page 38
\item \textsuperscript{115} UKDPC (2009), page 34
\item \textsuperscript{117} UKDPC (2009) page 34
\end{thebibliography}
4.7 Key Findings

- There is consistent evidence of the effectiveness of a range of interventions available to meet these needs
CHAPTER 5: EXAMPLES OF GOOD PRACTICE

This section provides summary examples of services in which these principles have been implemented. It sets out examples identified from the review of literature as well as reports on field visits conducted.

5.1 Examples from the literature

5.1.1 North United Communities (Glasgow) – Family/Carer Support

Available for families who are affected by substance misuse within Glasgow North CHCP, NUC aims to adopt a holistic approach to supporting families affected by addiction. The project works in partnership with families to assess their needs and identify the issues that are affecting them.

A family/carers support worker provides support to families referred to the service. It is anticipated that the role will enhance current service provision by enabling greater co-ordination of existing resources to provide an anticipatory support service.

They provide support by carrying out assessments of families/carers to identify the issues that require to be addressed and what supports can be accessed to meet these. A clear referral system is in place to assist agencies and organisations to understand the services on offer and how these can be accessed.118

5.1.2 East Ayrshire Carers Centre

This project was set up to tackle the lack of provision for young carers affected by parental substance misuse which was identified in the East Ayrshire area. East Ayrshire Council and the local Carers Centre developed a range of supports to allow this group to access individual and group based support, training and education programmes, leisure and social activities, financial assistance, information and advice, and short breaks. The project agreed referral pathways with social work and educational services.

The group benefit from inclusion in mainstream services and specific services for young carers. They value the information and advice made available to them. The project ensures that young carers are supported by the relevant agency while also helping them to carry out their caring role effectively and appropriately to their age, needs and circumstances.

There has been external evaluation of this service which had positive findings. The young people report feeling better about themselves and having a reduced sense of isolation and stigmatisation.\textsuperscript{119}

\textbf{5.1.3 Glasgow Association for Mental Health (GAMH) – Carers Support Service}

This service aims to equip people in Glasgow who care for someone with mental health problems with the tools, skills and knowledge essential to support themselves in their caring role and to reduce isolation experienced by mental health carers. It also works with BME mental health carers and other excluded groups.

The intention is to give them more knowledge, awareness and understanding of mental health issues and recovery and to increase their confidence in communicating with service providers and service users, while at the same time being aware of their rights as a carer. All carers participate in the partnership assessment tool which enables GAMH to personalise their support to the carer’s individual journey of recovery.\textsuperscript{120}

\textbf{5.1.4 National Schizophrenia Fellowship (Scotland) Prospect}

This project delivers a programme developed by the European Federation of Associations of Families of People with Mental Illness (EUFAMI). Carers of those experiencing mental illness have the opportunity to meet with others when they are able to look at the issues that are relevant to them directly.

The programme is delivered by four facilitators, who are all carers in their own right, to approximately 15 carers during a residential weekend in a group setting with a follow up weekend five months later. Together they explore how to ‘recover’ their own lives as carers. They look at recognising the pressures, identifying and acknowledging stress, loss and grief resolution, coping skills, support mapping, and change and goal setting.\textsuperscript{121}

\textbf{5.1.5 NSF (Scotland) Dumfries and Galloway Carers Support Service}

This service, aimed at carers of adults experiencing mental illness, provides flexible and skilful person-centred support and facilitates carers’ peer support groups. It provides information on diagnosis and mental health care systems, and how to use them. It gives out information on support systems that are in place to support them

\textsuperscript{119} Scottish Government (2010) \textit{Good Practice}, page 37-38

\textsuperscript{120} Scottish Government (2010) \textit{Good Practice}, page 11-12

\textsuperscript{121} Scottish Government (2010) \textit{Good Practice}, pages 19-20
and provides help to make the best use of these services. The service works closely with the health and social service agencies, the Princess Royal Trust for Carers, and carers.\textsuperscript{122}

\textbf{5.1.6 Tayside Carers Support Project - Liaison and Collaboration Initiative}

This initiative with the Mental Health Service Hospital for Dundee (Carseview Centre) was implemented in 2003 in order to improve communication between carers and staff, to bring about positive tangible benefits for both carers and service users. It is available for anyone who cares for a relative or a friend with a severe and enduring mental illness such as bi-polar mood disorders, schizophrenia, severe depression, or personality disorders that lives within Dundee City.

There is ongoing fostering and commitment of senior managers to open honest communication and dialogue between service providers and carers. Overall, all of the changes implemented are extremely beneficial for carers as well as service users.\textsuperscript{123}

\textbf{5.1.7 The Princess Royal Trust for Carers – Mental Health Development Worker}

Young carers attending the Scottish Young Carers Festival in 2009 highlighted the need for improved help in understanding and dealing with mental health issues. In response, the Scottish Government has funded a young carers Mental Health Development Worker, who has been appointed by the Princess Royal Trust for Carers in Scotland.

The Development Worker will have the dual role of developing accessible information for young carers on mental health issues and advancing a range of measures to enhance young carers’ own mental health and well-being.

The worker will liaise with mental health agencies, advocacy services, befriending organisations, NHS Boards and local authorities to develop a network of support for referrals to young carers’ services and from young carers’ services to other external agencies as required. The worker will raise awareness of young carers’ specific needs around mental health and well-being so that information being provided by mental health organisations and others, including NHS and local authority services is tailored to their needs.\textsuperscript{124}

\begin{flushleft}
\textsuperscript{122} Scottish Government (2010) \textit{Good Practice}, page 19
\textsuperscript{123} Scottish Government (2010) \textit{Good Practice}, page 29
\textsuperscript{124} Scottish Government (2010) \textit{Good Practice}, page 41
\end{flushleft}
5.2 Visits to projects

Visits to four family support projects across Scotland were made with the aim of identifying examples of good practice that could be adapted in the Borders.

Services were asked the following questions:-

- How was the service established?
- What support did they offer families?
- How were they funded?
- What were the challenges faced?

5.2.1 Lighthouse Foundation in Kilmarnock

The Lighthouse Foundation is stand alone specialist family support service initiated by carers themselves. Members of the local peer support group recognised the complexity of their needs could not be supported by peer support alone, and progressed to push their group into becoming services that could address their needs. The service offers;- 

- Emotional support,
- Information about addiction and other specialist services that can help carers,
- Practical advice for example regarding financial and housing issues,
- Peer support groups,
- Training course relevant to the issues carers were challenged with,
- Social respite,
- Provide a link to other helpful services such as services that provide support with benefits and housing issues,
- Supporting carers whose family member was in prison,
- A service dedicated to supporting children affected by substance misuse,
- Specialised service supporting bereaved families.

The project used a range of different ways to engage with carers: face to face on an individual basis, support groups, drop-in facilities, home visits, telephone and on-line contact.

The project highlighted funding as being a major issue, of increasing relevance in this current economic climate, with some having to reduce supports offered due to insufficient funding. Funding was sought from Health and Social Care budgets, Big Lottery and other charities alongside the project fund raising events.
5.2.2 **Stirling Family Support Services**

SFSS is another stand alone family support service, which was created by carers themselves. The service offers similar support to the service above and is delivered in the same way. Funding was sought from Health and Social Care budgets, Big Lottery and other charities alongside the project fund raising events.

5.2.3 **West Lothian Drugs and Alcohol Services (WLDAS)**

WLDAS family support service is attached to a drug and alcohol specialist service. This service was initiated due to contact addiction workers had with carers via their service users. The service was funded by Health and Local Authority. The budget to provide this service had decreased dramatically in the past 2 years resulting in a reduction of the support and how it is delivered. They are now currently offering:

- Emotional support (with limited one to one capacity),
- Information about addiction and other specialist services that can help carers,
- Signposting for practical advice for example regarding financial and housing issues,
- Peer support groups (which have reduced from 6 groups to 2 due to funding issues).

5.2.4 **Vocal**

Vocal is a generic carer’s organisation in Edinburgh which provides a specialist service for those affected by substance misuse issues. Again this service was initially developed by carers themselves. Staff at Vocal have undergone training in substance misuse and treatment approaches in order to provide a specialised service. They have also fostered closer links with their local addiction services and are actively involved and are readily considered as a means of support for the service users’ carers. Our local carers centre lack the training and knowledge required to provide the same level of service as Vocal. The project deliver their service in a range of different ways: face to face on an individual basis, support groups, drop-in facilities, home visits, telephone and on-line contact. The support they offer was:

- Emotional support,
- Information about addiction and other specialist services that can help carers,
- Practical advice for example regarding financial and housing issues,
- Peer support groups,
• Training course relevant to the issues carers were challenged with,
• Social respite,
• Provide a link to other helpful services such as services that provide support with benefits and housing issues,
• A service that offered support families who were visiting their family member in hospital due to substance misuse,
• Family therapy.

Again this project had a number of funding streams.

5.2.5 Challenges identified during visits

All the projects highlighted funding as being a major issue, of increasing relevance in this current economic climate, with some having to reduce supports offered due to insufficient funding.

Stigma and the fear of being recognised were identified by all projects as a major barrier for carers to accessing support. Projects identified that protecting carers anonymity was important, advocating that they should not be located in the same building as drug and alcohol services.

The focus for these projects was on the carer and the person misusing substances. They were not advocating carer involvement with treatment services but instead their aim was to build carers resilience with coping with the affects of someone substance misuse.

5.3 Key findings

• Generic carers' services are well-placed to provide support for those affected by substance misuse as they can provide the necessary support and access relevant advice and information more readily. However, they do need to have knowledge and understanding of substance misuse issues.

• Projects felt that for carers to be truly supported there has to be a long term financial commitment from funders to enable a robust service to be developed.

• Services must be able to cope with a complex range of needs and careful consideration should be given to the location of the service.
CHAPTER 6: NEEDS OF CARERS IN BORDERS

6.1 Introduction

The purpose of this chapter is to identify the stated needs of families and friends of individuals misusing substances. The data has been gathered from two surveys conducted in Borders: family and friends’ survey and service provider survey. The term ‘Carers’ is used throughout this section to refer to family members and friends. Similarly, service providers are referred to as ‘Providers’. This chapter identifies concerns that carers have for the health and wellbeing of the substance user as well concerns that they have for their own health and wellbeing.

6.2 Relationship to substance user

The carers’ survey revealed that the majority of respondents were partners (36%) and parents (34%) of substance users. A smaller number of children, siblings and step parents also responded (14%, 5% and 5% respectively). Other respondents included one friend, one ‘facilitator’ and one ex-wife.

Similarly, Providers were asked what relationship carers have with their clients who are misusing substance. Their responses revealed a similar pattern to that of the carers’ survey; the majority stated that they see parents and partners (56% and 44%) while a minority stated that they see siblings, children, friends and grandparents (20%, 18%, 14% and 4% respectively).

It is not clear from the data whether the term ‘Children’ refers to young people or adults caring for elderly parents. However, as the target group for the questionnaires were adult carer groups, it is assumed that the 14% referred to by carers and providers are adults caring for an older parent.

6.3 Primary concerns of carers

According to the carers’ survey, the majority of respondents (41%) stated that alcohol misuse was the main problem and 23% stated that it was drug misuse. One third of respondents (34%) stated that both alcohol and drugs were the problem.

Service Providers also provided similar responses where one third (33%) stated that alcohol issues in service users require most of their time and support. A quarter of respondents (24%) stated that drug issues require most of their time while over one third (38%) felt this was true for both alcohol and drug issues. The remainder (5%) did not answer.
Carers were presented with a list of questions and asked to tick any that they felt applied to their situation. These questions along with carers’ responses are displayed in the table below.

**Table 6.1: Carers concerns/needs**

<table>
<thead>
<tr>
<th>Questions</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much should I put up with before saying NO MORE?</td>
<td>37 (N=44)</td>
</tr>
<tr>
<td>How can I cope with their behaviour?</td>
<td>36 (N=44)</td>
</tr>
<tr>
<td>How do I stop them taking alcohol and drugs?</td>
<td>35 (N=44)</td>
</tr>
<tr>
<td>What can I do to help?</td>
<td>35 (N=44)</td>
</tr>
<tr>
<td>What harm is the alcohol or drugs doing?</td>
<td>34 (N=44)</td>
</tr>
<tr>
<td>Where do I go for help?</td>
<td>34 (N=44)</td>
</tr>
<tr>
<td>Am I to blame for their drug and alcohol use?</td>
<td>26 (N=44)</td>
</tr>
<tr>
<td>What would I do if they overdosed?</td>
<td>23 (N=44)</td>
</tr>
<tr>
<td>What drugs have they taken?</td>
<td>22 (N=44)</td>
</tr>
<tr>
<td>How can I tell if they have taken drugs?</td>
<td>19 (N=44)</td>
</tr>
<tr>
<td>What if people find out?</td>
<td>14 (N=44)</td>
</tr>
</tbody>
</table>

It can be seen from the table that the majority of respondents were affected by at least 9 of the 11 issues that were presented to them. In particular, over 80% were worried about themselves in terms of ‘how much they have to put up with’ and how they can cope with the substance users’ behaviour. Additionally, over three quarter of respondents were concerned about the substance user in terms of the harms of alcohol/drugs and what they can do to help. Over half were concerned about issues of overdose, types of drugs taken and if they were to blame for the use of substances. Less than half were concerned about how to tell if a person had taken drugs or about what would happen if people found out.

As mentioned previously, the majority of responses came from parents and partners. (Cross tabulation) analysis revealed that parents and partners were most likely to worry about what drugs SUs have taken, whether they will overdose, whether they are to blame for SU misusing substances and whether people will find out.

Carers were asked if they have concerns for their own health and wellbeing as a result of coping with the effects of someone else’s substance misuse. They were presented with a list of issues and asked to tick any that apply; their responses can be seen in the table below.
Table 6.2: Impact on carers due to someone else's substance misuse

<table>
<thead>
<tr>
<th>Concerns</th>
<th>Number (N=44)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your Emotional Health</td>
<td>37</td>
<td>84%</td>
</tr>
<tr>
<td>Family Relationships</td>
<td>33</td>
<td>75%</td>
</tr>
<tr>
<td>Money Issues</td>
<td>24</td>
<td>55%</td>
</tr>
<tr>
<td>Your Physical Health</td>
<td>23</td>
<td>52%</td>
</tr>
<tr>
<td>Work</td>
<td>15</td>
<td>34%</td>
</tr>
<tr>
<td>Housing Issues</td>
<td>14</td>
<td>32%</td>
</tr>
<tr>
<td>Legal Issues</td>
<td>9</td>
<td>21%</td>
</tr>
</tbody>
</table>

It can be seen that the majority of respondents were worried about how the substance user affects their emotional health and family relationships. Just over half were concerned about their own money issues and physical health while one third showed concern about their own work and housing issues. Just under a quarter were worried about their legal issues.

The majority of the above responses regarding self concerns came from parents and partners of substance misusers.

Cross tabulation analysis indicate that there is no relationship between the type of substance used by substance users and the concerns that carers have about themselves. In other words, these concerns were felt equally by carers of alcohol users and carers of drug users.

6.4 Employers’ perceptions of needs of carers

The Healthy Working Lives Service (which aims to improve the health of employees) provided support for this study by inviting local businesses to participate. Twenty-seven businesses were approached to participate in the study, but only seven responded. However, this included NHS Borders and Scottish Borders Council - two of the largest employers in the Borders. The remaining five businesses were located within Roxburghshire and Selkirkshire. The aim of the survey was to identify:

- If employers are aware of employees being affected by drug or alcohol problems within their families
- What impact this has on employees
- How this impacts on employers
- How employers respond
6.4.1 Awareness of the issue

Three of the seven businesses had identified that this was an issue for their staff, or felt that they had supported employees affected by someone’s alcohol and/or drug misuse. The number of employees involved in the past year varied:

- NHS Borders had seen approx. 100 employees who had been affected by this issue alongside a multitude of other concerns.
- Scottish Borders council were unable to quantify.
- The smaller business had supported 1 carer solely for this issue.

6.4.2 Impact on employees and employers

Employers identified the negative impact on family relationships as well as noting that carers often suffer from poor emotional health which reflects on the quality of work, absence from work and has an impact on their finances.

Most employers stated that they try to assist their employees by signposting them onto services which they felt would be able to offer support, the large employers also offered individual support or have been able to refer employees direct to a services which may be able to provide additional support.

A list of potential sources of help was provided (including family support networks, employers support service, psychological support services and specialist drug and alcohol services). Most employers were aware of Al-non and some specialist drug and alcohol services, but awareness of where else such help might be accessed was limited.

6.5 Key findings

- Most carers described themselves as either partners or parents
- Most identified difficulty in dealing with the impact of an individual’s behaviour and not knowing how to help as being their biggest challenges
- Predominate concerns were with regard to the impact on their own emotional health and on family relationships rather than concerns over money, work, housing or legal issues
- These concerns were felt equally by carers of alcohol users and carers of drug users.
CHAPTER 7: AVAILABILITY OF SUPPORT FOR CARERS

7.1 Introduction
This chapter provides a detailed description of the types of support available to carers in Borders and what services have been accessed by them. Furthermore, it also discusses the extent to which carers and providers think these services are useful.

7.2 Services for carers
Provider respondents (N=79) were asked to estimate the number of carers that they have contact with. Half of respondents stated that they see between 1 and 50 carers, 17% stated that they see between 50 and 150, while a minority (6%) said that they see between 150 and 350 carers. A few respondents (4%) mentioned that they see over 350 carers. The rest of the respondents stated that they were unsure or did not provide an answer.

When providers were asked how many appointments are given to carers, the majority who responded (55%) stated that they give appointments as required. However, under a quarter (21%) stated that they do not give appointments to carers. A minority provided the specific numbers of appointments that they give to carers; 11% provide between 1 and 5 appointments per week while 8% provide between 5 and 15 appointments per week. The remainder (5%) provided other comments which included ‘ongoing contact ‘and ‘fortnightly appointments’

The providers were then asked how long their average appointments are and majority of responses (75%) suggested these were between 10 and 60 minutes. A minority of responses indicated that appointments last over 60 minutes while just under a quarter stated that the length of appointment varies.

Service providers were asked what ratio of their time is spent on carers compared to service users; their responses can be seen in the table below.
Table 7.1: Ratio of provider time given to substance users vs. Family members

<table>
<thead>
<tr>
<th>Ratio</th>
<th>Number (n=73)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>100% FM</td>
<td>7</td>
<td>10%</td>
</tr>
<tr>
<td>20% SU: 80% FM</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>50% SU: 50% FM</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>70% SU: 30% FM</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>80% SU: 20% FM</td>
<td>5</td>
<td>7%</td>
</tr>
<tr>
<td>90% SU: 10% FM</td>
<td>8</td>
<td>11%</td>
</tr>
<tr>
<td>95% SU: 5% FM</td>
<td>9</td>
<td>12%</td>
</tr>
<tr>
<td>98% SU: 2% FM</td>
<td>4</td>
<td>5%</td>
</tr>
<tr>
<td>100% SU</td>
<td>32</td>
<td>44%</td>
</tr>
<tr>
<td>other</td>
<td>3</td>
<td>4%</td>
</tr>
</tbody>
</table>

It can be seen from the table that half (52%) of those who responded to this question provide some level of support to family members. Amongst these, it can be seen that 10 services provide half or more than half their time to family members.

7.3 Service Availability and Accessibility

Over one third of carers mentioned that they have accessed support groups and one-to one-support from specialised organisations (39% and 34% respectively) to help them cope with someone else’s substance use. A smaller proportion stated that they have accessed psychological therapies and complimentary therapies from a private therapist (18% and 14% respectively) while a minority had accessed family therapy work and complimentary therapies from a specialised organisation (9% and 2% respectively). However, over one third (39%) stated that they had not accessed any services to help them cope with someone else’s substance misuse.

7.4 Providers’ views of support provision

Service providers were asked to tick the types of support that they provide regularly to carers or service users. The majority stated that they provide signposting and one to one support (86% and 77% respectively). Over half said that they provide information/training and telephone support (56% for both). A smaller proportion stated that they provide psychological therapy and support groups (15% for both). A minority stated that they provide complimentary therapies and family therapy networks (6% and 5% respectively).

Service Providers who provide these supports were asked to rate to what extent they thought that these are useful for carers. The table below illustrates their responses.
Table 7.2: Providers (N=79) ratings on how useful supports are for carers.

<table>
<thead>
<tr>
<th>Support Method</th>
<th>Very useful</th>
<th>Quite useful</th>
<th>Not useful</th>
<th>No Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Signposting (n=68)</td>
<td>51</td>
<td>9</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>One-to-one Support (n=61)</td>
<td>49</td>
<td>5</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Information/Training (n=44)</td>
<td>31</td>
<td>5</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Telephone Support (n=56)</td>
<td>28</td>
<td>12</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Psychological Therapies (n=12)</td>
<td>7</td>
<td>2</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Support Groups (n=12)</td>
<td>6</td>
<td>2</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Family Therapy Work (n=4)</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Complimentary Therapies (n=5)</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

It can be seen from the table that the majority of service providers considered signposting, one-to-one support, information/training and telephone support as being very useful methods of support for carers. Less than 9% of respondents considered psychological therapies and support groups as being very useful and there was virtually no support amongst providers for interventions such as family therapy work and complimentary therapies.

In addition to the list of support interventions above, several respondents mentioned other services that also provide support to carers of substance users; the majority (35%) were aware of Al-Anon and Quest. A smaller proportion mentioned Addaction, BCAT, The Big River Project and Face-to-Face (23%, 20%, 18% and 15% respectively). A list of all other services that were mentioned can be found in Appendix 1.

7.5 Carers’ perspectives on sources of support

Carers were asked where they obtained support to help them cope with someone else’s substance misuse; the table below demonstrates their responses.

Table 7.3: sources of support (N=44)

<table>
<thead>
<tr>
<th>Support Method</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist Drug/Alcohol Services</td>
<td>16</td>
</tr>
<tr>
<td>Family and Friends</td>
<td>17</td>
</tr>
<tr>
<td>Family Support Groups</td>
<td>12</td>
</tr>
<tr>
<td>GP Practice</td>
<td>15</td>
</tr>
<tr>
<td>Internet</td>
<td>7</td>
</tr>
<tr>
<td>National Telephone Help lines</td>
<td>5</td>
</tr>
<tr>
<td>Police</td>
<td>3</td>
</tr>
<tr>
<td>Domestic Abuse Services</td>
<td>1</td>
</tr>
<tr>
<td>Religious Groups</td>
<td>1</td>
</tr>
<tr>
<td>Local Chemist</td>
<td>1</td>
</tr>
</tbody>
</table>
The table indicates that over one third stated that they got support from family and friends, the GP practice and specialist drug/alcohol services (39%, 36% and 36% respectively) while 30% got support from family support groups. A smaller proportion found support from the internet and national telephone helpline (16% and 11% respectively) while a minority got support from the police, religious groups, local chemist and domestic abuse specialist services ( 7%, 5%, 2%, and 2% respectively).

A cross tabulation analysis was used to investigate any relationship between the type of substance abuse that carers have to deal with and the type of support that they have obtained. Those who were caring for a family member misusing alcohol (n=18) were most likely to go to family and friends, the GP and family support groups to get support. Those who were caring for a family member misusing drugs were most likely to go to specialist drug/alcohol services and the GP to find support. Finally, those who were caring for a family member misusing ‘both alcohol and drugs’ were most likely to family and friends, specialist drug/alcohol services, the GP and family support groups (respectively) to get support.

Carers were asked to rate to what extent that they found the above support mechanisms useful. These responses can be seen in the table below.

Table 7.4: Carers’ (N=44) ratings on usefulness of the support that they received

<table>
<thead>
<tr>
<th>Support Method</th>
<th>Very useful</th>
<th>Quite useful</th>
<th>Not useful</th>
<th>No Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist Drug/Alcohol Services (n=16)</td>
<td>12</td>
<td>3</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Family and Friends (n=17)</td>
<td>7</td>
<td>9</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Family Support Groups (n=12)</td>
<td>7</td>
<td>2</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>GP Practice (n=15)</td>
<td>6</td>
<td>6</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Internet (n=7)</td>
<td>2</td>
<td>5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>National Telephone Help lines (n=5)</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Police (n=3)</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Domestic Abuse Services (n=1)</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Religious Groups (n=1)</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Local Chemist (n=1)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

The table shows that specialist drug/alcohol services, family and friends, family support groups and GP practice received the most responses. The majority of those who used specialist drug/alcohol services found them to be very useful and a further three people rated them quite useful. It can be seen that majority of those who got support through ‘family and friends’, family support groups, and GP also found them useful.
7.6 Gaps in Services

Service providers and carers were asked to comment on any gaps in the availability of services and were also given the opportunity to provide additional comments. The majority of service providers (90%) agreed that there are gaps in services in their area while a minority (10%) felt there were no gaps.

Just over half (55%) of the carers provided additional comments. Most of those centred around having more support available for family and friends of substance misusers, reducing waiting lists for services and tackling the issue of stigma/attitudes towards substance misusers.

The majority (80%) of service providers also provided additional comments. Similar to the carers, nearly half were concerned about a lack of support network for families and friends of substance users and 22% felt that services need to provide increased support for family and friends as well as catering for the service users.

Just under a quarter (22%) of providers raised concern regarding the lack of awareness of what is available to carers; they felt that services need to do more to publicise what they offer and encourage carers to come along.

7.7 Key findings

- About half of services surveyed provide a level of support for carers although this is most often on an *ad hoc* basis rather than a structured, resourced provision.
- Over a third of carers (39%) stated that they had not used any support services
- Interventions most often accessed by carers were support groups and one-to-one support
- Interventions regarded by providers as being most effective were signposting, one-to-one support and information/training.
- The perceived benefits provided by support groups was much higher valued by carers than by providers
CHAPTER 8: CONCLUSIONS AND RECOMMENDATIONS

8.1 Conclusions

In most areas of health and community care carers are family members who fulfil a role of providing emotional, physical or social support to someone with a diagnosis of physical or psychological ill health.

In the substance misuse field there are a number of stigmatising factors which add to the difficulties carers experience. These include a perceived lack of illness, shame and/or embarrassment at what is often regarded as a ‘self-inflicted’ condition as well as the perpetual risk of overdose.

It is therefore reasonable to suggest that the provision of support to carers of drug and alcohol users should reflect, and be able to accommodate these needs and be assertively promoted in order to ensure that all carers that may wish to access help are able to do so in a safe and supportive manner.

There is a high level of compatibility, in terms of what should be available, between the strategies and policies at national and local level (Chapter 2), the evidence of carer needs (Chapter 3), effective practice in carer support (Chapter 4) and the views of carers and service providers in Borders (Chapter 6).

In particular, the consistency in findings between the research evidence of effective practice and the experiences of carers in Borders in terms of the supports that they have accessed and found to be useful provides a level of confidence that the recommendations set out here are not only evidence based but also locally relevant and applicable to the larger, hidden population of carers who’s voices have not yet been heard.

The strategies and policies consistently emphasise the need to identify hidden carers, provide information to carers, ensure that staff are trained to identify and help meet carer’ needs and be able to signpost carers to other types of support services.

The types of supports required by carers can be grouped under four main headings; health, finance, training & information and family & social. Whilst some of these can be provided by generic health and social care providers this should not detract from the provision of specific carer support services as a point of first contact as well as a provider of support in its own right.

Although it is the case that most carers accessing services in Borders are women, and this is consistent with other findings, the provision of support and routes of access to support should also take cognisance of the needs of male carers and the needs of carers of different age groups. This underlines the need to have, or to be able to access, a wide range of support options.
The terms *Carer aware* and *Family aware* were highlighted earlier in this report in the context of the remits and roles of treatment provider services. As a rule of thumb it would be reasonable for treatment providers to consider that for every 100 clients in their service there will be around 65 adult carers with their own needs. With regard to this services will need to consider the steps that they are currently taking to

- ensure that all clinical and reception staff are aware of the need to support carers and receive training in how this can be achieved;
- identify these carers and offer/arrange a carer’s assessment;
- provide information about the drug or alcohol, its effects and available treatment options; and
- engage meaningfully in their family member’s care including agreements to share information in line with the client’s consent.

Service providers in Borders do appear to have an awareness of some of the elements of effective practice set out in Chapter 4 and the vast majority highly rated the usefulness of interventions such as Signposting, One-to-one support, Information/training and telephone support however less than 9% had regard for the efficacy of interventions such as psychological therapies, support groups and family therapies; all of which have been shown to both effective and highly rated by carers.

Although a small number of carers in Borders indicated that they source support through remote means such as national helplines and the internet the vast majority use a local face-to-face means via drug and alcohol services, family and friends, family support groups and GPs. It would therefore be appropriate to consider how a wide range of support services can be accessed through three channels in Borders – specialist substance misuse services, family support groups and general practice. This is illustrated in Table 8.1 below.

**Table 8.1: Examples of routes of support**

<table>
<thead>
<tr>
<th>Channel</th>
<th>Access to</th>
<th>Provision of</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist Substance Misuse</td>
<td>• Support groups</td>
<td>• Information and Advice</td>
</tr>
<tr>
<td>Service</td>
<td>• Psychological therapies</td>
<td>• Family therapies</td>
</tr>
<tr>
<td></td>
<td>• Practical support</td>
<td>• Telephone support</td>
</tr>
<tr>
<td></td>
<td>• Carer’s assessment</td>
<td></td>
</tr>
<tr>
<td>Family Support Group</td>
<td>• Information and advice</td>
<td>• Practical support (finance, legal)</td>
</tr>
<tr>
<td></td>
<td>• Training for carers</td>
<td>• Peer support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Telephone support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Complimentary therapies</td>
</tr>
<tr>
<td>General Practice</td>
<td>• Respite provision</td>
<td>• One-to-one support</td>
</tr>
<tr>
<td></td>
<td>• Family therapies</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Psychological therapies</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Carer’s assessment</td>
<td></td>
</tr>
</tbody>
</table>
In order to support these, a number of recommendations are set out below for the consideration of Borders Alcohol and Drugs Partnership.

### 8.2 Recommendations

1) Outreach family support services should be developed to work with specialist substance misuse services, general practice and other health and social care providers in Borders to raise awareness amongst practitioners and clients of the availability of support for families and carers.

2) A review of the resources and structures of existing carers services should be undertaken to consider how best these can be utilised or strengthened to enable the interventions set out in this chapter to be delivered according to demand and in line with local and national policy.

3) A programme of awareness raising and training to be put in place for staff in NHS Borders and Scottish Borders Council in order to enable them to recognise carers and identify ways to support them in line with the remit of their organisation and their own role within that.

4) Discussions with service managers of substance misuse services and GP representatives within the Community Health Partnership regarding reviewing assessment procedures and information sharing protocols to ensure that, where appropriate, carers can play an active and informed role in the planning and delivery of care to family members with alcohol or drug problems.

5) Borders ADP to take the lead role in developing an action plan to support the implementation of these recommendations and review progress periodically.
APPENDIX: Services that providers are aware of who provide support to families of substance users

AA
ADDACTION
ADFAM
AL-ANON
ALCOHOL LIAISON SERVICE
APEX
BAPFO
BCAT
BIG RIVER PROJECT
BORDERS YOUNG CARERS
CHILDREN 1ST
DAAT
FACE-TO-FACE
FAMILY SUPPORT SERVICES
GP
LET'S TALK
MENTAL HEALTH TEAM
NEW HORIZONS
PENUMBRA
PRINCESS ROYAL TRUST BORDERS CARERS CENTRE
PROGRESS TO WORK
QUEST
SOCIAL WORK
TAKING STEPS
TALK TO FRANK
THROUGHCARE AND AFTERCARE