

Supporting Carers & Family Members affected by the Substance Misuse of Others



A Somerset Study

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Somerset Drug & Alcohol Action Team

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Chapter 1 Introduction

1.1 Background

In September 2006, the National Treatment Agency for Substance Misuse (NTA) published a guide entitled 'Supporting and involving carers'. The aim of this guide was to ensure that all Drug Action Teams (DATs) and Crime and Disorder Reduction Partnerships:

- Commission consistent, effective and quality services for carers and family members affected by someone else's drug use.
- Involve carers and family members effectively in their planning.

In September 2008, the NTA published further guidance on supporting and involving carers, targeted at substance misuse commissioning managers and joint commissioning group members within partnerships.

The NTA acknowledges that it does not work to tag carers' needs on to the needs of users. At times, the interests and needs of the two groups coincide, but they are often in conflict. Carers and family members have their own needs and focusing on these through the provision of dedicated support services will enable them to function more effectively and provide the opportunities for users to take responsibility for their own actions. Systems and processes designed for user involvement may well not work for carers – they need systems and processes that work for them.

1.2 Key Aims

In October 2008, the Somerset Drug and Alcohol Action Team (DAAT) commissioned Evidence Base Ltd to conduct an in-depth study in order to identify the support needs of carers and family members in Somerset. The evidence gathered from this study will enable the Somerset DAAT Partnership to plan the delivery of effective, quality support services that reflect the needs of carers and family members in the county.

The study sought to identify:

- The support needs of carers and family members and the types of services that they would like to access.
- Whether carers and family members have tried to access support services and, if so, their experiences.
- Whether carers and family members have tried to access a carer's assessment and, if so, their experience of this process.
- Whether carers and family members currently access support services and, if so, their experiences of these services.
- Whether there are gaps between carers and family members' service needs and current service provision.

- Existing carer support services in Somerset and the extent to which the support needs of carers and family members affected by someone else's substance misuse fit into existing services.

The study focuses on the support needs of adult carers and family members. The impact of family members' substance misuse on children and young people is covered in an earlier study entitled "Hidden Harm: Identifying a Way Forward for Somerset" (Collins, March 2008)

1.3 Key Objectives

The key objectives of this study were:

- To gather the evidence required to enable the Somerset DAAT and its partners to plan the delivery of effective, quality services to support carers and family members across Somerset.
- To conduct a series of consultation exercises in order to gather primary evidence of support needs in Somerset.
- To involve carers, family members, and other key stakeholders in identifying service needs in Somerset.

1.4 Methodology

A series of research methods were incorporated into this study in order to provide us with the depth and breadth of information required by the Somerset DAAT Partnership, including:

- A review of relevant national and local strategies and guidance.
- A survey of carers and family members in Somerset.
- Group discussions with carers and family members in Somerset.
- Face-to-face interviews and telephone discussions with staff from Turning Point Drug & Alcohol Treatment Service, Somerset County Council, Somerset Partnership NHS Foundation Trust, and Somerset Racial Equality Council.

1.5 Intended Outcomes

The findings from this study will support the work of the Somerset DAAT Partnership by improving our understanding of:

- The experiences and support needs of carers and family members affected by someone else's substance misuse problems.
- Carers and family members' experience of accessing (or trying to access) local services.
- Carers and family members' experience of accessing (or trying to access) a carer's assessment.

- Existing carers services in Somerset and whether they currently support carers looking after someone with substance misuse problems.

The evidence gathered in this study will enable the Somerset DAAT Partnership to plan and deliver quality services that meet the needs of carers and family members living in the county.

Chapter 2 Policy Context, Strategies & Guidance

There is a wealth of relevant national policies, strategies and guidance that provide a strong basis for commissioning support services for carers and family members affected by someone else's substance misuse, and involving carers and family members in planning services and the process of treatment. This chapter summarises key documentation.

2.1 National Drug Strategies

- 2.1.1 The **Updated Drug Strategy** (2002) provided the key policy directive for work in this field, in recognition of the fact that parents, carers and family members need support.

Support for parents and carers

Family members are usually the first to spot that a young person is having problems and the first to provide support, and can influence the success of any drug intervention their child receives. Parents are also a key group needing support in their own right, often experiencing enormous fear and concern and feeling they are dealing with problems alone. This situation cannot continue and the Government is committed to extending provision for parents and families.

The strategy calls for “more support for parents, carers and families so they can easily access advice, help, counselling and mutual support”.

- 2.1.2 **The 2008 Drug Strategy, ‘Drugs: protecting families and communities’**, sets out the Government's aims for the next ten years in drug treatment and prevention, which include objectives for meeting families and carers' needs. The strategy aims to address the needs of parents and children as individuals, as well as working with families to prevent drug use, reduce risk and get people in to treatment. It highlights the importance of making better use of family-oriented initiatives, including supporting family members to take on caring responsibilities, and involving carers and family members in service planning. The strategy calls for “a new package for families”, which includes supporting kin carers, such as grandparents, who take on care responsibilities for the children of substance-misusing parents; supporting and involving young people and their parents and carers more in the planning and process of treatment for young people; and involving carers' and users' groups in the design and planning of treatment services.

2.2 National Carers Strategies

- 2.2.1 Following the launch of the first national carers strategy **‘Caring about Carers’** in 1999, improving the lives of carers became a major policy issue and one of

the Government's key priorities. By recognising the important role that carers play in supporting family members, friends and wider society, the strategy began a journey towards improved support for all carers.

One of the principal actions to emerge from the strategy was the introduction of the **Carers Grant** to enable councils in England to increase the level of support that they provide to carers, particularly through the provision of planned breaks. Since its introduction in 1999, the grant (which stands at £224 million in 2008/9 and is due to rise to £256 million in 2010/11) has provided over £1 billion of additional support to local councils (Department of Health, 2008).

Caring about Carers also highlighted the importance of accurate, up-to-date and comprehensive information to support carers so that they can become better aware of their entitlements and relevant support available in their locality.

2.2.2 The 2006 White Paper "**Our health, our care, our say**" announced a **New Deal for Carers** made up of four parts:

- **A national information helpline and website, which will be launched in spring 2009.** Through one telephone number carers will access all the information they need directly, or be referred onto more appropriate support.
- **A training programme for carers called Caring with Confidence, which will inform carers of their rights and the services available to them and help develop their advocacy and networking skills.** The training will be available on a face-to-face basis from August 2008, and on a distance learning basis, from December 2008.
- **£25 million additional funding per year has been made available** to councils in England to provide emergency care cover.
- **A major review of the 1999 Carers' Strategy.**

2.2.3 Following the review of *Caring for Carers*, a new carers strategy was launched in 2008, entitled '**Carers at the heart of 21st-century families and communities "A caring system on your side. A life of your own"**'. The strategy recognises the increasingly important role that carers play in our society, alongside the wide variety of caring roles and the diversity of those within these roles. It acknowledges that carers need more help and support than has been available in the past.

The strategy's definition of carers **specifically makes reference to those caring for someone with substance misuse problems:**

Who are carers?

A carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.

The strategy notes that we also need to be aware that there are a significant number of carers who do not identify themselves as carers. This includes people caring for a family member or friend as a result of substance misuse, who often do not see themselves as eligible for carers services.

The strategy sets the following shared 10-year vision and responsibility between central and local government, the NHS, the third sector, families and communities:

By 2018:

- Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;
- Carers will be able to have a life of their own alongside their caring role;
- Carers will be supported so that they are not forced into financial hardship by their caring role;
- Carers will be supported to stay mentally and physically well and treated with dignity; and
- Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the *Every Child Matters* outcomes.

One of the key points raised in the strategy is the need for the various agencies responsible for providing care and support to work effectively, behind the scenes:

The carer should not have to piece together support from many ‘suppliers’ who seem very often to be working against each other and against the carer. Delivery of our vision will be characterised by carers feeling that not only are services working together but they are “on their side”.

2.3 Legislative Changes

Since 1999, there have been a number of legislative updates that further reinforce the development of support services for carers. The **Carers (Equal Opportunities) Act 2004** builds on previous carers legislation, placing a duty on all local authorities to inform carers who provide “regular and substantial care” of their right to a carer’s assessment. Depending on the outcome of this assessment, carers may be eligible to access a carers grant to enable them to take a break from caring and access services that can support them in their caring role.

The **National Service Framework (NSF) for Mental Health (1999)** built on carers legislation by requiring all services providing structured care to those with mental health needs, including dual diagnosis, to ensure that their carers receive an assessment and

are able to access support. This strand of the NSF has specific targets, milestones and funding attached to it.

The **Work and Families Act 2006** extended the right to request flexible working to employees who care for adults. This built on the introduction (through the **Employment Act 2002**) of the right to request flexible working for parents of children under the age of six (or 18 if the child is disabled). An independent review has now recommended that the right to request flexible working should be extended to cover parents of children aged 16 and under.

2.4 National Guidance

2.4.1 Drug Interventions Programme (DIP)

The growing recognition of the impact of drug use on families is reflected in the recent guidance for DATs on the development of throughcare and aftercare services within the **Drug Interventions Programme (DIP)** – formerly known as the Criminal Justice Interventions Programme (CJIP). The guidance emphasises the importance of involving and supporting carers and family members, in recognition of the key role they play in successfully reintegrating users into the community after treatment or when coming out of prison.

2.4.2 **We Count Too (2005) Good Practice Guide and Quality Standards for work with family members affected by someone else's drug use**

Funded by the Home Office, *We Count Too* was produced by Adfam, PADA and FAMFED to stimulate good practice in relation to both the commissioning and provision of carer and family support services. The aim of the project was to develop good practice and quality standards from the experiences of people who had used, developed or commissioned services. This included what family members said had helped them, and what service providers felt was important in developing services. Similarly, the good practice for commissioners is based on DAT members' own experience of what has worked.

We Count Too documents the enormous and devastating impact of drug misuse on family members and carers. Families who are not supported can experience ill health, including substance misuse by family members themselves, and family breakdown, which is very costly in the long run. However, there is evidence that the provision of dedicated support services for carers and family members can have a range of positive benefits, including improvements in family health, self-esteem and functioning. The guide also notes that addressing the impact of drug use on partners is also an important element of sexual health strategies and domestic abuse policies and practice.

We Count Too includes specific examples of commissioning practice and sets out simple quality standards, which can be applied to both small and more developed services. It also provides a 'Good Practice Menu of Services' for

family members, designed for groups and services to use as a checklist against which progress can be measured, and from which new ideas can be generated. Each menu item includes relevant examples of family support groups, projects and services in England. A summary of the quality standards and menu of services can be found at Annex A.

2.4.3 Working with the Children and Families of Problem Drinkers: A Toolkit (Templeton *et al.*, 2006) lays out a wide range of issues relating to developing and delivering services to affected family members. Although the guidance is oriented to setting up services for family members of people with alcohol problems, almost all of the issues it raises are equally as appropriate to setting up services for carers and family members of drug users. The toolkit contains information on planning the service, getting it up and running, maintaining the service and other useful resources.

2.4.4 NTA Guidance for Commissioners of Young People’s Substance Misuse Services: ‘Young People’s Substance Misuse Treatment Services – Essential Elements’ (2005)

The NTA guidance for commissioners of young people’s substance misuse services identifies “support for family members” as an essential service that must be available to carers and family members of young people in treatment by 2006. This is now part of the performance management of partnerships.

2.4.5 NTA’s Guidance on Supporting and Involving Carers (2006)

This guidance aims to ensure that all DATs and Crime and Disorder Reduction Partnerships

- Commission consistent, effective and quality services for carers and family members affected by someone else’s drug use.
- Involve carers and family members effectively in their planning.

The guide, which is designed to be used in conjunction with We Count Too (2005), provides practical advice and guidance on the following areas:

- Commissioning dedicated and specific support services for carers and family members.
- Carer and family member involvement in partnership and treatment service planning.
- Carer and family member involvement in individual care planning for the treatment of drug users.
- Implications of the above for the commissioning of drug treatment services.

The following key messages underpin the guide:

- Carer involvement works most effectively when support services for carers and family members are in place.
- Carers have separate and distinct needs from users.
- Family and carer support services cannot be fitted simply into models of care for drug treatment services.
- Carer and family support services need to reflect and draw on carers and family members' own experience.
- Partnerships have a lead role to play in commissioning services for carers and family members.

The guide acknowledges that there is an urgent need for dedicated support services for carers due to the significant negative impact that drug misuse can have on their mental and physical health and wellbeing. However, there are also clear messages emerging from research that support for family members and carers of substance misusers can have a significant, positive impact on:

- The engagement of users in treatment services.
- The retention of users in treatment.
- The outcomes from treatment and sustainability of treatment outcomes.

It is noted that partnerships have a responsibility to reduce the harm caused by drug misuse to communities as a whole, including the families and carers of drug users, **whether or not the users are accessing treatment.**

The guide also recognises that carers and family members can be a valuable resource as potential volunteers and paid workers in the substance misuse field, drawing on the experience and expertise gained from living with a drug user.

2.4.6 **NTA Guidance for Commissioners and Providers on Supporting and Involving Carers (2008)**

This guidance builds upon and extends the NTA commissioning guidance *Supporting and Involving Carers* (2006) to help further develop provision, and encourage areas that have not yet put in place robust provision to consider how they may take this agenda forward. The 2008 guidance places a strong emphasis on the benefits that providing services for carers and family members can have on **improving outcomes for whole families**, including drug misusers.

The guidance notes that effective support for family members and carers in their own right, and involvement of families and carers in drug users treatment, can be achieved by:

- Commissioning consistent, effective and quality services for family members and carers who are affected by someone else's drug use, either

through generic mainstream carer services or through specialist substance misuse family member and carer services.

- Ensuring services that treat drug users involve family members and carers in their treatment, as far as this is possible and appropriate.
- Involving family members and carers effectively in the planning and commissioning of drug treatment, and family and carer services.
- Embedding effective monitoring systems and practices relating to work with family members and carers within commissioned services.
- Local commissioners tracking delivery of these services via robust delivery assurance systems.

The guide states that, when contracting services, it is essential that providers are able to demonstrate comprehensive understanding and experience of the impact of drug use on families, carers and local communities. It is also important for providers to **demonstrate how they will ensure clear separation between provision for family members and carers, and provision for drug users.** This is particularly relevant where services for families and carers are delivered by the drug treatment service.

Key principles for effectively involving families and carers when **commissioning** services include:

- Building in family and carer involvement in care planning and care plan reviews into treatment service specifications, when commissioning or reviewing services.
- Developing care pathways defining how families and carers can access help, advice, and support, both for themselves and in conjunction with their drug-using relative.

Key principles for effectively involving families and carers when **providing** services include:

- Taking a holistic, whole family approach, in relation to the impact of drug misuse on others, and families and carers' contributions to addressing it.
- Including standard questions in drug user assessments about whether the user has a family member or carer, and what support they may require, followed up by the offer of a family member or carers' assessment to any of those identified.
- Offer all family members and carers information (such as information on the specific addiction, treatment and how to look after themselves as carers) and a referral to family and carer support services.
- Training treatment service staff on the impact on families and carers of drug use, and on support offered by family and carer support services.

- Enabling specialist staff to develop the competencies to offer psychosocial interventions to families and carers where these are indicated.
- Joint working between treatment services, family and carer services and other local agencies that may be a source of support.

2.4.7 **The NTA's Needs Assessment Guidance for Partnerships** (2007) states that carers and family members are an important element in the delivery of treatment and should be fully included in the needs assessment process. The guidance outlines a range of methods for assessing needs, which apply to drug misusers and their family members and carers. The guidance notes that, in order to assess needs, estimates should be developed to clarify the size and range of needs among the local family and carer population. It is important to also identify hidden need. Working with the drug treatment agencies to identify the number of users who are being supported by a family member or carer and consulting them about their needs will help this process. It is also useful to build partnerships with local community organisations where family members and carers, particularly from black and minority ethnic communities, may be receiving informal support.

2.4.8 **Drug Misuse and Dependence: UK Guidelines on Clinical Management** (Department of Health *et al.*, 2007) provide guidance on the treatment of drug misuse in the UK. The guidelines address the importance of meeting carers' needs and involving carers in drug misusers' treatment, and recognise that families and carers are an important resource in treating drug misusers with their own support needs. They advise that where practical and possible, carers should be active partners in drug misusers' care, and also provide specific information on the range of services that should be offered to carers to meet their own needs.

2.4.9 The National Institute for Health and Clinical Excellence (NICE) issued two sets of guidance in 2007, on **Psychosocial Interventions (NICE clinical guideline 51)** and **Opioid Detoxification (NICE clinical guideline 52)**. Both include recommendations on supporting families and carers, and give specific guidance on how families and carers may be able to support people with drug problems and get help for themselves.

2.5 Somerset Multi-Agency Carers Strategy

The purpose of the Somerset Multi-Agency Carers Strategy 2008-2011 is to provide a framework within which all agencies can provide quality services to carers. The strategy provides the following definition of carers:

In Somerset, you are a carer if...

'...you give up your time, without pay, to look after a family member, a friend, or a neighbour who is ill, frail, or has a disability.'

'You may be a young carer, parent carer, or care for an older person or other adult with care needs.'

Unlike the definition of carers adopted in the national Carers Strategy 2008, Somerset's Strategy does not make specific reference to carers that look after someone with substance misuse problems.

Underpinning the Somerset Strategy are four key principles, taken from the Somerset Carers Charter, which are:

- **Recognition of carers' expertise and knowledge:** The carers' role and expertise should be recognised and respected.
- **Carers involvement in care planning to be welcomed:** Carers should be involved in deciding the outcomes for the person they care for and agreeing how these can be achieved.
- **Responding to carers needs:** Carers needs should be recognised, responded to, and reflected in support planning. Carers should have access to the right sort of help and support to meet their identified outcomes.
- **Valuing carer involvement in service development:** Carers should be given the opportunity to be actively involved in the planning, development and evaluation of services.

The strategy sets out a series of key objectives based on the following ten priority areas:

1. Information, Identification and Recognition
2. Assessments and Ongoing Support
3. Health and Wellbeing
4. Work, Leisure and Lifelong Learning – Opportunities Beyond Caring
5. Giving Carers a Voice
6. Carers of those with Mental Health Needs
7. Carers of those with Learning Disabilities
8. Young Carers
9. Providing Third Sector Support
10. Equalities

At the time of writing, an Action Plan to accompany the Somerset Carers Strategy 2008-2011 was in development.

Chapter 3 Sources of Support for Carers & Family Members in Somerset

This chapter provides details of current sources of support for carers and family members in Somerset. Sections 3.1–3.3 focus on support specifically targeted at carers and family members affected by someone else’s substance misuse problems, while Section 3.4 provides details of wider carers services operating in Somerset. Section 3.5 provides an insight into views of staff from existing service providers on their vision for a future carers and family members service in Somerset. The information provided in this chapter is largely based on feedback from staff interviews and telephone discussions.

3.1 Turning Point

In April 2008, Turning Point was contracted by the Somerset DAAT to provide the county’s new, open access community-based drug and alcohol treatment service. The service provides tier 2 and 3 interventions at five open access centres across Somerset, located at Bridgwater, Taunton, Yeovil, Wells and Glastonbury. The service is also contracted to provide a central point of telephone contact within office hours, an Advice and Information Service for service users, carers and family members, and a monthly Family and Carer Support Group in Bridgwater.

3.1.1 Advice and Information Service

The Turning Point Advice and Information Service is available to clients, carers and family members from 9am – 5pm on weekdays and up until 8pm on Thursdays. The service can be accessed by telephone or by visiting one of the five open access centres. No appointment is necessary.

According to the staff interviewed, the carers and family members that contact Turning Point predominantly need someone to talk through issues with them and confide in. They often feel very alone, isolated and are experiencing a whole host of complex emotional issues, including feelings of anger, fear, frustration, worry and anxiety. They want advice on how to cope and channel these emotions, in order to look after themselves and support the user. Carers and family members also seek advice and information on wider issues and concerns, including their rights, legal issues, how to manage relationships, child safety, concerns that their children may be taken away, or how to deal with children that are acting suspiciously and could be using drugs/alcohol.

Carers and family members often have a strong desire to help the person with substance misuse problems and support them during the treatment process, and they want Turning Point to inform them of how they can help. Members of staff noted that carers and family members play a crucial role in supporting those going through the treatment process, especially in home detox situations. Recognising that carers and family members often feel powerless, staff members

mentioned that it can be beneficial to include them in the treatment process so that they feel they are doing something positive and constructive; this could be something as simple as ensuring that the person receives their medication on time. One member of staff recognised that there is great scope to develop family-based treatment and therapy services and make them more readily available in the county.

Staff recognised the limitations of the current opening hour arrangements for the Advice and Information Service. It was mentioned that the feasibility of extending the service's opening hours, including negotiating with landlords to extend office opening hours and the provision of an out-of-hours helpline, is something that needs to be explored. Two members of staff also mentioned that it would be useful to develop web/email support. Turning Point is currently in the process of extending the opening hours in its Taunton office to include evenings and weekends. This is a pilot service and, if successful, may be rolled out to other areas of the county.

3.1.2 Family and Carer Support Group

Turning Point inherited a family members' support group from the previous service provider. The group meets once a month in Bridgwater. The group used to be very well attended; however, during the summer 2008, the group was unable to meet due to the unavailability of a facilitator. Since September 2008, Turning Point has held monthly group meetings; however the number of attendees is significantly lower than before. One of the key issues appears to be the fact that Turning Point was unable to contact previous attendees of the family group as there was no record of attendance or contacts database. The service is currently making efforts to try and increase the number of family members attending this group. Turning Point is also in the process of setting up three additional family groups. Carers and family members will be able to choose which groups they attend; some will prefer to access a group that is outside their home town, while others may choose to attend more than one group.

The members of staff interviewed noted how valuable support groups can be for providing on-going support for carers and family members. It was recognised, however, that not all carers and family members are willing or able to attend a support group. Some lack the confidence to speak within a group setting, while others may be concerned about anonymity and worried that someone may recognise them. One member of staff mentioned that, prior to inviting a carer/family member to attend the support group, Turning Point staff tend to invite the person for a 1-2-1 discussion in order to talk about their individual situation and their needs; they may simply want information, or they may wish to meet other people with similar experiences. In the latter case, they will be given information about Turning Point's support group.

3.1.3 Turning Point's New Assessment and Support Services for Carers

Historically, the resources made available within Somerset for developing support services for carers and family members affected by someone else's substance misuse problems have been very limited; however, Somerset County Council, working through the Somerset DAAT Partnership, are currently seeking to address this issue.

In Autumn 2008, it was agreed that funding would be made available from Somerset County Council to develop assessment and support services for carers of Turning Point service users.¹ The aim is to develop a high quality, accessible service that provides carers with the support they need in order to manage their own lives, whilst at the same time looking after someone using drugs or alcohol. The specification for this new service is currently in draft format and will be reviewed following the completion of this study.

The following are key aspects of the draft service model:

- **Dedicated project worker:** The Carers Service will appoint a project worker with link work responsibilities for families and carers. The project worker will offer services and help to coordinate carer and family services offered by Turning Point across the county. The project worker will also help establish and maintain care/referral pathways with other community services and support structures for carers and family members, such as the In Touch Project and Al-Anon.

At the time of writing, it was envisaged that a project worker would be recruited early in 2009.

- **Staff training:** Turning Point will ensure that no less than five members of staff complete appropriate training courses around 'Working with Families and Carers' with the aim of establishing peer support services across Somerset. These new services will augment existing Turning Point groups. Turning Point will also offer up to 12 staff the opportunity and encouragement to attend "5 step" family and carer training run by Bath University, or other equivalent training, with the aim of enhancing the skills and knowledge of each area team and their staff.

At the time of writing, Turning Point was planning to enrol 5 ex-service users on the University of Bath's Family and Carer training programme, in order to equip them with the skills necessary to help support and co-facilitate the family groups.

- **Weekly carers & family members support groups:** The service will offer weekly carer and family groups in the main Turning Point offices and through satellites in the community, including primary care facilities where available and appropriate. Group meetings will be run during the evening

¹ Since the completion of the draft version of this study report, the specification has been amended to ensure that the service is available to *all* carers (resident in Somerset) of adults who have a serious problem with drug and/or alcohol misuse.

to enable people who are working during the day to attend. During this time the service will also offer individual appointments to complete assessments and offer personal support.

At the time of writing, Turning Point was in the process of planning the set-up of an additional three support groups, covering the areas of Taunton, Wells and Yeovil. It was envisaged that the Taunton and Wells groups will be running by March 2009, with the Yeovil group shortly afterwards.

- **Carers' Assessments:** Turning Point will adopt existing Somerset County Council policies for carrying out the statutory requirements of carers' assessments, based on three options as follows:²
 - A full assessment of the carer's needs at the same time as that of the service user. This option would be applicable where there is an understanding between the carer and service user about each others' position, and an openness in the relationship.
 - A full assessment of the carer's needs at a separate time from that of the service user. This option would be applicable where, for example, there is conflict between the carer and service user, requiring the assessment to be completed in confidence and away from the service user, or where the needs of the carer are sufficiently complex in their own right to require a substantial package of support.
 - A discussion with the carer about their needs. This option would be applicable where the carer is in a position to manage independently and does not want any follow up services.

Until recently, the Somerset Partnership NHS Foundation Trust has been conducting carers' assessments for those looking after someone with mental health-related issues, including problematic drug/alcohol misuse (a prerequisite is that the person they care for has to be registered with the Trust). However, following the tendering process for the Integrated Drug & Alcohol Treatment Service in Somerset (which was awarded to Turning Point), a decision was taken in 2008 to also commission Turning Point to carry out carers' assessments specifically for carers of adults with serious drug and/or alcohol misuse problems. Two members of staff from Turning Point will be available to start conducting the assessments early in 2009.

3.2 In Touch Project

The In Touch Project is a small project set up in 2007 by a small group of volunteers who, themselves, have been affected by someone else's drug or alcohol use and wanted to 'reach out' to others in need, living in and around Somerset. The project aims

² Annex B provides details of the NTA's guidance on assessing carers and family members, which could be of use when developing the service model for Somerset.

to provide a confidential, informative, supportive and therapeutic range of services for people over 18 who have been affected by someone else's drug or alcohol use.

Recognising that different people have different needs at different times, the In Touch Project seeks to offer options and choices about what people themselves say they need. The aim is to create a holistic approach and to get 'beyond the problem'. In order to do this, it is considered important to access and use a variety of resources. In 2008, for example, the Project held a workshop at Action on Addiction (formally Clouds), and it has received funding to hold 4 day workshops at Broadway Lodge in Weston Super Mare.

The development model for the Project is based on a 'Recovery Wheel' designed by one of the volunteers (details of which were originally published in an article in [Drink and Drugs News](#) on 3rd December 2007; see Annex C). The Project offers family members the choice to:

- Meet in a public place of choice to have coffee and informally chat
- Talk through options available
- Help to access information
- Loan useful publications, books, and videos from its own library resource
- Help find support in local areas, including self help groups and support groups, and try and support the person along to their first meeting
- Link up and gain hope from others who understand, including the opportunity for respite and having fun days out.

The Project encourages people to build their own support networks, and will signpost to other relevant sources of help if required.

To date, the Project has received funding from a variety of sources, including Somerset DAAT, Somerset Partnership Fund, Somerset Community Foundation, Grassroots, Somerset Community Chest, Carers UK, and Lottery Awards 4 All.

Further details are available at www.intouchproject.org.uk

3.3 Twelve Step Fellowships, Charities and Self Help

3.3.1 Families Anonymous ('FA')

Families Anonymous is a "world wide fellowship of relatives and friends of people involved in the abuse of mind-altering substances, or with related behavioural problems". FA groups meet regularly throughout the country. Any concerned person is encouraged to attend the meetings, even if there is only a suspicion of a problem. The Fellowship is a self help organisation with a programme based on the Twelve Steps and Twelve Traditions first formulated by Alcoholics Anonymous.

In Somerset, an FA group has been meeting in Street on a monthly or twice monthly basis for the past nine years. A full list of venues and dates is available on the FA [website](#).

FA also organises weekly online 'e-meetings' and has an online discussion board. A telephone helpline is available Monday - Friday 1pm - 4pm and 6pm - 10pm, and on weekends 2pm - 10pm.

3.3.2 Al-Anon

Al-Anon is for anyone who is, or has been affected, by someone else's drinking. It is based on the Twelve Steps and Twelve Traditions adapted from Alcoholics Anonymous. It is non-professional, self-supporting, non-religious, non-political and multi-racial. Its membership includes adult children of alcoholics, teenagers, parents, partners, spouses and other relatives and friends of alcoholics.

Al-Anon meetings provide an opportunity for members to speak about their experiences, and listen to and learn from others in a similar position. In Somerset, Al-Anon groups meet on a weekly basis in Taunton, Bridgwater, Minehead, and Wells. Further details of venues and dates of group meetings are available on the Al-Anon [website](#).

Al-Anon also operates a Family Group Helpline, which is available 10am-10pm daily.

3.3.3 Rethink

Rethink is a campaigning membership charity working with people with severe mental illness, their carers, families and friends through a network of mutual support groups around the country.

In Somerset, Rethink carers groups currently meet in Yeovil (monthly); Taunton (twice monthly); Highbridge (weekly); and (Ilminster/Chard and Langport (four to six times a year). Further details of venues and dates of group meetings are available on the Rethink [website](#).

Rethink operates a national helpline, which is available from 10am – 3pm on weekdays. The Rethink website has dedicated sections for [carers](#) and on the subject of [Dual Diagnosis](#), both of which provide a wealth of useful information.

3.4 Wider Carers Services operating in Somerset

3.4.1 Somerset County Council & the Somerset Partnership NHS Foundation Trust

Somerset County Council and the Somerset Partnership NHS Foundation Trust (the 'Trust') provide a range of support services for carers, including emotional

help and support; personal care at home; sitting service; short breaks; day care; adaptations to the home; equipment; direct payments; and advice about benefits.

The carers services provided by Somerset County Council are targeted at adult and young carers that look after someone that is ill, frail or has a disability. The Council provides the following definition on its website:

Who is a carer?

If you give up your time, without pay, to look after a family member, a friend, or a neighbour who is ill, frail, or has a disability, then you are a carer.

You may be a parent carer, a young carer, or care for an older person.

www.somerset.gov.uk

Somerset County Council has a dedicated area on its website that provides information for carers. There is also a series of leaflets that carers can download, including 12 Carers Information Sheets which describe the full range of services available and how to access them.

The Council contracts **Care First** to provide a counselling service for carers in Somerset. 'Counselling for Carers' is a free service that is available 24 hours a day, every day of the year. Carers can talk to a counsellor by telephone or arrange to meet. Care First can usually offer up to 5 sessions of up to one hour with the same counsellor. If someone needs help for longer or specialist help that Care First cannot give, then the counsellor will put the person in touch with relevant local or national organisations. The service literature notes that the counselling service is available for all carers in Somerset who provide care and support for a family member or friend of any age; however its definition does not specify carers looking after someone with substance misuse problems:

Who is a carer?

Carers are people who care for a family member or friend who has long-term health needs, disabilities, mental health problems, learning difficulties, or an older person.

'Counselling for Carers' Fact Sheet

The **Somerset Partnership NHS Foundation Trust** provides a range of services for carers that look after someone with mental health problems. The Trust provides the following definition of carers:

Who is a carer?

A carer is someone who provides or intends to provide practical and emotional support to someone with a mental health problem. You may or may not live with the person you care for. You may be a relative, partner, friend or neighbour. You may be a young person, but now find yourself in the position of needing to support an unwell person.

www.somersetcarers.org

The Trust has a dedicated website for these carers, which provides online information and downloadable documents, including a 61 page information pack. Hard copy information packs are also given to carers that get in touch with the team.

While the focus of the Trust's service is on carers looking after someone with mental health problems, staff noted that the emotional support needs of this group of carers often overlap with the needs of those looking after someone with substance misuse problems. In some cases, carers are looking after someone with dual diagnosis.

The Trust has a team of Carers' Assessment Workers that provide advice, information and support to carers looking after someone with mental health problems. The Carers' Assessment Workers also currently support a number of carers looking after someone with a dual diagnosis. Staff were unable to provide details of the number of the carers looking after someone with a dual diagnosis that are registered with the Trust, as their database does not identify the reason(s) why a person is a carer (this information is only recorded in the individual case notes). Staff mentioned that, when carers affected by someone else's substance misuse present themselves to the Trust, they often refer them to Al-Anon, which they consider to be a very good support group.

Until recently, the Trust conducted **carers' assessments** for those looking after someone with substance misuse problems. However, as previously mentioned, Turning Point has been contracted to carry out these assessments, commencing in early 2009. At the time of writing, the Trust is continuing to carry out carers' assessments for those looking after someone with dual diagnosis, who are registered with the Trust

Staff at the Trust mentioned that they will try and help anyone affected by the substance misuse of others that contacts them. This may involve the provision of some basic information and signposting. To qualify for longer term support, the person has to be caring for someone registered with the Trust for dual diagnosis. For example, these carers are able to access up to six, free **one-to-one counselling** sessions.

The Carers' Assessment Workers facilitate a number of **carers groups** across the county, which are open to carers looking after someone with mental health-related issues, including substance misuse problems. The Carers' Assessment Workers and Carers Group Facilitators interviewed for this study mentioned that a number of carers affected by someone else's substance misuse attend the groups that they facilitate. The groups provide carers with social and emotional support and involve general discussions that are not specific to any particular type of carer. The Carers' Assessment Workers interviewed for this study mentioned that they try and help everyone that attends their groups, whatever their background; they provide them with printed literature and signpost them to relevant support programmes.

One Carers' Assessment Worker that facilitates a group which has a number of members that are affected by someone else's substance misuse suggested that it would be useful if Turning Point or the Somerset DAAT could arrange a workshop or talk for the group. The group members would be interested in finding out more information about the services available in the local area, as well as coping strategies and advice on how they can help the person they care for. The Carers' Assessment Worker is currently putting together a programme for the next six months and would be interested to know whether a member of staff from Turning Point or the Somerset DAAT would be willing to attend a session and provide a talk.

It was acknowledged that carers looking after someone with substance misuse problems also need **dedicated support groups** which are able to focus on their specific issues and experiences. Staff mentioned that, in their experience, carers looking after someone using drugs/alcohol can feel very helpless, as they cannot make the person seek treatment. The person needs to recognise that they have a problem and seek treatment themselves, and this can be very hard on the carer. One member of staff noted that, in some ways, the behaviour of someone using drugs or alcohol can be more complex and difficult to understand than that of someone with a mental health condition. For many, there is also a stigma attached to problem drug/alcohol use, which can form a barrier to carers coming forward or joining a support group.

The Trust has run **workshops and courses** for carers looking after someone with mental health problems. These events have proven to be very successful. Staff recognised that there is a need for workshops and courses specifically for carers looking after someone using drugs/alcohol, which could help to empower the carers and give them a range of skills, including strategies for coping, managing behaviour, and personal safety.

The Trust runs a **short breaks scheme** for carers looking after someone with mental health problems. Carers can receive up to £250 to allow them to take a break and de-stress. A carer's assessment will determine whether a carer qualifies for the scheme.

There is a **Young Carers Project** in Somerset which provides support to all types of young carers, including those looking after someone with a drug or alcohol problem. The Project has a dedicated Project Coordinator and Project Workers based across the county. Further details of the Young Carers Project are available at www.somersetyc.org.uk. Staff at the Somerset Partnership NHS Foundation Trust recognised that there are a lot of young people in Somerset that are affected by their parents' drug and alcohol use and it is vital that these young people access the support they need.

3.4.2 Community Development Workers Black and Minority Ethnic (BME) Health and Wellbeing Team, Somerset Racial Equality Council (SREC)

The Team Manager explained that they support people experiencing a whole range of issues, including mental health problems, family breakdowns, and domestic violence. Many people affected by drug and alcohol misuse seek advice and support from the team, although it is usually the individual with substance misuse problems that seeks help, rather than the carers or family members.

SREC has venues where people can drop in, talk to a member of staff, and gain assistance. Staff will listen to the individual and talk through issues, inform them of what help is available, and signpost them to relevant agencies. Those affected by substance misuse will be referred to Turning Point, while those with mental health problems will be referred to the Somerset Partnership NHS Foundation Trust. When needed, staff from SREC will accompany the individual to meetings with other agencies, including appointments with GPs. The Team Manager noted that it can be difficult to identify an individual's needs as a carer. The individuals that contact SREC are often experiencing complex problems and are not always willing to discuss all the issues that are affecting them. Sensitive issues, such as drug and alcohol use, are often kept hidden.

The Team Manager explained that the people who contact SREC are often in a very distressed state and present complex cases. A number of agencies can be involved with the cases, including the police, immigration, customs, and social services. In the Manager's experience, individuals tend to approach SREC once they have had partial interaction with other organisations and failed to receive the support they need. Certain ethnic groups can be subject to stereotyping (e.g. "the Polish are heavy drinkers") which can be a real barrier when they try to access services. Staff at some agencies may tend to overlook an individual's needs because of stereotyping. For other individuals, it may be the case that their community refuses to accept that drugs and alcohol are an issue for them, which, again, can present barriers to them accessing the help they need. One such example is the Muslim community.

SREC is aware that limited awareness of cultural issues is still an issue in Somerset and it is an ongoing process to raise awareness and help agencies understand cultural implications. SREC is currently involved in raising awareness

of cultural issues as part of the local delivery of the national training programme on Race Equality and Cultural Capability (RECC).

Somerset is a large, rural county with a small, dispersed BME population. The Team Manager noted that this presents a double disadvantage: not only is it difficult to access support as a carer, but the geographical aspect and cultural issues make it that much harder. There are approximately 25 BME associations operating across Somerset with support from the Somerset Black Development Agency (SBDA). SREC is currently trying to work with these associations to give them the skills to support members of the community, but it is challenging work. The Somerset Chinese Association has a helpline. The Team Manager noted that it would be beneficial if the service could be extended to other BME groups in the county.

The Team Manager noted that there is a real need to develop support services for BME carers. The BME associations are probably best placed to assist with this and may be able to help with awareness raising and the dissemination of information.

3.5 Staff Views on Developing Support Services for Carers and Family Members in Somerset

3.5.1 Views of Turning Point Staff

When members of staff from Turning Point were asked whether they felt that Turning Point was the most suitable provider of support services for carers and family members, they responded in the affirmative. However, they were aware that there are a number of pros and cons regarding a drug and alcohol treatment service providing carer and family members services, which are summarised below:

- **Pros**
 - **Turning Point staff are highly experienced and trained.** They have a wealth of knowledge and expertise in terms of precipitating factors and drug/alcohol treatment, and can support carers and family members with advice and information on what works in terms of treatment and how they can support the person using drugs/alcohol.
 - **Turning Point has a lot of links with other service providers in the locality,** which means that they are in a good position for signposting carers and family members to relevant services. The staff can provide basic information on a range of subjects and signpost to other, relevant agencies for more detailed information.
- **Cons**
 - **Some carers and family members do not want to approach a drug and alcohol service for support,** and would prefer to access an

independent service. Some may feel embarrassed about accessing a service in a venue that provides drug/alcohol treatment, while others may have concerns that they will be recognised by members of the community. Providing services for carers and family members in rural communities is a particular challenge, due to the stigma and embarrassment that can be felt in communities where everyone knows each other. One member of staff mentioned that GP surgeries and health centres are the most obvious choice of venue for offering support within rural localities; however the drawback is the issue of anonymity.

- **Some carers and family members may perceive Turning Point to be a service for drug and alcohol users only.** Raising awareness of Turning Point's carers and family members' service and signposting from other services, will help to overcome this perception.

When asked whether there were any **barriers or constraints** preventing Turning Point from supporting carers and family members, staff members gave the following responses:

- **Finance:** There has been a lack of funding available within Somerset to provide a dedicated support service for carers and family members. Towards the end of 2008, Somerset County Council informed Turning Point that funding will be made available to set up a dedicated service for carers. The service is due to be launched early in 2009.
- **Limited opening hours:** The service is currently limited to office hours which can be a barrier to providing carers and family members with the support and advice they may need, particularly during times of crisis. Turning Point is currently negotiating the extension of opening hours with their office leaseholders.
- **Reaching carers and family members:** A lot of carers and family members are reluctant to talk to agencies due to the sensitive nature of drug/alcohol issues. Some are wary about contacting a drug and alcohol service due to the perceived stigma or for fear of being recognised in their local area, while others are unaware that the service can provide advice, information and support to carers and family members.

The Acting Group Manager at Somerset County Council also acknowledged that it can be a challenge for services to engage with these carers, partly due to the stigma attached to substance misuse, but also due to the fact that drug use is a criminal activity. When promoting the new carers service, he suggested that it would be helpful to raise awareness of the issue and acknowledge that it is a real problem in the county, so that carers feel supported rather than condemned.

When asked to describe their **vision of the carers and family members support service** that they would like to see Turning Point deliver, staff explained that they would like it to be a credible service, that values carers and family

members; is respectful; listens; identifies needs; provides the appropriate level of support, information and advice; and gives carers and family members the choice and flexibility to access the service when they want it and how they want it.

Staff members identified the following specific ways in which they would like to see the carers and family members' service develop:

- **Broaden the range of services available for carers and family members:** Turning Point is currently looking to set up courses and workshops for carers, as well as expanding peer support through the development of a further three family support groups. One staff member mentioned that they would like to see Turning Point develop a one-stop-shop service for families affected by drug and alcohol misuse.
- **Develop a range of family care options:** One member of staff noted that there is a need to develop good family care in Somerset and make it more readily available, including family-based therapy and treatment services.
- **Formalise links with other agencies and family support groups:** Staff noted that Turning Point already has good links with other agencies and family support groups, such as Al-Anon, but there is potential for these links to be improved and formalised.
- **Improve accessibility:** Carers and family members should be able to access good quality information, advice, support whenever they need it. It is important that the service reaches carers and family members that live in all areas of the county, including those that are unable to leave their homes. The service should be extended and made available outside standard office hours. One member of staff also mentioned that carers' assessments need to be made more accessible.
- **Consult and involve carers and family members:** Staff members recognised the importance of developing carer and family involvement in service planning and delivery, particularly with regards to shaping the new service for carers and family members.

3.5.2 Views of Staff from the Somerset Partnership NHS Foundation Trust

Staff from the Trust mentioned that, to date, there have not been any detailed discussions with Somerset County Council or Turning Point on how the Trust will fit in with the new service for carers. Staff emphasised the **need for strong links** between the two services and a **clear, agreed, working relationship**. At present, there are areas of overlap in the services provided, as well as gaps. One particular gap mentioned by staff was support services for carers looking after someone with substance misuse problems who is not in treatment. One member of staff noted that these carers often do not know where to go or who to approach for support or general information.

Of particular concern to staff at the Trust was the need for clarity on which service will support carers looking after someone with **dual diagnosis**. The staff interviewed for this study were disappointed that the Trust had lost the contract to

provide a drug and alcohol service, as they felt it made sense for one service to provide holistic support and treatment for clients with dual diagnosis and their carers. They felt that there is a lack of clarity as to whether these carers should be in contact with Turning Point and/or the Trust. Until this is clarified, there is a risk that these carers may simply fall between the services and fail to access the support they need.

At the time of writing, Turning Point and the Somerset Partnership NHS Foundation Trust were working together to agree a dual diagnosis joint working protocol based on an agreed definition of dual diagnosis. The Somerset DAAT is also involved in this work. Once finalised, the protocol will be implemented across the county. It will also be incorporated into the county's dual diagnosis strategy.

Carers' Assessment Workers interviewed for this study explained that they are continuing to work with existing clients that care for someone with dual diagnosis, but are unable to provide specialist drug and alcohol support as they no longer have an in-house team of drug and alcohol specialists that they can call upon. One Carers' Assessment Worker wondered whether Turning Point or the Somerset DAAT could arrange **staff training workshops** on drug and alcohol issues and how to support carers affected by someone else's substance misuse. She said that training would be highly welcomed as it would enable staff to better support carers and would give them more confidence to talk to carers affected by this particular issue.

Staff mentioned the importance of **joint working** and ensuring that all agencies that provide services for carers have good links and work in a coordinated way. In particular, it would be good to formalise the relationship between the Trust and Turning Point as soon as possible. Staff felt that it is important that the agencies provide a **seamless service** and that a carer does not have to repeatedly explain to staff at different agencies about their background, experiences and issues. One Carers' Assessment Worker provided an example of a carer that they have been supporting for the past four years. The carer is not physically well herself, but supports her daughter who has drug and alcohol problems and also suffers from mental health problems. They experience financial difficulties and the carer has two jobs in order to provide for the family. The carer's needs are complex and long-term. The carer is currently in weekly contact with a Carers' Assessment Worker. Case histories such as this highlight the importance of providing a seamless service as a carer cannot be expected to repeat all this history to every agency involved. It is important that this information can be shared and accessed across the relevant bodies where appropriate.

One member of staff thought that it was important to **avoid 'reinventing the wheel'**. It was mentioned that the Trust has a range of resources that could be useful to Turning Point, including a Carer's Charter, job descriptions for staff

supporting carers, and course material. There is a lot of potential for the two services to work together and share resources

3.5.3 Views of the Acting Group Manager, Communities Directorate, Somerset County Council

For the Acting Group Manager at Somerset County Council, the vision is to bring services for carers looking after someone with substance misuse problems in line with services provided for other types of carers in the county. He noted that the Somerset Carers Strategy has been commended by national government as an example of good practice. The vision is to develop services for this group of carers, which equally achieve recognition for their quality and accessibility.

Chapter 4 Survey of Carers & Family Members in Somerset

4.1 Introduction

4.1.1 In order to enable carers and family members residing in all parts of Somerset County to participate in the study, a survey questionnaire was developed in paper and electronic formats.

4.1.2 The survey sought to identify:

- The support needs of carers and family members and the types of services that they would like to access.
- Whether carers and family members have tried to access support services and, if so, their experiences.
- Whether carers and family members have tried to access a carer's assessment and, if so, their experience of this process.
- Whether carers and family members currently access support services and, if so, their experiences of these services.
- Whether there are gaps between carers and family members' service needs and current service provision.

4.1.3 The survey was promoted and disseminated in a number of settings:³

- A volunteer from the In Touch Project disseminated copies of the survey to carers and family members with whom she is in contact, via the In Touch Project and local self help groups, including Families Anonymous ('FA') and Al-Anon.
- Staff at Turning Point promoted the survey and disseminated questionnaires at the Turning Point offices and via the Family Group.
- Staff at On the Level promoted the survey to parents that visit their office.
- The survey was promoted via an advert in the Somerset County Council staff magazine.
- A link to the survey was added to the homepage of the In Touch Project website; and within the Carers, Adult Social Care and Community Safety sections of the Somerset County Council website.

4.1.4 By Tuesday, 6th January 2009, 41 valid responses had been received. 21 respondents had completed the paper questionnaire, while 20 respondents had

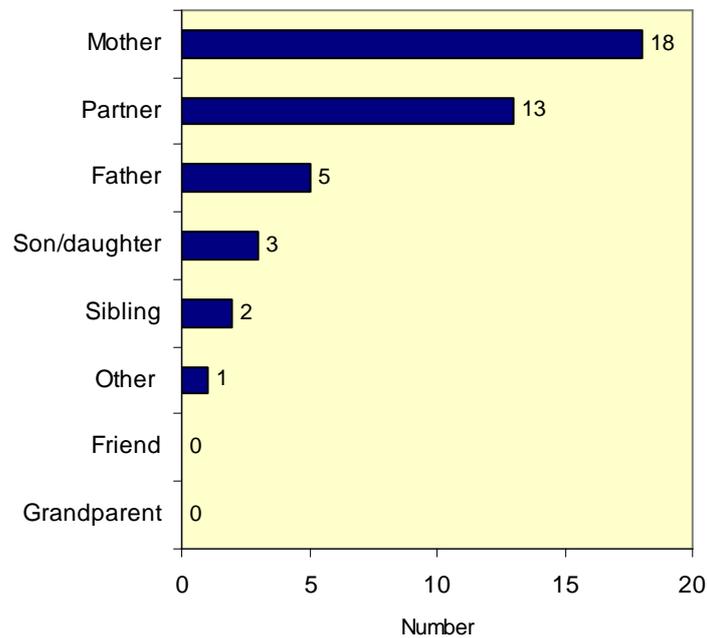
³ Since the questionnaires were predominantly disseminated to carers via the staff and volunteers with whom they are in contact, this could result in an element of bias in the survey results. This should be borne in mind when reading the survey findings.

participated in the online survey. Since the survey involved less than 100 returns, the survey findings have been presented in terms of respondent numbers, rather than percentages.

4.2 Respondent Profile

4.2.1 Respondents were asked to identify their relationship to the person using drugs/alcohol. By far the highest proportion of respondents indicated that they were either the mother or partner (see Table 1 below).⁴

Table 1: What is your relationship to the person using drugs/alcohol?

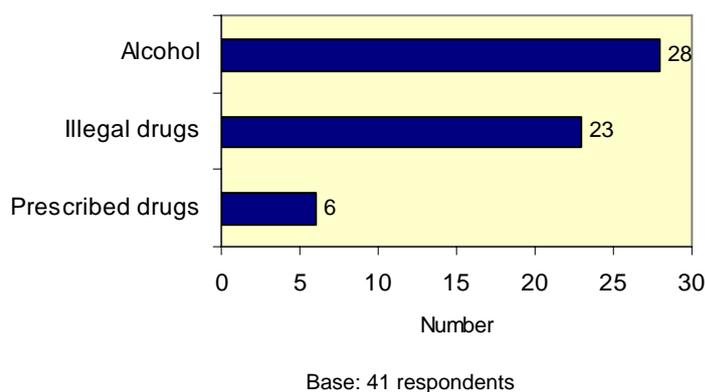


Base: 41 respondents

4.2.2 All respondents indicated that they were aware of the substances that the person was taking. The highest proportion of respondents indicated that the person was using alcohol, followed by illegal drugs (see Table 2 overleaf). Only 14 respondents indicated that the person was using a combination of drugs and alcohol. The most common combination (selected by 10 respondents) was illegal drugs and alcohol.

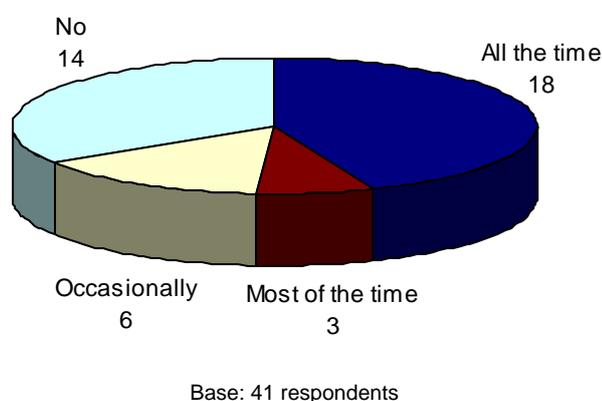
⁴ One respondent indicated that they were both the mother and sibling of family members affected by drug/alcohol use.

Table 2: Are you aware of the substances they are using?



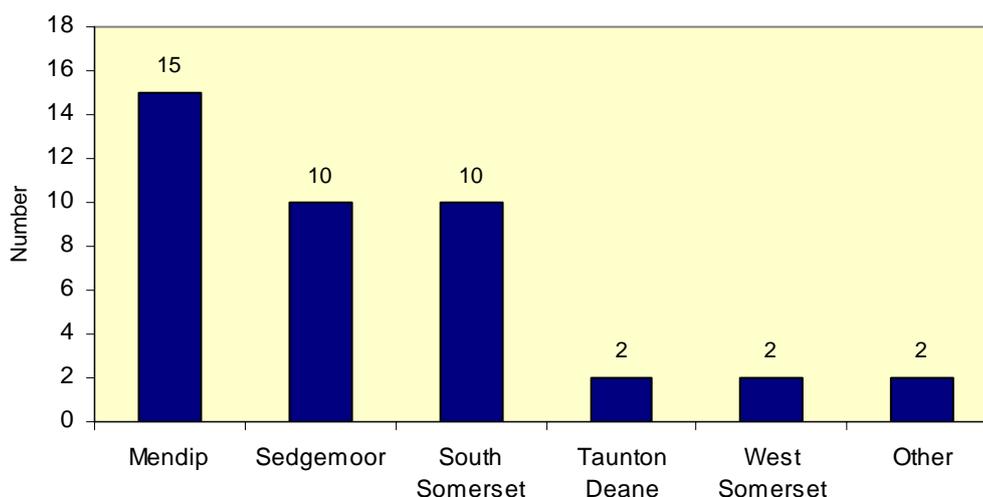
4.2.3 Respondents were asked to indicate whether the person was living with them ‘all the time’, ‘most of the time’, ‘occasionally’ or ‘not at all’. The highest proportion of respondents (18 out of 41) indicated that the person was living with them all the time; while a slightly lower proportion (14 out of 41) indicated that the person was not living with them at all (see Table 3 below). The majority of respondents that were living with the person using drugs/alcohol all the time were their partners (12 out of 18). In contrast, the majority of respondents that were not living with the person using drugs/alcohol were parents (11 out of 14).

Table 3: Is the person living with you?



4.2.4 In terms of location, the highest proportion of respondents were living in Mendip, following by Sedgemoor and South Somerset (see Table 4 below). 2 respondents indicated that they lived in a neighbouring county; one in Berkshire and another in Dorset.

Table 4: In which district do you live?



Base: 41 respondents

4.3 Impact of Someone Else's Substance Misuse on Carers and Family Members

4.3.1 In order to gain an insight into the impact of a person's substance misuse on carers and family members, respondents were presented with a range of issues and were asked to indicate whether they experienced these issues 'all of the time'; 'most of the time'; 'occasionally'; or 'never'. The issues were broken down into a series of categories: 'Mental health/emotional issues'; 'Domestic abuse'; 'Financial & employment issues'; and 'Social issues'. The survey findings reveal that carers and family members experience a wide range of issues as a result of someone else's substance misuse problems.

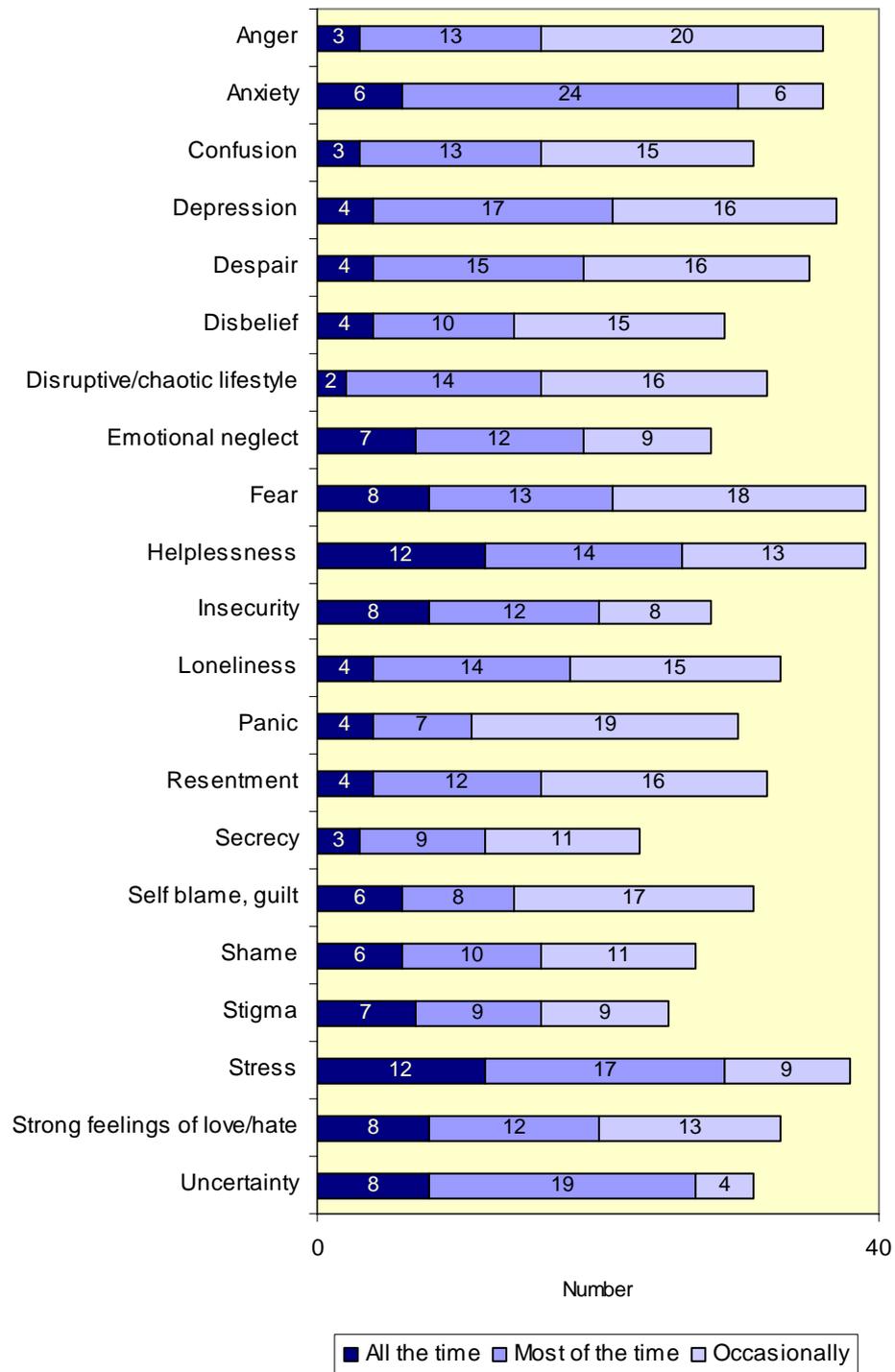
- **Mental Health/Emotional Issues**

Key Findings:

- The largest majority of respondents indicated that they experienced **all** of the 21 mental health/emotional issues listed, at least occasionally (see Table 5 below).
- The most common issues, experienced by 39 out of 41 respondents, were 'Fear' and 'Helplessness', followed by 'Stress', 'Depression', 'Anxiety', 'Anger' and 'Despair'.
- The issues experienced by the highest number of respondents 'all the time', were 'Stress' and 'Helplessness'.
- The issue experienced by the highest number of respondents 'most of the time', was 'Anxiety'.
- 'Other' mental health/emotional issues added by respondents were 'powerlessness', 'worry', 'independence', 'detachment', 'loss',

'feeling of wanting to run away', 'frustration' and 'thoughts of suicide'.

Table 5: As a result of the person's drug/alcohol use, do you experience any of the following mental health/emotional issues? (Please tick all that apply)



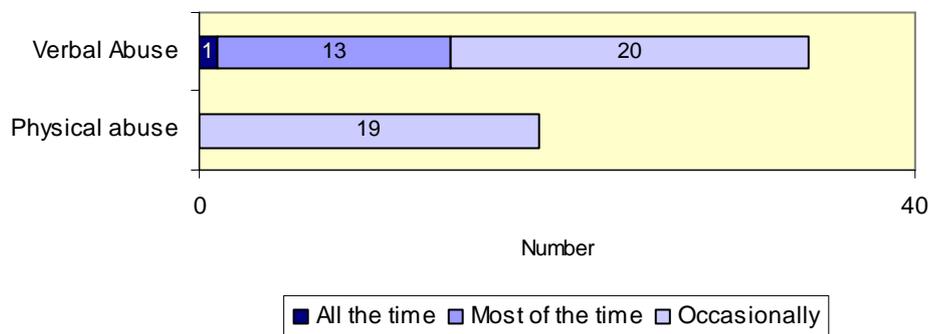
Base: 41 respondents

- **Domestic Abuse**

Key Findings:

- By far the largest majority of respondents (34 out of 41) indicated that they experienced verbal abuse at least occasionally. 1 respondent experienced verbal abuse ‘all the time’, while 13 indicated that they were subject to verbal abuse ‘most of the time’.
- Just under half of respondents (19) indicated that they occasionally experienced physical abuse.
- 3 respondents mentioned that they have experienced damage to property, including things getting smashed in their home and damage to cars.
- 1 respondent explained that they have been subject to emotional blackmail.
- 1 respondent (a sibling) mentioned that, while he/she has occasionally been subject to physical and verbal abuse, his/her parents have suffered a lot of abuse.

Table 6: As a result of the person’s drug/alcohol use, do you experience any of the following forms of domestic abuse? (Please tick all that apply)



Base: 35 respondents

- **Financial & Employment Issues**

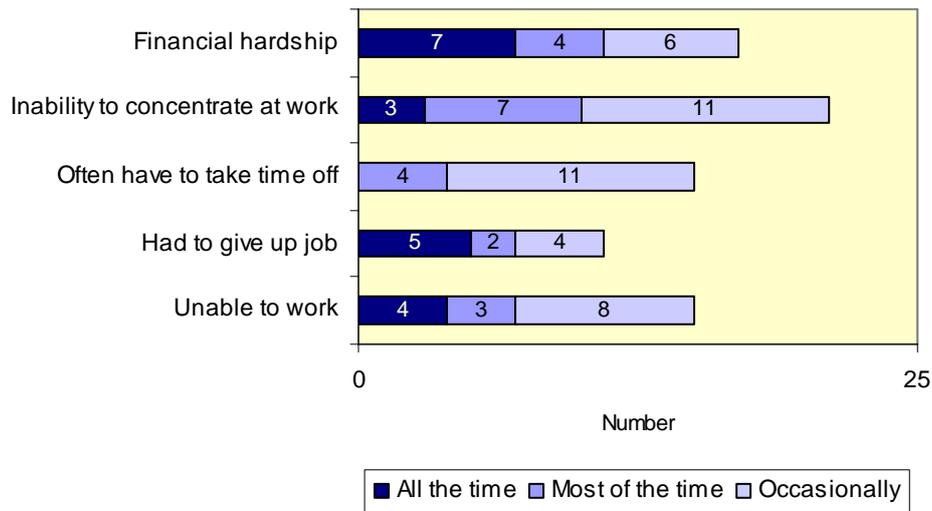
Key Findings:

- The most common employment issue, experienced by just over half of respondents, was an ‘inability to concentrate at work’ (see Table 7 below).
- Other issues, experienced by at least a third of respondents, were ‘financial hardship’; ‘inability to work’; and periods where they frequently ‘have to take time off’.
- One respondent explained that “stress and depression caused health problems which made it impossible to work”; while another

mentioned that they have experienced financial hardship due to “theft of household, personal and garage items”.

- Three respondents mentioned that they were retired. All three were parents, and two had the person using drugs/alcohol living with them all the time. One respondent (aged 77) was also looking after her grandson.

Table 7: As a result of the person’s drug/alcohol use, do you experience any of the following financial and employment issues? (Please tick all that apply)



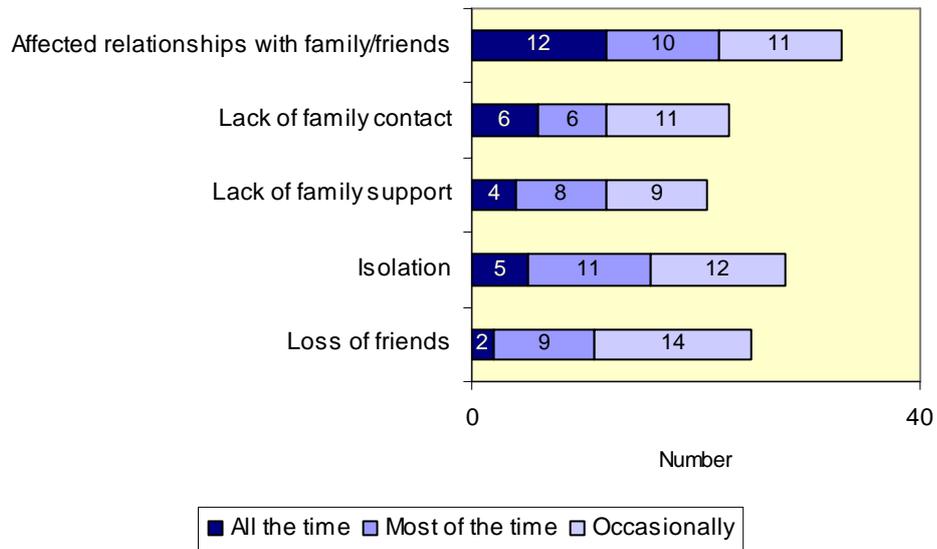
Base: 33 respondents

• **Social Issues**

Key Findings:

- The majority of respondents indicated that they experienced **all 5** of the social issues listed, at least occasionally (see Table 8 below).
- By far the largest majority of respondents (33 out of 41) indicated that they have experienced ‘affected relationships with family/friends’.
- Four respondents added the following details of further ways in which the person’s drug/alcohol use has impacted on them socially:
 - “Constraints on social intercourse/conversation”
 - “Cannot plan things. Cannot leave home for holidays”
 - “Lack of self esteem so don't go out”
 - “Affected my social life greatly”

Table 8: As a result of the person’s drug/alcohol use, do you experience any of the following social issues? (Please tick all that apply)

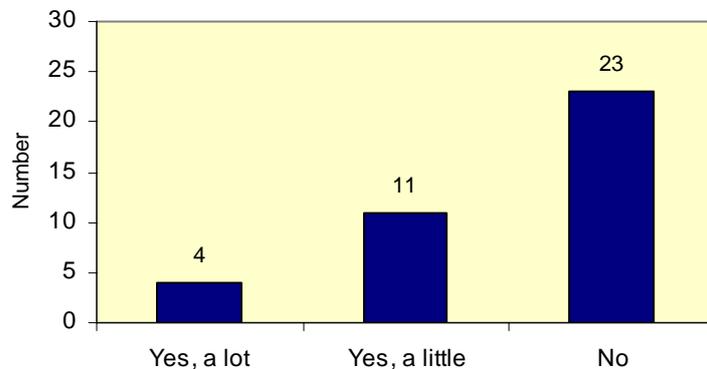


Base: 37 respondents

4.3.2 Respondents were asked whether they felt that their own use of drugs (prescribed or non prescribed) had increased to cope with the situation. 15 respondents replied in the affirmative: 4 respondents indicating that their use of drugs had increased ‘a lot’, while a further 11 respondents indicated that their use of drugs had increased ‘a little’ (see Table 9 below).

Just over half of respondents replied in the negative. 5 respondents specifically mentioned that they do not use drugs. 1 respondent mentioned that they have “never had any, as drugs are not the solution”, while another explained that they have “no intention of treating drug misuse with further drug use!”

Table 9: Do you feel your own use of drugs (prescribed or non-prescribed) has increased to cope with the situation?

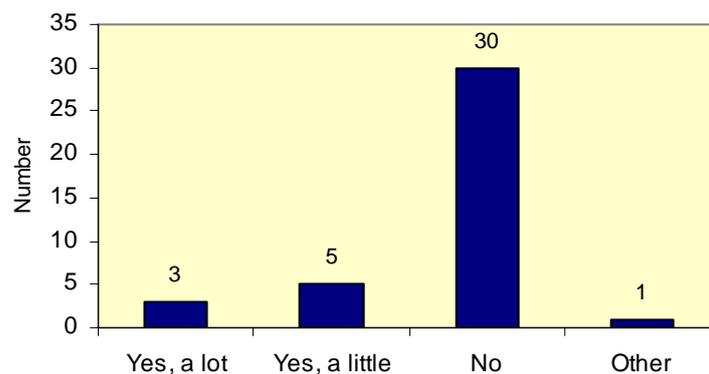


Base: 38 respondents

4.3.3 When asked whether they felt that their own use of alcohol had increased to cope with the situation, 9 respondents replied in the affirmative. 3 respondents indicated that their use of alcohol had increased 'a lot', while 5 respondents indicated that their use of alcohol had increased 'a little'. 1 respondent noted that their use of alcohol increased at certain times more than others.

However, by far the largest majority of respondents indicated that their use of alcohol had not increased (see Table 10 below). 2 respondents specifically mentioned that they do not use alcohol.

Table 10: Do you feel your own use of alcohol has increased to cope with the situation?



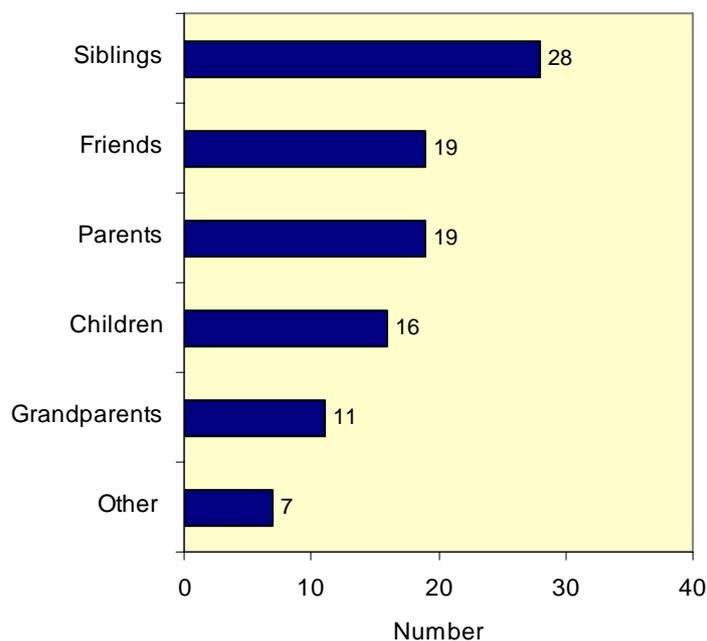
Base: 39 respondents

4.3.4 Respondents were asked to indicate whether they felt that others may have been affected by the person's drug/alcohol use. They were presented with a list of 5 options and could add 'other' responses.

Key Findings

- Almost all survey respondents (39 out of 41) indicated that at least one other family member had been affected by the person's drug/alcohol use, while half (20 out of 41) indicated that at least 3 other family members/friends had been affected.
- The majority of respondents (28) indicated that siblings had been affected, while just under half of respondents (19) indicated that parents and friends had been affected.
- Over one third of respondents (16) indicated that children had been affected by the person's drug/alcohol use (see Table 11 below).

Table 11: Do you think others may have been affected by the person's drug/alcohol use?

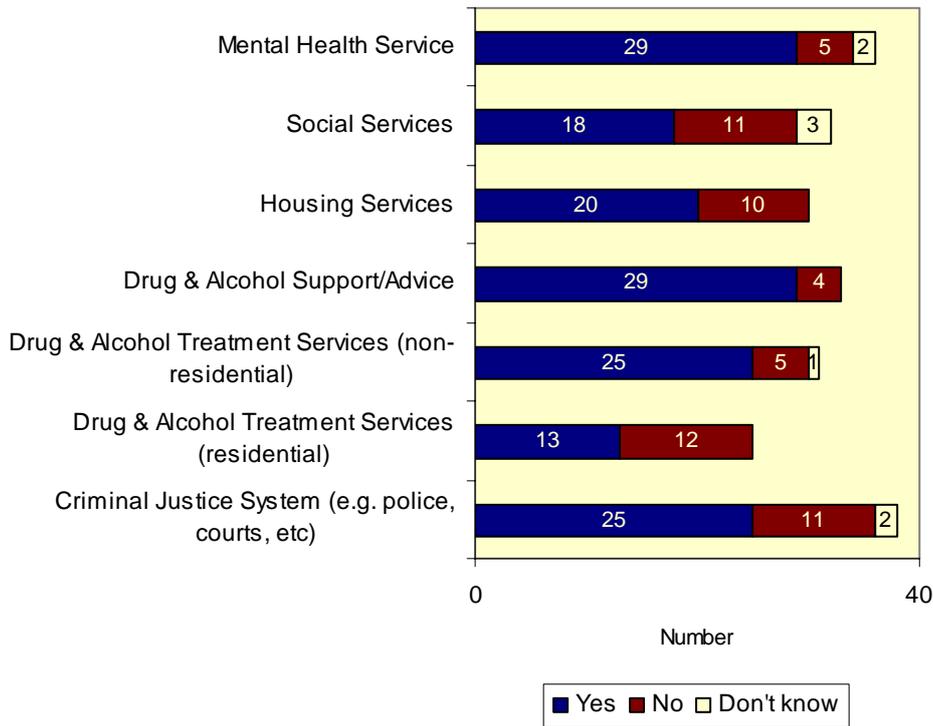


Base: 39 respondents

4.4 Experience of Services

4.4.1 Respondents were presented with a list of seven services operating in Somerset and were asked to indicate whether the person using drugs/alcohol had been involved with any of these services. The majority of respondents indicated that the person had been involved with the Mental Health Service; Drug & Alcohol Support/Advice; Drug & Alcohol Treatment Services (non residential); and the Criminal Justice System. Around half of the respondents indicated that the person had been involved with the Housing Services and Social Services (see Table 12 below).

Table 12: Has the person using drugs/alcohol been involved with any of the following services?



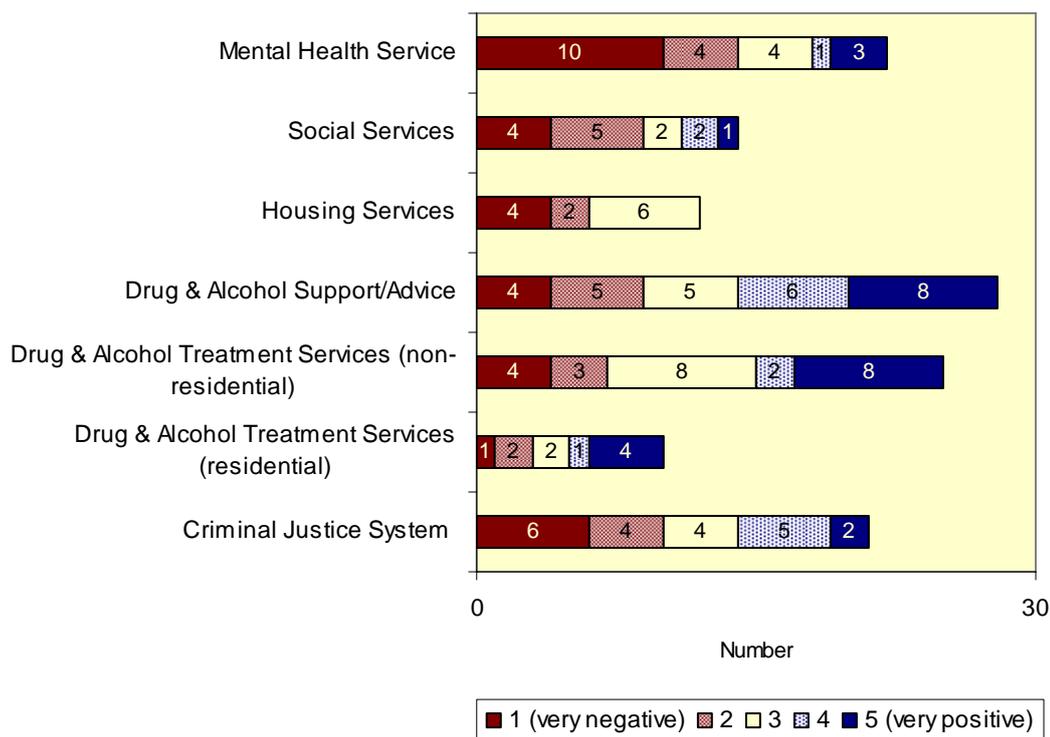
Base: 41 respondents

4.4.2 Respondents were asked to rate their own experiences of these services on a scale of 1 to 5, where 1 is 'very negative' and 5 is 'very positive'. The results show that the respondents have had mixed experiences of these services.

Key Findings

- No service received an overall positive rating (4 or 5 out of 5) from respondents.
- Drug & Alcohol Residential Treatment Services received the highest average positive rating (3.50).
- Housing Services received the lowest average rating (2.17).
- The largest number of respondents gave the Mental Health Services a negative rating. 10 respondents rated the service as 'very negative' (1 out of 5), while a further 4 respondents gave a negative rating of 2 out of 5. In contrast, only 4 respondents gave a positive rating (4 or 5 out of 5). The average score for respondents' experience of this service was 2.23.

Table 13: On a scale of 1 to 5, where 1 is 'very negative' and 5 is 'very positive', how would you rate your experience of these services as a carer/family member?



Service	1	2	3	4	5	N/A	Rating Average
Mental Health Service	10	4	4	1	3	14	2.23
Social Services	4	5	2	2	1	20	2.36
Housing Services	4	2	6	0	0	22	2.17
Drug & Alcohol Support/Advice	4	5	5	6	8	6	3.32
Drug & Alcohol Treatment Services (non-residential)	4	3	8	2	8	9	3.28
Drug & Alcohol Treatment Services (residential)	1	2	2	1	4	18	3.50
Criminal Justice System	6	4	4	5	2	16	2.67

Base: 40 respondents

4.4.3 Respondents were asked whether they had any further comments that they would like to add about their experiences of these services. 15 respondents took the opportunity to add further comments:

“When the service was run by Somerset Drug Service they were very helpful to me. When Turning Point took over that support declined dramatically for myself”.

“My frustrations with mental health team, almost tipped my own mental health to a dangerous level. This not only happened once, and was in the height of chaos, when trying to deal with horrendous circumstances”.

“No one seems to care”.

“Nobody will speak to you once the adolescent has become an adult. Nobody will listen”.

“Very little information/support for family members. No support for couples.”

“I wish the help was easier and more immediate”.

“Astounded to be told partner could control his drinking by Turning Point”.

“Difficulties when trying to give information - always being told about confidentiality even when not asking for information to be given back”.

“I was not involved or contacted throughout treatment. Condition was confidential”.

“My parents' experience [of services] has not been good and created a lot more stress”.

“Drug and alcohol treatment services: I would like my grandson to be able to talk to a children's counsellor so I asked my son to ask his key worker for a contact. He said he didn't know, so ask our GP. I did this about the end of August, he said he didn't know either but leave it with him and he would get back to me. I am still waiting.”

“It's a ball of confusion and a minefield trying to work out who can help what with all the leaflets and pamphlets and adverts everywhere”.

“Total lack of cohesion between these services.”

“Funding appears to be a huge problem. Treatment should be readily available, but in my experience there has been a delay”.

“I have only recently found out that I am classified as a carer as well as a parent. Previously I have had little support and dealing with my son has been difficult, now I have much more support and this has helped how I feel and engage with my son. Life is definitely much better with the carer support”.

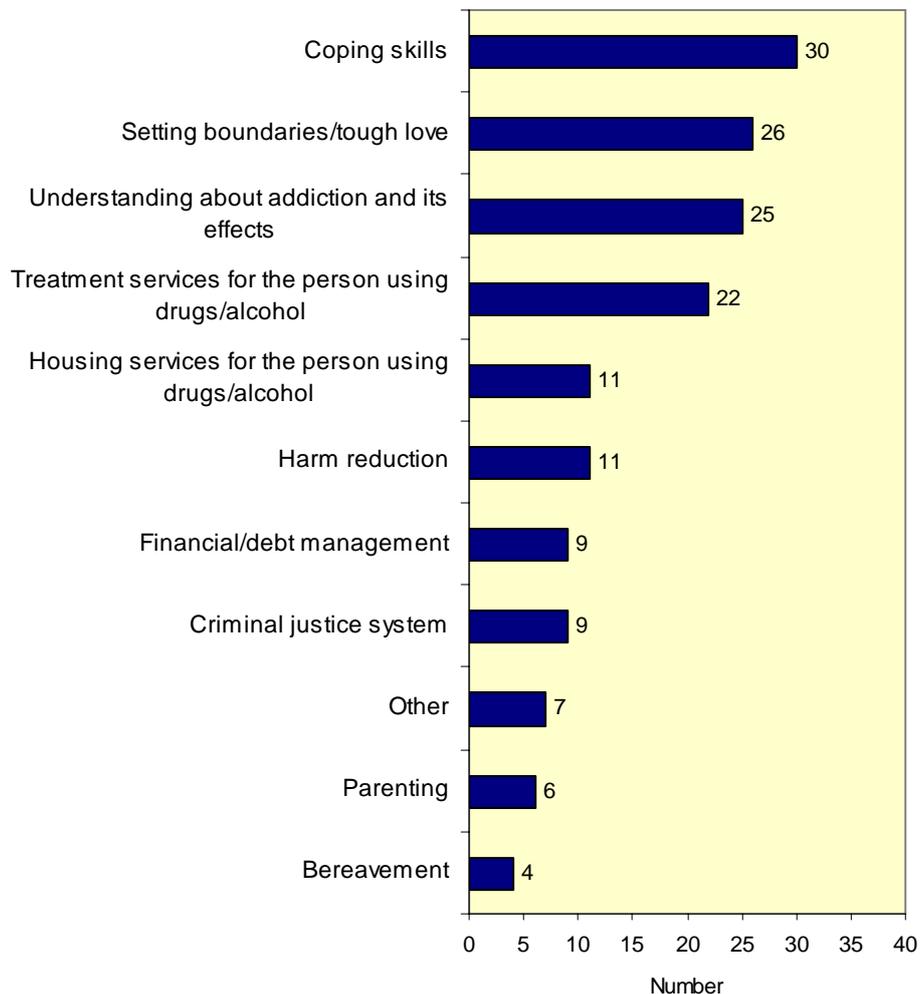
4.5 Information, Advice and Support for Carers and Family Members

4.5.1 Respondents were asked whether, as carer/family members, they felt that they would benefit from information, advice or support on a range of issues. They were presented with a list of 10 subjects and could add ‘other’ responses. By far the most popular subject, selected by 30 out of 41 respondents, was ‘coping skills’ (see Table 14 below). Other popular subjects, selected by over half of respondents, were ‘setting boundaries/tough love’; ‘understanding about addiction and its effects’; and ‘treatment services for the person using drugs/alcohol’.

‘Other’ responses added by respondents were:

- Crisis situations when the person is at risk of harm to self and others
- Counselling for the addict's young son
- Mental health information
- Better mental health advice
- Information re the cycle of addiction

Table 14: As a carer/family member, do you feel that you would benefit from information, advice or support on any of the following issues? If so, please tick all that apply.



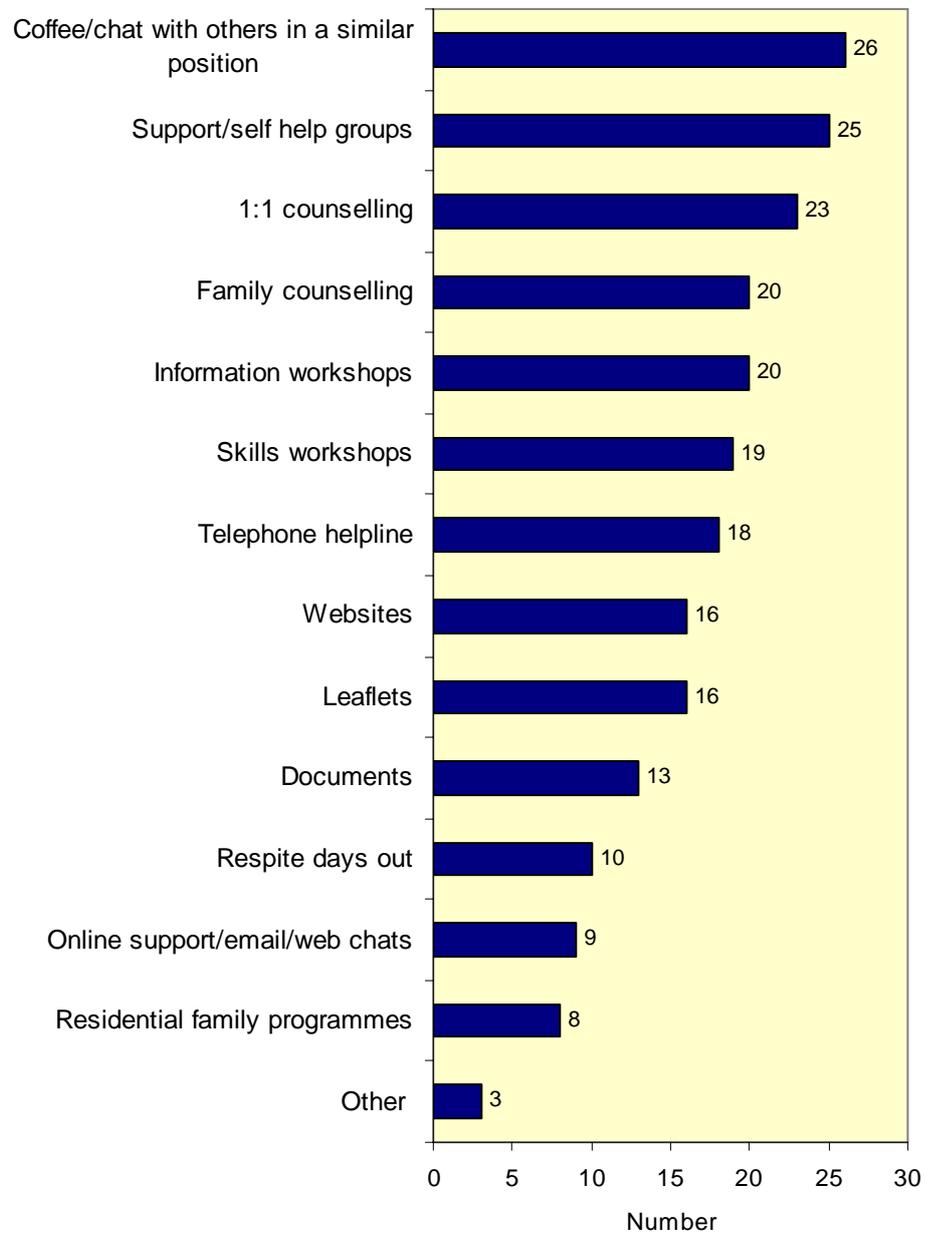
Base: 36 respondents

4.5.2 Respondents were asked to indicate the ways in which they would be interested in accessing information, advice or support. They were presented with a list of 13 options and could add 'other' responses. The results show that respondents would like to receive information, advice and support via a range of methods (see Table 15 below). The top three methods, selected by the majority of respondents were 'coffee/chat with others in a similar position'; 'support/self help groups'; and '1:1 counselling'. 'Family counselling', 'information/skills workshops', 'telephone helpline', 'websites' and 'leaflets' were also popular methods.

'Other' responses added by respondents were:

- Emergency contact numbers
- 1:1 counselling for the addict's son
- Opportunities to talk to other siblings

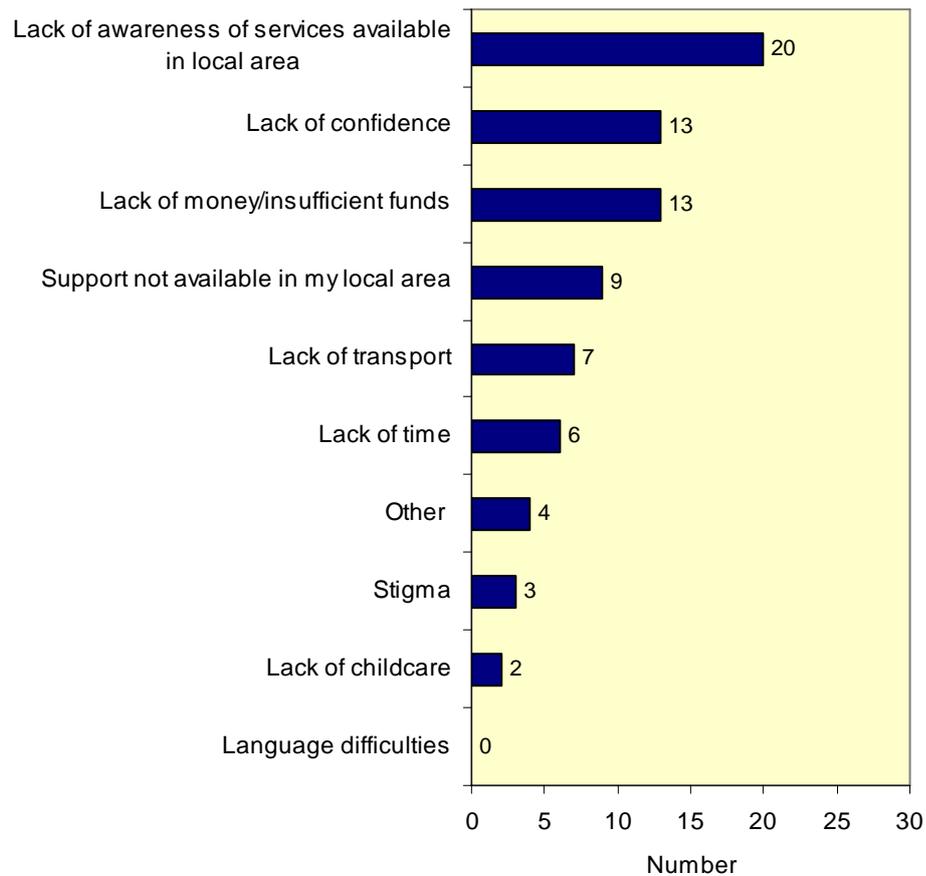
Table 15: Would you be interested in accessing information, advice or support via any of the following methods? If so, please tick all that apply.



Base: 38 respondents

4.5.3 Respondents were asked whether there were any barriers preventing them from accessing information, advice or support. They were presented with a list of 9 potential barriers and could add 'other' responses. By far the most common barrier, selected by 20 respondents, was 'lack of awareness of services available in the local area'. The next most common barriers, selected by 13 respondents each, were 'lack of confidence' and 'lack of money/insufficient funds' (see Table 16 below).

Table 16: Are there any barriers that prevent you from accessing information, advice or support? If so, please tick all that apply.



Base: 31 respondents

4 respondents added the following comments about the barriers that they have experienced:

“Once again, lack of cohesion between services”.

“‘Relevant’ information is the problem”.

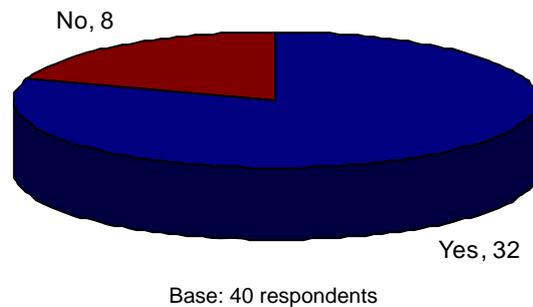
“Neither my son's key worker or my GP seem to know anything about a children's counsellor though I have heard it mentioned in the support group I go to”.

“I have made it my 'mission' to FIND help for myself”

4.6 Seeking Information, Advice and Support

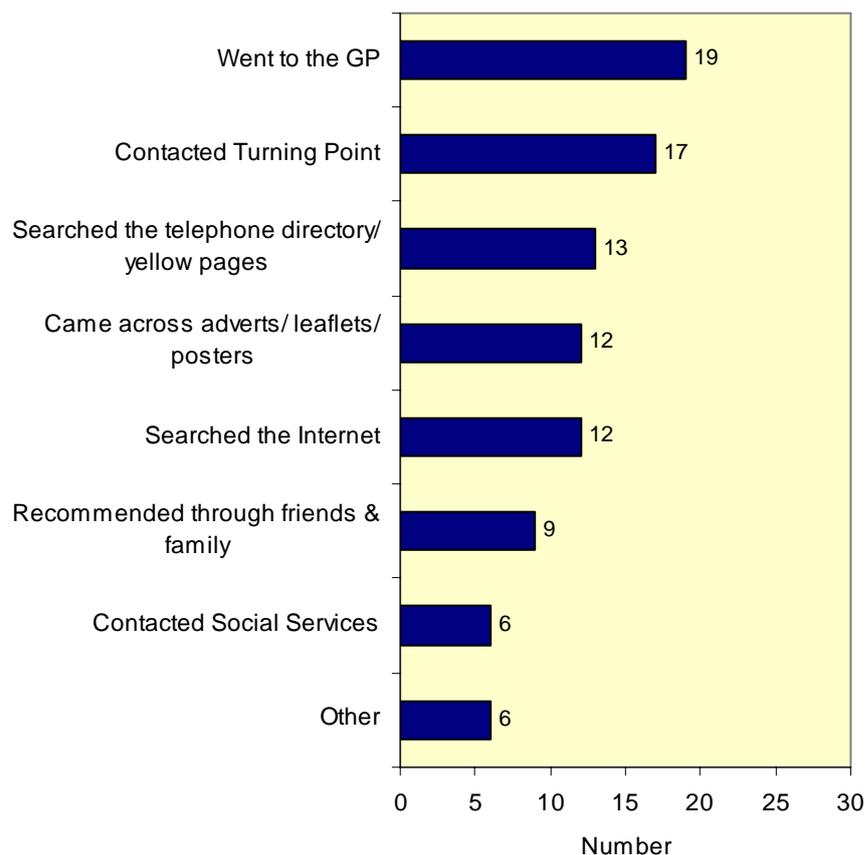
4.6.1 When asked whether they had ever sought information on support services in the local area for carers and family members, by far the largest majority of respondents replied in the affirmative (see Table 17 below).

Table 17: Have you ever sought information on support services in the local area for carers and family members?



4.6.2 Respondents were asked to indicate from where they had sought information. They were presented with a list of 7 options and could add 'other' responses. The two most common responses, selected by just over half of respondents, were 'went to the GP' and 'contacted Turning Point'. Other popular responses were 'searched the telephone directory/Yellow Pages', 'came across leaflets/posters' and 'searched the Internet' (see Table 18 below).

Table 18: How did you seek information on support services for carers and family members? (Please tick all that apply) (Base: 32 respondents)

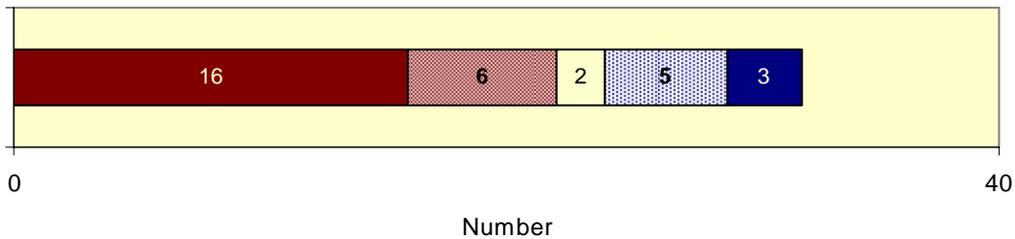


'Other' responses added by respondents were:

- Contacted Mental Health Services/Somerset Partnership (3 respondents)
- Recommended through work
- Via attendance at a day long workshop and various public meetings
- Turning Point signposted to Broadway Lodge. The latter then signposted to Families Anonymous

4.6.3 Respondents were asked to rate their experience of trying to find information about support services for carers and family members on a scale of 1 to 5. By far the most common rating, given by 16 respondents, was 1 out of 5 ('very difficult'). The average rating score for this question was 2.16.

Table 19: On a scale of 1 to 5, where 1 is 'very difficult' and 5 is 'very easy', how would you rate your experience of trying to find information about support services for carers and family members?



■ 1 (very difficult) ■ 2 ■ 3 ■ 4 ■ 5 (very easy)

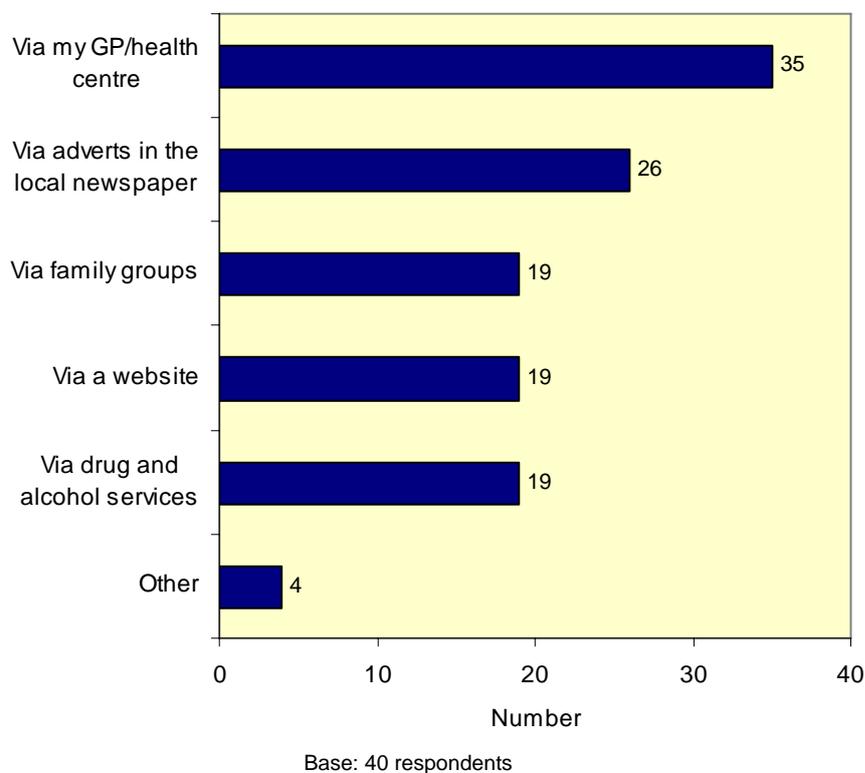
1 (very difficult)	2	3	4	5 (very easy)	Rating Average
16	6	2	5	3	2.16

Base: 32 respondents

4.6.4 Respondents were asked to indicate what would be the best ways, in their opinion, of reaching carers and family members and informing them of support services available in the local area. They were presented with a list of 5 options and could add 'other' responses. All five options were popular with respondents, indicating that there are a range of ways in which services can reach carers and family members. However, by far the two most popular options, selected by 35 and 26 respondents, respectively, were 'via GPs/health centres' and 'via adverts in the local newspaper' (see Table 20 below).

'Other' responses added by respondents were via 'Mental Health Teams'; 'Local radio and TV'; 'Email', and 'Door-to-door leaflet drops'.

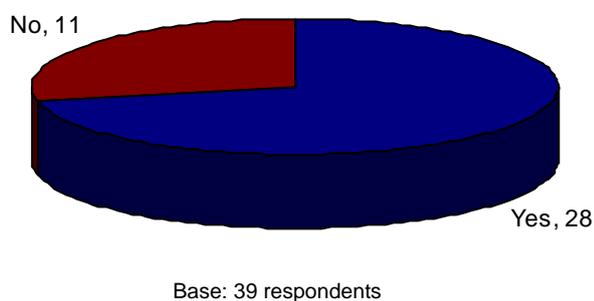
Table 20: In your opinion, what would be the best way(s) to reach people, such as yourself, and inform them of support services available in the local areas? (Please tick all that apply)



4.7 Accessing Services for Carers and Family Members

4.7.1 When asked whether they had accessed services for carers and family members, the majority of respondents replied in the affirmative.

Table 21: Have you ever accessed support services for carers and family members?

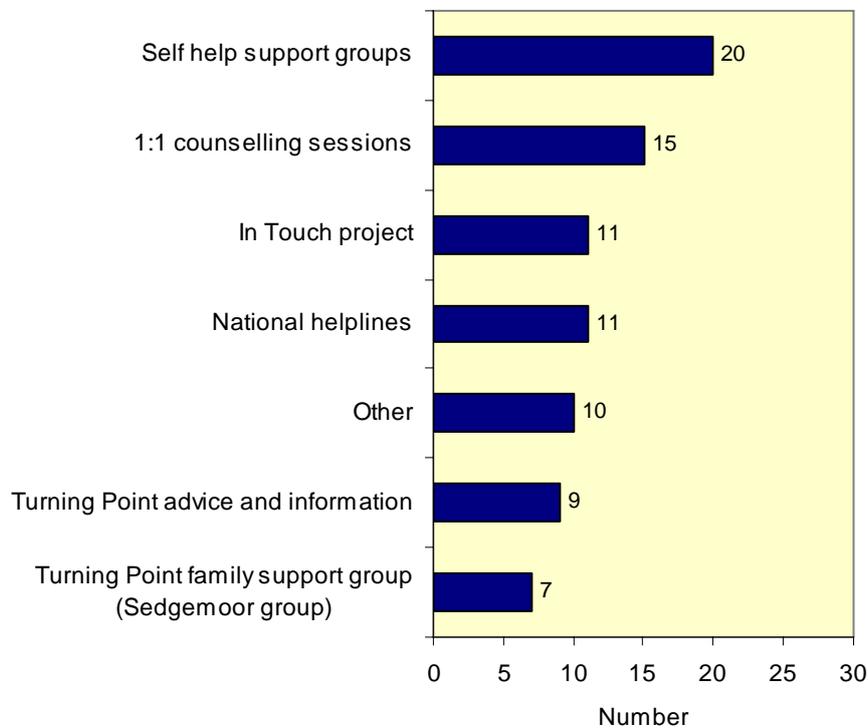


4.7.2 The respondents that had replied in the affirmative were asked to indicate the services that they had accessed. They were presented with a list of 6 options, and could add 'other' responses. The most common support service, selected by the majority of respondents, was 'self help groups' (see Table 21 below).

'Other' responses added by respondents were:

- Family programme at Broadway Lodge (2 mentions)
- Al Anon/AA (3 mentions)
- Action on Addiction
- McGarvey Fellowship, Wells
- Family therapy
- Families Plus
- Carer's assessment – Mental Health Service
- Occupational Health
- Rethink

Table 21: Please tell us which type(s) of support services you have accessed.



Base: 28 respondents

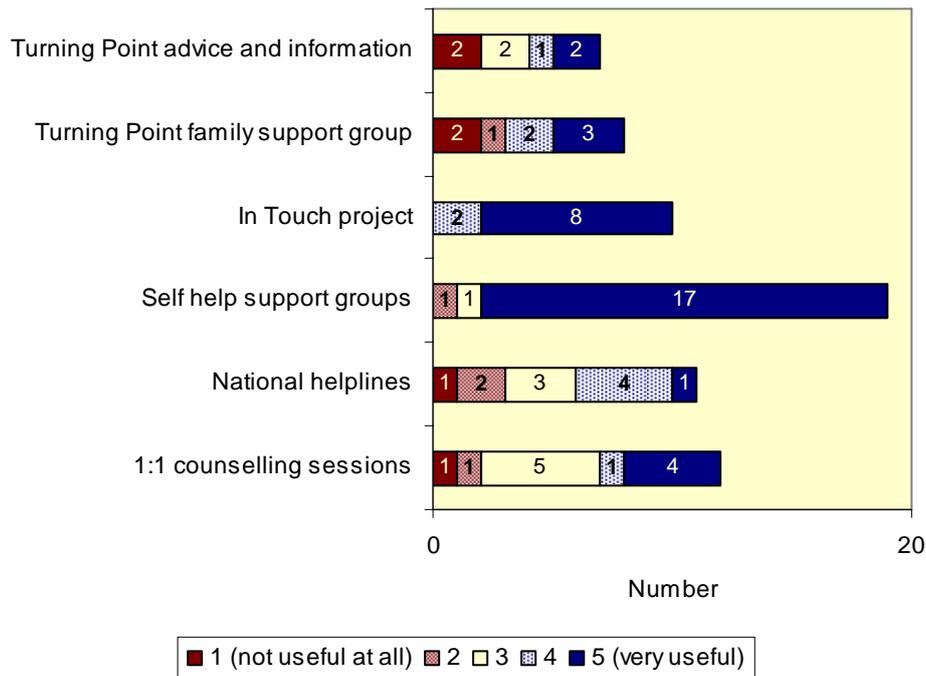
4.7.3 Respondents were asked to rate how useful they had found the services they had accessed on a scale of 1 to 5, where 1 is 'not useful at all' and 5 is 'very useful'. Self help support groups and the In Touch Project received by far the highest positive rating. 17 of 19 respondents rated self help groups as 'very useful' (5 out of 5), while 8 out of 10 respondents rated the In Touch Project as 'very useful' (see Table 22 below).

'Other' services added by respondents and given a rating of 5 out of 5 were:

- Family programmes at Broadway Lodge' (2 respondents rated this service as 'very useful')

- Al Anon
- Family Therapy
- Families Anonymous
- Families Plus

Table 22: How useful have you found the support services that you have accessed? Please rate each service on a scale of 1 to 5, where 1 is 'not useful at all' and 5 is 'very useful'.



Service	1	2	3	4	5	Rating Average
Turning Point advice & information	2	0	2	1	2	3.14
Turning Point family support group	2	1	0	2	3	3.38
In Touch project	0	0	0	2	8	4.80
Self help support groups	0	1	1	0	17	4.74
National helplines	1	2	3	4	1	3.18
1:1 counselling sessions	1	1	5	1	4	3.50

Base: 26 respondents

4.7.4 Respondents were asked whether they had found any services particularly useful and, if so, to name the service and explain why they found it useful. 12 respondents mentioned that they had found **self-help groups** (notably **Families Anonymous** and **Al-Anon**) particularly useful, as these groups put them in touch with people that have experienced similar situations; make them aware that their situation is not unique; understand the impact that a person's drug/alcohol use can have on a carer's life; and share the same problems and fears. One respondent mentioned that they found Families Anonymous particularly useful as

they have a 12 step programme for carers and a rotating leader in recognition of the fact that “no one person is the expert” and that “everyone’s experience is invaluable to all”.

9 respondents mentioned that they had found the **In Touch Project** particularly useful. They valued the support given by the Project in a range of areas, including:

- One-to-one coffee meetings
- Opportunities to talk to someone that has shared similar experiences, who understands, can empathise and offer useful advice
- Supply of useful literature
- Educational workshop arranged by the Project on setting boundaries

“After several years have found the In Touch Project who take the time to listen”.

“In Touch, they meet me first on a one to one, no pressure, but plenty of info/options of where I could go to get support.”

“Coffee meetings with In Touch Project - the support invaluable. So much help is needed.”

“In Touch offered immediate one to one personal empathic support from someone in the same situation I was going through”.

“The In Touch Project - the lady I saw was & still is very caring and is always available to contact by phone. She has sent me useful information too by post”.

“In Touch Project - all problems answered in one place, help with who to contact for what problem”.

The following services each received one mention by a respondent that had found them particularly useful:

- Turning Point Family Group (useful for meeting others in a similar situation)
- Turning Point Advice & Information (staff “very helpful and supportive”)
- Somerset Partnership Carers Groups & Family Therapy
- Workshop courses run by the Mental Health Services
- 12 Step residential for carers at Broadway Lodge
- Extra Drug Project based in Blandford
- On The Level, Wells (described by one respondent as “efficient, understanding, broad minded, and considerate of mental health issues”)
- Police at beat level (described by one respondent as “very understanding when situation explained” [re. son’s mental health problems]).
- One respondent commented that their “Local Carer Support Co-ordinator has been wonderful, which has made my [life] much easier to live”.
- Another respondent explained that they have found “advice on coping with difficult behaviour” particularly useful, as well as the Carer Assessment

Worker and Community Psychiatric Nurse who have “listened non-judgementally”.

4.7.5 Respondents were asked whether they had accessed any services that had not been very useful and, if so, to name the service and explain why they were not useful.

Six respondents mentioned that they had not found Turning Point to be very helpful when approached for information, advice or support. Two respondents specifically mentioned that Turning Point had not informed them of support groups, such as Families Anonymous.

Four respondents mentioned that their GP/Doctor’s Surgery had not been very helpful. Two of the respondents were disappointed with the approach taken by their GP:

“GP had a ‘does not like drug use, it is wrong, therefore deal with it yourself’ attitude”.

“GP couldn’t help me even though I was crying in his office. Said there was a waiting list but I could see a psychiatric nurse re depression!!!”

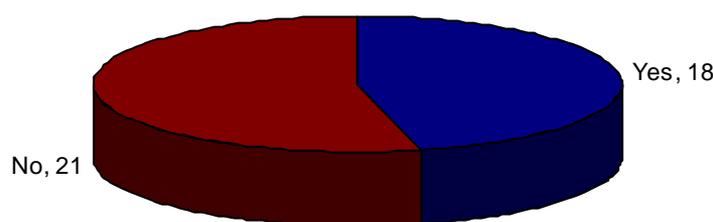
The following services each received one mention by a respondent that had not found them very useful:

- Social Services (“quoted the Data Protection Act so couldn’t/wouldn’t help”).
- Frank (“played down problem”).
- Drug Service in Glastonbury (“My daughter and her partner decided to seek help for themselves in Glastonbury, they were turned away because they weren’t taking anything other than cannabis. But I’ve witnessed cannabis destroy both of their lives”).
- Sompar Mental Health Service (one respondent mentioned that their experience of this service was very negative).

4.8 Carers’ Assessments

4.8.1 When asked whether they were aware of carers’ assessments, just under half responded in the affirmative (see Table 23 below).

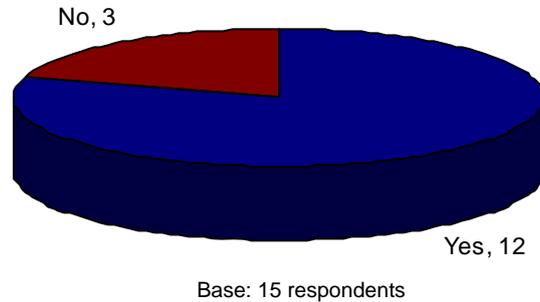
Table 23: Are you aware of carers’ assessments?



Base: 39 respondents

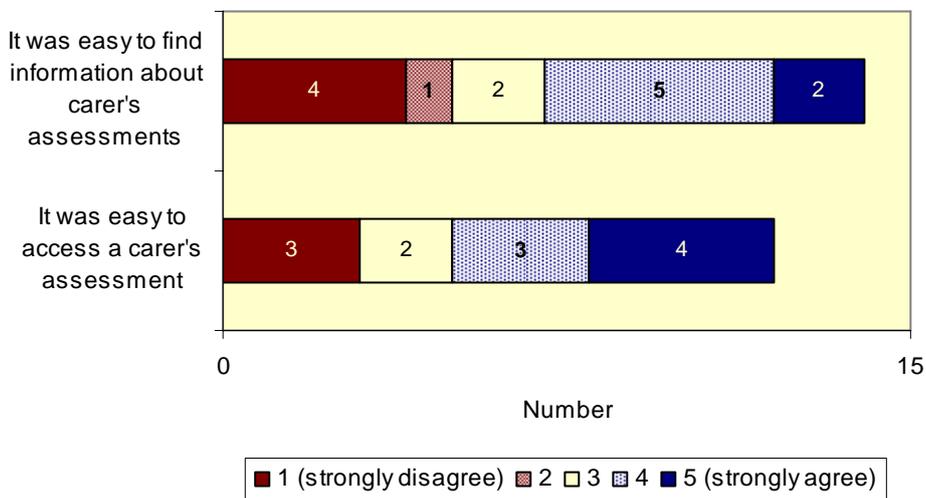
4.8.2 Those respondents that indicated that they were aware of carers' assessments were asked whether they had ever tried to access one. 12 respondents replied in the affirmative.

Table 24: Have you ever tried to access a carers' assessment?



4.8.3 Those respondents that had tried to access a carer's assessment were presented with two statements and were asked to indicate on a scale of 1 to 5 how much they agreed with the statements (where 1 is 'strongly disagree' and 5 is 'strongly agree'). The results show that respondents have had mixed experiences in terms of the ease in which they have been able to find and access a carer's assessment (see Table 25 below).

Table 25: If you have accessed a carers' assessment, please indicate how much you agree or disagree with the following statements...



Answer Options	1	2	3	4	5	Rating Average
It was easy to find information about carer's assessments	4	1	2	5	2	3.00
It was easy to access a carer's assessment	3	0	2	3	4	3.42

N.B. Caution must be taken when using these figures due to the very low base number

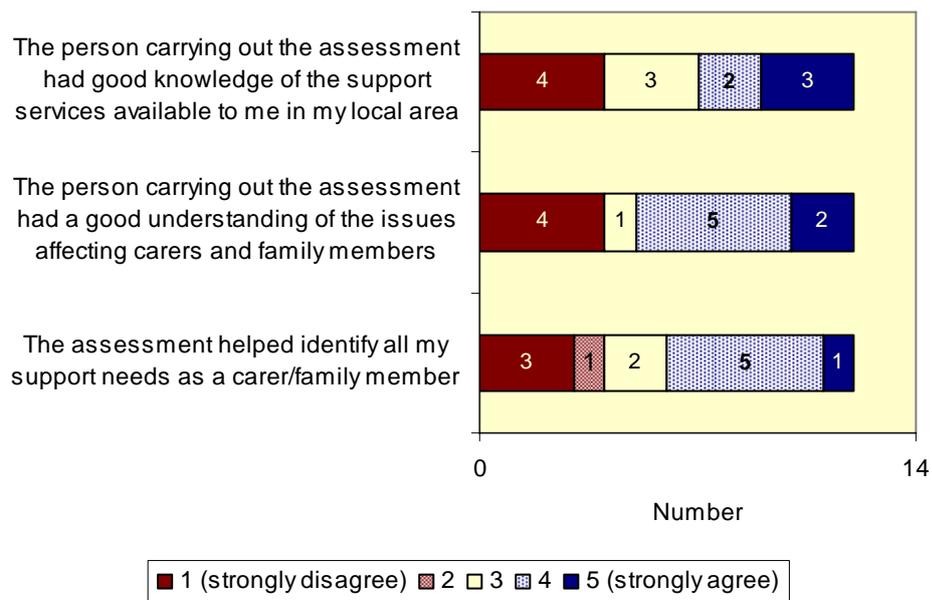
Base: 14 respondents

4.8.4 When asked whether they had already had a carer's assessment, 12 respondents replied in the affirmative. These respondents were presented with 3 statements regarding their experience of the assessment and were asked to indicate on a scale of 1 to 5 how much they agreed with the statements. The 3 statements were:

- The assessment helped identify all my support needs as a carer/family member
- The person carrying out the assessment had a good understanding of the issues affecting carers and family members
- The person carrying out the assessment had good knowledge of the support services available to me in my local area

The results show that respondents have had mixed experiences of carers' assessments. All 3 statements received an average rating score of 3 out of 5 (see Table 26 below).

Table 26: If you have already had a carer's assessment, please indicate how much you agree or disagree with the following statements...



Answer Options	1	2	3	4	5	Rating Average
The assessment helped identify all my support needs as a carer/family member	3	1	2	5	1	3.00
The person carrying out the assessment had a good understanding of the issues affecting carers and family members	4	0	1	5	2	3.08
The person carrying out the assessment had good knowledge of the support services available to me in my local area	4	0	3	2	3	3.00

N.B. Caution must be taken when using these figures due to the very low base number

Base: 12 respondents

4.8.5 Respondents were asked whether they had any further comments that they would like to add about their experience of accessing, or trying to access, a carer's assessment. 5 respondents provided the following comments on their experiences:

"I'd never hear of it until I was in a crisis, and I happened to choose a number on a card I was given and it just happened to be the number of a care assessment worker. Nothing had ever been explained to me before, this was 11 years of suffering the situation before any sort of help".

"I only requested a carers assessment by the mental health team because I needed someone to put in writing the concerns I had about my son. Nobody was listening to the concerns I had about him killing himself or someone else".

"My carers assessment worker didn't seem to have any knowledge of the affects of addiction on the family".

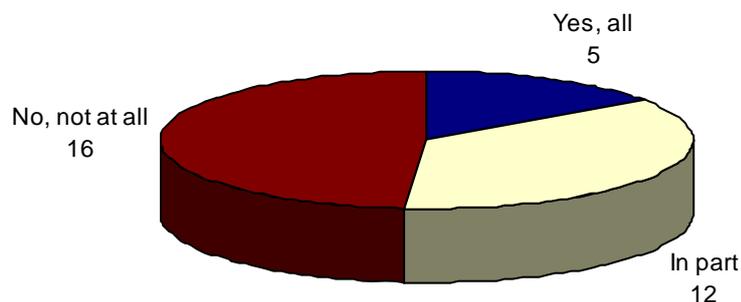
"Carers assessment [worker] was understanding but was not allowed to help pursue relevant therapies".

"Have heard from others it is very difficult to get an assessment".

4.9 Supporting the Needs of Carers and Family Members

4.9.1 Respondents were asked to indicate whether their support needs have been met by the current service provision in their local area. 33 carers/family members responded to this question. Only 5 respondents indicated that all their support needs had been met, while 12 respondents indicated that their needs had been met 'in part'. Around half of respondents (16 in total) indicated that their support needs had not been met at all.

Table 27: Have your support needs been met by the current service provision in your local area for carers and family members?



Base: 33 respondents

4.9.2 Those respondents whose service needs had not been met by the current provision were asked to identify the gaps in services for carers and family

members in their local area. 18 respondents identified a number of gaps in services, including:

- The need for regular support group meetings in their local area. One respondent mentioned that their nearest group is located 26 miles away.
- Easy access to help for those in crisis.
- Emotional support for carers and family members.
- Support to enable carers and family members to get on with their own lives.
- Information and advice on how to support someone using drugs/alcohol and how to look after oneself.
- Workshops for carers and family members on a variety of subjects.
- Not enough advertising of the problem or information made available about support services for carers/family members. Some carers/family members are not aware of any services available in their local area.
- Services need to know more about issues wider than alcohol or drugs e.g. housing, police, domestic abuse and how they could help.
- Access to a counsellor for children with parents that use drugs/alcohol.
- Financial assistance for private treatment.

Four respondents mentioned the following gaps in services for the person they care for:

- Alcohol treatment programs
- “Psychological therapy for our son”
- “Accommodation for my son so he can move out and become independent”.
- “Lots of promises, no follow through on therapies i.e. CBT etc for client”

4.9.3 Finally, respondents were asked whether they had any further comments that they would like to add about their support needs as a carer/family member or their experiences of access services. 17 respondents took the opportunity to comment:

“When things were really bad I needed someone to listen and direct me to anything that would help me and my family. I felt very alone because there wasn't enough on offer to me. My first port of call was to my GP who put me on antidepressants and told me to kick my son out! That wasn't helpful to me at that time”.

“Used to hide away from the world because [of how] I felt, now I try to help others who feel and share such problems. There has to be a more forward thinking plan. Families are torn apart and lives ruined”.

“I am very vulnerable and need counselling to help with this”.

“I would like another carers assessment”.

“Frustration of trying to get help compounded problem. Frustration of Mental Health team left many scary moments! Mental health of several other people affected by trying to cope!”

“Much more information, help and support is needed and made easier for people to find”.

“I did not know that a parent could be classified as a carer and therefore have struggled with my son on my own which has made family life for my other two sons difficult and they now have nothing to do with him. It is a shame that we did not get help sooner and then maybe the family would still be together. It is difficult for me being “piggy in the middle”; and very stressful. The stress has had a great impact on my life and I am only now getting help which has improved my health and well being greatly. It is a pity that it did not happen sooner!!”

“If services worked more together and were willing to do this, then much more could be achieved. Also I feel that many workers for the drug/alcohol user have very narrow attitudes regarding family members”.

“People do not always listen to family members, they ignore what you say. My son might be alive today if action had been taken, when I tried to get it for him”.

“Experience has been an absolute disaster [...] Carers are often reluctant to complain as they fear even less help will be forthcoming”.

“Discussion would be a start - with people who have 'been there’”.

“I think informal coffee mornings, or one to one meetings for coffee would help those like myself that did not feel able to enter a group of strangers first time. Also an online service, like msn, where people can talk to counsellors in real time, with anonymity, as an introduction to meeting. Sharing thoughts/feelings with those going through the same thing, rather than 'counsellors' so perhaps a helpline/email to other family members, i.e., “call Jane on 000444”; rather than AA or Turning point. I think it is less intimidating for those encountering this for the first time”.

“Would prefer non-statutory support from those with personal experience”.

“Just that it is great to talk to someone who can answer all queries without saying “can't, you have to see this person”; end up going around in circles most of the time”.

“Without the support of the carers group I would have found it difficult to know which services were accessible to carers”.

“Apart from close friends and family who sympathise, I don't feel I know what to expect from services”.

“After a while you begin to hear the same mantras all the time and lose hope. In other words if the young person isn't prepared to seek help there is nothing you can do. I feel my life has been put on hold for the last 4 years and I don't see any way out”.

Chapter 5 Group Discussion with Family Members

Arrangements were made for a researcher to attend the Turning Point Sedgemoor Family Group meeting on 2nd December 2008 in order to discuss the support needs of carers and family members. At this particular meeting, there were only two family members in attendance. Both group members were willing to participate in the discussion. This chapter provides a summary account of the key points raised by the family members regarding support needs in Somerset.

- 5.1 When discussing the availability of support services for carers and family members in the county, it was mentioned that the main form of support available was group meetings. It was mentioned that there are a number of good self help groups available in the county, including Al-Anon and Families Anonymous. It was recognised that this form of support will not be suitable for everyone, plus it can be extremely daunting to attend a group for the first time. One family member explained that it can be petrifying to walk into a room full of strangers and participate in discussions on an issue that is so personal and emotionally sensitive. To attend these groups, one needs to feel confident and have a lot of courage; both of which family members often lack.
- 5.2 One of the real gaps in support identified by the family members was a process for easing someone into a support group. Prior to attending a group meeting for the first time, most carers/family members need reassurance and opportunities to build their confidence. Many would appreciate an informal meeting (i.e. 'coffee and chat') with someone in a similar position to them; someone who could perhaps attend the first meeting with them in order to make the experience less daunting. One of the family members explained that she would not have had the confidence to attend the group, had she not had an initial 1-2-1 meeting with a volunteer from the In Touch Project and someone to accompany her the first time.
- 5.3 Some carers/family members are also put off attending support groups due to the fear of being recognised by someone they know. The availability of groups outside their immediate local area can help to overcome this barrier.
- 5.4 The family members mentioned that there are many barriers preventing people from joining groups and barriers preventing people from staying. The structure of groups varies and does not always suit everyone. Getting the balance right for the largest number of family members can be a delicate process.
- 5.5 In addition to self help groups, the family members suggested that a telephone helpline and web/email support could be really useful. These forms of support are easy to access; they do not require appointments or for the person to wait until the next group meeting (often the next month) in order to get in touch with someone for information, advice or simply a chat.

- 5.6 When asked to identify what carers and family members need from a support service, the family members mentioned that they need a service that helps to empower them and build their confidence. They want easy access to information and they want to learn skills to help them cope with their situation. They also want to be able to “off load” and talk about their issues. It is important to simply have someone available that listens and understands what they are feeling.
- 5.7 With regards to support groups, the family members felt that it was important to have a facilitator that is experienced, sensitive, understanding, friendly, and easy to talk to. The group members need to feel that they can talk openly and honestly. They need to feel welcomed into the group and valued. One family member mentioned that it can be useful to have someone facilitate the group that has personal experience. This can help the family members feel that the facilitator really understands. The family members felt that it was important to provide a balance between ‘offloading’ and learning new skills (such as coping strategies), otherwise a person can leave a group meeting feeling worse than when they arrived! It was mentioned that it is useful when groups set an agenda for subsequent meetings or organise a programme of topics for discussions/talks, so that group members can see what is going to be covered in the meetings and what they are going to learn.
- 5.8 One family member mentioned that it would be useful to develop a support programme, in a similar way to drug users receive their treatment. She felt that there needs to be a systematic approach to supporting carers and family members, from establishing their individual needs to providing emotional support and appropriate information on the complex issues that are affecting them. There should be a unique plan of action for each individual. There should also be a one-stop-shop; a single point of contact where their needs are dealt with in a holistic way. Agencies need to work together and ensure that they can signpost to relevant services, such as housing, support for domestic violence, legal advice, relationship support and advice, etc. She stressed that the issues that carers and family members experience are very complex and cross-cutting, and often need intervention from a wide range of services.

Chapter 6 Concluding Comments

- 6.1 National and local research has revealed that a person's substance misuse problems can have a devastating impact on the lives of carers and family members. It can affect many aspects of a person's life, including their mental and physical health, finances, employment, relationships with family and friends, and children. The Somerset survey has shown that many carers and family members have also experienced verbal and physical abuse as a result of a person's drug/alcohol use. The survey also highlighted how a person's substance misuse problems can affect multiple lives, including those of parents, siblings, children and family friends.
- 6.2 There is a wealth of relevant national policies, strategies and guidance that provide a strong basis for commissioning support services for carers and family members affected by someone else's substance misuse, and involving carers and family members in planning services and the process of treatment. National guidance acknowledges that there is an urgent need for dedicated support services for carers and family members due to the significant negative impact that drug misuse can have on their mental and physical health and wellbeing. However, there are also clear messages emerging from research that support for family members and carers can have a significant, positive impact on the engagement and retention of users in treatment services, the outcomes from treatment, sustainability of treatment outcomes, and outcomes for whole families.
- 6.3 National guidance recommends that a range of local, dedicated support services should be available to carers and family members in recognition of the specific issues that these people experience as a result of someone else's substance misuse problems. The guidance states that these services need to be available to **all** carers and family members, regardless of whether the person affected by substance misuse is receiving treatment. It is often the case that a person with substance misuse problems will fail to admit that there is a problem or refuse to seek treatment. Carers and family members should not be excluded from accessing support services simply because the person with substance misuse problems is not receiving treatment.
- 6.4 At present, the availability of support services for carers and family members in Somerset is very limited. However, the recent commitment by Somerset County Council and Somerset DAAT to provide funding means that there is great potential to plan and develop a range of quality services that meet the support needs of carers and family members in the county.
- 6.5 There is also currently a lack of clarity regarding the carers services available in Somerset and whether they are accessible to carers looking after someone with substance misuse problems. This issue is compounded by the different definitions of carers adopted by different agencies in the county. Unlike the national Carers Strategy 2008, the definition of carers included in the Somerset Multi-Agency Carers Strategy 2008-2011 does not make reference to carers looking after someone with substance

misuse problems, which makes it unclear as to whether the strategy applies to this group of carers.

- 6.6 The Somerset survey revealed that carers and family members have had mixed experiences of their contact with services that support people with substance misuse problems. While some have found the services to be supportive and helpful, others have been disappointed by the way in which service staff have interacted with them. A number of family members that participated in this study mentioned feelings of being “ignored”, “not listened to” or “being low priority”. Carers and family members can be incredibly vulnerable at the time when they contact a service. It is important that staff are fully aware of the issues that carers and family members can be experiencing; they need to have the skills to interact with them in a sympathetic and non-judgmental way, and the knowledge to be able to offer relevant information, advice and support.
- 6.7 The carers that participated in this study also reported mixed accounts of their experiences of accessing a carer’s assessment. Some felt that the person conducting their assessment had little knowledge of the effects of drugs and alcohol on family members while, in some cases, carers mentioned that their assessment had not resulted in any action, such as signposting or referral to relevant services. It is vital that the new carer’s assessment service takes into account this feedback and ensures that the staff conducting the assessments are fully trained in how to support carers and knowledgeable of the services available to this group of carers in the county, including those delivered by the voluntary and charity sector.
- 6.8 The Somerset survey demonstrated how difficult it can be to access information relevant to carers and family members affected by someone else’s substance misuse problems, including information on support services available in their local area. At present, information is scattered and produced in different formats by different agencies, which makes it very difficult to work out what services are available and who is entitled to access them. As previously mentioned, different agencies in Somerset also use different definitions of the term ‘carer’, which is confusing for those seeking information. In light of this, it would be beneficial to review carer definitions, literature and web-based information provided by Somerset agencies in order to provide easy access to relevant information for the end user.
- 6.9 The study findings have revealed the need to ensure that agencies in Somerset that support carers and family members work closely to ensure that they provide a joined-up, seamless service. It is particularly important that the Somerset Partnership NHS Foundation Trust and Turning Point have a close working relationship due to the fact that both agencies support people with dual diagnosis and their carers. The finalisation of the dual diagnosis joint working protocol (which is currently being developed by the Trust and Turning Point) will assist in bringing greater clarity to this working relationship.
- 6.10 The Somerset survey revealed that carers and family members would value information, advice and support on a range of subjects, including coping strategies; setting boundaries; understanding about addiction and its effects; and treatment options for the

person using drugs/alcohol. Popular ways in which carers/family members would like to receive this information, advice and support is via informal meetings with others in a similar position (i.e. 'coffee and chat'); support/self help group meetings; 1:1 and family counselling; workshops; telephone helplines; leaflets; and websites.

- 6.11 In terms of existing services available for carers and family members in Somerset, self help/support groups and the In Touch Project are particularly favoured. Popular self help groups accessed by carers and family members in Somerset include Families Anonymous ('FA') and Alcoholics Anonymous ('Al-Anon'). One of the key features of self help/support groups and the In Touch Project that appeals to carers and family members is the fact that they provide opportunities to meet others that have shared similar experiences and understand what they are going through.
- 6.12 When asked whether there were any barriers preventing them from accessing information, advice and support, the most common responses from carers/family members that participated in the survey was a 'lack of awareness of services available in the local area.' This finding highlights the need to raise awareness of support services available in Somerset. According to the Somerset survey, the best ways of reaching carers and family members and informing them of support services are via GP surgeries/health centres and adverts in the local papers. Other popular methods are via family groups; drug and alcohol services; and websites.
- 6.13 Another common barrier preventing carers and family members from accessing services is a lack of confidence. For many, the prospect of contacting a drug and alcohol service or attending a support group can be very daunting. The survey revealed that many carers and family members would prefer opportunities to initially meet with someone on a one-to-one basis in an informal setting, such as a coffee shop or at home. This is a service that the In Touch Project is currently able to provide on a small-scale.
- 6.14 The Somerset survey also revealed that a lack of finances prevents a number of carers and family members from accessing the services they need. This finding highlights the need to ensure that support services are free and easy to access, so that they are affordable to all.

Chapter 7 Recommendations

This section provides recommendations on the ways in which the Somerset DAAT Partnership can help to meet the support needs of carers and family members in the county. The recommendations are based on the carers and family members survey, staff interviews and discussion, and national guidance.

7.1 Develop a range of integrated and personalised services in Somerset to ensure that carers and family members can access the support they need.⁵ This includes:

- 7.1.1 Access to quality, up-to-date information specific to substance misuse and addiction, as well as wider issues such as domestic violence, housing, benefits, employment, finances, legal rights, and services available in the local area for those with substance misuse problems and their carers and family.⁶
- 7.1.2 One-to-one support services, including counselling and a dedicated Support Worker.
- 7.1.3 Telephone helpline (available for extended hours, including evenings and weekends).⁷
- 7.1.4 Peer support, including regular family group meetings, a 'buddying service', and opportunities to meet others in informal settings (e.g. 'coffee and chat'). This could build on the existing work of the In Touch Project, which is highly valued by family members.
- 7.1.5 Family support services, including family therapy.⁸
- 7.1.6 Regular programme of workshops and courses on a range of subjects, including coping strategies, setting boundaries, and understanding about addiction and its effects.

⁵ **We Count Too** is a valuable reference when developing services for carers and family members as it provides quality standards and a wealth of good practice examples. The NTA guidance for commissioners on **Supporting and involving carers** (2008) provides a wealth of information relating to all aspects of commissioning services for carers and family members, including details of areas where providers can usefully collect data and aspirations for delivery can be set.

⁶ The research report prepared by Research Works Ltd for COI Communications on behalf of the Home Office and Adfam entitled **Information Resources for 'Family' Members who are Supporting Drug Users** is a useful resource when developing literature targeted at family members.

⁷ A number of telephone helplines already exist at the national and local level. It would be useful to review the extent to which these helplines can support carers and family members in Somerset prior to setting up a dedicated helpline.

⁸ It is important to bear in mind that domestic violence and aggression accompany many instances of drug or alcohol misuse. **The Stella Project** is a source of expert guidance on this subject. It advocates that it is unsafe to offer couples counselling or family based network therapies where domestic violence exists (see www.gldvp.org.uk). **Relate** has been developing policy in this area for the past five years and has procedures in place to ensure safe working with couples (such as seeing all couples separately to ask about domestic violence regardless of whether it has been disclosed in a joint session).

7.1.7 Opportunities for respite, including away breaks, access to complementary therapies, and social events.

Key issues to consider:

- Carers and family members need to be able to access support whenever they need it, particularly at times of crisis.
- All carers and family members should have access to support, regardless of whether the person is receiving treatment.
- Services need to be within easy reach of carers and family members across the county, including those with mobility problems or without private transport. In a large, rural county such as Somerset, there will be a particular need to develop outreach services.
- Relevant services need to be available for different carer groups, including grandparents, partners, children and young people, and people from BME communities. It is recommended that a strategy for developing access to services for carers and family members from BME communities be developed in conjunction with the Somerset REC.
- If Turning Point is to deliver Somerset's support service for carers and family members, it is vital that it has the relevant resources to provide this countywide service. Carers and family members need to be able to access a service that is specifically dedicated to them. One of the risks of a drug and alcohol treatment provider delivering a carers and family members service is that carers and family members may feel that their support needs are second to those of substance misusers. This risk needs to be borne in mind and mitigated when developing the new Somerset carers and family members service.

7.2 Improve access to information about support services available for carers and family members in Somerset.

7.2.1 Information needs to be comprehensive: One suggestion would be the production of a pocket-sized booklet, which would include summary information specific to carers and family members and details of where to go for further information; details of local support services; and emergency contact numbers. There is also a need for similar information to be made available in web-format.

7.2.2 Information needs to be available in a format that is easy to understand. It needs to be in plain English, with use of simple terminology. Booklets or information packs should be limited in size to ensure that they are not off-putting for the reader.

7.2.3 Information needs to be made available in a range of venues, including GP surgeries/health centres, drug and alcohol services, and mental health services. The information should also be easy to access via internet searches.

7.3 Raise awareness

There is a need to raise awareness in Somerset of the impact that a person's substance misuse problems can have on the lives of carers and family members, and the support services available. At present, many carers and family members are suffering in silence due to issues of stigma and lack of awareness of the support available.

7.4 Joint working in order to provide a seamless service:

7.4.1 There is a need for all agencies that provide support services for carers in Somerset to coordinate their work to ensure that there are clear paths for referral and signposting; and clarity on which services are provided for which carer groups. This includes joint working between treatment services, carer and family services, the criminal justice system, domestic violence support services, and other agencies that are potential sources of support. In particular, there is a need for a close working relationship between Turning Point and the Somerset Partnership NHS Foundation Trust and agreement on how support is best provided to carers looking after someone with dual diagnosis.

7.4.2 It is recommended that carers service literature and websites provided by Somerset County Council and the Somerset Partnership NHS Foundation Trust be reviewed to ensure that they are coordinated and complement each other.

7.4.3 It is also suggested that all Somerset agencies should agree to adopt a single definition of a carer (the definition published in the national carer's strategy 2008 is a good example).

7.4.4 It would be useful for the Somerset DAAT to be linked into the development of the Action Plan for the Somerset Carers Strategy 2008-2011 which, at the time of writing, is in development. This would provide opportunities to agree a single definition of carers and develop a coordinated approach to the delivery of carers services in the county.

7.5 Staff Training, Ongoing Supervision and Support

7.5.1 If services are to effectively identify, assess and intervene with family members and carers and involve them in the treatment plans of those with substance misuse problems, their staff will require training, ongoing supervision and support.

7.5.2 All staff in contact with carers and family members need to be equipped with the relevant skills, knowledge and attitude to support them. In addition to Carers' Assessment Workers and Drug and Alcohol Workers, it is also important that GPs are aware of the support needs for carers and family members and are able to signpost them to relevant support services and groups. The Somerset survey revealed that carers and family members often approach their GPs and health centres for information on support services. Thus it is vital that GPs and health centres are kept up-to-date with details of the services available.

7.6 Involve carers and family members in service planning and delivery:

- 7.6.1 It is vital to involve carers and family members in service planning in order to ensure that the services developed meet their needs. This includes the development of literature and websites targeted at carers and family members.
- 7.6.2 Carers and family members should be regularly involved in service evaluation in order to ensure that services continue to meet their needs.
- 7.6.3 Opportunities to involve carers and family members in care planning and the process of treatment should be developed, in recognition of the positive benefits this can have on the engagement and retention of users in treatment, the outcomes of treatment, the sustainability of treatment outcomes, and the outcomes for whole families.
- 7.6.4 Opportunities for training carers and family members as potential volunteers and paid workers in the substance misuse field should be explored. The experience and expertise that they have gained from living with someone with substance misuse problems makes them a valuable resource, which could be utilised in the development and delivery of support services for carers and family members. In particular, it would be beneficial to consider the role that they could play in terms of providing support to others in an informal setting (e.g. 'coffee and chat').

Annex A

We Count Too (2005)

Essential Requirements and Quality Standards

The key aims of the Essential Requirements and Quality Standards are:

- To deliver the highest quality services possible to family members.
- To be able to demonstrate that this is being achieved.

Used together, the Essential Requirements and Quality Standards should enable family support services to:

- Monitor and evaluate outcomes of their service.
- Demonstrate to commissioners that they are meeting basic standards.
- Ensure that family members are actively engaged in service delivery.
- Guard against risky or poor practice, including lack of boundaries.

The requirements and standards should help DATs, in partnership with family support groups and services, to:

- Develop the best possible quality services for family members.
- Provide a framework for use in training both for service providers and for commissioners of family support services.
- Use as a basis for developing Service Level Agreements with providers.

Five Essential Requirements

The organisational processes that are necessary in order to deliver quality services:

1. Family members affected by drug use are actively involved in the organisation:

- Family members with personal experience have an effective voice in the service/group design, management, delivery, monitoring and review processes.

2. The service works in partnership with other relevant local organisations and services:

- The service has access to other services and good networks, which they use to contribute to making sure that families get co-ordinated support.
- The service works jointly with other drugs services and family support services to maximise choice and opportunity.

3. The service is clear about its principles, aims and focus and how these will be achieved and monitored:

- The service is clear about its purpose and aims, e.g. whether it is focused on support and/or on campaigning.
- The service is clear about its target group(s), e.g. parents, grandparents, partners, children and young people.
- The service has clear monitoring and review processes in place.
- The service is clear about who it is accountable to and has a clear management structure.
- The service has an agreed development or business plan.
- The service has in place sufficient funding to deliver its aims in a sustainable manner.

4. The service has in place policies, procedures and protocols covering confidentiality and its legal responsibilities. These include:

- Confidentiality.
- Data protection and record-keeping.
- Health and safety.
- Insurance.
- Complaints.
- Equal opportunities.
- Legal and medical advice.
- Child protection.
- Drugs and alcohol in the workplace.
- Volunteers.
- Service specific protocols (depending on type of service provided).

5. All service staff are appropriately trained and supported:

- All staff (paid and unpaid) and management committee members/trustees receive the training they need to enable them to carry out their roles.
- All staff (paid and unpaid) have clear roles and responsibilities.
- All staff (paid and unpaid) receive regular support and supervision, including around how their personal experience impacts on their work.

Five Essential Requirements

1. Active involvement of family members affected by drug use.
2. Working in partnership with other relevant local organisations and services.
3. Clarity of principles, aims and focus and how these will be achieved and monitored.
4. Policies, procedures and protocols covering confidentiality and its legal responsibilities.
5. Appropriate training and support for all service staff.

The Seven Basic Quality Standards

Quality Standards focus on the outcomes for family members who use the services.

1. Confidentiality and safety

- Is discreet and confidential and has clear ground rules for all services.
- Is clear about what information can/cannot be shared, and when confidentiality may need to be broken.
- Provides safe opportunities to talk in a group or one-to-one setting.
- Provides opportunities to share with others and off-load where comfortable.

2. Offering choices

- Tailors choices to individual needs and allows individuals to move at their own pace.
- Gives advice as to the choices available, without telling people what to do.
- Provides service users with different things including:
 - Help to survive or change their situation.
 - Non-judgemental support.
- Ensures that service users can access any services that they find useful.
- Provides opportunities for face-to-face service (one-to-one or support group).

3. Accessibility

- Provides free services that are friendly, cheerful, welcoming and accessible to all.
- Services and facilities are culturally appropriate and physically accessible.
- Services and facilities are well advertised, give a clear idea of what is on offer, and operate at times and in places convenient to service users.
- Offers flexible services (phone and face-to-face) to enable people to access help and support outside normal office hours.
- Provides speedy and appropriate responses to calls for help.
- Works in partnership with local Black and minority ethnic and other minority communities.

4. Supporting family members to look after themselves

- Supports family members to focus on their own needs.
- Provides opportunities for them to 'have a break', socialise and 'have a laugh'.
- Offers personal learning and development opportunities.

5. Non-judgemental and caring approach

- Friendly and genuine, open-minded and caring.
- Unbiased – able to have a 'balanced' view of substance misuse.
- Respectful, understanding, non-judgemental and empathetic.
- Staff and volunteers have a heart and a passion for their work.

- Active listening skills, responsive and willing to learn.

6. Clear boundaries

- Knows the limitations (time, capabilities, commitment) and is honest about them.
- Ensures workers/volunteers are at the right stage themselves to give a service to others.
- Knows who can help if the service can't and passes to other services if unable to deal with that situation.
- Encourages people who provide the service to do as much as they are happy with, without allowing this to detract from the quality of their own lives.
- Is clear about accountability and responsibilities.
- Supports family members to set their own boundaries.

7. Being informed and informing

- Values personal experience as expertise.
- Ensures that the service is knowledgeable about drugs, relevant services and related issues.
- Has access to the right information to give to people.
- Ensures that the service has information to advise and support different family members.

Seven Basic Quality Standards

1. Confidentiality and safety.
2. Offering choices.
3. Accessibility.
4. Supporting family members to look after themselves.
5. Non-judgmental and caring.
6. Clear boundaries.
7. Being informed and informing.

Good Practice Menu of Services

The Good Practice Menu is designed for groups and services to use as a checklist against which progress can be measured, and from which new ideas can be generated. The following services for family members are included in the menu:

- One-to-One Support Services (including outreach support).
- Information for family members affected by drug use.
- Personal learning and development opportunities for family members affected by drug use, delivered in a group context.
- Telephone helplines.

- Support Groups.
- Support to help family members work together.
- Service that provide a break (respite).
- Service for grandparents.
- Services for partners of a drug user.
- Support for children and siblings.
- Services for people with a family member going through the court system or in prison.
- Service for family members who are bereaved by drug use.

Further detail can be found in Chapter 7 of We Count Too. Each Menu item in the Guide includes some relevant examples of family support groups, projects and services in England.

Annex B

Supporting and Involving Carers: A guide for commissioners and practitioners (NTA, 2008)

Assessing Family Members and Carers (Section 3.3.2)

The depth of the assessment should be considered and should be in line with the capacity of the service to meet identified needs. Clients of family and carer support services often start by focusing on the drug user – the purpose of an assessment is to focus on families and carers' own needs, so information and discussions around the user should be kept to a minimum in the assessment process. The assessment should be carried out by a staff member who is competent to carry out an assessment of need. A family member and carer assessment would include personal and contact details, including any information required for monitoring purposes, as well as the following areas:

- What the family member or carer wants to know about, for example substance use, relevant harm reduction measures (such as safe sex for partners), treatment services and the criminal justice system.
- The family member or carer's relationship with the user, including whether the user is living with them and how well they communicate.
- Impact of drug use and the user's behaviour on the family member or carer's feelings and personal functioning, including physical and mental health, and social and professional life.
- Impact of drug use and the user's behaviour on relationships with other members of the family and close friends.
- Whether there are domestic violence or harassment issues.
- Whether the family and carer has been involved with the criminal justice system.
- Any child protection issues.
- How the family member or carer copes or deals with the drug use and the user's behaviour, and the effects of that coping.
- How much and what type of social support the family member or carer receives, as well as what they feel they would need to continue caring.
- Discussion of the family member or carer's goals for the next six months in terms of the issues identified through the above assessment.

Once clients are aware of the range of services they can access, it is important to agree which of these will be helpful in terms of achieving their goals.

A simple support plan can be developed from the family member and carer assessment, which sets out what services they will receive. The family member and carer's support plan will include a date when progress is to be reviewed (normally every 3–6 months). It will also include realistic, agreed goals for the carer, around areas such as:

Self-care

- Risks, and family and carer safety; for example learning how to minimise harm, changing the locks and only allowing users in the house when they are calm.
- Improving the family member or carer's emotional and physical wellbeing, for example anger management, fewer arguments with other family members and reducing self medication.
- Using other sources of support, information and advocacy, such as going out to meet friends more often (or at all).
- Identifying own interests and exercising choices, for example education (attending a further education or training course), work (going back to full-time work, or taking up part-time employment) and leisure (taking breaks and having a respite from caring).

Supporting caring responsibilities for drug users

- Being informed about substance misuse problems, the effects of drugs on the user, harm reduction and treatment approaches.
- Learning how best to help and assist their drug misusing relative, for example not paying for the user's drugs and overdose management skills.

Supporting caring responsibilities for the wider family

- Recognising the impact of the relative's substance misuse, for example minimising the implications of a parent's substance misuse on his or her caring role on children in the family.

Support plan review meetings assess progress toward current goals, assess any changing circumstances and set new goals. Feedback from clients and workers on the support plan process can assist service development by providing information

Including family members and carers in the assessment of drug users (Section 4.4)

Information can be routinely gathered from drug users about their family members and carers as part of their own assessment. The information can be used to help assess the families and carers' needs and can be achieved in a number of ways, including:

- Asking drug users during their own assessment about their opinions on the needs of their carers and family.
- Asking drug users whether they are happy for the service to send information about drugs and drug services to their families and carers directly.
- Asking drug users for consent for families and carers to participate in their treatment and assessment sessions.
- Enquiring about young people affected by the adult's drug misuse.
- Undertaking an appropriate assessment (for example, via the drug-misusing parent who is currently being assessed) of the needs of these young people.

- Referring any young people to appropriate local services.

Clearly, a key element of the assessment of family members and carers, and drug users, is their own willingness to be involved in this way, which remains their decision. However, to encourage both users and families or carers to be jointly involved, staff can stress that:

- The involvement of members of the drug user's social networks who are able to encourage change is an important step in reducing or stopping drug misuse.
- Family members are among those most likely to encourage and support that change.

However, users and family members or carers' expectations in the care planning process need to be handled carefully, to ensure that users themselves, not carers, take primary responsibility for treatment engagement and outcomes.

Annex C

'Inventing the Wheel', by Sue H

Drink and Drug News, 3rd December 2007

www.drinkanddrugs.net

Inventing the wheel

In common with many loving parents, seeing her youngest son in the throes of alcohol addiction drove **Sue H** to despair and the point of illness. Constructing her own 'Recovery Wheel' gave her a way of coping, as well as highlighting the professional support that would have made a difference earlier on.

It's a November evening and I am sitting in the Bristol Hippodrome watching *Cats*, a wonderful production, people all around me with looks of sheer enjoyment on their faces. So why is it I feel so sad? So very sad that I feel tears starting to roll down my face.

It's just one of the many confusing feelings going on for me right now. Next week my youngest son enters treatment for his addiction to alcohol. Why am I sad? Because of 12 years of living with addiction in the family. It's something that as a parent I never thought would happen to us – particularly with alcohol, a legal substance, that lots of people have a great time with.

My youngest son's drinking has taken our family down a road of darkness I would never have dreamed about. Sadness is only one part of it. Guilt and shame, anger, frustration, hate, loss, fear, isolation, confusion, despair, and the big one – powerlessness – all take their part on a daily basis. For a long time I did not cope. I went into a deep depression, a black hole that I could see no way out of. Looking back now it feels scary that I was so close to ending my life because I just could not stop my son from drinking. I had reached the point of giving up because I could not find the help I needed.

But something happened that put me on the road to where I am now. It feels good to be alive now – I have a serenity in me that I thought did not even exist. I was asked to speak at the SGDAS (South Gloucestershire Drug and Alcohol Services)

three-day Family Forum as a family member. I had to speak for about 15 minutes on what I needed, and perhaps what I did not get.

How could I illustrate 12 years and the pieces of the puzzle that had got me to where I was now? This was how my Recovery Wheel began. Armed with board and coloured pens, I stepped back in time 12 years and began my journey once more. The feeling of desperation for help felt as real as it did then. One particular memory of a visit to the GP sprang to mind. I was in absolute surrender for help and it brought me nothing. When I left that day if I had thought of it, I would have laid down in the main road outside of the surgery. I had hit my rock bottom and I hope that no family member now would ever need to feel like that. I changed my GP

So what do I need?

This is the beginning of My Wheel...

I need an understanding GP. If you are a GP, please listen, acknowledge my pain, and have access to at least one service or a 12-step fellowship that you could direct me to for help. Take responsibility for trying to keep in touch with new services for family members – in the long run it could make your job much easier!

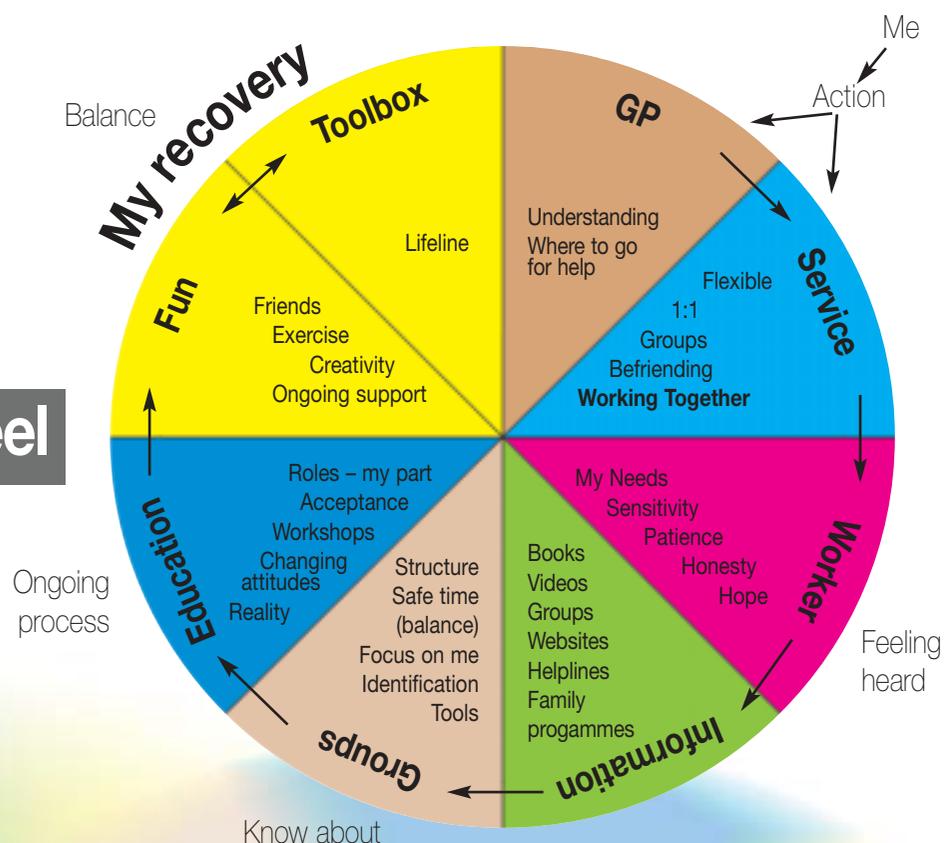
I need a service that will fit me. If you have a service, please let me know it is there. This is the place where I am ready to take action. Many family members find this the hardest thing to do. I am ready

– be there for me, help me find the right support. Be flexible, don't just expect me to fit the service. We are all unique and have different needs. Opportunities for one-to-one, group work and a 'buddy' system will encourage me to share my experience with other family members and help me to help myself. If your service does not have what I need, then direct me to one that does. Give me options and choices, and be a service that does that willingly.

I need a support worker that has sensitivity and

patience. I may know what I need to do, but it can take a long process to get the courage to do it. I need ongoing support to enable me to make small changes – fear can keep me doing the same things over and over; I used to fear that if I stepped back or detached, my son could get worse or even die. Help me to focus on my own needs and stop me spending the whole time talking about the 'other person'. Getting me to focus on myself for maybe an hour a week is a huge start. I need to build a very special rapport with you, so I can be totally honest with my feelings; the slightest hint of feeling judged and you might not see me again. You may experience my incredible anger or unpleasantness – my life is in chaos and I am full of emotional distress. Please not only listen, but hear what I am saying! I also need honesty from my worker, it's no good giving me false promises. I need to be facing reality not hiding from it. But at the same time, help me have hope. Take me to an open Alcoholics Anonymous or Narcotics Anonymous meeting to help me see that people do and can get better.

Recovery wheel



I need as much information as possible. I need to know where to find local groups for family members like Families Anonymous and Al Anon, good literature like books on co-dependency, informative websites, and any national organisations with publications. Twenty-four hour helplines can help in the middle of the night when the fear is too much to bear. Help me to build a library of information for when I need it.

I need education on family roles. I need to know about enabling, controlling, changing my attitudes, listening, communication, acceptance. How do you learn to accept that someone you love so much is slowly destroying themselves and you are unable to stop them? Acceptance of reality is so hard; I need to learn how to put the focus back on me, and how to say 'no' and set boundaries.

I need groups to empower me. I want to feel safe in my group and know that anything I say there stays there. Attending a group can be scary for all sorts of reasons. When you get me at your group, try and ensure that I stay. If I am too dominant, shut me up. If I am quiet, please see me; don't assume I am OK. And please give me 'tools' to help me cope with my situation – don't let me leave feeling more depressed than when I arrived.

I need to have some fun again. Fun got lost very early on. How am I going to get any of that back in my life? It's not easy to begin with, so help me to do that. I need pushing, I need to see the value of having fun.

I need tools to help me along. Over 12 years I have built my own toolbox. It's a silver bag with a label that says 'thanks for being there', sent from another family member who shared a similar experience. In the bag I have a range of objects – a bottle of HP sauce, which reminds me I need a Higher Power to 'help me along', as well as headphones, spinning top, an acceptance card, candle, earplugs, battery, rubber, and a small ladder – all of which have their own significant meaning to me. Help family members to build their own toolbox and they will be able to help themselves. Living with someone who has an addiction is like being on a rollercoaster – at its highest and then its lowest within seconds. The rollercoaster can be just as big for family members: So many professionals think we do not need support when someone goes into treatment, but it is often needed more, so that family members can continue to change alongside the person in treatment.

This brings me back to the beginning of the wheel, and it's an ongoing process. My journey into the past comes to an end, I am back in the moment. I shall enjoy the rest of *Cats* – I know I can, because I have the 'tools'. I know that in reality I shall have many moments of sadness, and that's life. But I also have my Recovery Wheel, and it is achievable.

Let's help family members to help themselves, and by doing so give them a healthy way to help the one they love.

'My youngest son's drinking has taken our family down a road of darkness I would never have dreamed about. Sadness is only one part of it. Guilt and shame, anger, frustration, hate, loss, fear, isolation, confusion, despair, and the big one - powerlessness - all take their part on a daily basis.'

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