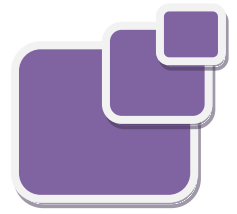


MCMILLAN ROME

SOCIAL RESEARCH AND TRAINING CONSULTANTS



LOTHIANS AND EDINBURGH ABSTINENCE PROGRAMME

Evaluation of the LEAP Family Programme

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CHAPTER 1: INTRODUCTION

1.1 Background

The Lothians and Edinburgh Abstinence Programme (LEAP) is a 12-week treatment and rehabilitation programme for those dependent on alcohol and other drugs. It was established in 2007 and is run by NHS Lothian in partnership with the City of Edinburgh Council and Transition.

In 2012 LEAP introduced a service for family members of patients who were currently, or had previously been, attending the LEAP programme.

The aims of the service are to:

- Help families develop insight into the ‘whole family’ dimension of chemical dependency
- Realise that recovery is possible, for families as well as for the chemically dependent person
- Develop strategies to build and reinforce the recovery resources of their family systems
- Support each other.

The LEAP Management Team believe in the ‘Recovery Management Model’, utilising the recovery capital of the individual and the family to achieve positive outcomes. The introduction of the Family Programme brought to fruition a long-standing commitment in LEAP’s overall Therapy Plan.

The programme is based on the Community Reinforcement Approach (CRA) developed in the USA in the early 1990’s. This is regarded as one of the most effective and cost-effective interventions in the world, ranking 6th out of 100 interventions reviewed in the Mesa Grande study.¹ The CRAFT² model was developed as an expansion of CRA. It is a scientific approach that is neither confrontational nor advocates detachment. It implies that family members *‘must change aspects of the community at home so that sobriety alone is positively reinforced (rewarded). Additionally, it involves having family members reinforce themselves directly by getting reconnected with pleasurable aspects of their extended community that typically have been disrupted as a result of dealing with a loved one’s chronic substance abuse problem.’*³

The service is delivered primarily through group meetings. The group offers continuous, open-ended support which includes audio-visual presentations, talks by guest speakers, and discussions facilitated by a member of the LEAP team. Members also have the opportunity to talk informally to others in a similar position over tea/coffee and to benefit from each other’s experience.⁴

The groups meet on Wednesday and Thursday evenings at LEAP where they have a designated Family Room. A working agreement is in place which sets out the ‘rules’ that govern the meetings, which are facilitated by an Addictions Therapist. (See Appendix 1)

¹ Miller WR, Wilbourne PL. Mesa Grande: a methodological analysis of clinical trials of treatments for alcohol use disorders. *Addiction*. 2002 Mar;97(3):265-77.

² Community Reinforcement and Family Training

³ Smith J E & Meyers R J (2008) *Motivating Substance Abusers to Enter Treatment: Working with Family Members*. (The Guildford Press, New York).pX

⁴ LEAP Family Programme leaflet

<http://www.nhslothian.scot.nhs.uk/Services/A-Z/LEAP/Documents/LEAP%20family%20and%20friends%20leaflet%20FINAL.pdf>

The Addictions Therapist is a specialist in Family Support and is employed by NHS Lothian on a part-time contract. In addition to facilitating the two evening meetings each week, the therapist meets with individual family members as required and contributes to the multi-disciplinary team meetings.

The overarching term used to describe these activities is 'The Family Programme' which mirrors the language and terms used in the main LEAP programme. This differs from other family support models in its combination of a structured therapeutic approach and a clear philosophy about addiction, addicts and recovery.

Initial funding for the Family Programme has been provided by the Edinburgh and Lothians Health Foundation. In June 2013 the LEAP Management Team commissioned McMillan Rome Ltd to conduct an external evaluation of the Family Programme.

1.2 Aims and Objectives

This evaluation sought to establish the extent to which the LEAP Family Programme (LFP) makes a difference to the family members of patients engaged in the Lothians and Edinburgh Abstinence Programme.

The objectives of the evaluation are to establish:

- The effectiveness of the model components, with regard to positive outcomes for families
- The reach of the service in terms of providing equitable access
- The strategic fit of the service within Lothian.

1.3 Scope of the Project

In order to be able to provide a rounded evaluation, taking evidence from a number of different perspectives, the evaluator sought to engage with a range of stakeholders. This included:

- Family members and carers
- Patients
- LEAP management and staff
- Local carers' services
- Mutual Aid Groups
- National organisations.

1.4 Purpose of this report

This document sets out the evidence drawn from a range of sources to ascertain the extent to which the Family Programme makes a difference to family members of patients engaged in the Lothians and Edinburgh Abstinence Programme.

It will be of assistance to the LEAP Management Team in informing decisions about the future capacity, direction and funding of the Family Programme.

1.5 Summary of methods

In order to collect the information required for the purposes of this evaluation a range of data collection methods were adopted. This included semi-structured interviews, focus groups and an online and paper-based questionnaire. Their use with specific groups is summarised in the table below.

Table 1.1: Summary of methods

Objective 1	Method	Sample
Establish the effectiveness of the model components	Semi-structured interviews (Qualitative)	Local carers' services Substance misuse service leads Third sector service providers
	Paper-based Survey (Quantitative)	Family members/carers
	Online Survey (Quantitative)	
	Focus Groups	
Objective 2	Method	Sample
Establish the reach of the service	Audit of project management data	All activity relating to output measures
	Paper-based Survey (Quantitative)	Family members/carers
	Semi-structured interviews (Qualitative)	LEAP management and staff Local carers' services National organisations Mutual Aid groups
Objective 3	Method	Sample
Establish the strategic fit of the pilot	Process mapping	Audit of referral pathways and processes. Nature and use of linkages
	Paper-based and Online Survey (Quantitative)	Family members/carers
	Focus Groups	
	Semi-structured interviews (Qualitative)	LEAP management and staff Local carers' services Substance misuse service leads Third sector service providers

Throughout the five-month fieldwork period the evaluator conducted six focus groups; four with family members, one with the LEAP Aftercare group and one with current LEAP patients. All participants were provided with an information sheet about the evaluation and written consent was obtained from each person prior to commencement.

Sixteen one-to-one interviews were conducted; 11 with LEAP staff and management and five with wider stakeholders identified by the commissioners.

The questionnaire for family members was designed around the three objectives and discussed with the family groups and LEAP management before being finalised. There were 97 unique families identified by the Addiction Therapist as having had some level of contact with the LFP since it started. Seventy-eight questionnaires were sent by email with a cover letter, information sheet and SAE for return. Nineteen were sent by post as no email address was given.

Twenty eight responses were received, 26 by email and two by post. This represents a 29% return rate.

1.6 Structure of report

Chapter 2 collates and analyses relevant national and local literature drawn together from a range of sources on effective practice in the delivery of family support. The key purpose of this chapter is to provide a clear picture of the type of interventions that have been shown to make a positive contribution to people affected by another's drink or drug use. This will provide a background and context against which to place the rest of the report findings.

Chapter 3 considers the impact that the LFP has had on family members, in terms of positive outcomes. It draws largely on the evidence of the family members who engaged in the evaluation process. It also provides evidence from the stakeholders on the extent to which the programme benefits patients and other family members.

Chapter 4 provides evidence on the extent to which the issues of equitable access to the Family Programme has been achieved across Lothian. This includes the promotion of the LFP to treatment services, other professionals, agencies and members of the community, the provision of signposting and basic information on services to family members on matters linked to substance misuse problems and the promotion of the service via a range of online media.

Chapter 5 seeks to comment on the strategic fit of the programme, particularly its linkages with other family support services and organisations across Lothian to ensure comprehensive support and the relationship between the LFP and the substance misuse services provided by NHS Lothian.

Chapter 6 draws together key findings from previous chapters to form the conclusions of the study and provide recommendations for the future development and delivery of the Family Programme at LEAP.

1.7 Use of quotations

Chapters 3, 4 and 5 contain an extensive number of quotations from family members, more than would perhaps normally be present in an evaluation report. The reason for including these is that they speak directly to the outcomes of the Family Programme. They are the evidence of impact and provide insights to the challenges that families are dealing with through treatment engagement and early recovery. These are supplemented by quotations from current and former patients and staff members where these add value.

Where two or more quotations are used sequentially these are bullet-pointed for clarity.

1.8 Terminology

The terms 'Family member' and 'Carer' are used interchangeably throughout this document to describe those individuals that seek support for themselves as a result of another's use of alcohol or other drugs. It is noted that some family members do not regard themselves as being carers and therefore the term 'family member' is used predominately in this report. However when citing research or policy documents (particularly in Chapter 2) the term 'Carer' is used where this is the descriptor used in these documents.

1.9 Limitations and Assumptions

There are a number of factors which should be taken into account when reading this report. These are:

- The views of stakeholders interviewed are given in good faith and are representative of their organisation.
- The views of family members are largely drawn from those who were prepared to complete and return questionnaires. This 'self-selecting' group may be positively disposed towards existing services, its staff and the interventions that they provide.
- The review of evidence does not constitute a comprehensive review of literature, but rather provides illustration of some of the key evidential writings on this subject.

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CHAPTER 2: WHAT IS FAMILY SUPPORT AND WHY IS IT IMPORTANT?

This chapter collates and analyses relevant national and local literature previously drawn together by the evaluator. It is collected from a range of sources on effective practice in the delivery of family support. The key purpose of including this information is to provide a clear picture of the type of interventions that have been shown to make a positive contribution to people affected by another's drink or drug use. This will provide a background and context against which to place the rest of the report findings. This is not a systematic review of literature.

2.1 Identifying the needs of family member

In considering the needs of family members an important point to note is that the impact felt is highly individualised; no two family members will experience exactly the same situations and emotions.⁵

2.1.1 Health

Caring can lead to physical and psychological problems, usually caused by the massive stress and strain carers are under.⁶ Specific conditions highlighted by the Effective Interventions Unit included depression, anxiety disorders, heart problems and stomach problems.⁷

Three quarters of carers say their own health is worse because of their caring responsibilities.⁸ Carers UK's analysis of 2001 census statistics showed that those caring for more than 50 hours a week are twice as likely to be in poor health (21% to 11%) and twice as likely to be 'permanently sick or disabled' as a result.⁹

A study in America found that family members of people with an alcohol or drug dependence disorder were more likely to be diagnosed with depression, substance use disorders and trauma than family members of people with diabetes or asthma, and to have higher healthcare costs. But the study did not determine the reasons why this was and the authors admit there may be genetic and environmental contributory factors.¹⁰

2.1.2 Financial and other practical support

Carers can often need a lot of help with financial and other practical issues, such as housing and employment.¹¹

⁵ Effective Interventions Unit (2002) *Supporting families and carers of drug users: A review*, page 12

⁶ EIU (2002), page 10 and Carers UK (2009), page 3

⁷ EIU (2002), page 10

⁸ *Ten facts about caring in Scotland*

⁹ Carers UK (2009), page 3

¹⁰ Thomas Ray, G. Mertens, J.R. and Weisner, C. (2009) 'Family members of people with alcohol or drug dependence: health problems and medical cost compared to family members of people with diabetes and asthma', *Addiction*, 104, 203-214, pages 208 and 213

¹¹ ADFAM (2010), page 7

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

Trying to balance the role of carer with other responsibilities can make it difficult to work. Over 250,000 people in Scotland juggle caring with holding down a job.¹² In the EIU study half of respondents said they had suffered problems at work such as trying to keep it all secret, lack of concentration and having to take time off.¹³ One study quoted by Carers UK found that 1 in 5 carers had given up work or turned a job down because of their caring responsibilities.¹⁴

Carers of substance misusers are not eligible for Carers' Allowance unless the user has additional health problems or disability.¹⁵ Even when awarded, the carers' benefit is worth just £53.10 for a minimum of 35 hours - £1.52 per hour.¹⁶

Three quarters of carers are struggling to pay utility bills and more than half are cutting back on food and heating to make ends meet.¹⁷ 72% are worse financially and 54% were in debt as a result of becoming a carer.¹⁸

In terms of extra costs it can often be the family members who have to pay to get the person the treatment they should be getting under the NHS.¹⁹ Sometimes they will pay for the users' drugs and drug debts as well as the additional costs of caring for dependents that arise.²⁰

2.1.3 Training and Information

Carers need good information to allow them to adequately care for the substance user and themselves,²¹ though this is of course subject to confidentiality between the patient and the treatment service.²² EIU interviews repeatedly found that a lack of information inhibited families from being able to best manage and cope with the circumstances.²³

There is a lack of awareness and recognition still amongst this group that they are carers, and about what services are available to help them.²⁴

¹² *Ten Facts about Caring in Scotland*

¹³ EIU (2002), page 11

¹⁴ Carers UK (2009), page 4

¹⁵ Blog by Drew Lindon, Substance Misuse Lead at Princess Royal Carers Trust on 24th February 2010. Found at: <http://carersblog.wordpress.com/2010/02/22/it%E2%80%99s-official-carers-of-people-with-substance-misuse-problems-have-got-a-rough-deal/>

¹⁶ *Ten Facts about Caring in Scotland*

¹⁷ *Ten Facts about Caring in Scotland*

¹⁸ Carers UK (2009), page 2

¹⁹ ADFAM and Drugscope (2009), page 4

²⁰ EIU (2002) page 11 and UKDPC (2009), page 23

²¹ NTA (2008), page 11

²² NTA (2007), page 17

²³ EIU (2002), page 43

²⁴ Audit Scotland (2009) *Drug and alcohol services in Scotland*, page 24, ADFAM (2010), page 3 and Kelly, T (2007) *Supported to Care? Carers' views of services*. Glasgow: Glasgow Caledonian University, page ix

There is also a need for training for carers.²⁵ This training should include drug/alcohol awareness as well as coping skills and strategies. Carers who have had training are able to manage their caring much better and feel less of a negative effect on their health.²⁶ One study also mentions that training is also needed for health and social professionals to help them support carers better instead of contributing to an increase in their stress, which can sometimes happen.²⁷

2.1.4 Family and Social impact

A caring situation can have a negative impact on family relationships. Almost all respondents to the EIU study felt that relationships with immediate family had been affected, resulting in arguments, tension and communications breaking down.²⁸ This group of carers often experience problems around the issue of rights and responsibility for any children the substance misuser has, which can make life more complicated for the carer.²⁹

There can be a massive social impact on the carer as well. They commonly suffer alienation by family and friends, are afraid to leave the family member alone at home, have trouble coping with the demands of looking after dependants, feel like they are being talked about by others and have little energy to go out.³⁰

They feel anger, shame, embarrassment³¹ and fear of social stigma.³² In one study staff in services identified unhappiness as one of the biggest impacts of familial drug misuse.³³ Unless the user has additional health problems or disability the carer is not protected from discrimination by association as other carers are.³⁴

This stigma and discrimination can be exacerbated by other factors. Families can sometimes experience additional difficulties when the person they are caring for takes drugs as opposed to alcohol due to the element of illegality which leads to different levels of stigma and guilt.³⁵ The situation can often be worse for those in Black and minority ethnic communities who can already feel exclusion from the community.³⁶

²⁵ Kelly (2007) page ix-x and EIU (2002) page 16

²⁶ Coalition of Carers in Scotland (2010) *Scotland's Carers Manifesto 2011-2015*, page 3. Found at <http://www.carersnet.org/docs/other/ManifestoFinalA4.pdf>

²⁷ Kelly (2007), page x

²⁸ EIU (2002), page 10

²⁹ EIU (2002), page 19-21

³⁰ EIU (2002), page 12

³¹ NTA (2008), page 12

³² ADFAM (2010), page 3, EIU (2002) page 15 and Parr. H (2009) *Carers and Supporting Recovery*. Edinburgh: Scottish Recovery Network, page 20

³³ UKDPC (2009), page 27

³⁴ Blog by Drew Lindon, Substance Misuse Lead at Princess Royal Carers Trust on 24th February 2010.

³⁵ EIU (2002), page 14

³⁶ ADFAM (2005) *'We count too' Good Practice Guide and Quality Standards for work with family members affected by someone else's drug use*, page 10-11

These factors strongly suggest that there is a need for different types of emotional support to this group.³⁷

2.1.5 Service Provision

In a report published in 2010 Adfam stated that there appears to be a lack of accessible services for carers to use.³⁸ In one study quoted by Carers UK only a quarter of working carers felt they received adequate support and the majority said they needed at least one support service which they were not getting.³⁹ The report noted that in some areas there were still no services which support the families specifically,⁴⁰ as well as no mechanism for consistent review of family support services and their quality.⁴¹ Another study, conducted in Glasgow, found that there was not enough respite care.⁴² Adfam also questions the 'approachability and effectiveness of a range of mainstream agencies and services' (e.g. GPs, social services) in supporting these families.⁴³

Adfam's consultation showed that families felt public services did not 'Think Family' – leading to them not recognising the needs of families and not sharing information intelligently.⁴⁴ The Glasgow study also found that interventions provided by services for the carers were often not quick enough.⁴⁵

Adfam recognised that the services often have insecure funding which hampers their development of innovative and effective services.⁴⁶

The report by EIU concluded that a range of appropriate support options is needed in recognition that all carers are different.⁴⁷

2.2 Good Practice in Carer Support

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

2.2.1 Provision of services

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

³⁷ EIU (2002), page 16 and Kelly (2007), page ix

³⁸ ADFAM (2010) *ADFAM's Manifesto for families: 5 key challenges for supporting families affected by drug and alcohol use*, page 3 and Carers UK (2009), page 4

³⁹ Carers UK (2009), page 4

⁴⁰ ADFAM (2010), page 3

⁴¹ ADFAM(2010), page 5

⁴² Kelly, T (2007) page viii

⁴³ ADFAM and Drugscope (2009) *Recovery and Drug Dependency: a new deal for families*, page 3

⁴⁴ ADFAM(2010), page 6

⁴⁵ Kelly (2007) page ix

⁴⁶ ADFAM(2010), page 7

⁴⁷ EIU (2002), page 16

- Information and advice (substance misuse specific)
- Practical support (non-substance misuse specific e.g. housing, money)
- Support groups accessible to all kinds of carers
- One-to-one support (outreach and centre based)
- Services available for whole family to work through issues together
- Respite provision
- Training for carers (e.g. harm reduction, overdose).⁴⁸

Evidence suggests that single interventions are not really effective; what works is good quality mainstream services and professionals across those services that are sensitive and carer-aware. Also important is joint strategic planning between health, local government and voluntary organisations.⁴⁹ The Scottish Recovery Network study suggests that carers don't feel valued and recognised by formal services⁵⁰ and that co-working between those two sources of support can assist the recovery from mental health problems.⁵¹

Adfam suggests that if we want families to provide such a massive resource for those who are recovering we must also invest in services to support them too.⁵² Services for families are often linked to services for the drug user – it is important that this link is broken and family members get services in their own right which would continue even if they disengage from the drug user or vice versa.⁵³ NTA also suggests that assessments in family and carer services should minimise as much as possible the discussion of the user, and instead should focus in on the carer's needs.⁵⁴ They also say a key principle of carer services should be that they reflect and draw on family members and carers' own experiences and expertise.⁵⁵

The EIU set out three principles for effective Family Support:

- The prime focus of family support should be to address the needs of the family and the carer
- Family support services should be open, accessible and non-judgmental
- Families and carers should be involved in assessing needs and designing services.⁵⁶

2.2.2 Information and Training

Adfam and Drugscope believe a valuable first step in the provision of information would be the production of resources just for carers.⁵⁷

⁴⁸ NTA (2008), page 13

⁴⁹ Department of Health (2010) *Recognised, valued and supported: next steps for the Carers Strategy*, page 32

⁵⁰ Parr (2009), page 19

⁵¹ Parr (2009), page 5

⁵² ADFAM and Drugscope (2009), page 7

⁵³ ADFAM and Drugscope (2009), page 8

⁵⁴ NTA (2008),page 14

⁵⁵ NTA (2008), page 13

⁵⁶ EIU (2002), page 73

⁵⁷ ADFAM and Drugscope (2009), page 5

For those who care for a person on opiates this may include training to avoid, recognise and deal with overdose situations.⁵⁸ They also need health information adequate for them to protect themselves, for example if the user has a blood borne virus such as HIV or hepatitis.⁵⁹

Issues that should be addressed in any staff training and development are negative perceptions of carers, staff worries over workload, lack of knowledge on carer support and holistic family approaches.⁶⁰

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

- Is the cared-for person capable of giving consent?
- What can professionals divulge to the carer?
- When does the carer's need for support conflict with confidentiality?⁶¹

Coping skills training has been found to be beneficial, particularly with parents, and has shown improvement in the parents' coping skills, family communication and frequency of assertive coping behaviours.⁶²

The EIU guidance stated that the ability to manage stress better and learning to be more assertive would assist the carers with coping and help their self-confidence.⁶³ NTA identifies a number of resilience processes and factors which can help a family's response – e.g. planning and coping strategies, problem solving skills, ability to deal with change – NTA suggests that carers' services should incorporate these sorts of measures to help increase resilience.⁶⁴

2.2.3 Emotional Support

Examples of the types of emotional support that carers would benefit from include local family support groups, counselling and telephone helpline services.⁶⁵ Family support groups are '*consistently highly valued by carers as a way of sharing experiences and providing mutual support*'.⁶⁶ How local the support is, is often important to carers as it suggests a greater awareness of what types of services and supports are available locally and provides a level of familiarity.⁶⁷ Scottish Recovery Network found that carer support groups were 'an essential point of knowledge transfer and key to promoting

⁵⁸ NTA (2007), page 72

⁵⁹ EIU (2002), page 17

⁶⁰ NTA (2008), page 11

⁶¹ Mental Welfare Commission for Scotland (2006) *Carers and Confidentiality*. Edinburgh: Mental Welfare Commission for Scotland.

⁶² UKDPC (2009) page 35

⁶³ EIU (2002) page 41

⁶⁴ NTA (2008), page 12

⁶⁵ EIU (2002), page 16

⁶⁶ Support in Mind Scotland (2010) '*It's their job – it's my life*', page 8

⁶⁷ EIU (2002), page 37

recovery-based practice.⁶⁸ There is evidence that family members attending an Al-Anon group specifically for them became more independent.⁶⁹

In 2009 Adfam and Drugscope reported that *'...availability and nature of [family support] services varies from place to place, but many of these local groups are becoming increasingly sophisticated, providing a robust evidence base that testifies to the demand for, and effectiveness of, family support'*.⁷⁰

2.2.4 Practical Support

Suggestions of practical support which should be provided include advocacy, befriending, assistance with child care and stress management methods such as complementary therapies.⁷¹

Advocacy services, which help the carer access services and to understand their rights, can empower the carer and increase their self-confidence. The advocacy work should be structured and set up to ensure good practice and consistency of support.⁷² The coalition of carers in Scotland states that access to an advocacy service is provided in only three areas in Scotland.⁷³

2.2.5 Respite

Carers UK reports that *'research has found that those not receiving a break were far more likely to suffer from mental health problems, 36% compared to 17% of those carers getting a break'*.⁷⁴ Respite is increasingly recognised as being useful for this group, especially where the carer has taken on care of children as well.⁷⁵

2.2.6 Five-Step intervention

UKDPC identified 5-step intervention as a way of reducing the family's stress symptoms and improve their coping responses. A recent study has also shown a brief version of this along with a manual to be just as effective as the full intensive course.⁷⁶ It is helpful for identifying carers and their needs because it is for use by primary care professionals who come into contact with family members for a range of other matters (see 2.1.1).⁷⁷ This intervention comprises five different components:

- Listening to and reassuring the family member
- Providing targeted information

⁶⁸ Parr. H (2009), page 5

⁶⁹ UKDPC (2009), page 35

⁷⁰ ADFAM and Drugscope (2009), page 3

⁷¹ EIU (2002), page 16

⁷² EIU (2002), page 39

⁷³ Coalition of Carers in Scotland (2010), page 3

⁷⁴ Carers UK (2009), page 3

⁷⁵ EIU (2002), page 38

⁷⁶ UKDPC (2009), page 34

⁷⁷ Copello, A., Orford, J., Velleman, R., Templeton, L. And Krishnan, M. (2000) 'Methods for reducing alcohol and drug related family harm in non-specialist settings', *Journal of Mental Health*, 9:3, 329-343, page 331

- Discussing ways in which the family member interacts with the user
- Exploring social support available
- Identifying any further needs for support or access to services.

Five-step is the main evaluated intervention model for families discussed in the UKDPC report.⁷⁸

2.3 Key Findings

- Caring can lead to physical and psychological problems, usually caused by the massive stress and strain carers are under.
- Carers need good information to allow them to adequately care for the substance user and themselves.
- Family members often feel anger, shame, embarrassment and fear of social stigma.
- Family members feel that public services do not 'Think Family' – leading to them not recognising the needs of families and not sharing information intelligently.
- A range of interventions have been identified which can provide support to family members.
- Staff training and development should address negative perceptions of carers and lack of knowledge on carer support.

⁷⁸ UKDPC (2009) page 34

CHAPTER 3: ESTABLISH THE EFFECTIVENESS OF THE MODEL COMPONENTS, WITH REGARD TO POSITIVE OUTCOMES FOR FAMILIES

'I've been attending the family group regularly for over two years. I was reluctant at first (I found the idea of going to 'bare my soul' to a group of strangers quite difficult) but as my partner was going into treatment to take care of himself, I was willing to try it and do something for me. I also trusted the 'push' from the LEAP staff member. It's one of the most positive things I've done.'

The principal aims of the Family Programme are to offer quality, up-to-date information on addiction and to empower solution-focused peer support.

The evaluation sought to explore the extent to which these aims are addressed by the service and make comment and recommendations regarding the quality of service provision. The purpose of this is to highlight the relative strengths and weaknesses of the service and provide constructive feedback to assist in the development of a quality improvement cycle.

In June 2013 a questionnaire was devised in collaboration with family members to seek to measure 'distance travelled' in terms of the challenges faced by family members and the degree to which the Family Programme has made a positive contribution towards alleviating these.

The results of this were discussed at focus groups where family members were invited to reflect and comment on the findings.

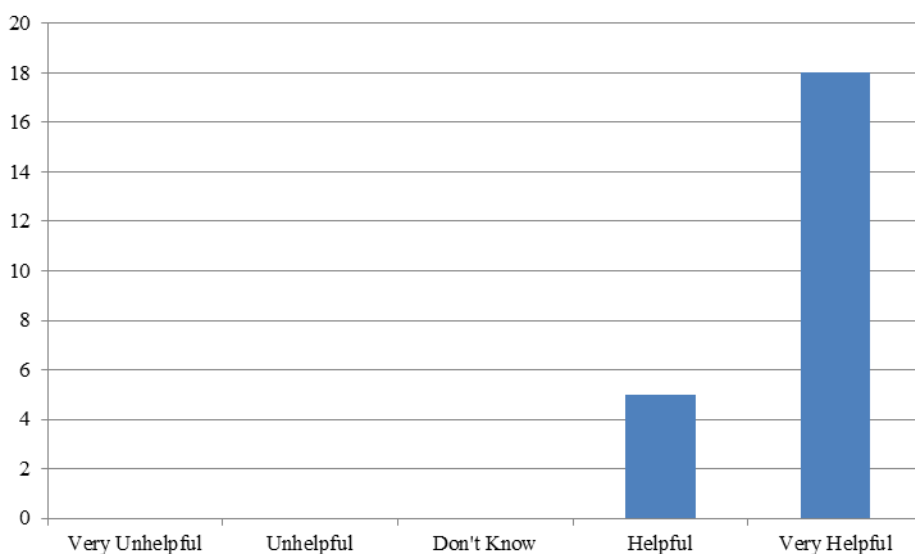
Outcomes are considered here at three levels: family members, wider family and patient.

3.1 Outcomes for family members

The family members who had been in contact with the Family Programme since its inception were asked about what benefit it had brought them.

How helpful has the Family Programme been for you?

Chart 3.1: How helpful has the Family programme been for you?



All of the respondents to the survey who answered this question (23/28) stated that the Family Programme had either been helpful or very helpful to them.

This 'help' was further qualified in the 'free text' section of the questionnaire. These have since been categorised under three main headings; *Transformational thinking*, *Improved understanding* and *Support*.

3.1.1 Transformational thinking

Brown and Lewis suggest that a family's adaptation to a traumatic environment, unhealthy systems dynamic and unhealthy attachments often creates further disturbance, and that the need for '*Family system collapse*' is central to the transformative process of recovery. '*You're not putting your life back together again, it's a new life*'⁷⁹

Even at a basic level it's about the family being able to say no...Quite often they think they are helping by buying the messages or giving them money to do this or do that, but actually it is just giving them money to buy drugs..because [it's perceived that] you're a bad parent if you say no.' (External Stakeholder)

This transformational thinking was evident in the comments from family group members.

- '*It has stimulated me to look at my own life and my interactions with my alcoholic son and break the chain of co-dependence and subconscious enabling. It allows me to air my fears and discuss with other members how to cope. It has taught me that I have a right of a life of my own, that my own sanity and serenity should not depend on how he is, that it is essential to step back and let go with love.*'
- '*It was only after having attended the group that I came to a realisation of how much of a blind eye I had turned and how much I had put up with, how much resentment was still there for me, how much of a knock-on effect the addiction had had and how I really wished to have the patient understand and see and hear this from me, in a calm structured therapeutic supported environment.*'
- '*Our lives are so different now and I'm grateful for every day. The family group has bolstered me with knowledge and skills to help me adjust and cope both with this new life and to be clear that I would not return to the way I was living before. I look back and wonder how I ever coped before.*'
- '*Education into the illness of addiction and a safe, objective, compassionate, welcoming environment where you are supported and encouraged to begin your own recovery.*'
- '*Life saver. Was well onto the way to being very mentally ill.*'

3.1.2 Improved understanding

The evidence set out in Chapter 2.2 identifies the need for better education and information for family members.

While it was acknowledged that in some cases family relationships have become very damaged and difficult to repair, there was a view that:

⁷⁹ Brown S & Lewis V (1999) *The Alcoholic Family in Recovery: A Developmental Model*. (The Guildford Press, London)

- *'Where there's maybe a wee bit of a chance, the knowledge and understanding of addiction and all the horrors that it brings might let [the family member] think a wee bit differently because often they think that [the patient] doesn't love them enough or they wouldn't be going down that road, they wouldn't be destroying our family. But once they start looking at it in a different light they might be able to be more supportive.'* (External Stakeholder)
- *'People want to understand what's going on, in terms of the addiction.'* (LEAP Therapist)

It was recognised that the team at LEAP has a particular perspective on understanding addiction.

'Most people working at LEAP have been through the (Twelve-Step) Programme and have dealt with these problems themselves. You can't get better than that.' (External Stakeholder)

Another external stakeholder made a similar observation. *'They (the Staff) are walking examples of recovery – that is a big strength.'*

The Family Programme enhances family members' knowledge and understanding of addiction through a range of media including talks by the Lead Clinician on the neurobiology of addiction, lending of books and other materials, and input from the facilitator and the wider team of therapists at LEAP. This input has resulted in family members being able to apply this learning to their own situation.

- *'This enabled us to understand what our son was facing and the background to the problem.'*
- *'It has helped me to gain an understanding of addiction and so has been very educational for me.'*
- *'We were completely ignorant of addiction and how to deal with it before attending the Family Group'*
- *'The DVDs have really helped me to understand more about my son's behaviour and realise I am not the only one in this position.'*
- *'It has helped significantly with my understanding of my son's problems and my feelings of isolation, anxiety, anger, frustration, guilt etc.'*
- *'Mutuality of understanding of problems/feelings'*
- *'Has made me calmer and more understanding.'*

3.1.3 Support

Smith and Meyers state that one of the goals of CRAFT is in helping the family members to increase their own happiness by targeting problems in various aspects of their lives.⁸⁰

Family members provided evidence of where this has been achieved through the mutual support and the shared understanding of the Family Programme.

- *'It has given me support in the situation I was in and a feeling of not being alone in the situation as everyone else in the group was going through very similar problems. Until I started attending the group I felt I had no one to talk to about my situation as no one I know could relate to it as they had not been in a similar position.'*

⁸⁰ Smith J E & Meyers R J (2008) *Motivating Substance Abusers to Enter Treatment: Working with Family Members*. (The Guildford Press, New York).p200

- *'We feel better informed and more able to make tough decisions which not only help us, but encourage our son to manage his own life and take responsibility for himself. I feel "different" from average parents. In the group I feel I am with people who understand, don't judge, can respect my troubled son, and whose advice I can listen to as they've been where I am. I have a sense of belonging.'*
- *'I have found it a safe and supportive way to talk through all the anxieties and worries especially during the first year of my partner's recovery, with other people who I know relate to what I'm talking about. I've learned how to focus on myself, that I cannot do anything to stop my partner from drinking, that I'm only responsible for myself. I feel very very lucky that my partner has stayed in recovery.'*
- *'I attended the family group every week for a long time. It was good to know that you are not alone and that there are many others dealing with the same problems.'*
- *'We were grateful for the friendship and comfort given to us.'*

3.2 Outcomes for wider families

The evaluation sought to ascertain whether the Family Programme has had any 'Ripple Effect' where the impact of the programme had a wider benefit than just the individuals who attend the groups.

Do you think the Family Programme has had a beneficial effect on your wider family?

Of the 22 family members who responded, 17 (77%) thought that the Family Programme had had a beneficial effect on other members of their family and on the family as a whole. The comments of respondents were categorised as *Improved understanding* and *Change in Family Systems*.

3.2.1 Improved understanding

- *'It helped my husband as well as myself to understand my brother's difficulties.'*
- *'Because the family understand that we now have less worry about our son.'*
- *'We understand now the problem.'*
- *'Educating family into the disease.'*
- *'We have a better understanding of the problems.'*
- *'A wider understanding of the illness.'*
- *'We all have a better understanding of addiction and how it affects us. This, in turn, has influenced our behaviour in response to our son's on-going problems.'*

3.2.2 Change in Family Systems

- *'I can pass knowledge and learnings on to wider family, also my kids benefit from my improved state of mind.'*
- *'Yes it has as I have been able to share information I have gained with them. The fact that it has helped me emotionally too has had a positive impact on the rest of my family.'*

- *'Because it made me step back and not focus constantly on my son. I sometimes forgot that I have two other sons and a daughter. Our relationships revolved around our family "problem". We can now talk about other things apart from his health and addiction.'*
- *'Only my youngest son and myself have attended however the help we have received I feel may have helped them a little too.'*
- *'Definitely - without any doubt. Although my family and friends knew about my partner's alcoholism, there was a lot that I kept from them. None-the-less I know that they were very worried about me. Now they can also enjoy my partner's recovery. I don't think that they worry about me anymore. I'm much less stressed and uptight and I don't have to call on them to help me deal with the many (often daily) 'dramas' when my partner was drinking. I felt very guilty about having to involve them before.'*
- *'I was able to see the light at the end of the tunnel. Therefore I could cope with my family in a more constructive way.'*
- *'We are less stressed, even in times of crisis. More able to prioritise our other son when he needs us.'*

The consistency of evidence provided by family members regarding the nature and extent of this wider impact is hitherto largely unreported. These outcomes have a clear relevance to the Scottish Government's National Outcome: *We have improved the life chances for children, young people and families at risk.*⁸¹

Five respondents thought that there had been no beneficial effect on the wider family. In each case this appeared to be as a result of persisting relationship difficulties rather than any deficit in the programme.

- *'For us, unfortunately other family members have felt unable to become involved in the Family Support Programme.'*
- *'I don't have a wider family who would be affected as they showed no interest in my daughter's addiction, therefore I have nothing to do with them.'*
- *'They do not attend.'*
- *'Neither of my children wanted to participate.'*

3.3 Outcomes for patients

The focus group held with current patients at LEAP provided a different perspective on the role of the Family Programme and the outcomes on families and individuals.

There was acknowledgement and consensus that the purpose of the Family Programme was to benefit the family members, rather than a way of supporting the patient.

'It's about support for them in their own right.'

⁸¹ <http://www.scotland.gov.uk/About/Performance/scotPerforms/outcome/childfamilies>

It was described as being a ‘Parallel Journey’ to the one that they were on, and a recognition that the outcomes may not necessarily be synergous.

‘There is a myth that family support or family therapy is about bringing the family back together. Sometimes it’s about giving them the support to leave.’

Patients were already seeing the benefits that the programme was providing to their family members.

‘I know my mum got a lot out of her share last week.’

Patients were also able to identify how relationships had changed as a result of the substance use and recognised that sobriety may change that.

‘I suppose a lot of times I’ve been treated like a child because of my behaviour. You give people the power to treat you that way... So hopefully that’s going to change now; it’ll be on an a more adult-adult basis.’

3.4 Key Findings

- Family members derive benefit from attending the LEAP Family Programme.
- There is evidence of transformational thinking amongst family members which is helping to change the way in which they perceive and respond to addictive behaviours.
- Family members have an increased understanding about addiction as a result of attending the Family Programme.
- The Family Programme provides a safe, supportive environment for family members to talk and be listened to in a non-judgemental way.
- There is a beneficial effect on the health and welfare of the wider family resulting from an improved understanding about addiction and changes in the way in which the family interacts.
- The Family Programme provides a parallel path for family members to learn about the 12-Step model and develop an understanding about how problems can be effectively managed in the future.

CHAPTER 4: TO ESTABLISH THE REACH OF THE SERVICE IN TERMS OF PROVIDING EQUITABLE ACCESS

The calculations used by UKDPC in estimating the number of adult family members of drug users in the UK were based, in part, on prevalence of drug users' data. As with access to services for problem drug users, it should be recognised that need is different from demand and therefore it would be unrealistic to expect to engage all family members in the Family Programme. The evaluation team worked with the service provider and wider stakeholders to identify the extent to which the Family Programme is accessible across the communities of Edinburgh and the Lothians in terms of geography, types of interventions, time of day and days of the week.

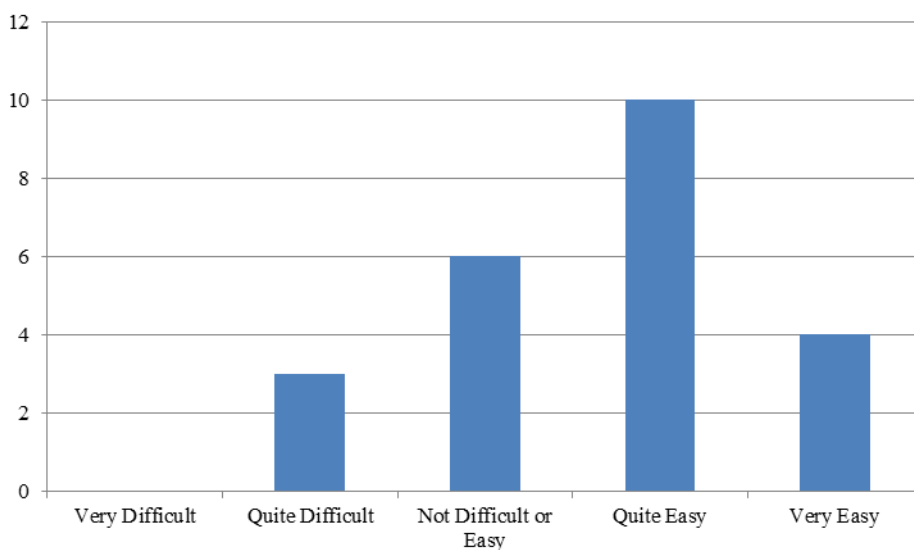
Between the date that the Family Programme started (01/10/2012) and the date of analysis (23/08/2013) there were 293 referrals of patients to the LEAP programme, of which 98 were admitted. During the same period there were 98 family members, from 93 different families, who had some level of contact with the Family Programme.⁸² Although it is possible that some of these may be related to patients admitted prior to October 2012, it provides an indication of a 1:3 ratio of family members to patients referred, and 1:1 ratio of family members to patients admitted.

4.1 Geographic access

LEAP and the Family Programme provide a Lothian-wide service, covering 700 square miles. The Family Programme operates out of a single site, Woodlands House, on the south side of Edinburgh. The evaluation sought to explore whether this arrangement created any barriers to attendance, particularly for those living in the more rural areas of Lothian.

Of the 28 family members who completed the survey 11 (39.3%) were from Edinburgh, 5 (17.9%) from Midlothian, 4 (14.3%) from East Lothian and 8 (28.6%) from West Lothian.

Chart 4.1: How easy or difficult is it to get to the Family Programme, in terms of its location?



⁸² Data provided by LEAP administrative team

How easy or difficult is it to get to the Family Programme, in terms of its location?

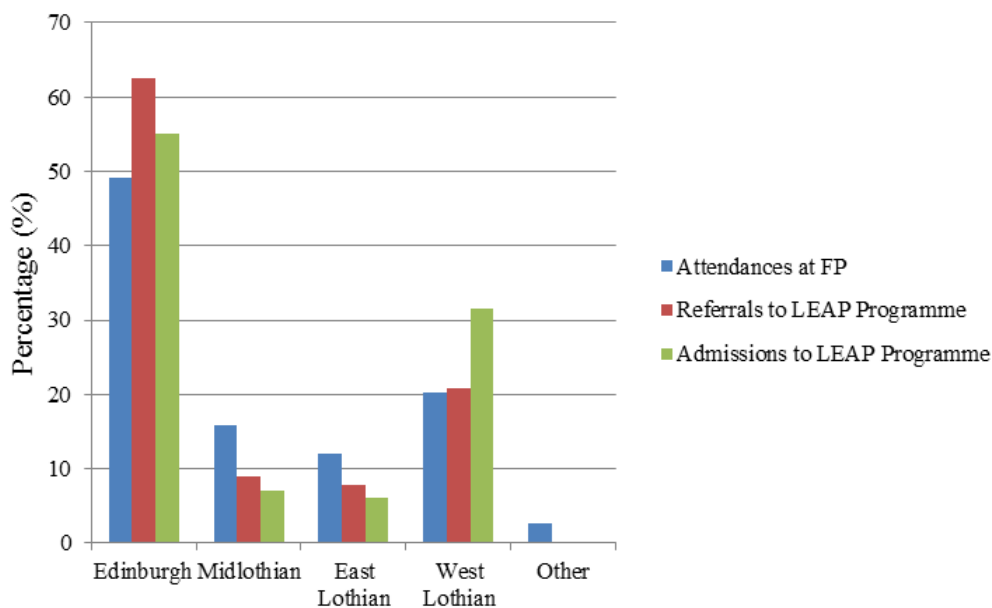
Most people (60.9%) stated that they found it either *quite easy* or *very easy* to access. Of the three people who stated that it was *quite difficult*, one was from East Lothian, one from West and one from Edinburgh. Most of the respondents qualified their answer by stating that they drive to the group and that using public transport can make access problematic.

- ‘If I don’t have transport I need to take 2 buses then have a 10 minute walk.’
- ‘OK when I can use my car but more difficult by public transport.’

One of the wider stakeholders stated that having to walk along Canaan Lane in the dark could feel ‘quite threatening’ and may deter people from coming to evening meetings. The same point was also made by one of the family members.

In the first 10 months of 2013 there have been 640 attendances at the Family Group. The distribution of attendances between the four Local Authority areas is set out in the chart below alongside the distribution of referrals of patients to LEAP from these areas and the subsequent admission rates. The reason for including patient admission data is that the number of family members offered the service is directly proportional to the number of patients referred for treatment.

Chart 4.2: Distribution of attendances, referrals and admissions by area (%)



The ratio often used to consider the proportional division of resource between these areas is 60:10:10:20 (Edinburgh City, Midlothian, East Lothian, West Lothian). In terms of access to the Family Programme the chart identifies two facts.

1. Attendances of family members from Midlothian and East Lothian are higher than the 10% expected for each area. West Lothian is on target at 20%.
2. Attendances by family members from Midlothian and East Lothian are proportionally higher than the percentage of referrals and admissions of patients to the treatment programme. West Lothian has the same proportion of family members attending as referrals to the treatment programme but lower than the admission rate.

Overall the ratio is observed in each of these categories. This proportional representation means that there is no evidence that distance to travel creates a barrier to access the service.

4.2 Timing of Family Programme meetings

The Family Programme meetings are held on a Wednesday and Thursday evening from 6.30pm until around 9.00pm. Occasionally the Addiction Therapist arranges to meet with individuals or couples outwith these times if there are particular issues that they wish to work on.

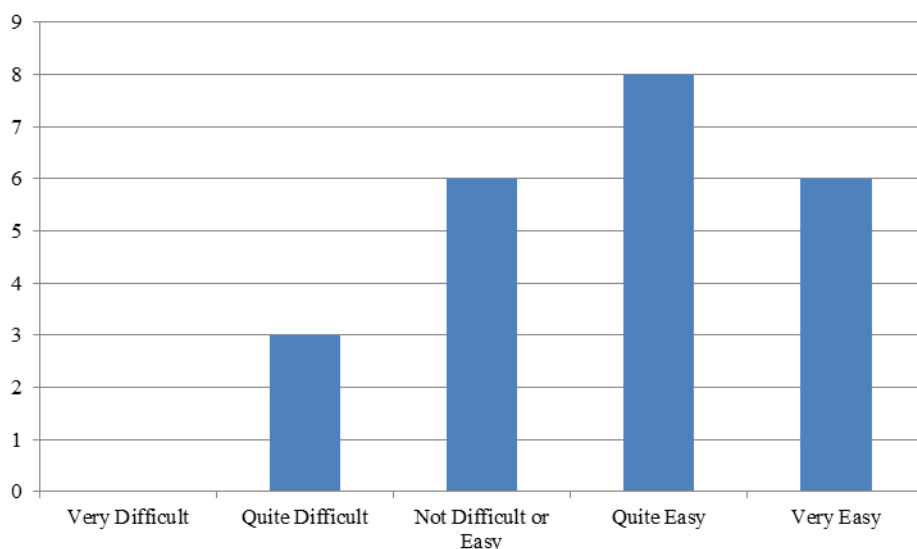
'I didn't go to the family programme as I did not wish to participate in a group session. I did go to meet the family support coordinator who was extremely helpful to speak to on a one-to-one basis.'

The evaluation sought to enquire whether the timings of the meeting proved a barrier to access.

How easy or difficult is it to get to the Family Programme, in terms of the days and times that it is held?

Chart 4.3 below suggests that the timing does not present a significant barrier to access however the respondents provided a number of explanatory comments which assist in interpreting the responses.

Chart 4.3: How easy or difficult is it to get to the Family Programme, in terms of the days and times that it is held?



4.2.1 Work Commitments

The three people who stated that it was *quite difficult* to attend were all because of work commitments.

- *'I work Wednesday and Thursday evenings which is when the meetings are held.'*
- *'Only because of my work commitments.'*
- *'For me I find it difficult to get there every week due to work.'*

Two of the respondents who stated that it was *very easy* to attend also identified work as a factor.

- *'The timings suit as I can go after work.'*
- *'Unless I am working it's easy to attend.'*

4.2.2 Traffic

Two respondents from West Lothian identified the rush hour traffic as being problematic.

- *'It would be ideal if was held later on as traffic is a nightmare and I'm usually late in arriving.'*
- *'Timing is ok apart from traffic congestion on way in to Edinburgh.'*

4.2.3 Personal/Family circumstances

It was noted by family members that their ability to attend the family Programme was also dependent on their personal circumstances.

- *'Quite easy for us as we are retired.'*
- *'Being retired we are flexible and the time suits us. May be difficult with young children. Crèche facilities. We are retired and flexible. Not everyone in that position.'*
- *'Again the days / times are convenient for me however I'm aware that for others, greater flexibility could mean they could attend the groups. For example, day times (when perhaps children are at school) and on the weekend.'*
- *'Circumstances allowing due to family commitments.'*

4.3 Profile of groups

It is not unusual for family groups to be predominately parents, most often mothers. One of the external stakeholders described a situation locally where a long-standing group was defined by its shared focus on loss, either death of a loved one or a resignation of long-term dependency. Whilst under the right circumstances this could be a supportive forum it could also risk alienating other relatives from attending, as it did in the example provided.

The evaluation sought to explore the types of relationships that group members had with the patient.

What is your relationship with your family member that entered the LEAP programme?

There was a good mix of relations amongst those who responded to the survey. Twelve (42.8%) of the respondent were parents (six mothers and six fathers), seven (25.0%) were partners or spouses, five (17.9%) sons or daughters, three (10.7%) were siblings and one (3.6%) was a friend.

This mix was also evident in the six visits made to the groups by the evaluator.

4.4 Routes into the Family Programme

There are a number of processes within the assessment, admission and treatment phases of the LEAP programme which actively encourage the involvement of family members. This was evidenced through the consistency of narratives from staff members, the patients and the aftercare group. Written

evidence of this was also provided in the form of template letters for the first assessment appointment and the information pack that is given to each patient prior to admission. These processes include:

- Following referral, initial letter invites the patient to bring someone with them to the assessment appointment
- Information pack given to the patient prior to admission includes invite for family members
- Families' day is the Saturday after the first month in treatment. Therapists actively engage with family members and inform of the Family Programme.

The current patients were in agreement that being invited to bring a family member with them for the initial appointment was a good thing and felt that they would feel more comfortable having someone with them. Many stated that they had taken this on board and had gone with a family member. They stated that, although they were aware of a couple of other services that made the same invitation, it was not widespread practice across Lothian.

It was suggested by members of the aftercare group that the initial stages of treatment may not always be the best time for families to be involved. Reasons given for this were uncertainty by the patient about whether the programme would be beneficial and that families had often had their hopes raised before by treatment episodes and may be reluctant to engage again until they saw evidence of engagement and benefit. This point was also made by a member of LEAP staff who suggested that there may be a number of reasons for this, including denial of problems and stigma.

'I am surprised by how few relatives take up family support. I don't know why. Perhaps most family members have withdrawn by the time someone reaches the point of wanting to go in to rehab.' (Family member)

The aftercare group also highlighted the fact that family members of those patients who are non-residential (i.e. they continue to live in their own accommodation throughout the 12-week programme) do not get invited to the 'Families Day' and therefore miss out on meeting with therapists and other family members.

How did you hear about the Family Programme?

Family members cited a number of different ways in which they first found out about the programme. Twenty one provided details; of these almost half (42.9%) heard about LFP through their family member (the patient), six (28.6%) were encouraged by a member of LEAP staff, two (9.5%) through other NHS Substance Misuse services and four (19.0%) through other means.

All responses are shown below.

4.4.1 Information via the patient

- *Through my son when he attended LEAP*
- *Through my family member who was the LEAP patient*
- *Via son in LEAP*
- *My partner was being assessed and she brought home information about the programme*
- *My daughter was in LEAP over a year ago*
- *We were invited to attend by the patient and this was followed up by a staff member*

- *Family member*
- *From my wife*
- *Through my daughter's recovery.*

4.4.2 Informed by staff

'My feeling is that I would not have had any contact at all had it not been that the support nurse was asking me for something to assist my ex-husband on the programme. It was only through that telephone conversation when I was upset and emotional that I was given help which I did appreciate.'

- *Contacted directly by Alastair McNaughton*
- *Through my daughter's therapist in LEAP*
- *During an assessment of my son, 'Dr. David' suggested it might help me*
- *On initial visit advised by head therapist*
- *One of the LEAP staff told me about it during my son's assessment interview*
- *I was advised of the family group during my partner's assessment process.*

4.4.3 Referred from other services

- *My brother was referred there (and was offered a place) by the Royal Edinburgh Hospital. He didn't actually take up the place.*
- *Chris Storey, Spittal St CPN*

4.4.4 Other routes

- *Newspaper articles*
- *One of my mother's carers told me about it as she did a placement there*
- *Through a former work colleague*
- *Google.*

4.5 Suggestions for improvement

Family members were of the view that the Family Programme should be advertised and promoted more widely, and specifically identified GP surgeries as being a key locus for providing information.

4.5.1 Advertising

- *Website information; in a directory of information about addiction*
- *More advertising more awareness; local papers*
- *More general advertisement i.e. radio, etc.*

- *Advertise? Articles in the news? I didn't know LEAP existed until my brother's involvement but I was impressed by what I heard when I attended for one evening.*

4.5.2 GP Surgeries

- *More publicity locally, for example medical premises. T.V., transport*
- *Promotion in health centres and inform Dr's in medical centres*
- *Have info in doctors' surgeries, and recovery hub centres about LEAP and the family programme*
- *promotional literature in GP surgeries*
- *Advertising and perhaps leaflets in Libraries and Doctors waiting rooms*
- *More advertising in Health Centres, etc.*
- *Other organisations such as GP's, Local Authorities, Police and the NHS could perhaps take a more active role in Promotion and Publicity*
- *Leaflets about LEAP in every doctor's surgery - making sure that doctors are aware of this service.*

One of the wider stakeholders wondered whether there are any leaflets for the Family Programme and suggested that it would be helpful for services to have these to distribute.

4.6 Key Findings

- There was little evidence found to suggest that the location of the service created any undue barriers to attendance.
- Although there are limited benchmarks available it would appear that the ratio of family members to patients admitted to LEAP is relatively high.
- The groups are well attended and comprise a good mix of age, gender and relationships.
- There are robust systems in place to invite and engage family members in the Family Programme. Notwithstanding these efforts, family members found out about the Family Programme through a variety of means.
- It remains unclear as to whether a daytime group would be attractive to family members who may find it difficult to attend in the evenings.
- There was a strongly held view that the Family Programme should be publicised and promoted more widely, particularly within GP surgeries.

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CHAPTER 5: ESTABLISH THE STRATEGIC FIT OF THE SERVICE

In 2012 Copello and Templeton produced a report on behalf of Adfam, with financial support from Scottish Families Affected by Drugs (SFAD), which drew together findings from three related UK studies regarding the support needs of adult family members.⁸³ This report set out 4 ‘Implications for Service Response’.⁸⁴

- To support family members, a comprehensive range of responses is required, including generic responses in non-specialist services as well as family involvement in drug treatment and specific services for family members in their own right. At the moment this is rarely provided.
- To ensure support is provided to family members early and irrespective of whether or not their drug-using relative is in treatment, there is a need to improve identification and recognition of adult family members affected by drug use and the provision of responses in non-specialist settings, e.g. General Practitioners, Police, Accident and Emergency.
- Coordination of services within drug treatment and with other generic services should be strengthened at the local level to provide access to the full range of services.
- There is a need for workforce development, both specialist and non-specialist, to raise awareness of the needs and contribution of adult family members affected by a relative’s substance misuse as well as more training in specific therapeutic interventions.

In 2013 Alcohol Focus Scotland reported on a research study which sought to better understand the scale and magnitude of alcohol’s harm to people other than the drinker in Scotland.⁸⁵ The research comprised three components, a National Omnibus Survey, Data Mapping and a Local Case Study which was conducted in Edinburgh. The report produced four recommendations, one of which related directly to supporting family members.

Recommendation 4 suggested that:

‘Practitioners providing alcohol treatment and recovery services also consider the impact the drinker is having on those around them. It is also important that practitioners who work with children and families have an understanding of the range of alcohol’s harm to others as it occurs within families, and are aware of where to get support if required.’

It also sets out specific actions for service providers:

- Routine screening for harm to others should be carried out by alcohol treatment and recovery services
- A ‘whole family’ approach should be taken when planning and delivering alcohol treatment and recovery services
- Assessment and mapping of the demand and availability of services to support those affected by another person’s drinking should be undertaken
- Improve identification and support for those affected by other people’s drinking by providing harm to others training for specialist and generic practitioners.

⁸³ UKDPC (2012) The Forgotten Carers: Support for adult family members affected by a relative’s drug problems

⁸⁴ Ibid, p20

⁸⁵ Alcohol Focus Scotland (2013) Unrecognised and under-reported: the impact of alcohol on people other than the drinker in Scotland.

These two reports identify similar important issues in providing family support services. These are: a range of options, services identifying and responding to the needs of families, co-ordination of services and awareness raising within the workforce.

These are further considered here in terms of how the LEAP Family Programme sits within a system of care in Lothian.

5.1 Range of options

Other than the LEAP Family Programme, what other family support services are available in your area?

Twenty of the 28 family members who completed the questionnaire provided further information on what other family support services they were aware of across Lothian. Nine (45%) stated that they did not know of any other service.

'There is a lack of a road map to all the services in Lothian, public or private. This means families have no ideas of the range of services available. Tried and failed to get the range of services available.' (Family member)

Table 5.1: Family support services identified by family members by area

Service	Edinburgh	Midlothian	East Lothian	West Lothian	Total
None	3	3	2	1	9
AI Anon	3	-	-	-	3
Families Anonymous	2	-	-	1	3
CHAI	1	-	-	-	1
WLDAS	-	-	-	3	3
Midlothian	-	-	1	-	1
Simpson House	1	-	-	-	1
Private service	-	-	1	-	1
No Answer	3	2	0	3	8
TOTAL	13	5	4	8	30*

*A number of respondents identified more than one service.

5.1.1 Challenges

Family members identified a number of difficulties in engaging with other family support services and offered views on how these could be overcome.

- *'Private counselling agencies which are expensive and not geared to addiction and a local service which I find difficult as I live in the same small community.'*
- *'It would be good for other support groups to be funded, not depending on the LEAP association. Hopefully also something for people with young families, People in East and West Lothian seem to have a dearth of support.'*
- *'More FACILITATED groups in localities. Groups with educational role rather than a meeting of family members discussing their day to day lives and crises...though this is also valuable. Aimed at challenging established patterns and encouraging new ways of relating to a loved one based on sound therapeutic models. It is a journey we share.'*
- *'More family support groups across the Lothians.'*
- *'Groups attached to every medical centre.'*

5.1.2 Choice

From the interviews conducted with individuals who run family support groups across Lothian for people affected by another's drug or alcohol use it is clear that they are in contact with a small number of people who have a family member that has been a patient at LEAP.

From these discussions there appears to be a number of scenarios which exemplify the need for a choice of options; family members who do not agree with the 12-step philosophy, those who would attend the LFP but have difficulty because of access issues or those who 'dip-in' to services in a way that suits them and those that prefer a 1-1 rather than a group setting.

- *'..Left Family Programme because of fundamental disagreement with a number of LEAP approaches.'*
- *'Twelve-Step is known to be a bit 'Religious' and is off-putting for some - it certainly is for my brother who refuses to go for that reason - (He says!).'*

There was also evidence of family members having tried other family support services before engaging with the LFP.

'The open, free style of the LEAP group suits me best. The groups have grown and blossomed in response to the needs of the people who attend, supported by a skilled facilitator; they are not prescriptive and it's refreshing not to have an 'I know best' attitude from the staff group.'

5.1.3 Dipping in

Interviews conducted with those individuals who run family support services across Lothian confirmed that family members are welcome to use local services in the way that best meets their needs.

- *'People have different opinions and views; I totally believe that people can have a choice to attend the LEAP 12-Step model and attend other services that are out there.'* (External Stakeholder)
- *'If they can't get in to Edinburgh they can come along to us..even if it's just to offload.'* (External Stakeholder)
- *'Even if it's for a bit of support on a bad week.'* (External Stakeholder)

Finally, in terms of ensuring that there is a range of options and choice available to family members, this was best summed up by one of the external stakeholders: *'You can't be everything to everyone.'*

5.2 Identification and response

Family members and stakeholders were of the view that drug and alcohol services could do more to identify the needs of family members, both initially and as circumstances change.

5.2.1 Initial contact

'I think LEAP do enough by contacting you and encouraging you to attend once your family member has been admitted onto the programme. Other drug and alcohol services could advertise this service

by means of posters etc. in their clinics. Therapists and nurses at these services could also speak about it if you are attending a consultation with the person who has the addiction.'

5.2.2 Ongoing support

- '[Family members]often feel that there is not a lot of support after, once the drug is away..A lot of services are set up to deal with 'The Now' and are not really looking at the future.' (External Stakeholder)
- 'While the patient is an inpatient and within the first six months of life post-LEAP, I personally found a real need to have some therapy session along with the patient and the therapist.'(Family member)
- 'I believe this family group is a great service and a great peer support environment, however additional family therapy which includes the patient and their family would for me mean LEAP would have the full package.'(Family member)
- 'I would like to see further support for the family member.... After relapse.... I was in this situation and feltI had 14 good weeks in rehab ... Tons of support... Then boom! Nothing.' (Family member)

5.3 Co-ordination of services

'Better co-ordination of services might help professionals recognise, understand and respond appropriately to the needs of family members; improved communication so that families get accurate information about the choices available and are helped to access support if they wish it. Ideas: develop a 'one-stop-shop' website / info pack for family members; hold a local Lothian-wide event to promote service for family members; every service provider could have the needs of family members as a core objective in their plans; stronger leadership from the ADPs to promote the needs of family members.' (Family member)

In relation to the development of recovery-oriented systems of care, there was a view that substance misuse services could be more family-focused.

I've often thought that a lot more can be done. I think perhaps people are focused on helping the individual that comes along and forgetting about the family member.' (External Stakeholder)

Another external stakeholder held similar views. *'Too often [service providers] are delivering services for the service user and only concerned with the person that's physically in front of them and they're not bothered about anyone round about.'* (External Stakeholder)

The 'Whole Family Approach' was identified through the consultations as being a key factor in how services can work together.

'[For LEAP patients who live outside Edinburgh] Alastair will phone me up or suggest that people come along to our group, so they have one local group here which can help to support the family through the difficulties as well. It's that whole family approach.' (External Stakeholder)

5.4 Awareness raising for professionals

Family members were asked an open question in the survey about what more could be done to improve the service.

In your opinion what more could be done to promote this service, a) by LEAP? b) by other drug and alcohol services in Lothian?

Awareness raising for professionals was, by far, the issue raised by most family members.

- *Awareness sessions for professionals who work with individuals with addiction problems.*
- *Raise awareness of the benefits of the family support group and encourage all relevant services, including GPs, to alert family members at an early stage.*
- *More understanding and knowledge about the illness from doctors.*
- *Educate the so-called health practitioners.*
- *More awareness for public sector organisations who work with/for people with addictions. I have contacted many community services in conjunction with my partner's addiction and no one ever recommended LEAP. I wish I had known about it sooner.*
- *From my experiencethe drug and alcohol services totally didn't suggest NA or AA.... Believing it's not good to put addicts together!!! Leap work the 12 steps along with other stuff.... Be good to get the word out to other services.....*

5.5 Key Findings

- There is good clear evidence regarding the range of responses required to meet the needs of family members.
- Family members experienced difficulty in identifying other family support services across Lothian.
- Family members are all different and will want different things from services. There needs to be choice available to them in order that they find a model that suits them.
- There is the potential for family members to 'dip in and out' of services but little evidence that this actually happens.
- Family members have not felt supported by Adult Substance Misuse Services across Lothian and there is a perception that the focus is too much on the individual at the expense of the family.
- The need for awareness raising and training amongst specialist services was one which was well recognized by family members.

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CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1 Conclusion

This evaluation sought to establish the extent to which the LEAP Family Programme makes a difference to the family members of patients engaged in the Lothians and Edinburgh Abstinence Programme.

The objectives of the evaluation were to establish:

- The effectiveness of the model components, with regard to positive outcomes for families
- The reach of the service in terms of providing equitable access
- The strategic fit of the service within Lothian.

The preceding chapters have set out the evidence, drawn from a range of sources, and produced key findings against each of these objectives.

The ordering of the objectives also represents the extent to which the staff and management at LEAP have the ability to influence the inputs and outcomes. The first objective sits very much within their sphere of responsibility, the second is dependent on a number of factors outwith their control and the third is largely dependent on the way in which other organisations engage in delivering family support within the services that they provide.

In summary, the feedback from family members and all other stakeholder groups was very positive, to the point where one individual regarded it as the best that they had seen.

'It's the Gold Standard for Family Support Groups in Scotland.' (External Stakeholder)

The Family Programme is now jointly owned. It is governed by LEAP management team and delivered by the Addiction Therapist but belongs very much to the family members who attend. This identification with the programme also brings a sense of protectionism from the family members.

'I think LEAP have started out in a very positive way to support family members and I believe that this was part of the original funding bid. It's a shame that funders didn't recognise the needs of family members earlier on in the development of the programme; it's also a shame that even now, the needs of family members are not supported through core funding and additional funding has had to be applied for. There is a strong message here for NHS Lothian and partners!!!' (Family member)

6.2 Recommendations

The recommendations set out below are drawn from the evidence collected and are presented for the consideration of the LEAP management team.

1. Consideration should be given to piloting a daytime family group in order to gauge demand from family members who find it difficult to attend in the evenings.

2. The experience and expertise of LEAP in engaging with family members should be utilised across the Substance Misuse Directorate to improve the response to families within other parts of the service.
3. Efforts should be made to ensure that General Practitioners across Lothian are aware of the existence, and benefits, of the LEAP Family Programme.
4. Opportunities to further engage family members in peer support roles should be explored.
5. In light of the evidence presented in this report, efforts should be made to secure permanent funding for the LEAP Family Programme.

APPENDIX 1: LEAP FAMILY PROGRAMME MISSION STATEMENT



Family Programme

Our aims –

- **To take a holistic approach to our treatment of addiction**
- **To improve the well-being of our patients' family members**
- **To increase the chances for our patients to sustain their recovery**

Our objectives –

- **Raise awareness** - of the 'whole family' dimension of addiction
- **Instil hope** - that recovery is possible for them as well as for the patient
- **Provide pathways to recovery** – which run parallel to patient treatment
- **Support positive change** - through psycho-education - group work - peer-support.

Our resources –

- **1 family support therapist** – operating as an integral part of the LEAP team - 30 hours per week for 2 years thanks to a generous grant from NHS Lothian Health Foundation
- **Small budget** - for admin support and materials
- **Lived experience** – from members - peer-supporters - staff

We offer -

- **Outreach to family members** – telephone - e-mail - personal invitation
- **One to one sessions** - to discuss individual support needs
- **Audio-visual presentations** - on the symptoms and phases of addiction - the effects on the brain - how family relationships are affected
- **Weekly group work sessions** - solution-focused and staged - both facilitated and peer-led - to learn from each other's experience and learning – to consider effective strategies - to provide emotional and practical support when difficulties arise

We empower members to -

- **Develop trust** - in the effectiveness of our abstinence-based patient programme and in the wider recovery community in Edinburgh & Lothian
- **Shift focus** – away from the patient - back to self
- **Concentrate** - on *personal* recovery to promote *family* recovery
- **Dismantle unhealthy relationship patterns** - identify what is not working - neither for them nor the patient
- **Build healthier family relationships** - identify and use what does work to promote recovery for the whole family
- **Link with mutual-aid** – Families Anonymous – AlAnon – SMART – for additional and ongoing support

Evaluation -

- **Internal** – Feedback from our members has been mostly positive so far and indicates that we are consistently meeting their needs (our aims). We are also measuring change in wellbeing by using a self-reporting measuring tool (CORE OM) at regular intervals.
- **External** – We have commissioned a robust independent evaluation which we are confident will confirm our belief that we are fulfilling our aims and objectives and will indicate areas for future growth and development.

What next?

- **Continue** - to use our learning to inform our practice
- **Disseminate** - our learning to other services
- **Continue** - to grow organically in response to our members' needs
- **Expand** - so we can offer more - to more people

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