

Volume One

Talking to People with Learning Disabilities and their  
Families about the Experience of Systemic Therapy

Laura Arkless

D. Clin. Psy 2004

University College London

UMI Number: U591806

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



UMI U591806

Published by ProQuest LLC 2013. Copyright in the Dissertation held by the Author.  
Microform Edition © ProQuest LLC.

All rights reserved. This work is protected against  
unauthorized copying under Title 17, United States Code.



ProQuest LLC  
789 East Eisenhower Parkway  
P.O. Box 1346  
Ann Arbor, MI 48106-1346

## **Acknowledgements**

I would like to thank all the participants in this study, who gave their time to talk to me. I am also extremely grateful to Katrina Scior and Sandra Baum who have given me a great deal of support, encouragement and provided helpful ideas throughout the process of carrying out this research. I would also like to thank those who helped (and didn't give up!) with the recruitment of participants to the study. Finally a very big thank you goes to those closest to me for all their support that was always there when I needed it.

| <b>Contents</b>                                                                                | <b>Page No.</b> |
|------------------------------------------------------------------------------------------------|-----------------|
| <b>Abstract</b>                                                                                | <b>1</b>        |
| <b>1: Introduction</b>                                                                         | <b>2</b>        |
| 1.1 Psychological therapies for people with learning disabilities:<br>A historical perspective | 3               |
| 1.2 Systemic therapy for people with learning disabilities and their families                  | 7               |
| 1.3 Researching psychological therapies with people with learning disabilities                 | 21              |
| 1.4 Researching systemic therapy: Other populations                                            | 26              |
| 1.5 Rationale for the present study                                                            | 36              |
| 1.6 Research Questions                                                                         | 39              |
| <b>2: Method</b>                                                                               | <b>40</b>       |
| 2.1 Recruitment                                                                                | 40              |
| 2.2 Participants                                                                               | 42              |
| 2.3 Procedure                                                                                  | 46              |
| 2.4 The semi-structured interview                                                              | 49              |
| 2.5 Therapists' questionnaire                                                                  | 54              |
| 2.6 Method of analysis                                                                         | 55              |
| 2.7 Reliability and Validity                                                                   | 57              |
| 2.8 Researcher's perspective                                                                   | 58              |
| <b>3: Results</b>                                                                              | <b>61</b>       |
| 3.1 Overview                                                                                   | 61              |
| 3.4 Themes emerging from the family members transcripts                                        | 62              |
| 3.3 Themes emerging from the transcripts of adults with learning disabilities                  | 92              |
| 3.4 Summary of results                                                                         | 105             |
| <b>4: Discussion</b>                                                                           | <b>107</b>      |
| 4.1 Overview                                                                                   | 107             |
| 4.2 Key findings                                                                               | 108             |
| 4.3 Clinical and service implications                                                          | 131             |
| 4.4 Methodological issues                                                                      | 137             |
| 4.5 Future research                                                                            | 147             |
| 4.6 Conclusion                                                                                 | 148             |
| <b>References</b>                                                                              | <b>150</b>      |

## **Tables**

|                                                                              |    |
|------------------------------------------------------------------------------|----|
| Table 1: Description of participants                                         | 45 |
| Table 2: Master and subordinate themes for families group                    | 63 |
| Table 3: Master and subordinate themes for adults with learning disabilities | 92 |

## **Appendices**

1. Families initial letter
2. Adults with learning disabilities initial letter
3. Families information sheets
4. Carer initial letter
5. MREC ethical approval letter
6. Family interview schedule
7. Adults with learning disabilities interview schedule
8. Therapists' questionnaire
9. Transcript example family
10. Transcript example adults with learning disabilities
11. Emerging themes example family
12. Emerging themes example adults with learning disabilities
13. Master themes examples family
14. Master themes examples adults with learning disabilities

## **Abstract**

Systemic family therapy is an approach to psychological therapy that is increasingly being offered to adults with learning disabilities and their families. To date there has been no published evaluation of the degree to which this is an approach that is effective in alleviating distress for this client group. The present study aimed to explore the experiences of adults with learning disabilities and their family members, who had attended systemic family therapy together. It also aimed to investigate whether it was an experience that had been helpful and in what ways, if any it impacted on their lives. Ten families and six adults with learning disabilities were interviewed about their experiences of attending systemic family therapy. The transcripts were analysed using Interpretative Phenomenological Analysis (IPA). Participants had mixed views about the degree to which systemic therapy had been helpful to them. Some family members saw it as having a positive impact on their views about and ways of approaching particular issues. However, for other families systemic therapy had not offered the kind of help they had expected and the experience was seen as relatively insignificant, vague or confusing. For the participants with learning disabilities there was a general sense that the opportunity to talk about difficulties was seen as valuable. However, the degree to which some of these participants felt they had a voice was limited. A combination of feeling pressure to 'know' what to say, and the presence of other family members in the meetings made it difficult for them to have their say. These findings suggest that although systemic family therapy can be helpful, particular aspects of the process may need to be adapted to ensure it is an approach that is accessible for this client group and their families.

## **1. Introduction**

Over the past decade there has been increasing interest in using systemic approaches in working with people with learning disabilities, their families and support networks (e.g. Vetere, 1993; Goldberg, Magrill, Hale, Damakinidou, Paul & Tham, 1995; Fidell, 1996). The issues faced in the lives of families where there is a member who has learning disabilities appear to fit with the focus of systemic approaches to therapy. There has however, been no attempt to find out whether the families themselves feel it is an approach that fits with and can benefit them. This study will aim to gain a better understanding of how adults with learning disabilities and their families view the experience of attending systemic therapy.

This chapter will begin by outlining the history of psychological therapies with people with learning disabilities to put developments in systemic practice in context. The application of systemic ideas and techniques to people with learning disabilities will then be described. Research around and evidence for different psychological therapies with people with learning disabilities and for the effectiveness of systemic therapy with other client groups will then be discussed. Finally, the rationale for the current study will be outlined. The terms systemic therapy, family therapy and systemic family therapy will be used interchangeably throughout the current study. This reflects the situation in the literature where the terms family therapy and systemic therapy do not refer to one method, but rather a collection of different approaches that are all underpinned by the same systemic principles (Reimers, 2001).

## **1.1 Psychological therapies for people with learning disabilities: A historical perspective**

Before examining the different ways in which systemic and other psychological therapies for people with learning disabilities have been researched and evaluated, the growing interest in systemic therapy will first be put in the context of the history of psychological therapies for this client group. This section will begin by outlining how there has been a lack of provision of psychotherapeutic services in the field of learning disabilities that existed until relatively recently. The main arguments from the published literature that have been put forward to explain this neglect will then be presented. Finally, more recent developments in the provision of various psychological therapies to this client group will be summarised.

### ***Neglect***

Historically, people with learning disabilities have been excluded from the potential benefits of ‘talking’ therapies (e.g. Bender, 1993; Sinason, 1992; Sternfert-Kroeese, 1997). In her account of the history of psychodynamic psychotherapy with this client group Sinason (1992) highlights how Freud (1904) described the psychoanalytic approach as unsuitable for people who were not verbally articulate. She proposes that Freud did not deliberately exclude people with learning disabilities from the approach, as they did not even enter his thinking around who may derive benefit from or be suitable for psychoanalysis. Bender (1993) argues that in the UK, however, the psychoanalytic movement used these ideas to exclude people that were not deemed to be desirable to work with. Bender proposes that the way in which Freud’s ideas were

simply taken as given, allowed for there to be no need for any justification for the basis of this exclusion.

As psychoanalysis evolved in the early part of the 20<sup>th</sup> Century there were few theoretical developments or accounts of work published that focused on people with learning disabilities until the late 1980's (Sinason, 1992). Since this time the limited work that has been published has been of case studies (e.g. Symington 1981, Frankish, 1989a, 1989b; Sinason 1992; Beail, 1994) and in more recent years of some clinically based outcome studies (e.g. Beail & Warden, 1996; Beail, 1998, 2000).

Behavioural approaches have traditionally been seen as the 'treatment of choice' for people with learning disabilities. Behaviourist principles meant psychological therapy for people with learning disabilities has focussed on managing or changing behaviour using reinforcement schedules, mostly by working through carers rather than engaging directly with the person with learning disabilities. This resulted in limited, if any, consideration of an individual's subjective experience (Stenfert Kroese 1997).

Since the emergence of cognitive-behaviour therapy in the 1980's (e.g. Beck 1964, 1976) it has grown in popularity and its usage in clinical psychology is now widespread. This development has not been reflected in the provision of cognitive-behaviour therapy for people with learning disabilities. Bender (1993) argues that the approach has not been seen as something that this client group can access and thus derive benefit from. However, more recent developments in clinical practice in this area have begun to identify and adapt elements of the cognitive behavioural approach to make it more

accessible to some people with learning disabilities (e.g. Dagnan & Chadwick, 1997; Sternfert-Kroese, Dagnan, & Konstsntinos, 1997; Dagnan, Chadwick, & Proudlove, 2000; Haddock, Lobban, Hatton, & Carson, 2004). These current developments in the application of cognitive-behaviour therapy for people with learning disabilities, will be discussed in more detail below in the section about research on psychological therapies with people with learning disabilities

### ***Why neglect?***

Bender (1993) argues that people with learning disabilities have been deliberately prevented from accessing psychotherapy. He states that psychotherapy requires therapist and client to relate to each other, in the context of an intimate relationship, over a sustained period of time. With people who have learning disabilities, Bender argues that developing this kind of relationship may be experienced by therapists as more aversive and requiring more effort, leading to this client group being viewed as unattractive.

According to Bender (1993) there are also aspects of clinical psychology as a profession, and of clinical practice in learning disabilities, which have contributed to the restriction of access to 'talking' therapies. Firstly, traditionally clinical psychology held up behavioural models as the approach that had most utility and relevance for this client group. The widespread influence of behaviourism, for a long time had the effect of discouraging innovation in clinical practice, thus preventing the development of knowledge about and interest in the potential benefits of other therapeutic approaches.

Secondly, Bender argues that the existence of different specialties in clinical psychology has contributed to inequality of access to therapy for people with learning disabilities. He highlights how the value attributed to behavioural interventions by psychologists in learning disabilities, combined with the attitudes of psychologists in other specialties, which he suggests are characterised by both a lack of interest and sense of obligation to provide other types of therapy to this client group, has resulted in there being nowhere where 'talking' therapies could be provided to people with learning disabilities.

The exclusion of people with learning disabilities from accessing 'talking' therapies has also been reflected in a lack of research around or interest in how different therapeutic techniques can be adapted to make them accessible for this client group. Bender (1993) proposes that in clinical psychology there has been a view where if an individual or group of individuals cannot access a particular therapeutic technique, they are deemed to be 'unsuitable' for that type of therapy, as opposed to the therapy needing to be adapted to make it accessible.

This exclusion can be viewed as unacceptable for a number of reasons. Firstly, on ethical grounds, people with learning disabilities should have the same rights as the rest of the population, including equal rights to access a wide range of healthcare services. Secondly, awareness of the emotional needs of people with learning disabilities is increasing as it has become clear that this population are more likely to experience psychological disturbance (Lund, 1985; Reiss, Levitan, & Mc Nally, 1982; Arthur, 2000); be subjected to sexual abuse (Turk & Brown, 1993); experience rejection, stigmatisation and live in adverse social conditions (Reiss, 1985); and have multiple

experiences of trauma or loss (Sinason, 1992). Finally, as the majority of people with learning disabilities are only mildly or moderately affected they are likely to have sufficient verbal skills to be able to engage with 'talking' therapies at least to some extent. Scior & Lynggaard (in press) have discussed this issue and highlight how language based therapies can be accessible for people with mild and moderate learning disabilities. They highlight how a slower pace of conversation is necessary, where language is kept relatively concrete and simple, drawings and pictures are used where appropriate and the clinician checks mutual understanding frequently.

## **1.2 Systemic therapy for people with learning disabilities and their families**

Over the past decade there has been an increasing interest in using systemic approaches when working with people with learning disabilities, their families and support networks (e.g. Vetere, 1993; Goldberg, Magrill, Hale, Damakinidou, Paul & Tham, 1995; Fidell, 1996, 2000). Although it is very much a developing area of clinical practice with this client group, particular issues and challenges faced by families where a member has learning disabilities have been highlighted in the literature and it has been argued that these render a systemic approach particularly suitable to this client group. These issues will be discussed below.

### ***What is systemic therapy?***

The term systemic therapy encompasses various models which although different in some respects, share a set of underlying assumptions (Hayes 1991). A broad definition of systemic therapy would therefore include the following elements. Firstly, focus on relationships is the essence of systemic practice. "Problems are understood within the

system of relationships within which they occur” Burnham (1986). Secondly, alongside there is an assumption that the actions or changes of one person in a system will inevitably have an effect on other people or parts of that system.

### ***The family life-cycle: Protection & loss***

Carter & McGoldrick (1982) propose that families go through a series of life cycle stages, which require them to manage transitions and re-organise. At each stage, for example adolescence, leaving school or leaving home, family members have different developmental tasks and changing roles to negotiate. Having a family member with learning disabilities can present challenges to expectations for the development of family members and of family life. For these families, the sequence of life events can often be different to other families (Vetere, 1993). The same issues and tasks for family life are present, however, having a person with learning disabilities in the family can mean that particular life events are more complex and difficult to negotiate, or may occur in an unusual sequence. For example, many adults with learning disabilities live with their parents and can be faced with leaving the parental home much later in life because an elderly parent is no longer able to care for them. In this example the family is required to negotiate adult offspring leaving the home at the same time as elderly parents are facing the consequences of the ageing process and the prospect of death.

Various authors have suggested that when a child is born with a disability, grief is experienced for the loss of a hoped for ‘perfect child’ (Oswin, 1991; Davis, 1993), and for the loss of an ‘ordinary life’ (Fidell, 2000). Goldberg et al. (1995) describe how each life cycle stage re-presents the family with the loss of previously held expectations. At

these times the failure of the person with learning disabilities to conform to the cultural norms of family development becomes increasingly apparent (Wikler, 1981). For family members each life-cycle stage evokes memories of these previous losses and grief. They argue that the pattern of grieving to those past losses may be recapitulated at the next loss. According to this view if family members have not resolved grief at previous transition points, the family may become 'stuck' and unable to negotiate current challenges successfully. Therefore according to Goldberg et al. (1995) grief and life-cycle issues are central to family therapy with adults who have learning disabilities and their families. Although the response that is evoked at points of life-cycle transition is viewed as constrained by those that have gone previously, it also opens a possibility for past losses to be re-grieved. They argue the task of therapy is for the family to re-grieve past and thus increase their capacity to manage future losses.

### ***Relationship to help***

Reder & Fredman, (1996) suggest that people's beliefs about and previous experiences of receiving and giving help influence the process and outcome of therapy. For families where a member has learning disabilities, by the time the person with learning disabilities reaches adolescence and adulthood their relationship to help may have been evolving over many years, through contact with numerous professionals and different services.

This relationship to help may impact upon the real and perceived control which family members have over the nature and extent of involvement with services. Fidell (2000), highlights how for families where a member has learning disabilities, professionals are

more likely to be involved in making personal decisions about issues that are usually private, than for other families, for example, deciding where an adult with learning disabilities is going to live once they leave the family home. Although families may accept help for their member with learning disabilities, it does not necessarily follow that they would choose to have the involvement of services in their lives. Therefore for some families it may be that they accept services out of necessity rather than choice.

A further consideration around families' relationship to help, highlighted by Fidell (2000), concerns how the referrer of a family for systemic therapy may have a certain view of the problem that is not shared by the family. Selvini Palazzoli, Boscolo, Ceccin, & Prata, (1980a) have discussed this issue as 'the problem of the referring person'. This poses important questions about the referrer's position to 'the problem' and highlights a need to clarify who it is that wants help and for what.

### ***Wider systems: Complex networks***

Donati, Glynn, Lynggaard & Pearce, (2000) highlight how a lifelong dependency on others is often a consequence of having learning disabilities, which can result in people with learning disabilities living and interacting in the context of large and complex networks of families, carers and support staff. Within these networks there exists potential for many and varied beliefs about different roles and responsibilities for providing support and appropriate services. Donati et al. (2000) describe how therapeutic work with this client group may therefore often have to be negotiated within the context of many different people and services. They argue that working within a systemic approach requires and respects the value of different perspectives, thus

enabling the relationships between different parts of the network to be explored, understood and worked with more effectively.

### ***Focus on strengths and resources***

Much research around the impact of having a son or daughter with learning disabilities on the family has focused on sources of stress rather than trying to understand the means by which they cope (Vetere, 1993; Bromley, 1998). As has been discussed above, for families with an adult member who has learning disabilities, by the time they are offered systemic family therapy they are likely to have had considerable experience of dealing with different services. Similarly, families will have inevitably faced and overcome many complex situations and challenges prior to the point of coming to family therapy (Fidell, 2000). Families with an adult member with learning disabilities will therefore have developed their own expertise over the years and will bring this to the therapeutic context.

As suggested by Donati et al. (2000) a systemic approach offers service users and their families an alternative choice of support which does not solely focus on problems, but seeks to identify strengths and resources within the system. It is possible that a focus on strengths and resources provides families with a helpful alternative, given that by their very nature the focus of support services which these families will have received in the past will have been on disability and difficulties.

### ***Involving adults with learning disabilities in family therapy***

Although the literature on systemic therapy with this client group highlights different issues which render a systemic approach particularly useful, there is very little discussion of how adults with learning disabilities have actually been included in therapy. The marginalised and disempowered position that people with learning disabilities occupy in society, can also be reflected in the context of their family and in the context of therapy. Roy-Chowdhury, (1992) has suggested that people with learning disabilities are particularly vulnerable to scapegoating, where they are positioned in the family and as someone different, complex and potentially difficult. The occurrence of problems can then serve as confirmation for such beliefs and thus further strengthen them. Problems can also be located by professionals and the wider society, as being intrinsic to the person with learning disabilities, without any consideration of the role of other parts of the system in the construction and maintenance of a problem. One consequence of this lack of power over their lives for people with learning disabilities is that with the many and varied opinions around in their networks of family, carers and professionals, the voice of the person with learning disabilities can be ignored or drowned out (Donati et al 2000).

In therapy, there is always an imbalance of power between family and therapist that demands acknowledgement. However, as outlined above, there is potential for power imbalances between the family and the learning disabled member, which also need to be addressed. For the family member with learning disabilities to be enabled to move out of a disempowered position in therapy and to consequently shift the balance of power in other areas of their system, it would be necessary for their voice to be heard and valued.

Donati et al. (2000) argue that the focus of systemic therapy, namely to invite different perspectives and opinions, is in itself a way to bring the voice of the person with learning disabilities into the conversation. However, historically people with learning disabilities have not been positioned in society in such a way that acknowledges they have a voice that should be listened to. This means that there is potential for individuals in all the different contexts of the lives of people with learning disabilities to be unused to communicating with and listening to them in this way.

People with learning disabilities themselves are often talked about as if they are not there or do not understand what is being said (Fuchs, Mattison & Sugden 2002). Therefore in the context of therapy, being expected to speak up, have a view, then share it with members of your family and therapists could well be an unusual or novel experience. This of course could be experienced very positively by the individual with learning disabilities, but equally it may present a situation that can be experienced as aversive and anxiety provoking. Similarly, family members may not necessarily want to talk in front of their son or daughter with learning disabilities or think that this would be helpful.

This presents a challenge to therapists; to balance the need for inclusion of the person with learning disabilities in a meaningful way with the risk of excluding or alienating other members of the family. Donati et al. (2000) advocate for the need to respect a family's communication style, to engage them in therapy. However, as Fidell, (2000) argues if in a family the learning disabled member is positioned in a way that

‘problematise’ and marginalises them, to go with the family’s communication style even in the short term risks colluding with and thus reinforcing the disempowerment of the person with learning disabilities.

### ***Making systemic therapy ‘user friendly’ for people with learning disabilities***

A number of suggestions have been made to overcome the challenges described above. This ways in which the processes and techniques of systemic therapy have been adapted with the aim of making it more accessible to people with learning disabilities will be outlined below.

### ***The voice of the person with learning disabilities***

The lack of recognition that people with learning disabilities have a voice or are listened to, discussed above, highlights the need for particular time and attention to be paid to how a person with learning disabilities can be enabled to talk in therapy, if they want to. Fidell (2000) discusses the importance of setting the sessions up in a way that offers the person with learning disabilities the opportunity to have some control over how the meetings run and what is talked about. If someone has not been used to being in a position of control in their lives and is thus less likely to feel they can make choices, it may be difficult for them to speak up or protest about things that they do not want to talk about or that feel too distressing for them. It may be that, as in other areas of their lives, people with learning disabilities are often in a position where one way of taking control is through their behaviour. In sessions there may be ways in which a person with learning disabilities opts out of the process, for example, by falling asleep or becoming quiet. It is therefore necessary to check out with the person themselves and the people

who know them well, in what ways they can let the meeting know if they are upset, or do not wish to talk. Family members can offer a resource to facilitate understanding as they know how their relative with learning disabilities communicates and may be the people best equipped to reinterpret things that are unclear in a more accessible way (Fidell 2000).

Engaging and working with different parts of the family system separately in the initial stages and then bringing the work together for joint meetings (e.g. Fidell, 2000; Donati et al. 2000), has been suggested as one way to ensure that the voice of the person with learning disabilities does not get ‘drowned out’. Fidell (2000) proposes that the person with learning disabilities in the family should attend the therapy even if their verbal skills are at a level where they cannot participate in the conversation by speaking words. She argues that to exclude them from the therapy would further marginalise and disempower them. Fidell also highlights how even if a person who has learning disabilities does not speak with words, their presence in the meetings provides opportunities to observe and gain information about patterns of interaction around the problem. Similarly, the process and interactions in therapy can show the basis by which an individual functions in other contexts of their lives.

A guiding principle of working within a systemic approach is to join with clients in therapy very much at the level of what they bring as important issues (Carpenter & Treacher 1993). In work with people with learning disabilities this demands that particular attention is paid to how information can be presented in accessible ways and how people can be enabled to contribute in a way that suits them. Fidell, (2000)

discusses how using genograms can enable a person with learning disabilities to give information about their families and thus be in a position of sharing some expertise. Fuchs et al. (2003) describe this as 'joining the language of the client', for example, by using drawings to facilitate understanding and enable the client to join in the therapy at an accessible and therefore meaningful level.

One systemic technique that has been adapted in work with children and families which may be relevant when working in this way with adults who have learning disabilities, is the use of circular questions. These require the ability to recognise and think from different perspectives, thus involving relatively complex cognitive functions. Benson, (1991) has described how these types of questions can be simplified and broken down to enable childrens' perceptions of the relationships in their family systems to be ascertained. Fidell (1996, 2000) describes how clients with learning disabilities can be asked to role-play an example situation and asked a series of questions about how things happen and who does what at home.

Fidell (2000) discusses some of the challenges of using particular systemic ideas and techniques in therapy with this client group. She highlights how difficulties understanding the concept of time can mean therapy is much more focused in the here and now with adults who have learning disabilities. Thinking about the future in relation to the past is something that Fidell highlights can be particularly challenging. She advocates depicting a historical perspective and linking past and present events through the use of life stories.

A further challenge to the usual ways of using systemic ideas and techniques in therapy is the use of reflecting teams (Andersen, 1987). The aim of a reflecting team is to offer clients the opportunity to listen to new ideas. Through this process it is possible for the client to become aware of different perspectives on a problem, which may in turn evoke new ways of viewing and relating to it. With clients who have learning disabilities the reflecting team process may place considerable demands on them for it to make sense or be useful. Fidell (2000) explains that she does not use a reflecting team in her work with this client group as it has the potential to be confusing. According to Fidell, this potential for confusion means that there is also the possibility to disempower people with learning disabilities by subjecting them to something that is unclear or they do not understand.

However, as noted by Fidell there is also potential for the use of a reflecting team to be a very positive experience for people with learning disabilities. Being invited to listen and comment on what is being said about oneself may be a welcome change from being talked about as if one did not have a view or was not present. Fuchs et al. (2003) describe how in their work using a reflecting team it was not clear whether the client with learning disabilities saw a role for themselves as taking part in the discussion. Goldberg et al. (1995) suggest that the process of reflecting team conversations effects a slowing down of the pace of sessions which they argue provides space for issues to be considered in their complexity.

It is clear that there is much scope for further development in this area of systemic practice with people with learning disabilities and their families.

The pace of therapy with adults who have learning disabilities and their families in general has been noted to be slower (e.g. Goldberg et al., 1995; Fidell, 2000). Fidell (2000) argues that the lifelong nature of learning disabilities means that the issues that are brought to therapy have been lived with for many years and thus take more time to shift. Fidell suggests that for some families, they may have organised their lives around an issue and the prospect of changing can be experienced as a threat which could invalidate many years of experience of living and developing their lives in a particular direction. For example, when an adult with learning disabilities does not become independent from the parents as in the usual sequence of the family life-cycle, parents may have spent many years anticipating that they will be in a position of having to be carers for their son or daughter into their old age. Thus parents would not have had the opportunity to plan for a retirement that they might have wanted where they had fewer care responsibilities. If the expected sequence of events does not occur, for example if the adult with learning disabilities exceeds expectations and leaves home to live independently, parents may be faced with having to acknowledge and adjust to a change in expectations for their own future role.

Goldberg et al. (1995) propose that the extended duration of therapy for families who have a member with learning disabilities also reflects the needs of many families to work through and repeat the grieving process for the multiple losses experienced over the course of their family's life.

### ***Different systemic approaches***

From the literature available on systemic therapy with adults with learning disabilities and their families there does not emerge one particular school of systemic therapy which

is the most appropriate way of working with this client group. However, a number of approaches have been suggested to offer useful ways of approaching issues that are often brought to therapy.

Based on work with children with learning disabilities and their families, Vetere (1993) suggests a structural family therapy model is most suited to the difficulties experienced around transition points within the family life-cycle. Vetere points out that this model is oriented very much towards parents and is accessible to them in its emphasis on practical problem solving and negotiating specific goals. However, as noted by Fidell (2000), although there may be some value in elements of the structural approach, an emphasis on parent-child hierarchies may be inappropriate when working with learning disabled adults.

A brief therapy model has also been suggested to be useful when working with families where there is a member with learning disabilities. Foster (1988) argues that the birth of a child with learning disabilities can undermine family members' confidence in their ability to cope and draw on their own strengths and resources. In a brief family therapy model there is a focus on (building) perceptions of strengths and competence, which can enable these particular issues to be addressed. Fidell (2000) highlights that although this approach appears to suit families who come to therapy with a definite agenda and relatively discrete problems, its utility is limited. According to Fidell (2000), these limitations arise where the focus on strengths and competence can move too rapidly away from discussion of a problem and associated distress, to positive exceptions. This

then poses a risk of communicating a message to families that they are expected to show resilience and be positive despite the difficulties they are experiencing.

Social constructionist ideas about disability have also been highlighted as providing a useful perspective to guide systemic practice when working with this client group. Oliver (1989) argues that disability is defined according to particular historical and cultural contexts. Therefore the meaning that 'learning disability' has for individuals and organisations will be dependent on the different contexts of their lives. Fidell (2000) describes how in therapy these ideas can offer an opportunity to re-define alternative and more helpful views of disability and what it means. This then created possibilities for a person with learning disabilities and their family to view themselves in a different and hopefully more helpful way, in relation to the different contexts that make up their world.

Systemic practice is still very much being developed with this client group and to date there is no evaluation of the benefits of systemic therapy in general or any particular systemic approach. As proposed by Fidell (2000), it would seem that to enable clinical practice in this area to continue evolving, different approaches, methods and techniques should be utilised on the basis of what suits and is most useful for each family who comes to therapy. Many would argue, however, that without solid evidence it is not possible to judge 'what suits' or 'is most useful'.

### **1.3 Research on psychological therapies with people with learning disabilities**

Currently, NHS funding for the development and provision of psychological services is increasingly dependent upon the ability to demonstrate that psychological therapy offered to clients is efficacious and clinical practice in an area is evidence-based (Roth & Fonagy, 1996). As argued by Arthur (2003), in this context the ethical principle that people with learning disabilities have the right to equal access is insufficient to secure appropriate services and change the current situation. As this client group have been one of the most neglected in terms of services and research into evaluation and development of therapeutic techniques (Reed, 1997), it is not currently possible to provide such an evidence base for different psychological therapies.

As noted by Beail (1995), in contrast to the paucity of research around ‘talking’ therapies with this client group, the number of evaluations of the effectiveness of behavioural interventions has been considerable. To date published research into the possible benefits of both cognitive-behavioural and systemic psychological therapies for adults with learning disabilities have focused more on providing accounts which demonstrate the approach can be applied in work with this client group, rather than outcome. As with the other therapeutic approaches, much of the literature concerning individual psychodynamic therapy with learning disabled adults, describes the application and process of therapy (Beail 1995). However, there has been a limited amount of clinically based research evaluating individual psychodynamic therapy for adults with learning disabilities (e.g. Beail & Warden, 1996; Beail, 1998, 2000), which has, on a very small scale, demonstrated some effectiveness for this way of working. A

brief summary of the main findings of cognitive-behavioural and psychodynamic research with this client group will be provided below.

Cognitive-behavioural interventions have been applied to a number of different presenting problems with people who have learning disabilities, such as: depression (e.g. Lindsay, Howells, & Pitcaithy, 1993); anger management (e.g. Taylor, Novaco, Gillmer, & Thorne, 2002); psychosis (Haddock, Lobban, Hatton, & Carson, 2004); and sex offenders (e.g. Lindsay, Marshall, Neilson, Quinn, & Smith, 1998). Although these studies have demonstrated positive effects and thus advocate the potential appropriateness and usefulness of cognitive-behavioural interventions for people with learning disabilities, a lack of controls, small sample sizes and the interventions often contain multiple components, such as including relaxation training alongside a cognitive component. Therefore the conclusions that can be drawn about the effectiveness of a particular intervention for a particular problem are limited and in need of further investigation (Sturmey 2004).

Psychodynamic psychotherapy as provided in routine clinical practice to adults with learning disabilities has been shown to provide some positive benefits. Beail, (1998) has provided an account of the outcome of weekly individual psychodynamic psychotherapy, of a mean duration of around 12 months. The study included twenty men with learning disabilities, who had been referred to a district clinical psychology service, as they presented with behavioural problems or had committed an offence. The problem behaviours and offending behaviours were eradicated in the majority of cases and maintained at 6-month follow up. Beail and Warden (1996) reported the outcome of

psychodynamic psychotherapy for twenty adults with learning disabilities who also had mental health problems. Post-intervention measures revealed a significant reduction in symptoms of psychological distress, improved interpersonal functioning and an increase in self-esteem for the participants in this study.

In a critical review of the available literature, Beail (2003) concludes that the lack of randomised controlled designs, small numbers of participants and absence of reliable and valid measures in studies examining outcomes of cognitive-behavioural and psychodynamic approaches in the learning disability field, means that they do not meet the criteria to be considered as demonstrative of evidence-based practice. However, Beail highlights the important distinction between this and practice based evidence, which can also provide valuable information to inform decision making about appropriate treatments.

### ***Psychological research into therapeutic techniques for people with learning disabilities***

There are particular challenges inherent in conducting outcome and evaluation research in the field of learning disability. Firstly, there are not the same established methods and measures available for this client group as there are in other areas. Those measures that are used in, for example, adult mental health, for quantitatively based outcome research usually involve self-report and thus require a certain level of reading ability (Beail, 1995). Although some of these measures have been adapted for use with people with learning disabilities and can be administered in interview format (Sturmey, Reed &

Corbett, 1991), their reliability and validity is not unquestioned. This means that obtaining valid and reliable outcome data can be difficult (Fidell, 2000).

A second difficulty for evaluation of therapy outcomes with this client group concerns the small number of potential participants. In the language of evidence based practice (Roth & Fonagy, 1996) the randomised controlled trial is held up as the 'gold standard' against which therapeutic efficacy and effectiveness can be judged. However, the stringent inclusion criteria for this type of research can rarely be met as numbers of people with learning disabilities are relatively small and as a group they show considerable heterogeneity, for example in terms of severity of learning disability, causes, communication skills and other associated disabilities. It is however possible to evaluate different therapies with this client group as they are provided in routine clinical practice. Recent research in clinical psychology has moved towards practice-based evidence, thus representing externally valid studies of service provision within naturalistic settings (Barkham & Mellor-Clark, 2000). As noted previously, such evidence has begun to be presented in relation to psychodynamic therapy and practitioners of cognitive-behaviour therapy in the UK are also currently gathering such clinically-based evidence in their work with people with learning disabilities.

A focus on outcomes does not, however, enable the individual's subjective experience of a particular therapy to be ascertained. An understanding of these experiences can offer information to enrich and strengthen the evaluation of a particular therapy. Qualitative methodologies, with their focus on the ways in which people experience events and make sense of the world (Willig 2001), provide a means to explore the complexities in

how therapy impacts upon the person in receipt of it from their perspective. Macdonald, Sinason & Hollins (2003) outline two ways in which this type of research can add information to quantitative outcome research. Firstly, it can provide information about clients' satisfaction with the therapy. Secondly, it can provide clinicians with feedback about elements of the therapeutic approach that are experienced negatively or are unpopular with clients.

There have been very few studies that have reported asking people with learning disabilities about their views on the experience of therapy, or about their level of satisfaction with psychological services (e.g. Chapman & Oakes, 1995; Macdonald et al., 2003). In an interesting qualitative study, Macdonald et al., (2003), interviewed adults with learning disabilities about their experience of group analytic therapy. The views and experiences shared by these participants presented a complicated picture where positive aspects of the group were spoken about alongside more negative elements, such as painful feelings being evoked by the experience. This detailed information about the complexities in how therapy is experienced could provide useful information for the development of methods for evaluating the impact of particular therapies.

### ***People with learning disabilities and qualitative research***

Historically, the voice and subjective experiences of people with learning disabilities have been excluded from research into issues that affect their lives. This situation can be understood as arising from a belief that having learning disabilities means an individual is unable or unlikely to provide reliable or accurate self-reports. However,

over the past decade there has been increased interest in conducting research that aims to represent and investigate the views and subjective experiences of this client group. This interest is reflected in a growing body of published literature in the field that uses qualitative methodologies. For example, Mattison & Pistrang (2000) used grounded theory to examine learning disabled adults' experiences of their relationships with keyworkers. Scior (2003) used discourse analysis in a study of the experiences of women with learning disabilities; in relation to gender and disability. Macdonald et al (2003) used Interpretative Phenomenological Analysis in their interview based investigation of how attending group therapy is experienced by adults with learning disabilities. As noted by Booth & Booth (1996) research aiming to represent the views of this client group faces a number of challenges, but what is common to all the studies cited here is a demonstration that when these challenges are considered and addressed in the design and process of research, adults with learning disabilities can express their views in a meaningful way.

#### **1.4 Researching systemic therapy: Other populations**

To date there has been no evaluation of the effectiveness of systemic therapy with people with learning disabilities, their families and the wider systems of their lives. Although systemic therapy with other client groups has been researched over many years, it has been suggested that this research has varied in terms of quality (Asen, 2002) and methodology (Addison, Sandberg, Corby, Robila & Platt 2002). Lerner (2004) argues that although there has been a wealth of research showing that family therapy can be effective, the criteria for what constitutes an evidence-based treatment excludes much of this research from the 'gold standard' of randomised trials, which require

manualisation and controlled independent replication. Lerner goes on to highlight how as systemic and family therapy are terms that refer to a collection of different approaches, that are all underpinned by broadly systemic principles, it is unlikely that any one methodology could do justice to this range of work.

The need for a broader definition of what counts as evidence in outcome research has to some extent been acknowledged in the five different categories of evidence defined in the UK National Service Framework for Mental Health (Department of Health, 1999): Type I evidence (at least one good systematic review and randomised control trial (RCT) for a range of problems), Type II evidence (at least one good RCT), Type III evidence (at least one non-randomised intervention study), Type IV evidence (at least one well-designed observational study) and Type V evidence (expert opinion, particularly of carers and service users). Asen (2002) conducted a review of the available literature on the effectiveness of systemic therapy. This revealed that according to these criteria: There is Type I evidence, a significant amount of Type II evidence and considerable Type III evidence. In the following summary this evidence will be briefly reviewed in relation to different clinical presentations which have been researched.

In a substantial review of controlled trials for family interventions with child focused problems, systemic therapy has been found to be effective for a wide range of presentations (Carr, 2000a). This includes child abuse and neglect, conduct, emotional and psychosomatic problems. A selection of these studies focusing on child and adolescent problems will be now outlined in more detail, for the purpose of illustration.

Systemic therapy has been shown to be effective in addressing issues of child abuse and neglect in families (Carr, 2000a). Brunk, Henggeler & Whelan (1987) compared multisystemic family therapy with behavioural parent training for 33 families where physical abuse and neglect had occurred. The multisystemic family therapy included family, marital and individual sessions and meetings with the wider professional network. Families were randomly assigned to the treatment conditions and outcomes were measured using self-report and observational measures of factors associated with child maltreatment. Overall the multisystemic family therapy group showed greater improvements in family problems and parent-child interaction, than the families who had received the behavioural parent training.

Family based interventions have also been shown to be effective for behavioural and conduct problems in children. Szapocznik, Rio, Murray, Cohen, Scopetta, et al. (1989) compared structural family therapy to individual psychodynamic treatment in a controlled study with 6-12 year old Hispanic boys and their families, who were recruited through schools and a radio advertisement. Sixty-nine participants were randomly assigned to one of the two treatment conditions, or a control group that provided recreational activities. Outcomes were measured using parent rated measures of child behaviour, child psychodynamic functioning and family functioning after six months of intervention and again at one year follow up. At six months both treatment groups showed significant gains at all three levels and there was no significant difference between the two treatment groups. However, at 12-month follow up the individual therapy group showed deterioration in family functioning, whereas for the family therapy group this had continued to improve.

The effectiveness of family therapy has also been demonstrated for a range of childhood psychosomatic complaints (Carr 2000a). One such example is a study examining the effectiveness of narrative family therapy compared to behavioural treatments for encopresis (Silver, Williams, Worthington & Phillips, 1998). A retrospective audit of therapy outcome for 108 children and families was conducted for the two equal sized treatment groups. Families were followed up 6 months after treatment and in 63% of the cases in the narrative family therapy group the children were not soiling, compared to 37% in the behavioural treatment control group.

Randomised trials have also shown systemic therapy to be effective in treatment of adolescent anorexia nervosa. For example, Russell, Szmulker, Dare et al. (1987) randomly assigned 80 participants to either systemic family therapy or individual supportive therapy for one year, following in-patient treatment. The results revealed that adolescents who had a short history of anorexia did better with family therapy than those with a similar history who received the control treatment. At 5-year follow up the benefits of systemic therapy remained evident (Eisler, Dare, Russell et al., 1997). These follow-up results revealed that 90% of those with a short history of anorexia continued to do well, compared to around 50% of those who had individual therapy, who were still presenting with significant eating disorder symptoms.

A recent Cochrane review included thirteen randomised controlled trials of family interventions for psychosis. Outcomes were measured in relation to: suicide, relapse and hospital admission and it was concluded that family intervention was effective in

decreasing the risk of relapse at 12 and 24 months and increasing the reliability with which medication was taken (Pharaoh, Mari & Streiner, 2000).

A randomised study has provided good evidence for the effectiveness of systemic couple therapy with people with depression living with a partner (Leff, Vearnals, Brewin, Wolff et al., 2000). Participants were recruited from a variety of sources, for example General Practitioners, Psychiatric outpatient or emergency departments and advertisements. The eighty-eight couples were randomly allocated to either 1 year of antidepressant medication or 1 year of systemic couple therapy. They were also followed up after 2 years. Results revealed that people with depression seen in systemic couple therapy did significantly better than those treated with antidepressant medication, both at end of treatment and at one year follow up. There were also notable differences in the dropout rates between the groups; 50% in the drug treatment group compared to 15% in the couple therapy group.

In a large meta-analysis systemic therapy has been found to be effective for child and adult focused mental health problems and relationship difficulties. The average treated case shows greater improvement than 70% of untreated control cases (Shadish, Montgomery, Wilson, Wilson, Bright, Okwumabua 1993). This growing body of evidence serves to highlight the value of systemic therapy as a major psychological treatment modality (Asen 2002).

### ***Researching Clients' subjective experiences of systemic therapy***

The National Service Framework for Mental Health (DoH, 1999) classifies the views of service users and carers as Type V evidence, along with the opinions of other 'experts'. This highlights how the experiences of service users can and should, contribute to the outcome research. As with the research on therapeutic outcomes, there is no literature on people with learning disabilities' accounts of their experience of systemic therapy. For this reason I will look at the general family therapy literature and a small number of studies that have explored service users' views on the experience of systemic therapy. In the process I will highlight issues that may be relevant and in need of investigation in the application of this approach to people with learning disabilities and their families.

In an early study exploring families' experiences of systemic therapy Howe (1989), interviewed families who had attended systemic therapy offered by social workers, who worked with one therapist in the room linked by video camera to a team behind a one-way screen. Of the twenty-one families interviewed only three saw the experience as helpful. A majority of them found the 'hi-tech' nature of the therapy unsettling and alienating. Reimers & White (1995) conducted a similar study aiming to represent families' experiences of systemic therapy. Families in their relatively small sample reported a mismatch between their expectations before going for therapy, which mainly focussed on wanting advice, and what they experienced in therapy, which emphasised exploring relationships and developing the families own ideas.

In a questionnaire study of families offered systemic therapy in a child and family service, Knott & Espie (1997) investigated families' perceptions of the initial interview,

using a team behind a one way screen. The families had all been sent an information leaflet prior to attending the first meeting, which provided information about the team approach and the use of equipment in their consultations with families. They asked 43 families to complete a questionnaire in their initial session, during the break when the therapist consulted with the team behind the screen. The families were asked about procedural aspects of the use of the screen, for example their prior knowledge of it, the information provided prior to and at the start of the session and whether families felt able to share their concerns about the screen. Families were also asked about their perceptions of the process of the session, which included the time it took to forget about or become at ease with the screen, how they felt about the break and the overall usefulness of the initial session. For the families in this study, feeling comfortable with the session was found to be associated with being able to forget about the screen, which was in turn associated with being informed about the screen prior to the initial session, having read the leaflet and feeling able to share concerns about the screen with the therapist. Only around half of respondents reported that they had read the leaflet provided prior to the first family therapy session.

One further study investigating service users' experiences of the reflecting team approach in family therapy, interviewed couples who had attended therapy together (Smith, Sells & Clevenger, 1994). Participants in this study reported feeling daunted by the process at first and did not recommend it for an initial session. However, they also valued the opportunity to become observers to their circumstances and saw the team as introducing a different experience where the usual struggles about who was correct were

not present. The participants in this study also described feeling less daunted when the team was present in the room, rather than behind a screen.

The above summary has illustrated that while there is evidence that a systemic approach can be effective when working with families, service user accounts suggest that the experience can be perceived as somewhat confusing and vague. Carpenter & Treacher (1993) suggest that historically practice in family therapy has valued technique and theorising over the families' experience. They propose that family therapy research should become equally focused on developing more 'user-friendly' practice, to assist therapists to engage with families in ways that are acceptable to them. Carpenter & Treacher argue that if families feel alienated by the experience of attending systemic therapy, they are unlikely to feel heard, understood and respected and thus less likely to be open to new ideas.

This need to develop 'user friendliness' also applies to children, who are invited to attend systemic therapy together with their families. There is a limited amount of research that has attempted to represent children's experiences of family therapy (e.g. Stith, Rosen, McCollum Coleman, & Herman, 1996; Cederborg, 1997; Shalan & Griggs, 1998; Strickland-Clark, Campbell, & Dallos, 2000; Lobatto 2002). A brief summary of the relevant aspects of this work will be provided below, which will highlight issues that may also be relevant to the inclusion of people with learning disabilities in the process of systemic therapy.

Children, like people with learning disabilities, are often placed in marginalised and disempowered positions that are maintained through socially constructed norms, such as being seen as too young to understand. It is therefore possible that in the context of family therapy this process of marginalisation is replicated. Children have been shown to have been positioned very much at the periphery of sessions in a study examining the degree to which different people participated in family therapy sessions in a Swedish child and family outpatient psychiatric clinic. Cederborg (1997) analysed twenty-eight videotaped sessions from seven families. Results revealed that children spoke only 3.5% of the content of sessions, compared to 56% by parents and 37.5% by therapists. When children's non-verbal participation was analysed they were found to spend 61% of the time as what were described as 'standby participants'.

In a qualitative interview study, Stith et al. (1996) sought the views of sixteen American children age 5-13 years. The children were interviewed on two occasions without their parents present. Analysis of the interview transcripts using a grounded theory methodology revealed that the children had mixed views about the experience of attending systemic therapy with members of their family. In this study the children were keen to be included, but not when the focus was exclusively on them and their difficulties. A preference to participate in ways that did not rely solely on language, such as through the use of games and play emerged from their accounts. There was also a sense of confusion about the reasons for attending therapy with their parents and some reported that they had been reluctant to attend meetings initially.

A further qualitative study interviewed five children between the ages of 11 and 17 years old (Strickland-Clark et al., 2000) about their experiences of attending systemic therapy with their families. The interviews were conducted over two meetings immediately after family therapy sessions, without their parents present. The main themes which emerged from the interviews were that children valued feeling listened to, conceptualised therapy as a challenge, found it difficult to speak out as they were concerned about reactions from other family members and felt the need for support in sessions.

A similar study was carried out by Lobatto (2002), who interviewed six children between the ages of 8 and 12 years old. Questions focused on eliciting their understanding of the reasons for attending family therapy; of the expectations of them during sessions; their experience of feeling heard and understood; and their ideas about the process of therapy. Lobatto's results showed that the children tended to locate the problem within themselves. They also experienced some uncertainty about rules of behaviour within the therapeutic setting, talked about feeling embarrassed, criticised and it felt at times as if the focus was too intensely on them.

These accounts of children's experience of systemic therapy are likely to share parallels with those of people with learning disabilities. Whilst it appears that children can participate in and make sense of the experience of systemic therapy they can also be confused by it and may require support to participate in the process. As Fidell (1996) suggests, the challenge for therapists working in the learning disability field is to practice systemic therapy in a way that a person with learning disabilities can understand and participate. Similarly, the findings from research in the general family therapy

literature, on user experience and satisfaction, apply to systemic practice in learning disabilities as they would for work using this approach with any other client group. As has been highlighted above, the information provided to families about the aims and process of family therapy meetings prior to and during therapy and the manner in which the team approach is set up, has the potential to influence the ways in which people engage with and thus benefit from the process of systemic therapy.

### **1.5 Rationale for the present study**

Currently there are increasing numbers of clinical psychologists and related professionals who are offering systemic therapy to people with learning disabilities and their families. There are accounts in the literature describing the application and process of therapy in this developing area of clinical practice. However, the question of outcome and whether it is an approach that is effective in alleviating distress or results in positive benefit for service users and their families, remains in need of investigation.

Outcome and evaluation research in the field of learning disability faces a number of challenges which mean that the stringent requirements of the randomised controlled trial are very difficult to meet. In recent years there has been a move generally in research in clinical psychology, towards broadening the definition of what counts as valid and reliable evidence (e.g. Barkham & Mellor-Clark, 2000; Reimers, 2001; Lerner, 2004). This has highlighted the utility of conducting evaluation and outcome research for different therapies as they are provided in routine clinical practice. A further extension of the debate in clinical psychology about reliable and valid evidence, concerns the importance of ascertaining service users' subjective experience of a particular

therapeutic approach. This information can provide feedback about client satisfaction and about elements of the approach that are experienced either positively or negatively, to contribute to evaluation of a therapeutic approach and thus inform the development of clinical practice.

Therefore, as the application of systemic approaches to working with people with learning disabilities and their families is a developing area of clinical practice, there is a need to seek information about service users' subjective experience of attending systemic family therapy. This would hopefully identify areas of clinical practice for further investigation and development, which could also contribute to a wider evaluation of therapeutic outcomes with this approach, to assist the decision making process about who and how systemic family therapy can help to alleviate distress.

There are also ethical reasons to enquire about service users' experience of therapy. The publication of *Valuing People* (Department of Health, 2001) has highlighted the need to examine working practices and service provision to ensure people with learning disabilities have more choice and control over their lives. Asking people who have learning disabilities and their families about their experience of therapy would enable their voices and opinions about issues that affect their lives to be heard.

The present study will aim to provide a qualitative exploration of how systemic therapy is experienced by adults with learning disabilities and their families. One long term aim is that this study will contribute to understanding of whether and how systemic therapy offers benefit to this client group.

### ***Rationale for using a qualitative approach***

The present study employs a qualitative approach to address the research questions as these methodologies are concerned with ‘the quality and texture of experience, rather than with identification of cause and effect relationships’ (Willig, 2001, p.9). They provide an opportunity to study how individuals ascribe meaning to particular events and how they ‘make sense’ of their experience.

Interpretative Phenomenological Analysis (IPA) was chosen as the most suitable method of qualitative analysis for this study. It was felt to be appropriate as the present study aims to gain an understanding of the experience of systemic therapy from the perspective of adults with learning disabilities and their families, and IPA is a method of exploring and capturing the experience participants have of a given phenomena and the meaning they attribute to it (Smith, 1994).

### ***Research Aims***

There were two main aims that guided the present study. Firstly, to provide an account of how families where a member has learning disabilities view their experience of systemic therapy. Secondly, to elicit the views of adults with learning disabilities themselves on their experience of systemic therapy.

These aims were addressed through asking the following questions:

## **1.6 Research Questions**

As the proposed study is exploratory in nature there are two main research questions and within this broad focus more specific sub-questions.

### ***Main Research Question – 1***

1. How do families where a member has learning disabilities experience systemic therapy?

#### ***Sub Research Questions***

- 1a. What aspects of systemic therapy were perceived as helpful and unhelpful?
- 1b. What are their thoughts on the involvement of the different family members in therapy?

### ***Main Research question - 2***

2. How do people with learning disabilities experience systemic therapy?

#### ***Sub Research Question***

- 2a. What do people with learning disabilities think about the process of therapy?

## **2. Method**

This study employed a qualitative methodology to explore the experiences of ten families, and six adults with learning disabilities, who had attended learning disability services for systemic family therapy. In-depth semi structured interviews were used to generate participants' accounts and to examine the ways in which they made sense of their experiences. Interpretative Phenomenological Analysis (IPA) was used to extract and analyse key themes that emerged from the interview data.

### **2.1 Recruitment**

Participants in this study were recruited through five community teams for people with learning disabilities who offer systemic therapy to families. The researcher presented the research design, aims and inclusion criteria to clinicians in these teams, who then sent an initial letter (see appendix 1) to families who met the inclusion criteria. This letter contained an information sheet (see appendix 2) about the study and details of how to contact the researcher for those interested in taking part. An accessible version of the information sheet was also sent to family members who had learning disabilities (see appendix 3). The letter to families contained a request that they go through this second letter with their relative with learning disabilities and assist them to contact the researcher if they were also interested in taking part.

If the members of a family did not all live together, for example, if the person with learning disabilities lived in supported accommodation, separate letters were sent to the different addresses. In such cases paid carers were sent a letter explaining the study, which also asked them to go through the information with the person with learning

disabilities they provided care for. It asked that carers assist with contacting the researcher if the person with learning disabilities expressed an interest in taking part (see appendix 4). The services involved in the study also identified some adults with learning disabilities who met the inclusion criteria who had been seen for systemic therapy with their partners. In these instances, letters were only sent to each of the partners.

It is unclear exactly how many people were approached about participating in the study as the recruiting services did not keep records of this. However, no more than approximately 15 to 20 families would have been approached, based on the small numbers of people seen by each of the services for systemic therapy.

As very few responses to the initial letters were received each of the services made telephone calls to all the families who met the inclusion criteria for the study. This was to ask for their consent for the researcher to telephone them about the study. All families who gave their consent were then contacted by the researcher, who explained the purpose of the study, what it would involve, answer any questions the family members had and if they were interested in taking part, to make an appointment to meet with the researcher.

The purpose of this initial meeting was explained to families over the telephone, which was to go through the information and consent procedure and conduct the interviews if they wanted to do so on that day. Families were also given the choice to arrange another time to meet to conduct the interviews. The majority of families preferred to go through

the consent procedure and the interview on the same day. Interviews with the person with learning disabilities were conducted separately, usually on a separate occasion.

In the initial telephone call the researcher also asked the family whether they felt that their relative with learning disabilities would be interested in taking part. The researcher asked about whether they would be able to answer questions about the meetings and talk about their experience. The majority of families gave a clear response around whether they thought their relative with learning disabilities would be able to participate in an interview. However, where it was not clear from the family's description, the researcher sought the opinion of clinicians in the service. If this was not possible due to time constraints, the researcher ascertained the level of the person with learning disabilities verbal skills on meeting them with their family.

## **2.2 Participants**

### ***Inclusion and exclusion criteria***

The following inclusion criteria were used in the study:

1. The work carried out fitted the following definition of systemic therapy: As focusing on 'problems within the system of relationships within which they occur' (Burnham 1986).
2. Families had attended a minimum of three sessions of systemic therapy no more than three years ago (from the time of interview). This included families who were still in therapy and those who stopped attending before an agreed end.

3. The term 'family' was conceptualised in a broad way to include single parent families, partners and siblings. The families did not have to be living together, to be included, but only those who attended family therapy together, were interviewed.
4. The members of a family did not have to be living in the same residence, but to be included in the study the focus of the work had to have involved the family and not been solely with paid carers, such as solely with a staff team.
5. The family member with learning disabilities did not have to participate in the interviews for other family members to be included in the study (although one aim of the study was to represent the views of at least some participants who have learning disabilities).
6. The person with learning disabilities may or may not have attended all of the family therapy sessions, but attended at least one.
7. Individuals had to be able to independently provide informed consent to participate in the study.
8. The therapy was conducted in English. The rationale underlying this inclusion criterion was to avoid interviewing participants through an interpreter. Firstly, organisational issues around funding and accessing appropriate services meant it was not possible to provide an interpreter. Secondly, it is possible that in

conducting an interview with an interpreter and a family, an additional perspective (that of the interpreter) would have to be considered in relation to the accounts given.

9. The person with learning disabilities was required to have communication skills of a sufficient level so that they are able to talk about their experiences. Information about this was gained from the therapists.

### ***Participant details***

Table 1 and Table 2 (see below) provide descriptive information on the sample. Ten families and six adults with learning disabilities participated in the study. Of the six people with learning disabilities, three were members of the families who also participated. The remaining three participants with learning disabilities had attended therapy with their partners, rather than with any relatives.

All of the adults with learning disabilities who participated in the study had been in receipt of learning disabilities services at some point in the previous three years, and therefore had at some point been defined as ‘having learning disabilities’. This represents a social systems perspective (Mercer, 1973) as opposed to classification in terms of IQ scores, which are not usually available and are used much less frequently by the majority of health professionals (Dowdney & Skuse, 1993).

**Table 1. Description of participants**

| Family identifier | Age of PLD* | Gender of PLD** | Ethnic background            | Who attended therapy? *** | Family members interviewed    | No. of sessions attended | No. of dna's  | No. Months between end of therapy and interview |
|-------------------|-------------|-----------------|------------------------------|---------------------------|-------------------------------|--------------------------|---------------|-------------------------------------------------|
| F1                | 46          | F               | British                      | PLD, M, F                 | M, F                          | Not specified            | Not specified | 18                                              |
| F2                | 44          | M               | British                      | PLD, M, F                 | M, F                          | 7                        | 2             | 20                                              |
| F3                | 47          | F               | Caribbean                    | PLD, M                    | M                             | 4                        | 0             | 2                                               |
| F4                | 26          | M               | British                      | PLD, S                    | PLD, S                        | 10                       | 8             | Ongoing                                         |
| F5                | 45          | M               | British                      | PLD, M                    | M                             | 12                       | 0             | 17                                              |
| F6                | 19          | F               | British & East African Asian | PLD, M, F                 | M, F                          | 3                        | 1             | Ongoing                                         |
| F7                | 21          | M               | British & Nigerian           | PLD, M                    | PLD, M                        | 6                        | 0             | >1                                              |
| F8                | 19          | F               | British                      | PLD, M                    | PLD, M                        | 5                        | 0             | 1                                               |
| F9                | 30          | F               | African                      | PLD, M, F                 | M, F                          | 20                       | 0             | Ongoing                                         |
| F10               | 19          | M               | Indian                       | PLD, M, F                 | M, F                          | 9                        | Not specified | Ongoing                                         |
| F11               | 23          | F               | British                      | PLD, P (as a couple)      | PLD                           | 9                        | 0             | 29                                              |
| F12               | 44 & 41     | M & F           | British                      | PLD (as a couple)         | Both PLD interviewed together | 3                        | 0             | Ongoing                                         |

\* PLD: Person with learning disabilities. \*\* Gender: Male (M), Female (F). \*\*\*Family Members: Mother (M), Sibling (S), Partner (P)

## **2.3 Procedure**

### ***Ethics***

Ethical approval for the study was gained from the Eastern Multi Centre Research Ethics Committee: MREC no 03/5/077 (see appendix 5 for letter of approval). In addition to the procedures for obtaining consent, the ways in which specific ethical considerations around ensuring participants were sufficiently informed and adequately supported in the study were addressed will be discussed below.

Participants with learning disabilities were offered the opportunity to be interviewed on their own or with a chosen person present. This was to avoid their voice not being heard in an interview with the rest of their family. All participants were given this choice, but it was felt to be particularly important for those who had learning disabilities for the reasons outlined above.

In the interviews I drew on my clinical experience of working with people with learning disabilities and other client groups when talking with them and their families about personal or sensitive issues. This involved monitoring the effect that the interview was having on the participant and responding appropriately. Participants were informed that the interview could be upsetting and that they did not have to talk about anything that they did not want to.

At the end of the interview time was spent reflecting with the participants on their experience of it, how it had left them feeling to enable the expression of any difficult or

upsetting feelings that had been raised for them by the interview. Participants were informed that the researcher would assist them to find any follow-up support from the psychology team or their GP if necessary.

Once participants had given their consent to be contacted about the study, the researcher telephoned them and were offered the opportunity to have an initial meeting, at either their home or at the service where they had attended family therapy. The aim of this initial meeting was to build rapport, provide an opportunity for participants' to ask questions, assess the participants with learning disabilities capacity to consent and complete the consent procedure. All participants were offered the choice to have an initial meeting and then to arrange a separate time for the interview. However, all participants elected to go through these initial procedures and the interviews on the same occasion. Only one participant, who had learning disabilities, opted to meet the researcher at their local learning disabilities service. The remaining participants were all seen in their own homes.

### ***Consent***

In the current study the procedure for ensuring participants with learning disabilities were enabled to make an informed decision about whether they wanted to participate, was guided by research around assessing consent with this client group (Arscott, Dagnan & Kroese 1998). The main elements of the study were explained to participants using simple language. This information included outlining what taking part would entail, any negative aspects of participating and it emphasised the voluntary nature of participation.

Confidentiality and anonymity were explained and the researcher's independence from the service was made clear.

Participants were asked a number of questions about the information they had heard to assess the degree to which they had understood it and thus assess whether they have given 'informed' consent (Arscott et al 1998). All participants answered the majority of these questions. However, in general they did not give any examples of negative aspects of the study, so the researcher provided this information a second time in an attempt to aid understanding.

These questions were:

1. What will I be talking to you about?
2. How long will I talk to you for?
3. Can you tell me any good things about talking to me?
4. Can you tell me any bad things about talking to me?
5. What can you do if you decide that you don't want to talk to me any more?
6. What can you do if you have any questions about the project?
7. Will I talk to anyone else about what you say?
8. Are you happy to carry on talking with me for the project?

Acquiescence has been shown to be a characteristic of the responses given by people with learning disabilities (e.g. Sigelman et al. 1981). However, Rapley & Antaki (1996), based on a conversation analysis of the 'acquiescence' of people with learning disabilities, conclude that it may be an artefact of the conversational organisation of

interviews as tests and that people with learning disabilities are able to resist the pressure to acquiesce. In considering these issues the researcher spent time explaining that participants had the choice to refuse to answer questions, that they did not have to talk about anything they did not want to, that they would not get into trouble for anything they said or if they did not want to participate or answer particular questions. The researcher also stated that any decision whether or not to participate, or anything they said, would not affect their care or support from the learning disabilities team.

It was explained to family members and carers that each person had to give their consent independently and that family members were welcome to participate in the study, even if their relative with learning disabilities declined to do so. This was to minimise the possibility of people with learning disabilities not being given the opportunity to decide for themselves whether they wanted to participate, or feeling under pressure.

The procedure for obtaining informed consent from other family members followed that outlined above. However instead of questions to assess understanding participants were asked if they had any questions for the researcher.

## **2.4 The semi-structured interview**

A semi-structured interview was chosen as the method of data collection. This type of interview provides a means of exploring an individual's account of their experiences that is structured, as there are particular areas to focus on, but also flexible enough to allow for exploration of issues that may arise unexpectedly (Smith 1995). These characteristics of a semi structured interview fitted well with the aims and subject matter of the study.

The current study aimed to explore families' and adults with learning disabilities' accounts of therapy, which is arguably a very personal event experienced in a unique way by each individual. The flexibility inherent in a semi-structured interview also enabled the questions to be tailored to the participants' own level of expression and comprehension (Fielding, 1993). In accordance with Smith's (1995) approach, efforts were made to ask questions that were as open ended, jargon-free and non-leading as possible.

The way in which the interviews were conducted was informed by general guidelines in the literature for good practice in interviewing this client group. Prosser and Bromley (1998) emphasise the importance of the same principles for good practice in interviewing adults and children in the general population. For example, setting up the interview by stating its purpose, describing the types of questions that will be asked, explaining who the information is for and how it will be used, stating how long the interview will take and reassuring the participant that there are no 'right' or 'wrong' answers.

Wynngaarden (1981) recommends an unthreatening, conversational, relaxed style of interview conducted in a private place. It is suggested that the interview should start with easier questions to help establish rapport and more difficult or emotional questions should be kept for the middle or end of the interview. He suggests this can be achieved by starting with closed questions and following with more open questions.

These recommendations were followed in the current study. To ensure that the interview followed a relaxed, more conversation-like style the schedule was used as a guide rather than be gone through question by question.

All interviews were audio taped and lasted between sixty and one hundred and twenty minutes.

### ***Interview schedules***

Two interview schedules were used (see appendix 6 & 7). Both explored similar themes but were worded differently so that the version for people with learning disabilities was simpler and easier to understand. The interview schedules were developed according to Smith's (1995) guidelines. The areas for exploration were determined by the research questions and from a review of the available literature and will be outlined below. The same format, covering these areas, was used for interviews with family members and for adults with learning disabilities and is presented below. The ways in which the interview schedule was adapted for the participants with learning disabilities will then be outlined.

#### ***1. General information***

This section was used to orient the participant to the interview and help put them at ease. In line with Smith (1995) this early part of the interview focused on more general questions to gather information about their family and details about where they went for therapy, what they thought of the setting and who attended the sessions.

## *2. Relationship to help*

Questions in this area focused on the circumstances that led the family to seeking help, what their expectations of therapy were and previous experiences of therapy or support from other sources.

## *3. View of the problem*

This area of exploration aimed to gather multiple perspectives on the problems which had led the family to therapy. Questions were asked about the views of the participants, other family members or important people in the system, and the families' perception of how the therapist saw the problem.

## *4. Process/techniques of therapy*

This section was concerned with how the participants experienced particular techniques and ideas that the therapists had drawn on that made the therapy 'systemic'. The researcher drew on information provided in the therapists' questionnaire (see section 2.5 and appendix 8) to focus questions around the particular systemic ideas and techniques that were used with a family. This also involved exploring participants' perceptions of any ways in which these aspects of the therapy had affected their behaviour, relationships or beliefs.

## *5. Changes*

This area aimed to explore participants' perception of any changes in the problem and to what extent the family therapy had offered the benefits they had hoped for.

## *6. Service development*

These questions were used to explore ways in which the participants thought the content or process of systemic therapy could be improved.

## *7. Process of interview*

The final part of the interview aimed to enable participants to reflect on the process of the interview with the researcher, to ask any questions and check whether participants might require follow-up in relation to any distressing issues which had been covered during the interview.

### ***Interview schedule for participants with learning disabilities***

This interview schedule was similar to the family schedule but it was adapted to enable the participants to share their experiences. This involved drawing on the literature around methodological issues involved in interviewing people with learning disabilities (Ambalu, 1997; Flynn, 1986; Sigelman et al., 1981). The recommendations that have emerged from this literature focus on the types of questions to use, how to ask them and the most appropriate setting for the interview.

The recommendation to use open-ended questions to minimise problems with acquiescence associated with yes/no questions in interviews with people who have learning disabilities was followed as far as possible (Sigelman et al., 1981).

In the interviews with people with learning disabilities, the researcher spent more time at the outset talking about general issues of interest to develop rapport and create a climate

where they felt more at ease with the researcher. Photographs of the therapists were used to facilitate the interview process and serve as cues to what would be talked about.

### ***Piloting the interview schedules***

Once a draft of the interview schedules had been produced it was given to two experienced clinical psychologists who worked in adult learning disability services for comment. It was then revised in light of their recommendations, which had identified changes in the way questions were worded and terms used to describe the therapy.

Due to the very small number of potential participants, it was not deemed feasible to formally pilot the interview schedules. Instead the first two interviews were reviewed as quasi-pilots and the format and order of questions were adjusted where necessary.

## **2.5 Therapists questionnaire**

A brief questionnaire was devised and completed by therapists before participants were interviewed by the researcher (see appendix 8). As several different therapy teams from several different services had provided systemic therapy to the participants in the current study, the questionnaire provided the researcher with information about the main systemic approaches, methods and techniques (Burnham, 1992) that were used with a particular family in their systemic therapy. This enabled the researcher to explore participants' perceptions and experiences of particular systemic techniques in the interview.

The questionnaire was not an attempt to provide any comprehensive definition of ‘what is systemic therapy’; this would have been a task beyond the scope of this study and of the researcher’s own knowledge base as a trainee clinical psychologist. It was an attempt to gain information about the main approaches, methods and techniques used by therapists with the families in this study to aid the interview process. The questionnaire was devised in consultation with the systemic literature (Hayes, 1991; Vetere, 1998) and the items it contains aimed to represent the approaches, methods and techniques that are generally used in current systemic practice.

## **2.6 Method of analysis**

Each interview was transcribed and then IPA was used as a systematic means of identifying key themes in the data. The guidelines for how to analyse data using this methodology produced by Smith & Osborn (2003), were followed in conducting the analysis.

The transcripts for the family members were analysed as one group and the adults with learning disabilities transcripts were analysed as another group. Each transcript was read and re-read to develop the researcher’s familiarity with the data, before using the margins to note significant things said by the participant or issues of interest. These notes were key words, preliminary reflections, summaries of connections, initial interpretations, emerging themes that conveyed the essential quality of the participant’s account. Examples of this stage of the analysis are presented in the appendix (see appendix 9 & 10).

The next stage for each transcript involved compiling lists of the emerging themes on a separate sheet to cluster the initial themes into groups. These were then further refined by returning to the original transcript and re-reading it in the context of these emerging themes. This process was gone through several times. A table of the emerging themes with all the relevant excerpts from the text was created (see appendix 11 & 12), which enabled the researcher to continually and easily check that the interpretations were based on the actual content of what participants had said. This process was completed for each transcript in turn. The researcher aimed to be open to new issues emerging from each transcript but was also guided by the analysis of the previous transcripts.

When this procedure had been completed with four transcripts, the emerging themes were presented to another two researchers who were familiar with IPA, for comment and discussion. This process aided the identification of connections and inter-relationships between the themes, and was an attempt to reduce researcher bias.

Then the emerging themes were organised into a list of master themes and sub-themes separately for each transcript, with verbatim quotations. This was represented in another table (see appendix 13 & 14). Once the analysis of all the transcripts was complete, a list of themes was produced which integrated the themes from each transcript into an inclusive master list. This process was discussed with another researcher and the different perspectives on the text they brought, highlighted and thus minimised the main researcher's bias. It enabled me think about how I had arrived at the integration of the themes and thus be open to different perspectives on the data. The presentation of a clear

account of the steps taken in clustering and organising the data, to this other researcher, was made possible in the series of tables produced through the process of analysis.

A final summary table was produced for each of the two groups, which presented a clear overview of the themes in a coherent order. The naming of the master themes aimed to closely reflect the content of the subordinate themes (Tables 3 & 4, Results section).

## **2.7 Reliability and Validity**

In the process of conducting the analysis using IPA it was important to approach it in a systematic and rigorous manner. However, it was also important to balance this with the researcher's own curiosity and the creativity in the process of interpretation (Smith et al., 1999). Guidelines have been produced to address issues of reliability and validity in qualitative research (Elliott, Fischer & Rennie, 1999). These outline a number of methods through which the validity and reliability of qualitative research can be assessed. The methods that were incorporated into the current study will be discussed below.

### *Owning one's perspective*

This involves explaining theoretical, methodological and personal orientations to the research (see section 2.8).

### *Situating the sample*

This aspect of good practice in qualitative research refers to providing descriptions of participants to assist the reader in judging the range of persons and situations the findings may hold relevance for (see section 2.2)

### *Grounding in examples*

This describes how raw data should be provided to determine the fit between conclusions and interpretation of the data (see Results).

### *Providing credibility checks*

This involves having more than one person analysing the data. It is important to not that the aim in qualitative research is not to check the objectivity of the master themes (Yardley, 2000), but it is to minimise researcher bias and assess the validity of the individual researcher's interpretations of the data (see section 2.6).

## **2.8 Researcher's perspective**

Qualitative research recognises the importance of the researcher's perspective in determining the way they approach the phenomenon under investigation and the way they make sense of the data. Willig (2001) emphasises the importance of understanding the researcher's perspective, especially at the stage of analysis. Elliott et al. (1999) suggest that it is good practice for the researcher to explicitly describe their values, expectations and the framework of understanding they bring to the research, to enable readers to evaluate the study in the context of this information. I will therefore outline the reasons for my choosing to investigate how families where a member has learning disabilities experience systemic therapy.

My personal orientation is that I am a 29 year old, female, white British, trainee clinical psychologist. I have a keen interest in using systemic ideas and approaches in psychological therapy. This interest has been encouraged through my training as a psychologist and from previous work with families in mental health and social services

for children and young people. During my training in clinical psychology I have completed two placements in learning disabilities services where systemic therapy has been offered to clients. Prior to training I worked with children with learning disabilities as a residential social worker in a respite care setting. These experiences have led me to believe that a systemic approach to psychological therapy, that locates difficulties not within an individual, but within the context of the relationships and systems within which they occur, is particularly suited to the issues and challenges frequently faced by people with learning disabilities and their families. As a result I have come to this research with an assumption that that systemic therapy has the potential to be helpful to people with learning disabilities and their families.

However, I also came to this study with a number of questions about systemic therapy with people with learning disabilities and other populations. As an assistant psychologist some years ago, the experience of being a member of a reflecting team behind a screen, in family therapy sessions with young people and their families, often left me wondering what the young people themselves really thought about the sessions. In some sessions a young person would be looking and acting 'bored', or would answer questions with a shrug and 'dunno' (if answering at all). I was often left questioning whether the family therapy sessions felt useful or relevant to the young person themselves.

These questions remained with me and seemed even more pertinent in my learning disabilities placement where I was involved again as a member of a reflecting team in sessions with adults with learning disabilities and their families. Here I was left

wondering how much of what had been said was understood by the person with learning disabilities themselves. So another set of expectations I had for this research was that although therapists may see some real possibility for providing therapy that can be helpful to these families, the families themselves may not necessarily see it like that. Again, this assumption is likely to have originated from my clinical work and along with the other assumptions described above, may have influenced my thinking in the process of carrying out this research.

However, during the research process I attempted to keep very aware of the possible and inevitable biases present in conducting research, which may have influenced the ways I thought about and approached the study. Hopefully this will have helped me to approach the analysis with reflexivity, thus helping me to consider whether and to what extent my personal beliefs may have influenced my interpretation of the data.

### **3. Results**

#### **3.1 Overview**

The themes generated using Interpretative Phenomenological Analysis (IPA), for both groups of participants will be presented. The transcripts were analysed as two separate groups, namely family members and adults with learning disabilities, and will be presented as such in this section. The results from the two groups will then be discussed in relation to each other in Chapter 4: Discussion.

Throughout presenting and discussing the results I will refer to this group as ‘family members’ or ‘families’. Of the ten families who were interviewed, five were families of both parents, four were mothers and one was a sibling who had been in the role of primary carer for some time. No younger siblings took part in the study. Of the six adults with learning disabilities who were interviewed, three were members of the above families. Two further participants with learning disabilities had attended therapy as a couple and were interviewed together for this study. One further person with learning disabilities had also attended therapy with their partner. However, only one person from this couple participated in the study.

For both groups, each master theme and corresponding subordinate themes will be presented in turn. An outline explaining the meaning of the first master theme will be given. Then each subordinate theme under that master theme will be outlined and illustrated by quotes from the participants’ transcripts. Each quote is labelled with a family identifier (referring to each of the 12 systemic interventions that were evaluated

in this study), page number and line number, representing its location in the original transcript (e.g. *F1 (2:32) refers to family 1, page 2, line 32*). When quotes are used that have text omitted this will be indicated by three dots (...) and the different parts of the quote will then be labelled with the participant or family identifier, followed by the relevant page numbers and line numbers referring to the point in the transcript where the beginning of each part of the quote is located (e.g. *F6 (8:23; 16:43) refers to family 6, page 8, line 23 and page 16, line 43*). The process outlined above will be repeated for the subsequent master themes and associated subordinate themes for both groups.

### **3.2 Themes emerging from the family members' transcripts**

The following table (Table 2) shows the master themes, subordinate themes and the prevalence of quotes for each of these themes. Prevalence is reported here to demonstrate the degree to which participants described similar experiences. The number in brackets indicates the number of families in whose accounts the themes occurred.

**Table 2: Master and subordinate themes emerging from the family members transcripts**

| <b>Master theme</b>                              | <b>Subordinate theme</b>                                                                                             |
|--------------------------------------------------|----------------------------------------------------------------------------------------------------------------------|
| <b>Relationship to help (10)</b>                 | Getting to therapy (9)<br>What kind of help (8)<br>Relationship with services (9)<br>Family life cycle/ why now? (8) |
| <b>Value of therapy (10)</b>                     | Changes (10)<br>Trust (8)<br>Experience of talking (7)<br>Views on the reflecting team (7)<br>Practical help (6)     |
| <b>Having a voice versus being silenced (10)</b> | Parent's voice (8)<br>Going together (10)                                                                            |

In the following discussion of the themes that emerged from the participant's accounts, prevalence has been categorised as the majority (greater than or equal to two thirds; 7 to 10 families), a moderate number (between one third and two thirds; 4 to 6 families) and a minority (less than a third; 3 or fewer families).

## **Relationship to help**

Different experiences, ideas and expectations that were brought to therapy emerged as an important master theme in the accounts of all the families. Participants described the circumstances that led to the decision to attend family therapy, their past experiences of involvement with various services and how different aspects of the help seeking process shaped their perceptions of what therapy could offer. There were four sub-themes.

## ***Getting to therapy***

The majority of family members interviewed talked about how the decision to attend family therapy came about. This gave an insight into how the referral process was perceived from their perspective. There was a general sense that the initial idea originated from professionals, none of the families talked about self-referral. A sense of confusion emerged about the reasons why they were offered family therapy, what led them to being offered the family sessions, or about the purpose of the meetings.

For a moderate number of families it was clear that the idea came from professionals. The following example, from the account of a man who cared for his sibling with learning disabilities, highlighted how in his view the suggestion of family therapy was made by the social worker:

*“They [social services] said, you two should go and see a counsellor, it seems like you have got issues against each other.” F4 (2:20)*

Confusion about how the initial contact with the service was made emerged in the accounts of some families. This is shown in the following comment made by the mother

from one of these families. The parents and daughter, who had learning disabilities, attended family therapy together:

*“...the teacher or college must say something. I am not sure. It must be the school or something.” F6 (3:22)*

A different mother, who attended family therapy with her son who had learning disabilities, explained that it was a surprise to be contacted and invited to attend family therapy:

*“I suddenly got a letter out of the blue inviting me to come.” F7 (2:2)*

### ***What kind of help***

A majority of families described having hopes and expectations prior to the start of therapy, for how it could help them. Despite the frequent apparent lack of clarity about the referral process, it emerged that the majority of the families saw themselves as having clear ideas at the start of family therapy, about the ways in which they wanted it to help.

Some of these families identified that they had hoped the family therapy would promote change in a specific problem. In the example presented below, a mother from one of these families expressed a wish that her daughter would learn to control feelings of anger more effectively:

*“My hopes has been that we can actually try and get hold of that anger and try and cool it down a bit.” F8 (7:19)*

For another of the families there was a hope that the family therapy could offer alternative ways to approach a problem. This is clear in how the mother explained the issues that she wanted the therapy team to provide help for:

*“I said to her now how do we make this step forward. How do we break that chain?” F 2(1:41)*

This mother from a different family, described her desire for change in the way they related with one another:

*“I hoped that I would have an opportunity to raise various things that I can’t deal with on my own in my relationship with [son].” F7 (3:5)*

For a minority of families there was a sense that family therapy was seen as a place where they could get advice. This seemed to reflect a hope that the therapists could Offer guidance and impart knowledge about how to help their adult son or daughter with learning disabilities develop their skills and help the family face future challenges:

*“I want more benefit for [son], how to work with him, the future, what we do.”*  
*F10 (7:10)*

A relative from a different family saw the family therapy as a route to getting appropriate support from other services:

*“I expected it to help us, or my [nephew] more than me, because I find it very hard in getting his rights as a person. I find I am losing track of social services not helping. So I thought it is another stepping stone for help for my [nephew], to*

*get a little bit more qualified people involved, to maybe get things rolling more quicker [sic], in some ways.” F4 (2:36)*

### ***Relationship with services***

The majority of the families in this study talked about previous contact with services. A general sense that there had been a lack of appropriate support available to them in the past emerged from their accounts. They referred to past involvement with both health and local authority services. For these families, past negative experiences of contact with various agencies appeared to influence their beliefs about and expectations of services, the likelihood that help was sought, or that services were seen as having anything to offer.

A moderate number of the families perceived themselves as having received little or no support in the past. For these families, there was an emphasis on how over the years families had been left to rely on their own strength and resources to cope with the challenges of bringing up a son, daughter or relative who has learning disabilities.

The comments of this mother conveyed a sense that the family had been left to struggle on their own, without support from services:

*“When I needed help where were you?” F9 (5:44)*

Another mother’s experience of the delay in help being provided for her son, appeared to contribute to a view that the family therapy had little relevance for their current circumstances:

*"I said well you are forty five years to late for that." F5 (9:4)*

A different participant, who cared for his sibling with learning disabilities, conveyed a sense of the hard work and personal sacrifice demanded by his role as a carer:

*"I'm left to do everything. I hardly ever go out and when I do it is only to [place nearby] and back again. That is my life." F4 (3:31)*

### ***Why now?***

As described in the previous sub-theme family members conveyed a sense that they had struggled on the best they could over the years. This raises the question what prompted the families to seek help, or more often be referred for help, for issues that they had often been living with for years. For a majority of the families it emerged that the point at which they came to therapy was when concerns about, and planning for, the future of their son or daughter with learning disabilities were becoming increasingly urgent their lives. At the point of entering therapy, these parents appeared to have an awareness that their son or daughter needed to move on, to become more independent. The experience of attending family therapy, appeared to have facilitated consideration of the options for the future and offered a place where their concerns about what it may hold could be expressed.

This father clearly expressed how prior to attending the family therapy, thinking about his daughter's ability to live independently was very difficult:

*"We could never imagine X living on her own...It was taboo even to think about it. If we was [sic] ever gone." F1 (7:43)*

For three families, a view that their son or daughter with learning disabilities would never be ‘without a problem’ appeared to shape their expectations for the future. The father from one of these families explained how he did not expect his daughter to develop skills that would enable her to be more independent:

*“They’d [sic] say, what do you hope for the future and what do you hope for X? I said it would be nice if she’d be able to read and write, nice if she could cross the road by herself and things like this. It is never going to happen I don’t think.”*  
F6 (13:33)

The mother, from the same family, shared her husband’s view that there would be problems to face in the future:

*“After the college...[pause], things to be worried about. What after that. At the moment she is there ok and everything, but afterwards is the problem.”*  
F6 (16:41)

An awareness of the closeness and mutual dependence in the relationship between mother and adult son or daughter with learning disabilities was highlighted in the accounts of some families. In one mother’s explanation of the issues that were focused on in the family therapy with herself and her son, she appeared to appreciate the need for him to move on and become more independent:

*“The one thing I really want for [son] is for him to have a place of his own. I know I could cope and I am quite sure [son] would flourish if he went. Probably*

*start off in a communal house. I think he would do well. I don't think [son] would really come into his own until he is able to get out from under me."* F7 (9:7)

The task of therapy for another mother, was seen as facilitating the process of separating from her daughter, to enable her to move out from the family home. Her account conveyed a sense that the emotional upheaval this entailed was seen as inevitable, but that it could be supported in the therapy:

*"It was only to prepare [daughter] for the move from home to the [pause] from this home to the home there, because we've been attached together for so many years I didn't know how she was going to take it, or myself".* F3 (4:29)

### **Value of therapy**

The second master theme pulls together different aspects of the process and outcome of family therapy, that were perceived as having a particular impact for all of the participants. There were differences between the families in how particular aspects of the experience of family therapy were perceived, as either bringing positive benefits, or making no helpful difference to their lives. This theme incorporates five subordinate themes.

### ***Changes***

All of the families talked about the impact that attending family therapy had for them. There were differences between the participants, in whether the family therapy was perceived as effecting any positive change. There were also differences in the areas of their lives that were seen as benefiting from the experience. A moderate number of

families, saw attending family therapy as offering benefits specifically for their relative with learning disabilities. Positive changes in the family's way of managing difficulties, stresses and transitions, were identified by a majority of the families. It also emerged that family therapy provided a forum in which they felt their own efforts in caring for their family member with learning disabilities were recognised and acknowledged.

While some perceived clear positive benefits, a minority viewed the very experience of being able to talk about distressing, or difficult events and feelings, as the most helpful aspect of therapy. These participants acknowledged that although certain things may never change, being able to talk about them and the feelings they evoke can in itself bring relief. In contrast, one family, felt that nothing had been gained from the experience of attending family therapy. It was seen as not effecting any change in their particular circumstances, or offering anything new or different. Finally, a minority of families had mixed views about the degree to which they perceived positive benefits as arising from attending family therapy. Although for these families there were some positive benefits, there were also areas in which family therapy was perceived as not effecting the change that had been hoped for.

- **Changes perceived in the person with learning disabilities**

Where families identified positive changes resulting from the family therapy, these often included changes in the adult with learning disability's view of the problem. For one family, where the parents were becoming increasingly elderly their son had become distressed about issues around death. They saw the family therapy as helping them to

approach ageing and death in a different way, that was less upsetting for everyone involved:

*“He does it in a light hearted way. He’ll say “so and so is dead.” I’ll say “if they’re dead they’re dead. Let’s go and get some flowers.” I take off lightly. He says “ no.” We treat it casually.” F2, (11:8)*

Another family described how the therapy had focused on preparing their daughter with learning disabilities to move out of the parental home and live independently. As well as helping the move to occur, these parents believed that the therapy helped their daughter to develop a more positive view of herself as confident and independent:

*“I think they gave her the confidence to break away from me. That she doesn’t need me and I am here if she does. She is independent.” F1 (23:13)*

A mother from a different family felt the most helpful outcome of family therapy had been to allow her son to develop a sense of direction:

*“[Son] has clarified since we started going, what he wants to do. He now has an aim in life. Whether he achieves it or not is irrelevant. The fact is, it is important to have an aim.” F7 (15:12)*

This same mother, described how one of the main issues in therapy had been frequent arguments, between mother and son and an expectation that the son needed to control his anger more effectively. Family therapy was perceived as helping him to achieve this by giving him specific ideas of what to do, resulting in a reduction in the frequency of the

arguments. From her comments, it also appeared that the family therapy had enabled mother and son to talk together about more constructive ways to approach ‘the problem’:

*“It used to be constant but now it’s only occasionally...So we were talking yesterday about it and he said, “yes but you did notice Mum I did go into my room and think” ...that is one of the strategies we discussed with [psychologist], the way we were going to handle these rows, what was going to happen. We were going to try and back away a bit.” F7 (7:42; 8:1; 8:2)*

Two families saw family therapy as only offering benefit to the person with learning disabilities and not for the whole family. The comments one of the mothers clearly express a view that the family therapy was seen as helpful only for her son:

*“Not really to me. It was helpful for [son].” F5 (4:45)*

- **Changes in the family’s ways of managing difficulties, stresses and transitions**

A majority of the families viewed the family therapy as resulting in benefits for other members of the family, rather than solely for the person with learning disabilities. They described how family therapy enabled them to find new and more helpful ways to approach or view a problem.

In the accounts of these seven families, the experience of therapy effected a change in their attitude towards the issues they had been struggling with. It seems that they were helped to make sense of their situation in ways that enabled the development of a more helpful outlook, which made it possible to see things more clearly:

*“It was like somebody throwing you a life belt. You were able to get out. You were able to look clearly, much more clearly at the situation without any of the sort of emotion and the tempest. You were just able to be calm. That’s the word. It calmed me down. It made me look at the situation much more realistically. Without all the emotions that mix you up so you can’t see things... It has made me a little more optimistic and hopeful. It helps me to retain a sense of balance.”*

*F7 (15:25; 13:7)*

There was a sense for a moderate number of families that therapy was an experience they learned from. A mother from one of these families explained how for her, ideas that were discussed in sessions were then taken and tried at home:

*“If I learnt something in that meeting I used it once I got out.” F8 (16:20)*

- **Having one’s own efforts recognised**

A further positive outcome of family therapy cited by a majority of the families was a sense that the challenges they face and the time and energy they have invested in caring for their son, daughter or relative, were recognised and acknowledged through the process of therapy.

One mother recalled how the therapists had complemented her on positive aspects of her parenting. From her comments it seemed that this allowed her to take some pride in what she had achieved in continuing to care for her daughter:

*“Well, they say I am a good mother, because how many mothers would sit down with [daughter] for how many years? I’m not the only one, but still, you give up all your life to look after somebody.” F3 (13:22)*

Similarly, for others, the recognition of their commitment to their relative with learning disabilities seemed to have had an important impact. The following comments from the account of another mother conveyed a sense that recognition by the therapy team, of her dedication to her daughter was experienced positively.

*“...it seems funny that it’s said it, but in a way it’s true, you know. We can see how much you care for her, we see how much you are trying to help her...feeling that they appreciated that I was trying to help her... it was a good thing to focus on and it gives you enthusiasm to continue. F8 (14:29; 15:7)*

Gaining a sense of recognition from the therapy seemed to have helped another family to feel confident in their own ways of approaching the problem:

*“We built her up to it and we told the psychologist that was what we were doing and she said that was great.” F1 (17:4)*

- **No perceived benefits**

Not all the families saw the family therapy as offering them positive benefits or effecting any of the hoped for change in their lives. One family felt it had not offered anything new or different. It seemed that they had wanted to take something definite away from sessions to feel they had achieved something:

*“We’d be there at the meeting maybe, what one hour, and you’d come out and think I am none the wiser. I don’t feel as though I have achieved anything. You know...We kept more or less saying the same things about what [daughter] can do and can’t do. It didn’t seem to be moving on sort of thing. That is why I thought to myself, at the end of the day if they said this was the last meeting I would say ok [sic] then.” F6 (6:10; 17:4)*

Another participant seemed to feel that support of a more practical nature is what would have been more useful than the systemic ‘talking’ therapy:

*“It is useful, but it is like, [pause] I don’t get no [sic] benefits from it... I haven’t got a problem. The problem is just life in general. It is too much responsibility on my back. I need help with other authorities that should be looking after [nephew], be involved. F4 (10:7)*

### ***Trust***

A majority of the families emphasised either the presence or absence of particular aspects of their relationship with the therapy team. The elements of the relationship that emerged as being important, included the therapists providing an environment where the families felt comfortable talking and perceiving the therapists as wanting to help:

*“They were very friendly and understanding and helpful. So you were more willing to go through it.” F8 (18:36)*

An appreciation of openness and honesty on the part of the therapist was highlighted by another mother:

*“[Psychologist] came back and said, it appears I made a big mistake. That is what I liked about [psychologist].” F7 (10:16)*

For a mother from a different family, the lead therapist’s response to feedback she gave, about something she disagreed with in the therapist’s approach, was important in establishing trust:

*“[psychologist] wrote back and said yes she could see where I was coming from. So we understood each other y’know [sic]... I was pleased, because then I didn’t have my back up any more, that she understood.” F1 (9:29; 20:24)*

The same mother expressed how she felt the therapy team understood their dilemma as parents; that if their daughter was to live independently, their feeling of freedom from the burden of caring would inevitably co-exist with worry about the potential risks involved:

*“I think they could understand our worry about it. But also the freedom it would give us.” F1 (18:9)*

Feeling listened to was another important aspect of the therapeutic relationship that emerged from the accounts of some families. The experience of feeling that professionals actively listen was a new experience for one of these families:

*“I will say that about [psychologist] she listened to us. It was probably the start of people starting to listen to us because in the past no one listened to carers. They would literally ignore em [sic].” F2 (17:29)*

Another mother recounted how she knew the therapists were listening because they referred to things she had said, using her language:

*“I made one comment and maybe a month or a couple of months later they’ve remembered that comment...another meeting a couple of months later, she used that word, get your head around it (laughs)...It seemed peculiar but it is nice that...they did listen to you and that you know they have listened to you, because they have actually brought a comment up that you made. So in a way that was important.” F8 (18:42; 19:1; 19:6)*

It emerged from the accounts of a moderate number of families that the elements of the therapeutic relationship outlined above contributed to the families feeling that they had made a firm connection with their therapists and established trust. This is demonstrated in this mother’s account of how she felt able to ask the therapists for advice outside of the sessions:

*“When I have been upset with [daughter], I actually rung them up for advice. Because being emotionally involved, my head wouldn’t be clear enough to see*

*what's going on. You know where you need to stand back a bit and see. So I tended to ring up, so that someone with a clear frame of mind could actually give me an idea, you know...because they was so helpful in the meetings I decided to use them outside the meetings. F8 (3:13; 18:18)*

For a minority of the families a sense that where a trusting relationship with the therapy team had been established, the families did not want the family therapy to end. The mother from one of these families, makes this point clearly:

*"I am quite sure it would be lovely for us to go every week for quite a lengthy period of time...As [psychologist] said, he said, you will always be able to maintain your link here and if there is cause for concern, please contact us."*  
*F7 (2:34; 2:35)*

Although the majority of the families who referred to the importance of trust reported that they felt they established a good relationship with their therapists, for one family there were obstacles that prevented this type of relationship from developing. The father from this family where they did not feel that a good relationship had been established with the therapy team, expressed his sense that the therapists' comments were not genuine:

*"I got the feeling that they were just trying to [pause]...you think are they just trying to make something up about [daughter]...I got the impression, they tried to talk like there was improvement in her, when you think well, we haven't noticed any change." F6 (11:16; 17:21)*

As a result he did not see much value in continuing with family therapy:

*"I'm, you know pretty neutral about going to any further meetings. I thought, what have I achieved going to the meetings? What have I gained?" F6 (6:43)*

Another mother's account of her experience of attending family therapy was in the main positive. However, she highlighted how for her the focus of therapy felt as if her parenting was under scrutiny, thus contributing to her feeling criticised:

*"We went to get this step forward, but [psychologist] went back to the past. Wanting to know what happened here, what happened there and how this happened, what caused this what caused that and it just makes me feel a failure." F2 (13:26)*

### ***Experience of talking***

A majority of the families reflected on their experience of the conversations they had in therapy. Their accounts focused on the impact of talking about personal or sensitive issues and their perceptions of the style of questioning. A minority of these families found the questions used and issues explored in family therapy a helpful aspect of the experience. However, a moderate number, identified elements that were perceived to have been more difficult to 'go through', or as not resulting in any positive benefit.

Talking about personal issues concerning their families was perceived as a challenging experience for some families. Although there was a perception that this kind of talking was not easy, as it could evoke difficult feelings, they acknowledged that it could also be beneficial:

*“It is good to talk. [Pause] I can talk as good as the rest of them, but when it comes down to private things about your own family that is a different kettle of fish. That becomes hard.” F1 (24:21)*

Some families found the style of talking in family therapy enabled conversations to be had in the family that engendered a more open style of communication. Sharing issues that, prior to family therapy, had not been talked about between family members was seen as helpful. The opportunity to learn about one another’s experience and feelings emerged as a positive outcome in the accounts of these two families. The mother from one of these families, expressed how family therapy enabled her to have different types of conversations with her daughter:

*“Sometimes she’d actually surprise me in what she had actually said. Because I didn’t know she actually felt that way because she has never really mentioned nothing...Things were said in the meetings that wouldn’t have otherwise been said, because we were both so frank.” F8 (11:7; 11:9)*

She went on to explain the impact that this different way of talking to each other had on the way she thinks about a problem:

*“It does make you sit and think...It’s good because you have to see both sides of the story if you are going to solve the problem” F8 (10:6; 12:10)*

A moderate number of families referred specifically to the style of questioning in family therapy. There were differences between them in whether the questions were seen as helpful. For two families the questions were seen as leading them to think about issues

in a useful way. One mother described how the questions provoked her to think about things:

*“Having someone probing, asking those questions, you tend to stop and think about those questions.” F8 (22:12)*

Another mother valued the way that the questions prompted consideration of issues that she had not expected to be the focus of therapy:

*“[Psychologist] sometimes lead us into areas that I had not expected to go into, but were very helpful.” F7 (12:35)*

However, the style of questioning was not always seen as useful. For a minority of families it seemed that the questions created more confusion rather than help to develop a clearer understanding or more helpful view of ‘the problem’. This family member (sibling) seemed unsure about the aim of the questions:

*“Some of the questions or answers were quite technical in the way they, it’s like manipulation [sic] in some way.” F4 (9:28)*

A father from another family, explained how for him the conversations in therapy were experienced as vague and lacking meaning:

*“They’re talking about things, going round the bushes, sort of thing. You think come on now lets stick to the point. Are they just talking for the sake of talking and you know. This is where you start losing your, you think oh God, what’s the time... They would go into one of their waffles, or whatever you want to call it.”*  
*F6 (8:5; 16:38)*

### ***Views on the reflecting team***

This sub-theme assimilates the different views that a majority of the families expressed about their experience of the team approach in family therapy. The majority of these families appeared to understand the purpose of having more than one therapist and found it a valuable experience. However, for a minority of families they were less clear about the reasons for having the therapy team and what each of their roles were.

Understanding of the roles of the team seemed to be related to how effectively it had been explained to the families:

*“[Psychologist] did the talking and explained that [other psychologist] would do the listening and take notes. And that [lead therapist] would do the talking and then they went away. I thought it was very well set up.” F7 (4:16)*

One father explained his understanding of the reasons for the therapy team and highlighted how he liked having the opportunity to hear the therapists’ conversation and comment on this:

*“Because we can hear what they are saying and they ask us opinion [sic]. What do you think about it? I think that’s very, very good.” F9 (6:34)*

However, when a member of another family was asked about their understanding of the roles of the different members of the therapy team, they appeared confused about the reasons for having a co-therapist:

*“[Co-therapist] and I think [co-therapist’s] lady, secretary.” F10 (1:19)*

Another mother expressed how having more than one therapist was initially experienced as unusual, but as time went on she became more comfortable with it:

*“It was a surprise but you go to the meetings you get used to it. You expect it.”*

*F8 (13:35)*

A mother from a different family described her view of the reflecting team as adding to the family therapy, by offering another point of view. She recounted how after the break she received feedback that a team member had noticed important things that the lead therapist had not:

*“They went away and they discussed their impressions they both got and [lead therapist] quite often said ‘I didn’t pick up on this, but [reflecting team] noticed’ you know. Certain things that a woman does pick up on about my relationship in the home with [son] that men maybe wouldn’t notice so dramatically as maybe a woman would. F7 (4:18)*

Although a different family thought that taking a break seemed an unusual thing to do, they seemed to understand the rationale at least partly:

*I used to think they were very strange indeed. But obviously they wanted to talk and then come back and talk to us what they thought of the meetings. F1 (22:11)*

Another family's experience again highlights the potential for confusion about the reasons for the format of the session:

*"When one person spoke, then somebody else spoke I thought, oh no. Then they said, well hang on these two are going to talk to each other. I thought well God help me, I am losing it here I am." F6 (9:17)*

### ***Practical help***

This sub-theme refers to how for a moderate number of families therapy was a route to obtain practical help with a range of issues. For all these families there was a sense that the therapists had acted as a co-ordinator, who helped the families access appropriate support from different services. This was something extra to the therapy that all of these families appreciated.

One mother expressed how she valued the therapists helping to access support for her daughter from different agencies:

*"It's like one person actually going round congregating all these people that you need to actually help you. The more help you have got in actually sorting it out in different areas, the better it has been for her." F8 (21:13)*

### **Having a voice versus being silenced**

The third master theme focuses on the process of the families telling their story to the therapists. All ten families talked about different influences on the degree to which they felt they had their say. They also reflected on positive and negative aspects of attending therapy with their relative with learning disabilities. There were two sub-themes.

### ***The parent's voice***

A majority of the families talked about things that they saw as influencing whether they felt they had been able to express their views and concerns. The common thread underpinning these accounts concerned the balance of power within the therapeutic relationship and in relationships with professionals in general.

One mother highlighted how she experienced negotiations about the content of the sessions, as generally led by the family not the therapists:

*“Every time we went to a meeting they asked us if there was anything that we would personally wish to discuss in that meeting. It could be a follow on from the last meeting we had. Has anything changed since the last meeting? Has any of the last meeting been helpful to you?” F8 (9:25)*

The parents from another family expressed their need to feel listened to and that their views as parents, who have unique knowledge about their son or daughter, were respected and valued.

*Father: “We have always said it, a lot of the professionals are only just realising that you have got to listen to us.” F2 (9:10)*

*Mother: “...Listening to what we have got to say in their care or the way they should be treated. How you should handle them.” F2 (17:26)*

The importance of feeling supported is highlighted by another mother's comment. For her, the presence of a friend in the meetings seemed to help her to feel in control and perhaps on a more equal footing with the professionals:

*"Well if like they used to do, they all used to ask you questions at the same time. You know [friend] would interrupt and tell them 'take it easy, one at a time...I knew she was there and I had somebody backing me up.'"*F5 (2:26; 6:33)

The need for this kind of support varied between the parents. A moderate number appeared to feel more empowered to let the therapists know if they didn't like something:

*"If I don't like it I will tell them. Believe me I know myself very well. So if I didn't like it I would say so."* F9 (6:45)

### ***Going together***

All ten families talked about their experience of and views on attending the therapy together with their family member who has learning disabilities.

For a moderate number of these families attending the therapy jointly was in some way seen as valuable. This applied to people with learning disabilities who were less verbally articulate and so could not join in the conversations as well as those who had good verbal skills. One mother clearly saw benefit from being engaged in family therapy with her son:

*"It affects [son] quite a lot, he does take notice."* F7 (8:5)

Another mother conveyed a sense that in her view, being in the meeting had an impact on and meant something for her daughter with learning disabilities. She seemed to suggest that in the context of therapy her daughter was more able to consider different views than when they were at home:

*"She tries to appreciate things a bit, at least when we are in the meeting."*

*F8 (15:23)*

For a minority of the parents, whose son or daughter was unable to express themselves verbally, they felt that he/she was nevertheless able to follow what was going on by picking up on various cues. For this reason the inclusion of the family member with learning disabilities was regarded as important:

*"Well it was helpful because she is there so she see [sic] what is going on. She can't speak but then she could see what's going on...The way I feel, I am crying. Then she take up some tissue and give me and, sometimes she wiped my eyes, and things like that...Though she can't speak, she hear what is said and she pick up on things that is [sic] said. F3 (2:12; 15:34; 17:10)*

The same mother also explained that being together with her daughter in the meetings showed their relationship as it really was, in the context of their lives:

*"They [the therapists] watched the ties we have between the both of us. They watch the ties between the both of us when they come. They watched the way we click with one another or that she get [sic] in grip with me." F3 (13:33)*

As outlined in the sub-theme on 'Changes' covered previously, family therapy was generally seen as benefitting the person with learning disabilities in some way. However, there were aspects of the experience for their relative with learning disabilities that raised questions for the families. For some of the families where individuals were less verbally articulate, there was a view that the situation placed perhaps too many demands on them. This then led to them 'opting-out' of meetings in their own way:

*"He was probably bored. My feeling is he has gone up there and he was probably tired out...He is under stress there and as I said to you he cuts you off."*

*F2 (6:36; 6:43)*

For a minority of the families there was a feeling that attending family therapy together was not always the best thing, as at least on occasion this might have silenced the voice of some family members. One relative seemed to believe that having the family together prevented them both from saying certain things:

*"He can't say nothing in front of me. He doesn't want to say things in front of me, because he feels embarrassed and thinks I am going to laugh at him...You ain't [sic] going to get very far if they have the family together. Because you're both going say your own little thing, but you are not going to get to the point of what is the problem." F4 (11:13; 14:8)*

The view that some things were more difficult to talk about with the family attending jointly, was also expressed where parents did not wish to talk about certain issues in front of their son or daughter:

*“Sometimes I say to [psychologist], we secret to talk [sic], without [son]. Because everything talking [sic] he catch it.” F10 (3:13)*

A further difficulty around talking together that families identified, was that some of the issues explored were upsetting for their relative with learning disabilities. This mother’s comment illustrates awareness of her daughter’s feelings and the need to consider them:

*“I have upset her in the meetings. Because I talk frank and she don’t sometimes like what I have to say...So sometimes I do tend to stop, knowing full well I am upsetting her, I let them know, I am not going to continue because it is upsetting her.” F8 (7:9 -11)*

A moderate number of the families acknowledged the difficulties inherent in trying to include someone who is not verbally articulate in a ‘talking therapy’ and they seemed appreciative of therapists’ attempts to engage the person with learning disabilities in the therapy:

*“They both tried desperately to converse with [daughter]. It’s very difficult.”*  
*F1 (15:6)*

*“They [the therapists] did their best, it is hard. F9 (10:13)*

There was a clear sense that the families of people with learning disabilities who were more verbally articulate thought it was hard for their relative to speak up in therapy:

*“Sometimes I think she was waiting for Mum to take the lead because she didn’t know what to say, she just agreed with what Mum said...She didn’t really either understand the question properly to actually answer it, or she didn’t know what*

*to say...It was easy for X if she wanted to admit. Because, you know, the barriers, there weren't know barriers up now. Everything was open and friendly...I think the embarrassment is a part of her."* F8 (19:43-46; 20:20-33)

A moderate number of families thought their relative with learning disabilities could not always understand what was being said and that at times issues explored in therapy were of a level of complexity which was beyond what the individual could manage:

*"I don't think he understands them, I don't think he really understands them to a point because he doesn't understand a lot. They [psychologists] come out with words that are, not technical, but are quite not understanding [sic] to him but to me they are. So he just sits down and when they ask him a question he just goes um...uuu...umm and doesn't know what to say."* F4 (12:2)

*"She [daughter with learning disabilities] wouldn't think that deep. She would just accept that they came and they talked and she wouldn't understand it all."*  
F1 (21:8)

A moderate number of the families conveyed (strongly) that they viewed themselves perhaps as the people best positioned to assist their relative with learning disabilities to access the therapy. This seemed to reflect a belief that they had particular skills and knowledge about how best to communicate and engage with them, that they were proud and willing to share with the therapists:

*“And they were all asking X questions and I told them you can’t do it like that with him. He can’t take you all in together; you have to do it one at a time.” F5 (1:25)*

Extracts from another mother’s account showed how knowledge of her daughter enabled her to see what was preventing her daughter from feeling able to contribute. In response she reported to the therapists that to engage her daughter in the therapy, instead of talking to her about moving out, they should first enable her to feel comfortable by asking her to talk about familiar topics that she knew about, such as her work or interests:

*“Now I know my [daughter] through and through, obviously, and I knew I had to get her in a good mood for when they started talking about moving or whatever...I got her talking to them. That is where I think it started from. That second time when they talked to [daughter] about something she knew about...Because she was in a happy frame of mind. It didn’t start off with her crying it started off with her being happy. I knew if I could get [daughter] in a happy frame of mind she’d accept them more. F1 (9:8; 19:40; 20:3)*

### **3.3 Themes emerging from the transcripts of the adults with learning disabilities**

This table (Table 3) shows the master themes, subordinate themes and the prevalence of quotes for each of these themes. Prevalence is reported here to demonstrate the degree to which participants described similar experiences. The number in brackets indicates the number of adults with learning disabilities in whose accounts the themes emerged.

**Table 3: Master and subordinate themes emerging from the transcripts of adults with learning disabilities**

| <b>Master Theme</b>                             | <b>Subordinate themes</b>                                                                            |
|-------------------------------------------------|------------------------------------------------------------------------------------------------------|
| <b>Relationship to help (6)</b>                 | Whose idea? (5)<br>What am I here for? (6)                                                           |
| <b>Value of therapy (6)</b>                     | Changes (5)<br>Talking about problems (5)<br>A bit upsetting (5)<br>Views on the reflecting team (4) |
| <b>Having a voice versus being silenced (5)</b> | Keeping quiet (4)<br>Support (3)                                                                     |

In the following discussion of the themes that emerged from the participant's accounts, prevalence has been categorised as the majority (greater than or equal to two thirds; 5 to 6 participants), a moderate number (between one third and two thirds; 3 to 4 participants) and a minority (less than a third; 1 to 2 participants).

### **Relationship to help**

A master theme that emerged in all six of the participants' with learning disabilities accounts concerned their views about why they attended systemic therapy with their families, what had led to this decision and how this process was experienced. There were two sub-themes.

### ***Whose idea?***

A majority of participants talked about who raised the initial idea about attending family therapy. Their accounts revealed a general sense that it was clear who arranged the meetings. However, it emerged that how this process was experienced varied amongst the participants, depending upon the degree to which they felt a sense of control over the process.

One participant's comments revealed an awareness of the different stages in the referral process that led to him attending family therapy. He explained that the decision to attend with his mother arose from individual meetings with a psychologist. It seemed the way that this idea was negotiated enabled him to feel in control of the process, thus contributing to a sense of ownership over it:

*"People that led me on to this place was [voluntary organisation], is like an employment agency to get people jobs with learning difficulties...I was with [psychologist] and she was saying would you like to do one to one, or have someone come with you, and I thought, my mum. I thought it was my idea, all on my own. I thought of that." F7 (6:37, 5:19)*

In contrast, for another participant the suggestion appeared to be seen as coming from professionals. Consequently he did not appear to feel a sense of control over the process:

*Interviewer: "Whose idea was it that you went together?"*

*Participant: "[psychologists] and [psychiatrist]"*

*Interviewer: "What did you think about the idea that you and [family member] go together?"*

*Participant: "Like, I thought that, I was a bit worried about it." F4 (9:26-33)*

### ***What am I here for?***

All six of the participants talked about their understanding of the reasons for attending family therapy. They all seemed to see it as a place to get help and support, but appeared to hold different beliefs about the potential benefits of therapy. One participant, who attended family therapy with her partner, clearly expressed a hope that it could help with difficulties in their relationship:

*"Well. I like to help us. Me and [partner], our problem." F12 (6:43)*

Comments from another participant's account, indicated that he saw family therapy as a place where he could receive help and talk about different kinds of problems:

*Interviewer: "When you went, did you want help with anything in particular?"*

*Participant: "Getting depressed... Like to get some help like for me..."*

*Interviewer: "Were there any other things that you wanted to talk about or wanted help with at that time?"*

*Participant: "Like about [professional]."*

*Interviewer: "What was it with [professional] that you wanted help with?"*

*Participant: "Like just to talk about things."*

*Interviewer: "What kind of things?"*

*Participant: "Like, I found it hard with [professional]." F4 (6:7-21; 8:16-27)*

This participant's account illustrates how she is aware of the reason for her referral, but she seems to want a different kind of help that is more practical in nature:

*"On, my behaviour... Budgeting... Shopping... and cooking..." F8 (10:9-23; 11:6-10)*

### **Value of therapy**

As in the analysis of the families' transcripts, a second master theme emerging from the accounts of all six participants with learning disabilities concerned different aspects of the process and outcome of family therapy that were perceived to have a particular impact. There were four sub-themes.

### ***Changes***

A majority of participants talked about the impact that attending family therapy had on them. Their accounts revealed that the therapy was generally seen as offering positive benefits. They viewed it as effecting specific changes in the issues they had hoped that the therapy would, or in the issues that led to the initial referral. This participant describes how she noticed a positive change in her behaviour towards her partner:

*"I think it got better... Well, I don't shout at him that much anymore. Not much. If I try he shout at me so I shout back at him (laughs)." F12 (13:2)*

A reduction in feelings that had been problematic and being able to go out more frequently were noticed as helpful changes as a result of the family therapy for this participant:

*Interviewer: "Thinking back from when you started going to the meetings to where you are at now. Do you think they have been helpful to you in any way?"*

*Participant: "A little bit."*

*Interviewer: "Have they helped you to do anything that you were finding hard to do before?"*

*Participant: "I go out a lot more."*

*Interviewer: "...When you say they were a bit helpful, did they help you to feel any different about yourself?"*

*Participant: "...A little bit, yeah."*

*Interviewer: "Can you give me an example of how they have helped you to feel a bit different about yourself?"*

*Participant: "Like not so panicky as I was." F4 (21:32-44; 22:6-14)*

Another participant felt that a positive aspect of the therapy, was that it provided an opportunity for him to learn about his mother's perspective:

*"Certain things that I hadn't known from my mum. Things that she didn't tell me... Wanted to know her feelings as well, what she thought." F7 (4:43; 5:6)*

### ***Talking about problems***

For a majority of the participants, the experience of talking about their difficulties in family therapy was seen as beneficial:

*"I think it's quite helpful to talk about problems." F8 (18:41)*

For this participant, their experience of talking in therapy seems to have been a positive one. There is a sense in his account that he felt he and his partner could benefit from further therapy to explore issues about their past experiences

*“It was good thing. Talk about your problems, talk about yourself. Talk about it...I am keep going actually, because the problems we can erm [sic], help with our backgrounds. What [partner] has gone through and I’ve gone through and all. F12 (11:24; 12:18)*

### ***A bit upsetting***

A majority of the participants talked about how the experience of therapy evoked some difficult and sometimes distressing feelings. Taken together with the previous sub-theme, where talking about personal and sensitive issues was experienced as beneficial, this seems to suggest that there is an awareness that although at times therapy can be emotionally painful, there is the potential for relief from these feelings to be found through the process of talking.

One participant talked about how some of the issues that were explored in family therapy were emotionally distressing:

*“It was a bit upsetting...To talk about some things.” F4 (4:5-9)*

For another participant, it was the experience of hearing certain things from her family that evoked difficult feelings:

*"There was some bits was upsetting, what is [sic] my mum been saying." F8  
(6:16)*

### ***Views on the reflecting team***

A moderate number of participants commented on their experience of the reflecting team. They talked about their feelings about it, the process of the reflecting conversation or break and feedback and the impact it had on them. There was a sense that initially having two therapists whom the person did not know was an unusual experience that took some getting used to:

*"It was weird, it was different. There was two of us and two of them. They didn't know us from Adam and we didn't know them from Adam...It made me feel nervous for a while." F7 (8:27-32)*

Another participant explained that meeting with two therapists was a surprise, thus contributing to her feeling anxious about the session:

*Interviewer: "So you expected that there was going to be" ... [participant interrupts]*

*Participant: "One. I didn't think there was going to be two."*

*Interviewer: "So what was that like when you walked in and there was two of them sitting in there?"*

*Participant: "I was nervous." F11 (5:1-7)*

When describing their views on the roles of the therapy team, there were differences in how much the participants appreciated the aims and purpose of using a reflecting team,

including the key aim to bring forth different perspectives. This participant's comment illustrates how she seemed to construct what the therapists' roles were on the basis of what she observed them doing in the session:

*"One needs to write down, and the other one to talk and write down." F8  
(13:32)*

However, another participant's explanation of the process of the reflecting conversation conveyed a clear sense of the idea of sharing different perspectives to then reflect on further. The reflecting team discussion and the conversations that led from this seemed to have a positive impact, as it appears what was said was understood and experienced as meaningful for the client :

*Participant: "They could see us, but we can't see them. And then we swap over. We go that room and they talk about what we talk about, and come and listen to them then they all swap back over and see what we think of what they said."*

*Interviewer: "And what did you think of that. Did you think it was a helpful thing or an unhelpful thing?"*

*Participant: "No. It a helpful thing because I think it was good."*

*Interviewer: "What were the kinds of things that they said about you that you remember?"*

*Participant: "Well all sorts. It's truth. What [reflecting team members] says it's truth." F12 (15:5-16)*

## **Having a voice versus being silenced**

Similar to the family members' accounts, the third master theme that emerged for the majority of participants with learning disabilities concerned their reflections on the experience of telling their story in the sessions.

### ***Keeping quiet***

A moderate number of participants reflected on the degree to which they felt comfortable or able to speak openly in the sessions, and the things that kept them quiet. For one participant, the therapists emphasising that he was free not to answer questions seemed to be experienced positively:

*"They don't put pressure on you. They say you don't have to answer this question. But would you try and at least answer the question. So I think it is OK how it is."* F7 (14:3)

Another participant's comments illustrated how for some participants the presence of family members in the meeting meant that they were less likely to speak up. Here he is talking about how he did not tell anyone that he felt anxious in the meetings and that it was hard to say anything. In his case it seemed to be the potential for embarrassment and worry about other people's response that silenced him:

*Participant: "Kept it a bit to myself."*

*Interviewer: "What made you keep it to yourself do you think?"*

*Participant: "It was a bit hard some of it...Like it was a bit difficult, my [family member] was there. F4 (9:6-10, 9:20)*

*Interviewer: "Did you feel able to let them know that what you were hearing was making you worry?"*

*Participant: "I didn't tell them...Because I found it difficult... Like if my [family member] might laugh or something." F4 (13:41; 18:9; 18:32)*

He went on to explain how the therapists also silenced him. He seemed to feel that by interrupting him they prevented him from feeling he had time and space to speak up and be heard, thus leading to feelings of frustration:

*Interviewer: "Was there anything that they did that made you feel you couldn't tell them?"*

*Participant: "Like, sometimes they interrupt, sometimes. When I say something [therapist] talks to my [family member]."*

*Interviewer: "What about when you got cut off by therapist]. How did that make you feel?"*

*Participant: "Annoyed as well." F4 (13:46; 14:2; 20:30-32)*

Although this was the case for only one participant, her experience is important to highlight as it illustrates how the disempowered position this woman had in her life was also, unintentionally, maintained in the therapy:

*Participant: "I didn't say nothing. My ex-boyfriend did it all, the talking... [partner] punched me and hit me round the face. That's why I think kept quiet in the meetings...."*

*Interviewer: "You kept quiet because of him hitting you? Can you tell me a little bit more about what you mean?"<sup>1</sup>*

*Participant: "He wouldn't let me tell anyone."*

*Interviewer: "So you went to the meetings and he wouldn't let you talk about certain things."*

*Participant: "Yes."*

*Interviewer: "How did he let you know that?"*

*Participant: "He told me before hand."*

*Interviewer: "So he'd told you before hand. What did he say to you before hand?"*

*Participant: "He said don't tell anybody I've been punching you and hitting you."*

*Interviewer: "And how did that make you feel"*

*Participant: "I wanted to tell someone." F11 (6:21; 7:11-33) <sup>1</sup>*

For some of the participants there was a view that individual meetings with a therapist would have enabled them to have more of a voice:

*Interviewer: "How was that different when you saw [psychologist] on your own with no one else there?"*

*Participant: "Nice, it was more better [sic]."*

*Interviewer: "Where did you get to say more of what you wanted to?"*

*Participant: "With [individual psychologist]." F4 (10:4-6; 14-16)*

---

<sup>1</sup> The interviewer checked with the participant that this abuse was no longer occurring and that professionals involved in her care were aware of what had been happening.

## **Support**

A moderate number of participants suggested things that they found helped them, or that would have helped them to feel more comfortable talking in the sessions. For some participants having their family member in the therapy with them was in itself a source of support:

*“To see a familiar face in the surroundings, in the place, you know. Just being there alongside me.” F7 (3:17)*

Another participant highlighted how she appreciated having her Mum to help her understand what was being asked:

*“It was helpful and confusing, but my mum had to explain it more...She [therapist] put it into sentence. Like you know kind of into sentence that I don’t understand. My mum put it into sentence that I do understand”. F8 (16:31-43)*

The presence of a friend in the sessions was valued by this participant:

*Interviewer: “What did you think of [friend] coming along?”*

*Participant: “I find it is OK.”*

*Interviewer: “What were the good things about having her there”*

*Participant: “Because since in school yeah, she, I used to help her with her problems and then she used to help me with problems...I am glad [friend] came, to support, for supporting.” F8 (2:13-22; 4:41)*

Another participant , who reported that having certain individuals present in the sessions silenced her, suggested an interesting way that would have given her the opportunity to talk openly with the therapists:

*Interviewer: "What do they need to do to make sure that people don't go feeling that they can't say certain things?"*

*Participant: "Talk to one. Outside the meeting, before hand."*

*Interviewer: "And how should they do that? Should they do that by meeting with you, or phoning, or letter"*

*Participant: "Meeting."*

*Interviewer: "Having a meeting separately... [participant interrupts]"*

*Participant: "Before hand."*

*Interviewer: "Before the big meeting with everyone there... [participant interrupts]"*

*Participant: "Yes."*

*Interviewer: "How do you think that would have made things different?"*

*Participant: "So I could talk better." F11 (11:44-46; 12:2-25)*

### **3.4 Summary of results**

Three broad themes emerged from interviews with ten families about their experiences of attending family therapy: Relationship to help, value of therapy and having a voice versus being silenced. Although there were differences between the families in the meaning that the experience held for them and the degree to which it brought positive benefit, consistencies emerged in the issues that were perceived as important. These

issues were represented by the three master themes and their associated subordinate themes.

Firstly, the families' 'relationship to help' emerged as a description of the hopes, expectations and preconceptions that were brought to family therapy. Secondly, the impact or lack of impact that different aspects of the experience had for the families is represented as the 'value of therapy'. Finally, the process of talking as a family, in therapy and their perceptions of what facilitated or limited different family members having a voice, emerged in the theme 'having a voice versus being silenced'.

Analysis of the interviews with six adults who had learning disabilities about their experience of attending family therapy, revealed their accounts reflected the same three master themes. However, there were some important differences in the subordinate themes between the two groups of interviewees. The most notable of these concerned the degree to which the family members with learning disabilities felt they 'had a voice'. For these people, the demands that the situation placed on them to speak up, answer questions and 'know' what to say meant that they did not always feel they 'had a voice'.

The similarities and differences between the two groups will be considered further in the following chapter: 4 Discussion.

## **4. Discussion**

### **4.1 Overview**

This chapter will begin by highlighting the main findings of the study, which will be discussed in relation to existing literature in the area. Following this the clinical and service implications of the findings will be presented. The methodological issues that arose in the process of the study will then be discussed. Finally, ideas for future research will be suggested.

#### **Research question 1 - How do families where a member has learning disabilities experience family therapy?**

This study aimed to explore the experiences of family therapy of families where one member has a learning disability. As part of this I hoped to investigate what aspects of therapy these families appeared to perceive as helpful or unhelpful. I was also interested in gaining an understanding of their thoughts on the involvement of the different family members in the therapy.

#### **Research Question 2 - How do people with learning disabilities view the experience of systemic therapy?**

Apart from examining the family's experience of therapy, the second main aim of the present study was to explore the experiences of people with learning disabilities of family therapy. As part of this I hoped to gain an understanding what ideas individuals with learning disabilities may have formed about the reasons for attending family therapy. Finally I wanted to examine what aspects of systemic therapy they perceived as helpful or unhelpful.

## **4.2 Key findings**

Ten families and six people with learning disabilities were interviewed about their experiences of attending systemic family therapy. Three of the participants with learning disabilities were members of families who also took part in the study. The remaining three adults with learning disabilities had attended systemic therapy with their partners. The interviews were analysed using IPA.

As one might expect, the results of this study revealed that participants' experiences were variable. However, there were several key issues that appeared to influence the ways in which participants perceived the experience of attending systemic family therapy. Firstly, an important aspect for the family members and the adults with learning disabilities, concerned the ways in which the therapy was set up, for example the information they had been given about what to expect from the meetings. Where this was not addressed adequately, it seemed to have a particular impact for the adults with learning disabilities. For the family members, it left them somewhat confused and bewildered about these issues but this did not necessarily result in a negative experience of therapy. However, for the adults with learning disabilities where these issues were not attended to effectively in the set up of therapy, they appeared to lack a sense of control over the process, thus highlighting the potential that they had gone along with the wishes of others rather than making their own informed decision.

A further issue related to how the therapy was set up that emerged from the participants' accounts was their experience of the reflecting team, which participants had mixed views about. For the majority it was seen as unusual and for some families the purpose of it was not clear. The degree of impact the reflecting team process had on participants was variable. Some participants with learning disabilities reported that the number of people present made them feel anxious.

Overall the participants with learning disabilities reported finding the experience of having an opportunity to talk about problems a valuable one. However, half of those interviewed, also expressed how they had at times not felt able to speak up in meetings and have their say. The presence of family members or other people in the meetings, the complexity of questions and not knowing what to say were some of the reasons they gave for having kept quiet in this way.

For families who saw the experience of attending systemic therapy as one that offered some benefit, they reported how it helped family members to effect changes in their views of problems and to strengthen beliefs in their own strengths and resources. Where families had received it, help that was practical in nature was very much welcomed and valued. In contrast, some families reported that the family therapy had not offered any benefit and had been experienced as vague and lacking meaning.

A further key issue that emerged from the participants' accounts was their perceptions of the quality of the therapeutic relationship. Clearly, believing that one's therapist is genuine, trustworthy and genuinely wants to help would apply to any therapeutic

approach. Absence of these fundamental aspects of the relationship are likely to have contributed to the negative experiences of some of the families in this study. However, some family members also particularly valued an open and honest approach to mistakes and active attempts to seek and respond to feedback, which would seem are issues that are likely to have been encouraged in a systemic approach.

Three consistent themes emerged in interviews with parents and other family members and from the adults with learning disabilities that help to address the research questions.

### **Relationship to help**

Reder & Fredman (1996) used the term 'relationship to help' to denote different beliefs about help and previous experiences of seeking and receiving help that clients (and therapists) bring to therapy. They proposed that these beliefs and experiences will have a strong influence on the process and outcome of therapy. In the accounts of the families and the adults with learning disabilities, particular issues emerged that characterised their relationship to help.

A predominant theme in the families' relationships to help concerned their perceptions that over the years support from services had not been available to them, or that past support had been insufficient to meet their needs. This theme was not reflected in the accounts of the participants with learning disabilities. Family members talked about the extent of the demands that had been placed on them as carers over the years and the challenges they had had to face. There was a clear sense that as a result family members felt they had been placed in a position where they had to draw on resources within their

own family and wider systems, rather than be assisted to do so by 'helping agencies'. These findings lend support to Fidell's (2000) argument that families where a member has learning disabilities will have faced and dealt with many complex and demanding situations, prior to attending any family therapy. This may include considerable experience of dealing with services, which may or may not have been perceived as helpful. This suggests that, for the families in this study, perceptions of past support provided by services as insufficient or unavailable, were taken to the context of family therapy in the form of (perhaps negative) pre-conceptions and expectations about the forthcoming experience of seeking help.

For both groups the idea that family therapy could be a source of help was perceived as originating from professionals. None of the participants in the study had previous experience of this kind of therapy, which suggests that the professional who initiated or proposed the referral was influential in determining the information provided about the forthcoming family therapy. Reder and Fredman (1996) assert that the development of a relationship to help commences from the point where initial conversations about the referral occur. The way in which the reasons behind a referral were discussed with the families and the adults with learning disabilities are therefore likely to have influenced their perceptions of and subsequent ways of engaging with the process of systemic family therapy.

Selvini Palazzoli, Boscolo, Ceccin & Prata (1980a) suggested that a referrer does not occupy a neutral position in the system, but can have their own reasons for 'sending' a family to family therapy. These may include, for example, a desire to terminate their

own contact with a family for whom they have provided interventions that have not been deemed to be successful or to have more services involved where a family's needs are experienced as overwhelming. Therefore, service users and their families may engage with the process of systemic therapy for reasons which do not necessarily reflect their own ideas about the kind of support they need.

In the current study, the degree to which participants saw themselves as involved in the thinking about the reasons for their referral for family therapy varied between families and between the two groups. Amongst family members some were confused about who had initiated the referral and the reasons for it. However, this was not necessarily seen in a negative manner as it appeared to reflect a lack of knowledge and clarity about the organisation of support services and the roles of different professionals.

For the participants with learning disabilities there seemed to be a link between their experience of the way in which the decision making process about the referral was negotiated and the degree to which they perceived themselves as having control and influence over the decision to attend systemic therapy with members of their family system. The two participants who reported having time spent with them talking about the reasons behind a referral, appeared to increase the likelihood that it was seen as something that the person themselves wanted and had chosen to be involved in. Conversely, participants had not been consulted in this way seemed to feel that they were mainly going along with what other people thought would be helpful for them.

Ensuring adults with learning disabilities are offered choices and enabled to give informed consent to issues that affect their lives is a central issue highlighted by the publication of *Valuing People* (Department of Health 2001). This legislation emphasises the need to examine working practices and service provision to ensure people with learning disabilities have more choice and control over their lives. As Baum & Webb (2002) argue, the marginalised position that people with learning disabilities occupy in society demands that health professionals work in a way which takes account of the influence of an individual's social, political and cultural context. As the provision of direct psychological therapies for this client group is increasing, it is important that developments in clinical practice address these issues perhaps more explicitly than is currently always the case.

In relation to the application of systemic approaches to working with adults with learning disabilities and their families, these results highlight how particular attention needs to be paid to the information provided about a possible referral for family therapy and the manner in which it is communicated. As has been argued by Roy-Chowdhury (1992), people with learning disabilities often occupy a marginalised position within their family system as well as in the wider systems of society. Therefore when inviting a person with learning disabilities to attend systemic therapy together with their family, it is possible that their views or concerns about the process may also be marginalised if special efforts are not made to ensure they are fully involved from early on.

It has been argued that the initial stages of the process of engagement should involve thinking carefully about how the family and person with learning disabilities are

contacted about the referral (Fidell 2000) In the current study family members were also somewhat unclear about these issues, thus suggesting attention needs to be paid to these issues for all involved in the therapy. The explanation given to the family member who has learning disabilities about why they would be attending the meetings and what it would involve is important. Firstly the issue of informed consent, for those who are able to give it, needs to be addressed. To be able to give such consent the person with learning disabilities requires appropriate information to be given, thus enabling them to make an ‘informed’ decision. This process starts when the family is contacted about the referral but would also be continued in the initial meetings with the family. Particular attention should also be paid to how the initial contact with the person with learning disabilities is made because it is likely to influence how they engage with and therefore potentially benefit from the therapy.

Fidell (2000) advises that an initial letter is sent to the family and a letter in a more accessible format (e.g. with pictures or symbols) is sent to the person with learning disabilities. Fidell suggests asking somebody who knows the person well, such as a keyworker or social worker, to explain the letter to the person as this is likely to increase their understanding of the reasons for attending family therapy and in turn reduce the risk that therapy is perceived as largely set up to focus on their own “wrongdoings” or problems.

The interviews revealed marked variation in expectations of therapy and the types of issues that different families and individuals with learning disabilities had expected the therapy to help with. For some, therapy was seen as a place where issues in their

relationships with one another could be addressed, or where a specific problem such as managing difficult behaviour could be thought about. Some wanted help with issues or difficulties that seemed to be more specific to families where a member has learning disabilities, than perhaps for other families attending this type of therapy-, for example in child and family services. A desire for practical help, advice and assistance with accessing and negotiating the complex networks of services and professionals that are commonly involved in the lives of people with learning disabilities emerged as issues that were important to these families. The adults with learning disabilities similarly held a range of ideas about the help they wanted from attending family therapy. These ideas covered a range of issues, for example wanting help with a specific issue such as anger or wanting practical support with learning everyday skills such as budgeting. It was not clear from their accounts whether they identified issues they had been told they needed help with or whether they genuinely expressed their own wishes.

The variation in issues that both groups took to the context of family therapy and expected to get help with, illustrates how there is potential for a mismatch to exist between families' and therapists' expectations for the focus and outcome of family therapy if there is not explicit negotiation of these issues during the initial stages. Riemers & White (1995) reported that for families they interviewed about the experience of family therapy often expectations for how the therapy might be able to help were not fulfilled in the process of attending therapy. A failure to negotiate expectations of therapy and goals early on may well contribute to familial dissatisfaction with therapy. In relation to the current study; if the process of therapy is seen as being initiated at the stages of thinking about and instigating a referral, it is likely that the ways

in which referrers and therapists communicated with families and the adults with learning disabilities from these early stages either facilitated, or hindered their subsequent engagement with the process of family therapy.

Key issues which family members perceived themselves as struggling with, but which were not raised by the adults with learning disabilities, concerns transitions through the stages of the family life-cycle (Carter & McGoldrick 1982) and concerns about the future. This finding offers some support for Goldberg et al.'s (1995) suggestion that family life-cycle issues are one of two themes (the other being grief) that predominate in family therapy with people with learning disabilities their families.

### **Value of therapy**

From the accounts of the ten families and the six adults with learning disabilities who participated in this study, there was not a consistent picture of the impact that the experience of attending family therapy had for them. This perhaps reflects the very personal nature of any kind of psychological therapy, where the meanings attributed to the experience will inevitably differ between individuals. Similarly, differences between the therapists in how they applied the systemic model in their clinical practice and in their personal attributes are also likely to have impacted on the manner in which family therapy was perceived by different participants.

However, despite a lack of consensus about the impact that family therapy had on their lives, participants consistently attached significance to similar aspects of the process and outcome of the therapy regardless of whether it was perceived to have been an

experience they benefited from or not. However, the differences between them were in whether the families saw them as present or absent from their experience of systemic therapy.

Although measurement of the effectiveness of family therapy for this client group was not an aim of the current study, some of the families and the adults with learning disabilities identified ways in which jointly attending systemic therapy had been beneficial. Overall, for the families who saw themselves as benefiting from the experience, there was a sense that attending family therapy helped to facilitate changes in the ways different members of the family system made sense of issues that had previously presented a problem. Those families who perceived positive outcomes as arising from attending family therapy did not seem to require a difficulty or problem to have been eradicated for the therapy to be seen as beneficial. The experience instead appeared to have enabled them to make changes in the ways they made sense of a situation and through this they discovered new possibilities for action. These families highlighted how different members of the family system were, through the process of family therapy, enabled to consider and develop different perspectives and views about an issue that had previously been seen as problematic. Some family members noted that the experience had provided them opportunities to consider different perspectives, in a context where they did not experience difficult emotions that were present at other times in their lives. This they felt in turn enabled them to develop a more helpful outlook that made it possible to see things differently. The families also described how the development of different views of and ways of approaching what had been ‘the problem’

was something that their relative with learning disabilities gained from attending family therapy.

Having a space to talk about problems was perceived as a helpful aspect of attending systemic therapy for the adults with learning disabilities. From their accounts a sense emerged that being given the opportunity to reflect on issues from their past, difficulties in relationships with families and with members of their wider system, for example other support staff, was valued by participants. However, the degree to which different individuals felt able to have a voice and express their concerns varied considerably between these participants. This issue will be discussed in more detail below (see “Having a voice versus being silenced”).

For the families in the current study the ‘presenting problems’ that they were often struggling with related to dominant ideas what it means to ‘have learning disabilities’. For example, concerns about an individual’s vulnerability and perceived need for protection were prevalent themes as were the implications of these beliefs for the person with learning disabilities and the family’s hopes and wishes for the future. It would seem that for these families the therapy helped to explore alternative discourses, such as independence and autonomy, and open up space for new thoughts and possibilities regarding the future.

Several recent papers have highlighted the potential usefulness of narrative therapy in working with this client group, as the central premise of the model concerns questioning of socially and culturally determined discourses (Lynggaard & Scior, 2002; Wilcox &

Whittington, 2003) They suggest that this way of working offers an opportunity to lessen the influence of stigmatisation and marginalisation which are so prominent in the lives of people with learning disabilities, or can at least allow the person and those around them to question ideas and practices they may have come to take for granted.

The experience of exploring different meanings and identities in family therapy was effective in helping some families to introduce helpful changes into their lives. This was reflected in how participants from both groups described family therapy as enabling them to have different kinds of conversations with one another, where parents, partners and adult sons or daughters with learning disabilities shared new information about their views and feelings. It emerged that the experience of engaging in such new or different conversations at times evoked distressing feelings for the adults with learning disabilities. There was a strong sense in their accounts that despite the difficulty they had experienced in talking about and hearing some things, they appreciated that it could be beneficial to talk even about these more upsetting issues.

For some families, the context of family therapy was seen as a place that provided recognition and acknowledgement for the commitment they had shown in caring for and supporting their relative with learning disabilities. They reflected on how the experience of having therapists notice and comment on their dedication to and close relationship with the adult with learning disabilities in their family, served to re-affirm that they were 'doing okay'. This is line with suggestions in the literature that for families to engage effectively with the process of therapy it is necessary for therapists to acknowledge that families have gained knowledge and skills and demonstrated strengths and

resourcefulness through their experiences of caring for their relative with learning disabilities (e.g. Dale, 1996; Fidell, 2000).

These families described the impact of feeling their efforts had been recognised as helping to strengthen their beliefs in their own abilities and their resolve to face and find solutions to current and future challenges. Donati, Glynn, Lynggaard & Pearce (2000) have argued that systemic approaches with families where a member has learning disabilities, provide ways of working that can focus on the identification of strengths and resources in the family system. The accounts of the families in this study, who saw the experience of attending family therapy together as a helpful one, lend support to the idea that systemic approaches are in a good position to offer methods and techniques which can help create a dialogue that moves away from the focus on disability and problems that is generally connected with the support that is offered by services for this client group.

Not all of the participants in this study found the experience of attending systemic therapy a helpful one. For some families it was seen as not offering them anything new or different. Conversations with therapists were experienced as vague and lacking meaning for the family and some felt under scrutiny by the therapists. As has been mentioned previously, the reasons that emerged as influencing the degree to which the adults with learning disabilities found the experience helpful, focused around whether or not they perceived themselves as having a voice. This will be discussed in more detail in the relevant section below.

A possible explanation of factors which may have contributed to the lack of any benefits being seen as arising from the experience for some of the families relates to a basic assumption of systemic therapy. The introduction of 'difference' into a system is one of the fundamental principles of systemic approaches, as it is assumed that introducing difference opens possibilities for change (Bateson 1972, cited in Ekdawi, Gibbons, Bennett & Hughes 2000). The degree of impact that difference being introduced into a system results in, is seen as determined by the ways in which its members perceive the difference. Bateson (1972) proposed that therapists need to 'find the difference that makes a difference'; thus if something is seen as too different it will not be perceived as relevant to the beliefs and organisation of that system and will therefore be ineffective in making an impact. Alternatively, if an idea is too similar to the family's own ideas it will be assimilated into the existing structure of a system and will not elicit any change.

A further issue that emerged from family members' accounts that is likely to have contributed to whether the therapy was seen as helpful or not, focused on aspects of the therapeutic relationship. These issues did not emerge from the accounts given by the participants with learning disabilities. In the accounts of family members in this study a contrast emerged between those who saw themselves as having gained a sense of recognition of their strengths and determination, compared to others for whom attending therapy had placed them in a position where they felt blamed and criticised.

The role of the therapeutic relationship in determining the outcome of psychological therapy has been a much researched subject over many years. In general, this body of research has proposed that elements of the therapeutic relationship, or as it has also been

termed the therapeutic alliance, comprise a pan-theoretical element of the process of psychological therapy that is responsible for a large part of the variance of therapy outcome regardless of model, technique or approach (Stiles, Shapiro & Elliot, 1986; Lambert, 1992; Ackerman & Hilsenroth, 2003). Lambert (1992), based on a meta-analysis of research into therapy outcome, suggested that the second largest proportion of variance in outcome, namely 30 %, arises from the therapeutic relationship; this compares to 40 % from 'client and extra-therapeutic factors' and only 15 % from 'model and technique factors'.

In a qualitative study exploring clients' perceptions of the therapeutic alliance in individual psychological therapy, Bachelor (1995) categorised participants' responses into three categories of alliance. However, she also found that, overall, participants ascribed importance to therapist qualities of being non-judgemental, listening carefully, being respectful and being seen as empathic to the client's difficulties.

These aspects of the therapeutic relationship were found to be experienced by clients as helping to create a climate of trust. The families in the current study attached significance to these same key elements of the therapeutic relationship. Where families perceived their therapist and the team as being friendly, understanding, listening to them and genuinely wanting to help, they felt able to trust the therapist and team. In contrast, for families where these aspects of the relationship seemed to be missing, the therapists' comments were seen as not genuine or meaningful for the families. These families perceived the therapy as having not offered them the help they wanted. Unfortunately, in this study it was not possible to interview any families who had dropped out of therapy

before an agreed end. These families were sent information inviting them to participate but, perhaps unsurprisingly, none responded. If families who disengaged from the process of therapy had shared their experiences, the information provided might have indicated further aspects of the therapeutic relationship and other elements of the process of therapy that can be experienced as missing, unhelpful or irrelevant.

None of the above elements of the therapeutic relationship that have been described so far could be seen as being specific to systemic approaches to family therapy. However, therapists being open and honest about mistakes and responding to negative feedback from clients emerged as important in the accounts of some of the families in this study. Although the value attributed to these elements of the relationship may not be specific to a particular therapeutic approach (Bachelor 1995), it could be argued that therapists using a systemic approach to family therapy are particularly well positioned to address these issues. Ekdawi et al (2000) describe the process of relational reflexivity (Burnham 1999, cited in Ekdawi et al., 2000), which refers to the means by which systemic therapists examine the therapeutic relationship from the different perspectives of client and therapist. They explain how the client's perspective is ascertained through a continuous process of seeking and responding to feedback from the client about their experience of the therapeutic relationship.

The ways in which particular methods and techniques of systemic family therapy were experienced by the families and the people with learning disabilities in this study was not consistent. The feelings evoked by the process of a reflecting team and how this was understood emerged from the accounts of the people with learning disabilities. The

families' accounts revealed information specifically about perceptions of the questions therapists asked and of the reflecting team process. The differences that emerged between the adults with learning disabilities and the families, for each of these aspects of the process of therapy will be outlined below.

Firstly, the reflecting team process did not operate in the same way for all of the participants. This arose because the participants for this study were recruited from several different services. Some experienced a reflecting team holding a conversation in the room, whereas for others the therapy team held their reflecting conversations in private away from the family, a further variation was that the reflecting team was sitting behind a one way screen but could be seen and heard by the family when they held the reflecting discussion. In general the families expressed a sense of wonderment about the reflecting team process. However, for some families, although initially experienced as a strange practice, once they became more familiar with the reflecting team process they felt more at ease. The experience of being in a room with the therapy team present emerged as one that was seen as strange and anxiety provoking for the participants with learning disabilities.

Fidell (2000) suggests caution in the use of reflecting teams in systemic work with people with learning disabilities. She argues that the process of listening to a reflecting conversation has much potential to confuse and thus further marginalise people with learning disabilities from inclusion in the process of therapy in a meaningful way. However, she also acknowledges that as people with learning disabilities are often talked about as if they are not there, the experience of being invited to listen and comment on

what is being said about them may be a new and empowering experience. In the current study the ways in which participants with learning disabilities made sense of the team approach emerged in their accounts as being focused on the different tasks that different people carried out in the session, for example seeing the co-therapist as being there to take notes rather than as adding anything to the session. However, two participants commented on the content of the reflecting conversation and they did not indicate that they could not understand or were confused. These participants expressed how what was discussed felt relevant to them. Therefore, the adults with learning disabilities in this study reported mixed views about the experience of the reflecting team, which may reflect differences in the way this was set up in different services or with different families.

The degree to which families understood the purpose of the reflecting team varied between participants. The key issues that emerged were that some families appeared to completely misunderstand the reasons for having more than one therapist. In these cases they were not sure who the team members were or why they were present. For others, the team was seen as there solely to help the lead therapist analyse the content of the session to assist with identification of the causes of 'the problem' and thus possible solutions to it. In contrast, some families saw the reflecting conversation as bringing forth different perspectives and ideas about the issues talked about in the room, which helped them to view a situation differently. It would seem that only for some participants, did the reflecting team fulfil its main purpose as described by Andersen (1987), namely to bring forth different perspectives, at least at the level of recognised experience. Of course one might argue that the reflecting team would have produced at

least some desired shifts in perception in all cases, but that this may have gone unrecognised by the families.

Despite the lack of clarity about the purpose of the reflecting team, the majority of families appeared to value the opportunity to hear different ideas, or have additional people thinking about and wanting to help their situation. However, from the accounts of some of the families it was clear the process of the reflecting conversation was experienced as confusing and as an unhelpful aspect of their experience of attending family therapy together. The results suggest that some of the differences in how the purpose of the reflecting team was understood may relate to the effectiveness of explanations given by therapists.

The questioning process in systemic therapy is seen as particularly important as a question is seen as an intervention in and of itself (Tomm 1987, 1988). The accounts of the families in the current study revealed that for some the questions therapists posed were seen as provoking thought and enabling consideration of unexpected but helpful issues. However, there were also families for whom the questions were experienced as unclear, confusing and manipulative. These findings lend some support to the proposal of Riemers (1995), who suggests that despite the emphasis in systemic therapy on creating elegant questions, they are not always experienced as positive or neutral and can be experienced as threatening or intrusive.

One final aspect of the families' experiences of attending systemic therapy that stood out in their accounts, concerned an appreciation of therapists providing some form of

practical help. As Donati et al. (2000) point out, people with learning disabilities often live within complex networks of family, carers and support staff. In the current study some families valued the therapists helping them to negotiate these complex networks to access different kinds of resources. These resources tended to be for support that was practical in nature, for example, getting access to leisure activities for their relative with learning disabilities.

### **Having a voice versus being silenced**

The way in which this theme emerged, not surprisingly, differed between the family members and the adults with learning disabilities. For the family members, they mainly felt they had been able to tell their story in the context of family therapy. In contrast for some of the adults with learning disabilities it was a place where they did not always feel able to speak up and have a voice.

One aspect of the process of therapy that emerged as contributing to an environment where family members felt able to talk openly, was a perception that they were in control of what was talked about and the therapists listened to them. This was reflected for some families in the way they felt empowered to give negative feedback to therapists if they were dissatisfied with issues in the therapy. On the basis of their research into developing ‘user-friendly family therapy’, Treacher & Carpenter (1993) have argued that for an effective therapeutic alliance to be developed and maintained, therapists have to start from the point where the client is at. They suggest that this creates a space where people can feel heard, understood and respected, which then increases the likelihood that they will be open to new ideas. It is therefore possible that for the families who felt the

context of family therapy placed them open to blame and criticism, the elements of feeling in control and listened to were not present.

For the adults with learning disabilities several issues influenced the degree to which they felt able to speak up and have a voice in the family therapy. Where therapists were perceived as giving space to the person with learning disabilities to contribute on their own terms this was experienced positively. In the current study, the adults with learning disabilities did not automatically feel at ease in the therapeutic setting. The participants concerned conveyed how at times the content of the sessions was difficult to understand and evoked distressing feelings for them. The importance of therapists paying special attention to ways in which people with learning disabilities can be helped to feel more comfortable in the family therapy setting emerged clearly from their accounts. This finding lends support to the points made by Fidell (1996, 2000) that the challenge for therapists using systemic approaches with this client group is to develop and adapt clinical practice in ways that increase the accessibility of systemic methods and techniques. While, to my knowledge, there is no research which can guide clinicians on how to achieve this in clinical practice, several authors have suggested drawing on the systemic literature regarding children. Fidell, for example, cites the work of Benson (1991) who describes how different types of circular questions can be used effectively with children using visual aids and role play to break down and make the different elements more concrete. Lynggaard & Scior (2002) draw on the work of narrative therapists in child and family work, such as Morgan (1999) and Freeman, Epston & Lobovits (1997), to illustrate how this may be achieved in clinical work..

A further issue that emerged as influencing the degree to which the people with learning disabilities felt they 'had a voice' concerned the presence of members of their family system in the sessions. It emerged from the accounts of some participants that the prospect of speaking up in front of family members resulted in feelings of anxiety that were of such an intensity that they kept quiet about issues that they were unhappy with about the therapy, or about difficulties they were experiencing. The issue underlying these concerns seems to relate to the marginalised and disempowered position in which people with learning disabilities are placed in society and thus in the other contexts of their lives, such as their families. The findings of the current study highlight the possibility that this situation can in fact be re-enacted and perhaps even reinforced in the context of family therapy.

Donati et al. (2000) have suggested that one of the challenges of working in this way with families in the field of learning disability is balancing the need to engage with the family, who may be placing the person with learning disabilities in a marginalised position, with the need to ensure the person with learning disabilities is supported in expressing their views and concerns. They propose that meeting with the adult with learning disabilities individually, for a number of sessions, is one way that this may be achieved. Some of the people with learning disabilities in the current study suggested that having individual meetings, either prior to family therapy or alongside it, was one way they would have been able to have more of a say.

It should be stressed though, that the presence of family members in the sessions was not invariably seen in a negative way by the adults with learning disabilities. For some, the

presence of a relative or friend was experienced as helping them to feel more at ease and that there was someone there who could help their understanding of questions and offer support if they were not sure what to say.

The accounts of the family members reflected some of the issues raised by the participants with learning disabilities. It emerged that they were sensitive to how some of the issues talked about in therapy were experienced as upsetting for their relative with learning disabilities. They also stated that they did not discuss particular topics at all or in any depth if they felt this was going to be uncomfortable for some family members. The families' accounts also revealed a sense that they were the people best positioned to help their relative with learning disabilities be included in the sessions. The families acknowledged some of the difficulties inherent in trying to talk about personal or complex issues with their relative with learning disabilities. In their accounts they emphasised how they were aware when their relative could not understand what was being said and how they had ideas about how to communicate with them more effectively.

Overall in the accounts of the families and the adults with learning disabilities there were both positive and negative aspects of attending family therapy with one another. Despite the elements of the experience that appeared to work less well for both groups, there were families who had valued the opportunity to attend family therapy together. This applied for families where the person with learning disabilities was less verbally articulate as well as those who had relatively good verbal skills. Having the opportunity to discuss difficult issues in a 'safe' space with their relative with learning disabilities

was valued by some of the families. Where the person with learning disabilities was not able to participate in the sessions verbally, some families felt that having them in the meeting was useful as it communicated to them that what was being discussed was an issue that was important to the family.

However, it is important to stress yet again that not all the families or people with learning disabilities saw the experience of attending systemic therapy as helpful. Some families felt that the sessions were at a level that was much too complicated for their relative with learning disabilities to follow what was going on. Furthermore, there was therefore considerable variation in the aspects of attending systemic therapy together that were seen as beneficial or unhelpful.

#### **4.3 Clinical and service implications**

This study has shown that systemic approaches to working with people with learning disabilities and their families can be experienced as helpful. However, the experiences of the participants in this study have indicated that there are aspects of the methods and techniques which need to be thought about much more carefully as clinical practice in this area develops.

#### **Meaningful inclusion of adults with learning disabilities in systemic family therapy**

It is clear from these results that particular attention needs to be paid to the ways in which the process of systemic family therapy is set up. Suggestions how this can be attempted have been made by Vetere (1993), Fidell (1996, 2000), Donati et al., (2000) and Lynggaard & Scior (2002). Certainly there seems to be a need to ensure that all

family members, including the individual with learning disabilities, has accurate and accessible information as to what the process of attending systemic therapy with members of their family will involve. This may include providing accessible written information for the person with learning disabilities and having someone who knows them well, for example a key worker, explain it to them.

It would seem from the results of the current study that these recommendations do not go far enough though. The degree to which the voice of the adults with learning disabilities was silenced in the process of family therapy highlights the need for considerable safeguards to be built into the process of convening and engagement to prevent this happening. Donati et al (2000) have suggested that it may be necessary to meet with the person with learning disabilities individually to ensure that their voice is not drowned out by the process of therapy and by the voices of other members of their system. The results of the current study support this idea.

It could be argued that to meet members of a family individually goes against the principles of systemic approaches to working with families. However, from an ethical position it would seem that for adults with learning disabilities to be given the opportunity to have an equal voice this may be a necessary feature of adapting systemic approaches to psychological therapy with this client group. As a group of people that often occupy a marginalised and stigmatised position in society, the voice of people with learning disabilities inevitably comes from a position of disempowerment where the person is not likely to be used to having a voice that is viewed as worth listening to or having something valuable to say.

In this context Fidell's (2000) recommendations do not seem to go far enough. As one of the issues that is brought to the context of therapy is the marginalisation and stigmatisation of a group of people in society, it would seem that simply providing an accessible leaflet and relying on someone outside of the therapy team to explain what it means, has the potential to address these issues in a tokenistic manner. If someone has not had the experience of expressing their views they will need more active support to explore their own views and beliefs about talking *before* being expected to speak up in the context of family therapy. This could be achieved through giving the adult with learning disabilities the opportunity to have a space for themselves to meet with a therapist to 'talk about talking'; what it means to them and their hopes and concerns about it. Individual meetings would also enable the process of systemic family therapy to be explained and the reasons why it could be useful to be discussed with the person with learning disabilities so they can give consent from a position of someone who is really 'informed'. These meetings could occur prior to and in preparation for setting up a meeting for the family to attend together. It is also possible that individual meetings could occur alongside the family therapy, or periodically as a way of reviewing progress.

These points are all well and good when working with people with learning disabilities who are verbally articulate. However, the inclusion of people who have significant communication difficulties in the process of systemic therapy highlights limitations of the suggestions outlined above. In this study families had mixed views about the value of their relative with learning disabilities being present in the meetings if they were not able to participate verbally. For some there was a recognition that their relative

communicated their perspective in other ways, such as through behaviour and non-verbal communication both in and out of the session. The accounts of people with learning disabilities represented in the current study are those of people who could participate in an interview with the researcher. Due to the limitations of the current study the views of those people with learning disabilities whose communication difficulties meant they could not participate in an interview were not sought. However, their family members expressed different opinions about how useful they felt it was to include them in the systemic therapy. Vetere (1993) suggests that family members who have communication difficulties should attend therapy with their family as the patterns of interaction between family members can provide information relevant to the issues explored in therapy. The results of the current study suggest that the decision whether to include an adult with learning disabilities who has communication difficulties in therapy or not perhaps can only be made on a case by case basis. This presents a challenge to therapists where the expertise of families could be drawn on to help include the person with learning disabilities in a more meaningful way. This may also help family members to feel that their contribution and knowledge is valued. However, there is also a danger that in using families as a means to facilitate the inclusion of people with learning disabilities, the person could be further marginalised.

### **Adapting methods and techniques**

The potential for the reflecting team approach to be confusing for people with learning disabilities and family members alike has been highlighted in the current study. This finding demonstrates that more attention needs to be paid to explaining and setting up this process with families. It also emphasises the need to apply techniques flexibly

based on the needs of each family. The need to adapt techniques based on the particular needs of a family or of individuals within that family seems to ask for clinicians to be creative and collaborative in the way they are applied.

The potential for questions to be experienced as complex and confusing emerged for the adults with learning disabilities and for some of the family members in this study. This highlights a need to use language that is meaningful and accessible to the client. The literature on including children in family therapy can provide some helpful pointers for adapting systemic techniques to make them more accessible to people with learning disabilities (e.g. Benson, 1991; Stith, Rosen, McCollum Coleman, & Herman, 1996; Cederborg, 1997; Shalan & Griggs, 1998; Strickland-Clark, Campbell, & Dallos, 2000; Lobatto 2002)

### **Engaging with families**

The families in this study expressed a desire for acknowledgement of their experiences of bringing up a son, daughter or relative with learning disabilities. For families to feel they can engage effectively with the process of therapy it would seem that this issue has to be addressed before they are in a position to hear new ideas (Carpenter & Treacher 1993, Fidell 2000). A systemic approach seems to be particularly well positioned to address this issue with families.

The results of the current study have highlighted how therapists working systemically with people with learning disabilities and their families are faced with the task of balancing the need to engage all members of the system without marginalising others.

In this study parents saw themselves as the people perhaps best positioned to ‘advise’ therapists how to communicate with their family member with learning disabilities. Given the potential for adults with learning disabilities to feel unable to have a voice in the context of family therapy, a challenge for the development of clinical practice in this area concerns how to engage the parents as a resource and respect their knowledge about how to communicate with their relative with learning disabilities whilst allowing that individual a space to develop their own ideas and express them.

### **The role of the therapist**

Where therapists were seen as helping families access support of a practical nature, this was seen as a valuable outcome of attending family therapy. This issue seems to accurately reflect the many roles played by the clinical psychologist working in learning disabilities services, which can involve a substantial amount of co-ordinating different services, acting as a ‘named person’ for a family, for whom the therapist is often the person who they contact with any issues and difficulties that arise, regardless of whether they are specific to the context of the family therapy. The multifaceted nature of this role has implications for how therapists who use systemic approaches to working with this client group and their families are enabled to work out and balance the demands it places on them. It would seem that these issues indicate an increased need for training and supervision.

The nature of the role of the therapists working systemically with families in learning disabilities services raises questions and uncertainties about how one remains true to systemic theory and techniques in one’s practice. In a recent paper McNamee (2004)

explores the relationship between systemic theory and clinical practice using a social constructionist framework. She argues that from this perspective the process of therapy is seen as creating meaning through dialogue between client and therapist, and that any theory or model has the potential to generate meanings that are helpful. Therefore theories, models and techniques are available to be drawn on as flexible resources which can be selected on the basis of what is practical and useful rather than what is 'right'. Asen (2004) has highlighted how systemic approaches, in their focus on holding and valuing multiple perspectives simultaneously, are very much suited to working in this way. It can therefore be argued that for clinicians working in the field of learning disabilities an openness to the ways in which different approaches (systemic and non-systemic) can be helpful within an overall systemic framework, offers ways of approaching and supporting the development of clinical practice in this area.

#### **4.4 Methodological issues**

This section will consider methodological issues in this research and how they may have impacted on the quality of the data obtained and the interpretation of it.

##### **Generalising findings**

Although large numbers of participants are not aimed for in qualitative research (Silverman 1993), the small sample size of ten families and six people with learning disabilities in this study limits the extent to which conclusions can be drawn about the provision of systemic family therapy for this client group more generally. The way in which participants were recruited to the study is likely to have generated some biases that suggest participants in this study may not be representative of families that attend

and are referred for family therapy in learning disabilities services generally. Although attempts were made to invite families who had dropped out of therapy to participate in the study, none responded or some services thought that the circumstances around their disengagement from therapy, such as a family crisis, meant it was not appropriate for them to be approached.

Attempts were also made to recruit families from a variety of cultural, social and economic backgrounds. However, as the majority of the families in this study came from inner city areas with high levels of deprivation, people from more affluent areas and higher socio-economic backgrounds are under-represented in this study. Families were recruited to the study from a range of different ethnic backgrounds, which is likely to be a reflection of the culturally diverse inner city areas that were covered by the services involved in the study. This aspect of representativeness can therefore be seen as a strength of the current study.

A further issue that warrants consideration in relation to generalisability is the duration between the end of therapy and the point at which the family was interviewed for the study. At the outset of the study the aim was to recruit families who had finished therapy a relatively short time before being interviewed. However, systemic approaches have only fairly recently been introduced in learning disability services and early enquiries indicated that even if recruiting through a large number of services numbers of potential participants would be limited. Significant difficulties with recruitment meant that the inclusion criteria had to be expanded to allow those who finished therapy some time ago, to be invited to participate.

For this reason it was decided to have broad inclusion criteria and include families who were still in therapy and those who had left therapy up to 3 years previously. Thus the time lapse between the end of therapy and the research interview varied greatly between the families. Different issues may be more pertinent at different times after therapy and it may take some time for families to perceive changes that may have been promoted by the experience of attending therapy. Furthermore, it could be suggested that the longer the time that has elapsed since the end of therapy the greater the possibility for recall of the experience to be limited. However, it did seem that for the families recruited to the study significant amounts of material about the experience of attending family therapy was recalled over 18 months later.

There are a number of possible explanations that may have contributed to the lower than expected initial response rate. Firstly, some families had ended therapy over 18 months ago. Receiving a letter about something that they did this long ago may have, at least for some families, been confusing or felt irrelevant to their current circumstances. In addition, many families of people with learning disabilities are involved with a complex network of carers, support staff, health and social services. It is possible that the sheer number of different professionals involved with people with learning disabilities can result in confusion for families about the roles of different professionals and support agencies. Therefore, sending a letter inviting people to comment about their experiences of family therapy meetings may have been seen as one thing too many or as adding to the confusion around the involvement of different services in their lives.

The letters that were sent out to families used the terms ‘family meetings’ and ‘family therapy meetings’. The wording of the letter had been chosen in consultation with a large number of therapists to reflect as accurately as possible what the project was investigating, as there were differences between and within services, in the terms that were used with families. It may be that the terms in the letters were different to those used by the clinicians in their explanations to families about the purpose of the systemic therapy sessions and so families were unsure what the letter was referring to. Conversations between the researcher and the various clinicians involved in recruiting to the study had raised this as an issue, as the term “therapy” was not consistently used with families. One reason given for this was that for some families the term ‘family therapy’ could be perceived negatively and could potentially put them off engaging with the service. In this example ‘family meeting’ or just ‘meetings’ were the terms used by the clinicians in the service.

Attempts to recruit people with learning disabilities to the study were also met with lower than expected response rates. This raises an issue around how people with learning disabilities are invited to participate in research about issues that affect their lives. Many adults with learning disabilities live with their families. Consequently, family members can play a part in either communicating information about participating in research projects or failing to do so, rather than the individual concerned necessarily having the opportunity to make a choice about whether they would like to participate. This seems particularly pertinent when interviewing families about personal or sensitive issues, where families may feel that they do not want to risk their privacy being intruded

upon. There may also be a desire to protect a family member with learning disabilities from what may be perceived as a potentially upsetting experience.

## **Ethical issues**

### *Informed consent*

The consent procedure aimed to ensure that adults with learning disabilities understood what the study involved before deciding whether they wished to participate. However, there were some limitations to this procedure. The study attempted to reduce the likelihood of coercion with regards to consent by meeting with the adults with learning disabilities separately. This does not completely rule out the possibility that other family members influenced the person's decision whether to take part.

### **Quality of the interview data**

There are a number of issues that may have affected the quality of the interview data in this research. Firstly, the researcher's relative lack of experience with conducting semi-structured interviews may have resulted in leading or poorly worded questions being used at times. The lack of opportunity to pilot the interview schedule, particularly the one used with participants with learning disabilities, meant that early interviews may have been of poorer quality than those conducted once the researcher had developed more familiarity with using the schedule. The participants in this study reported both positive and negative aspects of their experience of therapy. This included the adults with learning disabilities, which suggests that they were able to resist the pressure to provide acquiescent responses, previously documented in the literature (e.g. Sigelman et al., 1981; Rapley & Antaki, 1996). Therefore, despite the limitations described above,

the variability in the themes identified and the illustrative quotes emerged across all of the interview transcripts, thus suggesting that the data obtained was of sufficient quality to provide valid information about participants' experiences of attending systemic family therapy.

### **Reflexivity**

In qualitative research there is a requirement that the researcher makes their perspective explicit (Elliot et al., 1999). In a study using IPA, reflexivity about the research process is necessary as there is acknowledgement that analysis of interview data using IPA relies on the subjectivity of the researcher. Findings are therefore viewed as a reflection of the interaction between the researcher, participants and the data, rather than as providing any 'objective truth'. Although these assumptions mean that alternative interpretations are always possible, guidelines for good practice in qualitative research suggest a number of steps that can be taken to reduce researcher bias, ensure a systematic approach is taken to the process of analysis and check the credibility of the findings (Elliott et al 1999).

### *Reliability and validity*

The ways in which guidelines for good practice in qualitative research (see section 2) were followed in the current study will be described below. The researcher's perspective has been made explicit in the Method section and further ways in which this may have impacted on the research process and findings will be discussed below. Attention has been paid to situating the sample by describing demographic and other characteristics of the participants (see section 3, Tables 1 & 2). The themes have all been grounded in

examples to allow the reader to assess the fit between the participants' descriptions of their experience of attending systemic therapy and the researcher's interpretations of them. Two experienced clinical psychologists in learning disabilities with considerable knowledge of qualitative research methods provided credibility checks on the process of analysis. These checks found the process of analysis to be auditable as there was a logical progression that ran through the interpretation of the data to the master and subordinate themes. Finally, the study was found to be credible as it resonated with the literature in the area.

A respondent validity check (Silverman 1993) could not be carried out in the current study due to time constraints. This would have involved taking the themes back to the participants to check whether they resonated with them. In addition, for the family members this procedure would have strengthened the findings of this study as it would have established a feedback loop offering further perspectives on the categories and themes. However, for the participants with learning disabilities undertaking this procedure in a meaningful way so that the participants could really understand the information presented would perhaps have been unrealistic.

### *Researcher reflexivity*

This section will provide my reflections on the research process. At the outset of the study I was uncertain about whether reflecting on the experience of attending systemic therapy in an interview with a researcher who they did not know was going to be too difficult for the participants with learning disabilities. Although in the interviews these participants did at times provide brief responses to questions that did not convey a great

degree of information about their experience, overall the accounts of the of adults with learning disabilities highlight some very important issues about their experience of family therapy.

My experience of the process of the interviews with the people with learning disabilities was that at times it did feel as though I was being quite directive in the way I asked questions. On reflection, it seems that when conducting this type of research with people who have communication difficulties it is inevitable that the interviewer has a more interventive role in the process.

I had wondered whether when interviewing family members together, it was going to be a challenge to ensure that each person was given a chance to have their say. In reality, there certainly were more dominant voices in some of the family interviews, but I also noticed how at different points in the interviews different family members seemed to have more to say. This process did not really require much direction from me as the interviewer. The families seemed to have their own style of talking together which they stuck to in the context of the interview.

All of the participants with learning disabilities, except for one couple with learning disabilities who were interviewed together, were interviewed individually. This ensured that they had an opportunity to express their views. However, I do think that this was quite an anxiety provoking experience for these participants, at least initially. I am someone who has considerable experience of talking with people with learning disabilities from different contexts of my own life; therefore I was able to draw on these

experiences to help the participants feel at ease. However, I do wonder whether the participants' accounts would have been any different if I had been able to spend time getting to know them before talking to them about something as potentially personal and complex as going for family therapy.

As a trainee clinical psychologist, I have developed an interest in using systemic approaches to working with people of different ages, cultural backgrounds and levels of understanding. Coming from this perspective, I was very interested in participants' perceptions of the experience of attending systemic therapy, how they made sense of the impact the experience had/or did not have on themselves and the other members of their family. I also believe that working systemically with this client group is a valuable way of working and I had to be very aware that I was likely to be looking for aspects of the participants' accounts that were not in keeping with my views whilst I was carrying out the analysis. This was something that I discussed with my supervisors throughout the process of the research.

However, I was also aware that I was committed to hearing what the participants had to say and trying to capture their experiences as accurately as possible. I was clear with the participants that I was interested to hear about the positive and negative aspects of their experience of systemic therapy.

### *Analysis*

One of the benefits of IPA as a qualitative methodology is that it provides a systematic way to represent and explore the meanings people ascribe to their experiences of

particular phenomena. The clear guidelines (e.g. Smith et al., 1999) that are available concerning how to conduct research using IPA make it an accessible approach, especially for more inexperienced researchers (Smith, 2004). However, the assumption in IPA, that an individual's account of their experience equates to their experience of it has been criticised (Willig, 2001). Willig argues that language in fact constructs rather than describes 'reality' and therefore interview data in fact illustrates more about the ways in which individuals construct and ascribe meaning to their experiences in a particular context, rather than providing an account of their experiences per se.

The question of the suitability of IPA as a method of analysis for an interview based study with participants with learning disabilities was an issue considered by the researcher. There was a possibility that the interviews with participants would not yield rich enough data to use IPA to capture their experiences and the meanings they ascribed to them. Although the data obtained from the interviews with the participants with learning disabilities was less detailed than data from the interviews with family members, it was felt that IPA was still a suitable method of analysis for two main reasons. Firstly, as Smith (2004) has pointed out in a paper reflecting on the growing popularity of IPA as a qualitative research methodology, it is a suitable method where the task is to explore people's lived experience and the ways in which they make sense of those experiences. Secondly, Smith argues that IPA is not a method that is only suitable for the more verbally articulate. He argues that richness of data is associated more with the degree of significance a phenomenon under investigation holds for the individual, rather than their verbal capacity. Therefore as the experience of therapy is

likely to be one that holds considerable personal meaning for the individual IPA was used as it would help to capture this.

However, there are limitations in the extent to which the themes identified in this study effectively captured participants' psychological experiences. Many of the themes identified from the participant's accounts, actually reflected questions that the researcher asked in the interview. This suggests that some of the ways in which the researcher made sense of and grouped different elements of the participants' accounts, was according to answers to particular questions rather than more psychological meanings and experiences.

The researcher's own inexperience with using IPA and conducting qualitative analysis is likely to have contributed, at least to some extent, to these limitations of the analysis in the current study. Similarly, a lack of experience with semi-structured interviewing may have resulted in a more directive style, thus limiting the opportunity for participants to lead the researcher into different and unique areas of enquiry.

#### **4.5 Future research**

From the findings and limitations of the current study it is possible to suggest two main areas for further research.

Firstly, the provision of systemic therapy for people with learning disabilities and their families is increasing and there has not yet been any indication in the literature as to whether it is an effective approach, resulting in positive change for families. Therefore

one important direction for research in this area would be to investigate the outcomes of systemic family therapy with this client group, to contribute to the development of evidence that can assist the decision making process about what is most useful and for whom.

Secondly, a limitation of the current study was that the interviews with the participants with learning disabilities were not carried out with someone the participants knew and trusted. If more time could be spent getting to know the person before the interview more detailed information might be gained about adults with learning disabilities experiences of attending systemic family therapy. It would also be useful if people with learning disabilities could be interviewed about their experience of therapy over time. For example their views could be sought on an ongoing basis, by the same person as a part of reviewing their progress in therapy.

#### **4.6 Conclusion**

The current study clearly is only a starting point which has identified some of the aspects of systemic therapy that had particular impact for a very small sample of adults with learning disabilities and their families.

Several of the issues raised by the participants about their experiences of systemic therapy relate closely to the findings of research with other client groups on service users' experience of systemic therapy. This offers the systemic practitioner in the learning disability field a substantial body of literature that can be drawn on in the

application of systemic ideas and techniques to work with people with learning disabilities and their families.

However, the findings also revealed that there are some aspects in the application of systemic approaches to work with people with learning disabilities and their families that may not apply to other client groups. Firstly, the ways in which this type of therapy is set up needs to perhaps be more flexible with people with learning disabilities and their families. This would seem to be essential to ensure that people with learning disabilities can be included in this type of therapy in a way that is meaningful and in ways that support them to have a voice.

Secondly, recognition of the multifaceted role adopted by therapists in learning disabilities services, as people who can help co-ordinate and negotiate between resources and facilitate access to practical help, seems in need of recognition and support.

## References

- Ackerman, S.J., & Hilsenroth, M.J. (2003). A review of therapist characteristics and techniques positively impacting the therapeutic alliance. *Clinical Psychology Review, 21*, 1-33.
- Addison, S.M., Sandberg, J.G., Corby, J., Robila, M. & Platt, J. J. (2002). Alternative methodologies in research literature review: links between clinical work and MFT effectiveness. *The American Journal of Family Therapy, 30*, 339-371.
- Ambalu, S. (1997). Communication. In J. O'Hara & A. Sperlinger (Eds.), *Adults with learning disabilities: a practical approach for health professionals* (pp. 45-60 ). Chichester: Wiley Press.
- Andersen, T. (1987). The reflecting team: dialogue and meta-dialogue in clinical work. *Family Process, 26*, 415-28.
- Arscott, K., Dagnan, D., & Kroese, B. (1998). Consent to psychological research by people with an intellectual disability. *Journal of applied Research in Intellectual Disabilities, 11*, 77-83.
- Arthur, A.R. (2003). The emotional lives of people with learning disability. *British Journal of Learning Disabilities, 31*, 25-30.

- Asen, E. (2002). Outcome research in family therapy. *Advances in Psychiatric Treatment*, 8, 230-238.
- Asen, E. (2004). Collaborating in promiscuous swamps – the systemic practitioner as context chameleon? *Journal of Family Therapy*, 26, 280-285.
- Bachelor, A. (1995). Clients' Perception of the Therapeutic Alliance: A Qualitative Analysis. *Journal of Counselling Psychology*, 42, 323-337.
- Barkham, M. & Mellor –Clark, J. (2000). Rigour and relevance: the role of practice based evidence in the psychological therapies. In: N. Rowland & S. Glass (Eds.), *Evidence Based Counselling and Psychological Therapies: Research and Applications* (pp.127-44). London: Routledge.
- Bateson, G. (1972). *Steps to an Ecology of Mind*. New York: Ballantine
- Baum, S., Chapman, K., Scior, K., Sheppard, N., & Walden, S. (2001). Themes emerging from systemic therapy involving adults with learning disabilities and their families. *Clinical Psychology*, 3, 16-18.
- Baum, S. & Webb, J. (2002). Valuing People: what will it mean for clinical psychology services for people with learning disabilities? *Clinical Psychology*, 14, 20-24.

Beail, N. (1994). Fire, coffins and skeletons. In V. Sianson (Ed.), *Treating survivors of Satanist abuse*. London: Routledge.

Beail, N. (1995). Outcome of Psychoanalysis, psychoanalytic and psychodynamic psychotherapy with people with intellectual disabilities: A review. *Changes*, 13, 186-191.

Beail, N. (1998). Psychoanalytic psychotherapy with men with intellectual disabilities: A preliminary outcome study. *British Journal of Medical Psychology*, 71, 1-11.

Beail, N. (2000). An evaluation of outpatient psychodynamic psychotherapy for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 44, 204.

Beail, N. (2003). What works for People With Mental Retardation? Critical Commentary on Cognitive-Behavioural and Psychodynamic Psychotherapy Research. *Mental Retardation*, 41, 468-472.

Beail, N., & Warden, S. (1996). Evaluation of a psychodynamic psychotherapy service for adults with intellectual disabilities: Rationale, design and preliminary outcome data. *Journal of Applied Research in Intellectual Disabilities*, 9, 223-228.

- Beck, A.T. (1976). *Cognitive Therapy and the emotional disorders*. New York: International Universities Press.
- Beck, A.T. (1964). Thinking and depression: II. Theory and therapy. *Archives of General Psychiatry*, 10, 561-571.
- Bender, M. (1993). The unoffered chair: the history of therapeutic disdain towards people with a learning difficulty. *Clinical Psychology Forum*, April, 7-12.
- Benson, M., J. (1991). Accessing children's perceptions of their family: circular questioning revisited. *Journal of Marital and Family Therapy*, 4, 363-372.
- Booth, T., & Booth, W. (1996). Sounds of Silence: narrative research with inarticulate subjects. *Disability and Society*, 11, 55-69.
- Bromley, J. (1998). Working with families. In: E. Emerson, C. Hatton, & J. Bromley (Eds.), *Clinical Psychology and People with Intellectual Disabilities* (pp. 247-264). Chichester: Wiley.
- Brunk, M., Henggeler, S., & Whelan, J. (1987). Comparison of multisystemic therapy and parent training in the brief treatment of child abuse and neglect. *Journal of Consulting and Clinical Psychology*, 55, 171-178.
- Burnham J.B. (1986). *Family Therapy*. London: Routledge.

Burnham, J. (1992). Approach –Method-Technique: Making Distinctions and Creating Connections. *Human Systems: The Journal of Systemic Consultation and Management*. 3, 3-26.

Burnham, J. (1999). Diploma in Systemic Therapy Teaching, Clinical Year 2.

Carpenter, J., & Treacher, A. (1993). *Using Family Therapy in the 90's*, Oxford: Blackwell.

Carr, A. (2000a). Evidence-based practice in family therapy and systemic consultation II. *Journal of Family Therapy*, 22, 29-60.

Carter, E., & McGoldrick, M. (1982). *The Family Life Cycle: A Framework for Family Therapy*. New York: Gardener.

Cederborg, A.C. (1997). Young children's participation in family therapy. *American Journal of Family Therapy*, 25, 28-38.

Chapman, K., & Oakes, P. (1995). Asking people with learning disabilities their view on direct psychological interventions. *Clinical Psychology Forum*, July, 28-33.

- Dagnan, D., & Chadwick, P. (1997). Cognitive-behaviour therapy for people with learning disabilities: Assessment and intervention. In B. Stenfert Kroese, D. Dagnan, K. Loumidis (Eds.), *Cognitive-behaviour therapy for people with learning disabilities* (pp. 110-123 ). London: Routledge.
- Dagnan, D., Chadwick, P., & Proudlove, J. (2000). Toward assessment of suitability of people with mental retardation for cognitive therapy. *Cognitive Therapy and Research*, 24, 627-636.
- Dale, N. (1996). *Working with Families of Children with Special Needs*, London: Routledge.
- Davis, H. (1993). *Counselling parents of children with chronic illness or disability*. Oxford: British Psychological Society.
- Department of Health (1999). *National Service Framework for Mental Health*.
- Department of Health (2001) *Valuing People: A new strategy for learning disability for the 21<sup>st</sup> century*. London: HMSO
- Donati, S. Glynn, B. Lynggaard, H. Pearce, P. (2000). Systemic interventions in a learning disability service: an invitation to join. *Clinical Psychology Forum* 14, 24-27.

- Dowdney, L., & Skuse, D. (1993). Parenting provided by adults with mental retardation. *Journal of Child Psychology and Psychiatry*, 34, 25-47.
- Eisler, I., Dare, C., Russell, G., F., M., et al. (1997). Family and individual therapy in anorexia nervosa: A 5-year follow up. *Archives of General Psychiatry*, 54, 1025-1030.
- Elliot, R., Fischer, C. & Rennie, D. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.
- Ekdawi, I., Gibbons, S., Bennett, E., Hughes, G. (2000). Whose Reality is it Anyway? Putting social constructionist philosophy into everyday clinical practice. Brighton: Pavilion.
- Fidell, B. (1996). Making family therapy user-friendly for learning disabled clients. *Context*, 26, 11-13.
- Fidell, B. (2000). Exploring the use of family therapy with adults with a learning Disability. *Journal of Family Therapy*, 22, 308-323.
- Fielding, N. (1993). Qualitative interviewing. In N. Gibbert (Ed.), *Researching social life* (pp. 135-153 ). London: Sage

- Flynn, M.C. (1986). Adults who are mentally handicapped as consumers: issues and guidelines for interviewing. *Journal of Mental Deficiency Research*, 30, 369-77.
- Foster, M.A. (1988). A systems perspective and families of handicapped children. *Journal of Family Psychology*, 2, 54-56.
- Frankish, P. (1989a). Childhood repeated. In D. Brandon (Ed.), *Mutual respect: therapeutic approaches to working with people who have learning difficulties*. Surbiton: Good Impressions.
- Frankish, P. (1989b). Meeting the emotional needs of handicapped people: a psychodynamic approach. *Journal of Mental Deficiency Research*, 33, 407-14.
- Freeman, J., Epston, D. & Lobovits, D. (1997). *Playful Approaches to Serious Problems: Narrative Therapy with Children and their Families*. New York: Norton
- Freud, S. (1953) On Psychotherapy (1904). In *The Standard Edition of the Complete Psychological Works of Sigmund Freud, Vol. VII*. London: Hogarth Press.
- Fuchs, K., Mattison, V., & Sugden, K. (2003). Reflections on engagement. *Context*, 65, 21-22.

- Goldberg, D., Magrill, L., Hale, J., Damaskinidou, J., P., & Tham, S. (1995). Protection and loss: working with learning-disabled adults and their families. *Journal of Family Therapy*, 17, 263-280.
- Haddock, G., Lobban, F., Hatton, C., & Carson, R. (2004). Cognitive-behaviour therapy for People with Psychosis and Mild Intellectual Disabilities: A Case Series *Clinical Psychology and Psychotherapy*, 11, 282-298.
- Hayes, H. (1991). A Re-Introduction to Family Therapy Clarification of Three Schools. *Australian and New Zealand Journal of Family Therapy*, 12, 27-43.
- Hoffman, L. (1990). Constructing realities: an art of lenses. *Family Process*, 29, 1-12.
- Howe, D. (1989). *The Consumers' View of Family Therapy*. Aldershot: Gower.
- Knott, F., & Espie, C. (1997). Families' perceptions of the one-way screen in the first meeting. *Journal of Family Therapy*, 19, 431-439.
- Lambert, M. (1992). Implications of outcome research for psychotherapy integration. In J.C. Norcross & M.R. Goldfried (Eds.), *Handbook for Psychotherapy Integration* (pp. 94-129). New York: Basic Books.
- Larner, G. (2004). Family therapy and the politics of evidence. *Journal of Family Therapy*, 26, 17-39.

- Leff, J., Vernal, S., Wolff, Alexander, B., et al. (2000). The London Depression Trial. Randomised controlled trial of antidepressants v. couple therapy in the treatment and maintenance of people with depression living with a partner: clinical outcome and costs. *The British Journal of Psychiatry*, 177, 95-100.
- Lindsay, W.R., Howells, L., & Pitcaithly, D. (1993). Cognitive therapy for depression with individuals with intellectual disabilities. *British Journal of Medical Psychology*, 66, 135-141.
- Lindsay, W.R., Marshall, I., Neilson, C.O., Quinn, K., & Smith, A.H. (1998). Treatment of men with a learning disability convicted of exhibitionism. *Research in Developmental Disabilities*, 19, 295-316.
- Lobatto, W. (2002). Talking to children about family therapy: a qualitative research study. *Journal of Family Therapy*, 24, 330-343.
- Lund, J. (1985). The prevalence of psychiatric morbidity in mentally retarded adults. *Acta Psychiatrica Scandinavica*, 72, 563-570.
- Lynggaard, H. Donati, S. Pearce, P. & Sklavounos D. (2001) A difference that made a difference: introducing systemic ideas and practices into a multidisciplinary learning disability service. *Clinical Psychology*, 3, 12-15.

- Lynggaard, H., & Scior, K. (2002). Narrative Therapy and People with Learning Disabilities. *Clinical Psychology*, 17, 33-36.
- Macdonald, J., Sinason, V., & Hollins, S. (2003). An interview study of people with learning disabilities' experience of and satisfaction with, group analytic therapy. *Psychology and Psychotherapy: Theory, Research and Practice*, 76, 433-453.
- Mattison, V., & Pistrang, N. (2000). *Saying goodbye: When keyworker relationships end*. London: Free Association Press.
- Mc Namee, S. (2004). Promiscuity in the practice of family therapy. *Journal of Family Therapy*, 26, 224 – 244.
- Mercer, J. (1973). *Labelling the Mentally Retarded: Clinical and Social System Perspectives on Mental Retardation*. Berkley and London: University of California.
- Morgan, A. (1999). *Once upon a time: narrative ideas for working with children*, Adelaide: Dulwich Centre Publications.
- Oliver, M. (1989). Disability and dependency: a creation of industrial societies. In L. Barton (Ed.), *Disability and Dependency*. Brighton: Falmer Press.

- Oswin, M. (1991). *Am I allowed to Cry? The study of Bereavement Amongst People with Learning Difficulties*. London: Souvenir Press.
- Pharoah, F.M., Mari, J.J., & Streiner, D. (2000). Family intervention for schizophrenia (Cochrane Review). In *The Cochrane Library*, Issue 3. Oxford: Update Software.
- Prosser, H. & Bromley, J. (1998). Interviewing people with intellectual disabilities. In E. Emerson, C. Hatton, J Bromley & A. Caine (Eds.), *Clinical Psychology and People with Intellectual Disabilities* (pp. 99-113).Chichester: Wiley.
- Rapley, M., & Antaki, C. (1996). A conversation analysis of the “acquiescence” of people with learning disabilities. *Journal of Community and Applied Social Psychology*, 6, 207-227.
- Reder, P., & Fredman, G. (1996). The Relationship to Help: Interacting Beliefs about the Treatment Process. *Clinical Child Psychology and Psychiatry*, 1, 457-467.
- Reed, J. (1997). Understanding and assessing depression in people with learning disabilities: a cognitive-behavioural approach. In B. Stenfert Kroese, D. Dagnan & K. Loumides (Eds.), *Cognitive-behaviour therapy for people with learning disabilities* (pp. 53-66). London: Routledge.

Reiss, S., Levitan, G., w., & McNally, R., J. (1982). Emotionally disturbed mentally retarded people: an undeserved population. *American Psychologist*, 37, 361-367.

Reimers, S. (1995), 'Good morning, Sir!' 'Axe handle.' Talking at cross-purposes in family therapy. *Journal of Family Therapy*, 21, 360-376.

Reimers, S. (2001). Understanding alliances: How can research inform user-friendly practice? *Journal of Family Therapy*, 23, 46-62.

Reimers, S., & Treacher, A. (1995). *Introducing User-friendly Family Therapy*. London: Routledge.

Reimers, S., & White, C. (1995). Learning from users. In S. Reimers & A. Treacher (Eds.), *Introducing User-friendly Family Therapy*. London: Routledge.

Reiss, S. (1985). The mentally retarded, emotionally disturbed adult. In M Sigman (Ed.), *Children with emotional disorders and developmental disabilities* (pp. 171-192). New York: Grune & Stratton.

Roth, A., & Fonagy, P. (1996). What works for whom? A Critical Review of Psychotherapy Research. Guilford Press. New York.

Roy-Chowdhury, S. (1992). Family therapy, multi-disciplinary teams and people with

learning difficulties: a conversation. *Clinical Psychology Forum*. Jan, 12-15.

Russell, G.F., M., Szmukler, G.I., Dare, C., et al. (1987). An evaluation of family therapy in anorexia nervosa and bulimia nervosa. *Archives of General Psychiatry*, 44, 1047-1056.

Rycroft, P. (2004). When Theory abandons us – wading through the ‘swampy lowlands’ of practice. *Journal of Family Therapy*, 26, 245-259.

Scior, K. (2003). Using Discourse Analysis to Study the Experiences of Women with Learning Disabilities. *Disability and Society*, 18, 779-795.

Scior, K., & Lynggaard, H. (In press). New Stories of Learning Disabilities: The Promise Offered by Narrative Therapy. In S. Baum & H. Lynggaard (Eds.), *Systemic Approaches to Working with People with Learning Disabilities, their Families and Service Systems*.

Selvini Palazzoli, M. Boscolo, L. Ceccin, G. & Prata, G. (1980a). The problem of the referring person. *Journal of Marital and Family Therapy*, 11, 21-34.

Shadish, W., Montgomery, L., Wilson, P., et al. (1993). The effects of family and marital psychotherapies: a meta analysis. *Journal of Consulting and Clinical Psychology*, 61, 992-1002.

- Shalan, D. & Griggs, H. (1998). The age of consent: involving children in their own referral process. *Clinical Psychology Forum*, 116, 19-23.
- Sigelman, C., Schoenrock, C., Winer, J., Spanhel, C., Hromas, S., Martin, P., Budd, E., & Bensberg, C. (1981). Issues in interviewing mentally retarded persons: an empirical study. In R. Bruininks, C. Meyer, B. Sigford & K. Lakin, (Eds.), *Deinstitutionalisation and community adjustment of mentally retarded people*. Washington DC: Monograph no. 4, American Association of Mental Deficiency.
- Sinason, V. (1992). *Mental Handicap and The Human Condition New Approaches From The Tavistock*. London: FAB
- Silver, E., Williams, A., Worthington, F., & Phillips, N. (1998). Family therapy and soiling: an audit of externalizing and other approaches. *Journal of Family Therapy*, 20, 413-422.
- Silverman, D. (1993). *Interpreting qualitative data: methods for analysing talk, text and interaction*. London: Sage.
- Smith, J.A. (1994). Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11, 261-271.

- Smith, J.A. (1995). Semi structured interviewing and qualitative analysis. In: J.A. Smith, R. Harre, & L. Van Langehove (Eds.), *Rethinking Methods in Psychology* (pp. 9-26). London: Sage.
- Smith, J.A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11, 261-271.
- Smith, J.A. (2003). *Qualitative Psychology A Practical Guide to Research Methods*. Sage Publications. London.
- Smith, J.A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39-54.
- Smith, J.A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In: M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories & Methods* (pp. 218-240). London: Sage
- Smith, J.A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative Psychology A Practical Guide to Research Methods* (pp. 51-80). Sage Publications. London.

Smith, T., Sells, S., & Clevenger, T. (1994). Ethnographic content analysis of couple and therapist perceptions in a reflecting team setting. *Journal of Marital and Family Therapy*, 20, 267-286.

Stenfert Kroese, B., Dagnan, D., & Konstantinos, L. (1997). *Cognitive-behaviour therapy for people with learning disabilities*. London; New York. Burnner-Routledge.

Stenfert Kroese, B. (1997). Cognitive-behaviour therapy for people with learning disabilities. Conceptual and contextual issues. In B. Stenfert Kroese, D. Dagnan & K. Loumidis (Eds.), *Cognitive-behaviour therapy for people with learning disabilities* (pp. 1-15). London: Routledge.

Strickland-Clark, L. Campbell, D. & Dallos, R. (2000). Children's and adolescents' views on family therapy. *Journal of Family Therapy*, 22, 324-341.

Stiles, W.B., Shapiro, D.A., & Elliott, R. (1986). "Are All Psychotherapies Equivalent?" *American Psychologist*, 41, 165-180.

Stith, S., Rosen, K., McCollum, E., Coleman, J., & Herman, S. (1996). The voices of children: pre-adolescent children's experience in family therapy. *Journal of Marital and Family therapy*, 22, 89-111.

- Sturmey, P. (2004). Cognitive Therapy with People with Intellectual Disabilities: A Selective Review and Critique. *Clinical Psychology and Psychotherapy*, 11, 222-232.
- Sturmey, P., Reed, J., & Corbett, J. (1991). Psychometric assessment of psychiatric disorders in people with learning difficulties (mental handicap): A review of measures. *Psychological Medicine*, 21, 143-155.
- Symington, N. (1981). The psychotherapy of a sub-normal patient. *British Journal of Medical Psychology*, 54, 187-199.
- Szapocznik, J., Rio, A., Murray, E., Cohen, R., Scopetta, M., Rivas-Valquez, A., Hervis, O., Posada, V. & Kurtines, W. (1989). Structural family versus psychodynamic child therapy for problematic Hispanic boys. *Journal of Consulting and Clinical Psychology*, 57, 571-578.
- Taylor, J.L., Novaco, R.W., Gillmer, B.T., & Robertson, A. (2004). Treatment of anger and aggression. In W.R Lindsay, J.L. Taylor & P. Sturmey (Eds.), *Offenders with developmental disabilities* (pp. 221-240). Chichester: Wiley.
- Tomm, K. (1987). Interventive Interviewing: Part II: Reflexive questioning as a means to enable self healing. *Family Process*, 26, 167-183.

- Tomm, K. (1988). Interventive Interviewing: Part III. Intending to Ask Lineal, Circular, Strategic, or Reflexive Questions? *Family Process*, 27, 1-15.
- Treacher, A., & Carpenter, J. (1993). User-Friendly Family Therapy. In J. Carpenter & A. Treacher (Eds.), *Using Family Therapy in the 90's* (pp. 8-31). Oxford: Blackwell.
- Turk, V., & Brown, H. (1993). Sexual abuse and adults with learning disabilities: results of a two year incidence survey. *Mental Handicap Research*, 6, 193-216.
- Vetere, A.L. (1998). Family Therapy and Systemic Approaches. In P.M. Salkovskis (Ed.), *Comprehensive clinical psychology, Vol. 6: Adults: Clinical formulation & treatment* (pp. 85-103). Oxford, England: Pergamon/Elsevier Science Ltd.
- Vetere, A.L. (1993). Using Family Therapy in Services for People with Learning Disabilities. In J. Carpenter & A. Treacher (Eds.), *Using Family Therapy in the 90's* (pp. 111-130). Oxford: Blackwell.
- Wikler, L. (1981). Chronic stresses of families of mentally retarded children. *Family Relations*, 30, 281-288.
- Wilcox, E. & Whittington, A. (2003). Discovering the use of narrative metaphors in work with people with learning disabilities. *Clinical Psychology*, 21, 31-35.

Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham: Open University Press.

Wyngaarden, M. (1981). Interviewing mentally handicapped persons: issues and strategies. In R.H. Bruininks, C.E. Meyers, B.B. Sigford & K.C. Lakin (Eds.), *Deinstitutionalisation and community adjustment of mentally retarded people*. Washington DC: Monograph no. 4, American Association of Mental Deficiency.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-228.

**Appendix**

**1. Families initial letter**

Dear Service User

I am currently training as a clinical psychologist at University College London. For my final year dissertation, I am conducting some research on what it is like for people with learning disabilities and their families to attend family therapy meetings.

The study involves talking to families about their experiences of receiving this type of help. I would like to hear the views of any family members, even if this is only one person from your family.

This letter has been forwarded to you by the team at the

. It is important that you know I do not work for the service and that any views people share with me will be kept private from the team.

I have enclosed two information sheets about the study, which also discuss confidentiality, consent issues and how the findings from the research will be used. One of these sheets is a simpler version that is easier to understand.

I would be very grateful if you would talk to the person in your family who has learning disabilities about whether they would like to take part in the study and go through the information sheet with them. Please note, even if this person does not want to take part, I am still keen to talk to any other family members about their views and experiences of therapy.

If any members of your family are interested in participating please return the reply slip in the prepaid envelope to me at the above address, or e-mail me at , or leave a message on .

I will then get in touch with you to answer any questions you have about the study and make an appointment to meet with you to complete the consent forms.

If you prefer we can conduct the interview on the day that we meet to go through the consent forms. Alternatively we can arrange another time that is convenient to you.

Please do not hesitate to get in touch if you have any questions. Meanwhile I look forward to hearing from you soon.

Many thanks  
Yours faithfully

Laura Arkless  
Trainee Clinical Psychologist

Please see reply slip on next page.

**Appendix**

**2. Families info sheet**



Sub-Department of Clinical Health Psychology

**UNIVERSITY COLLEGE LONDON**

GOWER STREET LONDON WC1E 6BT

Tel:

E-mail:

## **INFORMATION SHEET**

### **“Talking to people with learning disabilities and their families about the experience of family therapy”**

You are being invited to take part in a research study being conducted by a trainee clinical psychologist. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask the researcher if there is anything that is not clear or if you would like more information. Thank you for reading this.

#### **Why am I being asked to take part?**

The aim of this research study is to ask people about their experiences of attending family therapy services for people with learning disabilities. By asking family members and people with learning disabilities themselves to tell us what they thought about this type of therapy, it is hoped that we can understand more about what is helpful to them. This information can then be used to help services make sure that what is offered fits with what families want and what they find useful.

#### **What will I have to do?**

The research project hopes to ask a sample of around 15 families to tell us about what it is like to participate in family therapy. Only people who are able to give consent and sign a consent form will be contacted. If you choose to take part in the study your family will be asked to participate in an interview inviting you to think about the therapy and how it compares to other help you may have received in the past. It is not necessary for everyone in the family to be interviewed to take part in the study. The interview lasts about an hour. It will be tape recorded and all family members who want to take part can choose to be interviewed either together or individually.

This study will also offer people with learning disabilities, if they wish, the opportunity to participate in their own interview. This will take about 30 minutes and the researcher will invite them to share their experiences of being part of family therapy and of receiving help in this way. It will also be possible for participants who have learning disabilities to have another person from outside of the family (e.g. a friend or keyworker) attend the interview if they prefer.

The researcher is independent and does **not** work for the *Name of Family Therapy Service.* Anything that participants say in the interviews will remain confidential to the participant and the researcher. However, if the researcher was told anything that indicated risk of serious harm to either the participant themselves or anyone else, this information may have to be shared with the appropriate agencies.

The researcher is able to visit you at home. If you prefer an alternative location can be arranged.

If after talking to the researcher you feel you want to talk to someone further about any of the issues you discussed, the researcher will be happy to arrange this.

**What will happen if I do not want to take part?**

Involvement in the study is voluntary and if you do not want to take part it will not affect the services or support you are offered. Similarly, if you initially agree to participate but then decide you no longer wish to be involved, this will not affect the support you are offered by your local services in any way.

**What happens to the findings?**

The views of individual service users will not be fed back to the team at the *Name of Family Therapy Service*. All names will be kept confidential and the information people share in the interviews will be anonymised. The results from all the families who take part will be put together and reported as a whole according to particular issues and key points that have emerged from all the interviews. The aim is to help those who provide services have a clearer understanding of how service users view the help that is offered and what could be done to make it more useful. I will write a summary report for all families and services to read and one for publication in an academic journal.

**Where can I find out more information?**

By contacting Laura Arkless (Trainee Clinical Psychologist) on Tel: (leave a message and Laura will get back to you), or by e-mail:

Alternatively if you fill in and **return the reply slip in the pre paid envelope**, Laura Arkless will contact you.

**Complaints**

If you wish to make a complaint about any aspect of the study or the way it has been conducted please telephone Clinical Psychologist at University College London on

**Indemnity**

The researcher is a student at University College London (UCL) and the study is therefore covered by the UCL indemnity policy which includes any inadvertent disclosure and breach of confidentiality.

**Thank you for taking the time to read this and I very much hope to hear from you**

**Laura Arkless**

**Trainee Clinical Psychologist**

## **Appendix**

### **3. Adults with learning disabilities initial letter**

Dear Service User

My name is Laura. I am from a college in London

I am doing a study. I want to hear people's views about what it is like to go to family therapy meetings for help when they feel sad or upset.

This will help services to know what people think about the meetings.

Do you want to help me do this?

I will come and talk to you and your family about what it was like to go to family therapy meetings.

You can choose to meet with me on your own, with other members of you family or someone else, for example a keyworker. If you want to stop at any time, just tell me and we will stop.

The questions I will ask are not a test and there are no right or wrong answers.

You will not get into trouble if you do not want to talk to me.

If you would like to know more you can phone me, or you can get someone to phone for you, on:

From  
Laura

## **Appendix**

### **4. Carer initial letter**

Dear Carer

I am currently training as a clinical psychologist at University College London. For my final year dissertation, I am conducting some research on what it is like for people with learning disabilities and their families to attend family therapy meetings.

The study involves talking to families about their experiences of receiving this type of help. I am contacting people with learning disabilities and their family members, who have used the

for family meetings at

some point over the last three years.

This letter has been forwarded by the team at the

. I have enclosed two information sheets about the study, which also discuss confidentiality, consent issues and how the findings from the research will be used. One of these sheets is a simpler version that is easier to understand.

I would be very grateful if you would talk to the person in your care who these letters have been sent to, about whether they would like to take part in the study. Please could you also go through the information sheet with them. Please note, even if this person does not want to take part, I am still keen to talk to any other family members about their views and experiences of therapy.

Although I am conducting research with the service I do not work for them and any views people share with me will be kept private from the team.

If the person in your care to whom this letter has been sent is interested in participating please could you assist them to either return the reply slip in

the prepaid envelope to me at the above address, or e-mail me at  
or leave a message on

I will then get in touch with to answer any questions they or you may have  
about the study.

I have also sent letters to the family members of the person in your care.  
If the whole family wants to take part in the study I can meet them all  
together or I can come to meet the person in your care individually,  
whichever they prefer.

At these meetings I will complete the consent forms and if they prefer we  
can conduct the interview on that day. Alternatively I will arrange another  
time that is more convenient.

Please do not hesitate to get in touch if you have any questions. Meanwhile I  
look forward to hearing from you soon.

Many thanks  
Yours faithfully

Laura Arkless  
Trainee Clinical Psychologist

Please see reply slip on next page.

## **Appendix**

### **5. MREC ethical approval letter**

**- Chairman**

**- Vice Chairman**

**Eastern MREC**

All correspondence to:

Papworth Hospital NHS Trust  
Papworth Everard, Cambridge, CB3 8RE  
Tel:  
Fax  
Email:

Our ref: catD03/035077/cadec03

11<sup>th</sup> December 2003.

Miss L Arkless  
Sub Dept of Clinical Health Psychology

Dear Miss Arkless

**MREC no: 03/5/077**

**Proposal Title: talking to people with learning disabilities and their families about the experience of systemic therapy.**

**Applicants ref no: L.Arkless**

**USE YOUR MREC REFERENCE ON ALL CORRESPONDENCE AND QUOTE IT WHEN MAKING TELEPHONE ENQUIRIES**

The Chairman and lead members agreed that there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you our approval on the understanding that you will follow the conditions of approval set down below. A record of the review undertaken by the MREC is contained in the attached MREC response form. The project must be started within three years of the date on which MREC approval is given.

While undertaking the review of your application the MREC noted the research involves the establishment of a new disease or patient database for research purposes/the use of an existing database collected for previous research or other purposes with subsequent patient contact. **For this reason you are asked to read carefully the sections concerning LREC involvement and local NHS management set out below as there are specific requirement involved when undertaking such research.**

#### **MREC Conditions of Approval.**

- The protocol approved by the MREC is followed and any changes to the protocol are undertaken only after MREC approval.
- If projects are approved before funding is received, the MREC must see, and approve any major changes made by the funding body. The MREC would expect to see a copy of the final questionnaire before it is used.
- You must complete and return to the MREC the annual report form (progress of study) that is enclosed, and the final report form when your research is completed. (use the progress of study report form for the annual and final report).
  - You must promptly inform the MREC of:
    - (i) any changes that increase the risk to subjects and/or affect significantly the conduct of the research;

- (ii) any new information that may affect adversely the safety or welfare of the subjects or the conduct of the trial.
- You must complete and return to the MREC the enclosed annual review form once a year, and when your research is completed.

### **LREC involvement**

When undertaking the review of your project the MREC observed that there is/ limited patient contact by a local clinician who is performing technical procedures or additional data collection as described in the MREC approved protocol/ initial contact by a local clinician for purposes of recruitment. It is felt that these tasks appear well within his/her routine professional competence and adequate facilities for such procedure are available as part of his/her normal professional practice.

For this reason you are asked to only inform the appropriate LREC of the project by sending a copy of this letter and also **giving the name and contact details of the local clinician involved**. If (unusually) the LREC has any reason to doubt that the local clinician is competent to carry out the tasks required, it will inform the clinician and the MREC that gave ethical approval giving full reasons.

You are not required to wait for confirmation from the LREC before starting your research.

### **Local NHS Management**

The local clinician must inform his/her NHS organisation of their co-operation in the research project and the nature of their involvement. Care should be taken to ensure with the NHS organisation that local indemnity arrangements are adequate.

### **Legal and Regulatory Requirements**

It remains your responsibility to ensure in the subsequent collection, storage or use of data or research sample you are not contravening the legal or regulatory requirements of any part of the UK in which the research material is collected, stored or used. If data is transferred outside the UK you should be aware of the requirements of the Data Protection Act 1998.

### **ICH GCP Compliance**

The MRECs are fully compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH GCP) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Standing Orders and Statement of Compliance are available with the application form and guidelines for researchers and on the Internet at [www.corec.org.uk](http://www.corec.org.uk).

Yours sincerely

MREC,

Enc. Response form  
Progress of study form

## **Appendix**

### **6. Family interview schedule**

## **Family Interview Schedule**

### **Introduction to interview**

The following information was explained to participants at the start of the interview:

“I am interested to hear about your family’s experience of attending meetings with [psychologist]. It does not matter if you find it hard to remember some details of the meetings as it is your views that I am interested in, not an exact memory of every meeting you had.”

### **Information Questions**

How long ago did you attend meetings with [psychologist]?

Who went to the meetings with you?

Did they all come to every meeting?

Whose idea was it that X attended? (*Ask each person*)

*For each person: Do you think that it was helpful or unhelpful that X came?  
Why?*

### **Demographic information**

Can you tell me who is in the family? Who lives at home?

### **Relationship to help**

Can you tell me a bit about what led to you meeting with [psychologist]?

*Was X or anyone else in the family having a difficult time or need anything?*

Before you went to the meetings, what were you expecting to get from them? [ask all]

*What do you think X was expecting?*

Have you had any other kinds of therapy in the past?

*Was it for similar issues that you took to the meetings with [psychologist]?  
In what ways was it helpful/unhelpful?*

### **View of the problem**

What do you think led to....(the difficulties)? Ask each person

*Where did your idea about...come from?*

How do you think (other family members, person with learning disabilities) understood the difficulties?

How do you think [psychologist] saw the difficulties?

*What did you think about their view?*

*If disagree, did they feel able to say so? If said something what happened, what was it like?*

Did you feel [psychologist] listened to your ideas?

*Understood them?*

*If no, did they feel able to say so, why not etc*

Did you feel that the therapist understood what your views were about the problem?

*And how you felt about it?*

## **Process/techniques of therapy**

Before you attended the first meeting what had you been told about what was going to happen in the meetings?

*Who told you?*

*What were you told?*

*How helpful/unhelpful was this?*

At the first meeting were you told how the team worked?

Can you tell me a bit about what you remember happened in the meetings?

*Can you tell me a bit about what sticks in your mind about the way they talked with you and X... [family members]*

*If the interviewees talk about impact of particular techniques ask:*

*When they did... [technique] did it make any difference to the way you*

*Felt about... [issue, relationship]*

*See yourself [e.g. as a parent, mother, young man]*

*See your family and the way are/ get on with each other*

*The way that you approached/ reacted to/did things*

## **Co-creating focus at beginning of therapy**

At the first meetings did you talk with [psychologist] about what you were going to focus on?

*How was this decided?*

*How did you find it?*

### Circular questions

What did you notice about the questions they asked?

*At the time did you think there was anything helpful about the questions/unhelpful?*

*Looking back do you still see them like this or has your view changed in any way?*

### Positive Connotation

What did you think about the words [psychologist] used to describe your situation?

*Was there anything that sticks in you mind about the words they used?*

*What effect, if any did this have on you?*

*Did it make any difference in the way you or [person with learning disabilities] felt about the problem?*

### Focus on strengths and solutions

Did they pick up on good things about you and [person with learning disabilities]?

*For example good things about your relationship*

*Or things about you as a person*

*Or how you had solved problems in the past*

### Reflecting team

What was it like having more than 1 therapist?

*At the time did it seem helpful or unhelpful?*

*How was the reason for having more than one explained to you? Was this explanation helpful?*

### Tasks

Did they ask you to do or think about particular things in between meetings?

*What did you think about this?*

### Giving a message from the team

Sometimes therapists try and say a few sentences about an idea or way of looking at a family's situation, like a little phrase that people can keep in their head or think about.

Can you tell me a bit about any phrases or messages that stick in your mind?

*What difference if any did it make to...view of self, actions, relationships?*

### Seeking feedback throughout about process of therapy

Did [psychologist] ask you about how you thought the meetings were going/ about how useful you were finding them?

*Can you tell me a bit about that?*

### Letters to summarise ideas & thoughts

Did [psychologist] write letters to you about what you had talked about in the meetings?

*What did you think of the letters, were they helpful/unhelpful?*

What do you think [person with learning disabilities] made of the meetings?

*Before they came*

*At the time*

*Looking back*

Is there anything you think they could have done differently?

## **Changes**

To what extent did you get what you expected/wanted from the meetings?

Has anything changed?

*To the way you*

*Felt about...*

*See yourself*

*See your family and the way are/ get on with each other*

*The way that you approached/ reacted to/did things*

How, if at all, do you think your family benefited from attending the meetings?

*Who benefited the most, and why?*

*The least and why?*

How, if at all, do you think [person with learning disabilities] benefited from attending the meetings?

Did you notice any changes in .... [the problem]?

*For the worse/better?*

Do you have any ideas why things changed? Or why things didn't change?

*Who in the family would have a similar view?*

*Who has a different view?*

Do you think attending the meetings led to other changes in X's (person with learning disabilities) life, perhaps indirectly?

What, if any, effect do you think attending the sessions had on other areas of your family's life?

## **Service development**

What do you think could be done to improve the service that is offered to families?

Would you recommend this to other families who were experiencing problems?

Would you consider seeking help from them again in the future?

*If not why not?*

## **Process of interview**

What has it been like talking about this today?

How do you feel now after talking to me?

Do you have any questions you would like to ask me?

Is there anything else you would like to say?

## **Interview Schedule for participants with Learning Disabilities**

### **Introduction to interview**

The following information was explained to participants at the start of the interview:

“I would like to talk with you about what it was like to go and talk to [say name of therapist and show picture of therapist] at [say name of service and show picture of service]. Before we start I want to let you know that this is not a test and there are no right or wrong answers. It doesn't matter if you can't remember things. I am just interested to hear your views.”

### **Information Questions**

What is your name?

What things do you like doing?

Who lives with you? Who else is in your family?

Who was at the meetings with you?

*What did you think about [family members] being there?*

What was it like to go there?

### **Relationship to help & view of the problem**

What did you think you were going to see [therapist's name] for?

Whose idea was it to go?

Did you want help with anything?

Did your [family members] want help with anything?

### **Process/techniques of therapy**

Before you went to the meeting, did anyone tell you what was going to happen?

*What did you think was going to happen?*

What happened in the meetings?

Who talked the most/least?

What did you talk about?

How did you feel talking about these things?

Was there anything that was hard to understand?

*Did you let them know it was hard to understand?*

*How did you show them?*

*What did they do to help you understand?*

What did you like/dislike about the meetings?

Was there anything about the meetings that made you feel sad, angry or upset?

*Did anyone else get sad angry or upset?*

*How did you feel about that?*

Was there anything about the meetings that made you feel better?

*If the interviewees talk about impact of particular techniques ask:*

*What did you think when they did... [technique]?*

*How did it make you feel about yourself?*

*Your family?*

*About the things that you could do?*

Co-creating focus at beginning of therapy

What did you decide to talk about?

*Who decided?*

*What did you like talking about?*

*What didn't you like talking about?*

Circular questions

Do you remember who asked the questions?

*What kind of questions?*

*Were they short or long?*

*Were they a bit strange?*

*Were they easy or difficult?*

Positive Connotation

What did you think about the words [psychologist] used to describe your situation?

*Was there anything that sticks in you mind about the words they used?*

*What effect, if any did this have on you?*

*Did it make any difference in the way you or [person with learning disabilities] felt about the problem?*

### Reflecting team

What was it like having more than one person to help you and your family at the meetings?

*What do you think about the kinds of things they said?*

### **Changes**

Were the meetings helpful?

*If yes –In what ways were they helpful?*

*If no- Why not?*

### **Service development**

Is there anything they could do to make the meetings better?

### **Process of interview**

What has it been like talking to me today?

How do you feel now after talking?

Do you have any questions you would like to ask me?

Is there anything else you would like to say?

## **Appendix**

### **8. Therapists' questionnaire**

**Talking to people with learning disabilities and their families about the experience of systemic therapy.**

**Therapist Questionnaire**

Please complete this brief questionnaire about the systemic therapy provided to ..... and his/her family. It will provide helpful information that can be referred to in the interview with the family.

**Thank you very much for your help.**

**Context**

1. Brief summary of reason for referral/ presenting problems: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
2. Start of therapy (approximate month & year): \_\_\_\_\_
3. End of therapy (approximate month & year): \_\_\_\_\_
4. Total sessions attended & number of DNAs (approximate): \_\_\_\_\_
5. Who attended sessions? \_\_\_\_\_
6. Were all present at all sessions? \_\_\_\_\_  
If not, who attended most? \_\_\_\_\_  
Who attended least? \_\_\_\_\_
7. Where were sessions held? \_\_\_\_\_

**Approach**

**Please indicate the predominant theoretical orientation which guided your work with this family (if appropriate tick more than one)**

- ☐ Structural or strategic family therapy
- ☐ Post-Milan Systemic Therapy
- ☐ Brief Solution Focussed Therapy
- ☐ Social constructionism
- ☐ Narrative therapy
- ☐ Other (please describe briefly) \_\_\_\_\_

## **Technique**

**Please indicate the main techniques you used in your work with this family (tick as many as appropriate)**

- ☐ How many therapists were involved in sessions (on average)? If more than one how did you work together (please circle)?
  - Co-therapist/s
  - Reflecting Team (in the room or behind screen or video link- please circle)
- ☐ Co-creating a focus for the therapy at beginning
- ☐ Circular questioning
- ☐ Genograms (developed jointly with client/ family)
- ☐ Time lines (developed jointly with client/ family)
- ☐ Maps e.g. relationship to help/ services (developed jointly with client/ family)
- ☐ Positive connotation
- ☐ Focus on strengths and solutions
- ☐ Giving advice
- ☐ Giving a message from team
- ☐ Homework tasks for family
- ☐ Paradoxical interventions
- ☐ Seeking feedback throughout about process of therapy
- ☐ Seeking feedback throughout about progress/ change
- ☐ Letters to clients to summarise ideas/ thoughts
- ☐ Explicit discussion/ exploring of power differences in the therapeutic relationship, e.g. in relation to ability, gender, culture, religion

**Other techniques used:** \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Please return to:**

**e mail:**

**2**

**Appendix**

**9. Transcript example family**

Laura Arkless  
Family 4  
L: Interviewer  
P: Participant

1 Because at the end of the day [psychologist] said what do you think of the meetings and  
2 all that. I just said look at the end of the day, I think it is good but I would prefer it if X  
3 saw one on his own, because I think you'll probably have a lot more positive that we're  
4 getting. Because it feels like we are getting nowhere. We are sitting there together, then  
5 we go out the room, then we go home. Its like did we go somewhere? You know what I  
6 mean.

Prefer  
individual  
↓  
would enable  
more to be  
talked about

7  
8 Whereas if X went somewhere maybe he can say what he feels to a complete stranger  
9 which he does, better than he would with me or something.

10  
11 L: Where you are all kind of sitting together.

12  
13 P: Yes, where he can't say nothing in front of me. He doesn't want to say things in front  
14 of me, because he feels embarrassed and thinks I am going to laugh at him and sometimes  
15 I think I do, because I think it is all a joke.

hearing  
voice of  
puro

16  
17 L: So you said that maybe it would be a good idea for X to see someone on his own and  
18 they listened to that.

19  
20 P: Yes, they have given him another counsellor.

21  
22 L: What do you think that X thought about the meetings?

23  
24 P: I don't really know because we don't really talk about it.

25  
26 L: What would you guess?

27  
28 P: I think he gets something out of them. Not from our meetings, from his own meetings.  
29 I think that benefits him, by him going and talking about things. Because obviously he  
30 has got a lot in his head and he likes to talk about it.

more  
useful/  
beneficial  
to have  
individual  
meetings

31  
32 L: What do you think he makes of it sitting in the room with you and [psychologists]?

33  
34 P: I think he thinks it is just funny. I think he finds it funny and hilarious.

35  
36 L: Can you tell me a bit about what you mean?

37  
38 P: Well when he went to, he used to go to these meetings [another service]. He told me  
39 that he used to have to draw things, and I said what you aint drawn none today. Shouldn't  
40 they have got crayons out and drawn some pictures or something and X just laughed. I  
41 said maybe we'll talk about the family tree again and watch it break and he just laughed.

42  
43 That's when I think if he doesn't take that seriously, he would rather take his own  
44 separate one more serious.

45  
46 L: What do you think he makes of the kind of questions that [psychologist] asked?

Laura Arkless  
Family 4  
L: Interviewer  
P: Participant

1  
2 P: I don't think he understands them, I don't think he really understands them to a point  
3 because he doesn't understand a lot. They [psychologists] come out with words that are,  
4 not technical, but are quite not understanding to him but to me they are. So he just sits  
5 down and when they ask him a question he just goes um...uuu...umm and doesn't know  
6 what to say.

hard  
not  
understanding

7 *know what to say*  
8 So at the end of the day I just think sometimes it is pointless.

9  
10 L: How what you want help for fit with what [psychologist] did.

11  
12 P: well it hasn't really helped a lot, because we are still where we are. We aint achieved  
13 nothing. It is just, I think it is just to be able to say something to someone else who is a  
14 complete stranger really.

15  
16 L: What do you think is helpful about that, being able to go and say something to a  
17 stranger?

18  
19 P: Well going back and saying to someone else, oh look this person has got this wrong in  
20 their life or something like that maybe. Maybe that is a good thing about it, you can say  
21 things to people and not, so it is like there is personal things that I have said to them, that  
22 what has happened [with family], and I felt like idiot. *Talks about what happened in*  
23 *family*

24  
25 L: Can you tell me anything you think they [psychologists] could have done differently?

26  
27 P: Maybe, in our situation it would have been better if we had singles. Have counselling  
28 for single sessions instead of having one and maybe progressing with that by having a  
29 family one. From that, then decide from there if you need to be a family. Not as a family  
30 and then go from whatever it is on his own.

preference  
for individual  
therapy.

31  
32 We should have been like that, been diagnosed as a point of maybe you need to, them two  
33 counsellors need to get together and say yeah, yeah, I think they need to get their  
34 priorities together. So then they could go from that and join up and say what one is doing  
35 and join them up, to get sort of an essay of questions. Like what you have got, of  
36 questions that won't confuse them but will, may get to the point of putting them two  
37 together and being them a lot more of a family. Because it looks like you put them in a  
38 room together and its like putting two nutters in a room and fighting each other. They  
39 probably need to basically separate them and have their own say, because people no  
40 matter who you are, won't say truth to everything in the room with the other person. So  
41 you need to have your separation to discuss with that person whatever it is. Then both  
42 counsellors can actually get together and talk about the problem and say maybe we need  
43 to do this, because this one says this and this one says this. As long as both parties agree  
44 on them discussing the files together to sort the problem they have got out, because that is  
45 the only way they are going to be able to do it.

confrontation  
watch what  
you say  
in front  
of other

46  
*that won't say the truth  
in front of the other person  
as needing to talk  
each other about what  
is in individual sessions  
work out what to*

## **Appendix**

### **10. Transcript example adults with learning disabilities**

- 1  
2 Interviewee begins to look sad at this point in interview. Decided not to ask further on  
3 this to avoid upsetting them further.  
4  
5 L: So thinking about the way that [psychologists] worked in the room. Did they have a  
6 conversation that you listened to.  
7  
8 P: Oh yeah. At the end of the meetings. They would talk, 'oh really so he had [activity  
9 participant had been involved with for a number of years, that demonstrated some of his  
10 strengths]'. They [psychologists] were also talking about how close they [participant and  
11 Mother] are together, that is what really impressed us. *Picking up on positives*  
12  
13 L: So they had a conversation that you listened in to and it sounds like in that  
14 conversation they picked up on some nice things about you and your Mum. I suppose, the  
15 things that you have done in the past, your successes.  
16  
17 P: That's right.  
18  
19 L: What was that like for you to hear that?  
20  
21 P: It's a good feeling.  
22  
23 L: Can you describe it?  
24  
25 P: It was you know, happy emotion. People who didn't know us were actually saying,  
26 you know, these nice things about us. *narrative: thickening things being noticed by others*  
27  
28 L: Feeling that happy emotion and hearing those nice things. Did it make any difference  
29 to anything you did?  
30  
31 P: I think I became more positive. *different perspectives*  
32  
33 L: And if you are more positive how was that shown in things that you do or the way that  
34 you see things?  
35  
36 P: well, how can I put this. Lets put it this way, there was a meeting I went to in [local  
37 place, about local council cuts and closure of voluntary organisations]. This [name], tried  
38 to cut me off and I went 'I have not finished yet', and I felt more confident, not only  
39 because of [CTLD], but also because of [voluntary organisation interviewee attends].  
40 You know, it made me feel confident.  
41  
42 This is a place where there are actually worse people off than me [voluntary  
43 organisation], who have learning difficulties, can't speak properly. Some are dyslexic you  
44 know. My friend [name] said, they are going to be thrown onto the streets once they close  
45 this place down.  
46

1 L: So you went to [CTLD] and you have had quite a bit of experience of the kind of  
2 things they do there now. If you had to kind of, think about it, do they do things any  
3 differently to how the other people that you have been bounced around have done things?

4

5 P: Well I have never had a freedom pass before.

6

7 L: So the freedom pass was a new thing. Was there anything else they did that was  
8 different or new?

9

10 P: The two of us going to therapy, which to me its wonderful. Mum thinks it is great that  
11 we actually go. She thinks it has been the best thing.

*value going together*

12

13 L: So that is what you think your Mum's view is, what about you?

14

15 P: I think that basically that is my view as well. We both feel the same.

16

17 L: So you both seem to have found it really positive. Thinking about the first meeting  
18 where you had [psychologists], you and your Mum. You said that [psychologist] had  
19 explained a little bit, that there was going to be two of them [psychologists]. Was that  
20 helpful that she explained that?

21

22 P: Yes.

23

24 L: Did you know what to expect when you went into that first meeting or was it still a bit  
25 weird?

26

27 P: Well it was weird, it was different. There was two of us and two of them. They didn't  
28 know us from Adam and we didn't know them from Adam.

*experience  
of  
therapy  
team set  
up*

29

30 L: How did that make you feel?

31

32 P: It made me feel nervous for a while. I think my Mum said it. The first time she wasn't  
33 too sure about [psychologist]. But the second time we came, it was something that he said  
34 to my Mum that I can't remember that, the second time we went made her relax more.

35

36 L: So it took a bit of time to feel comfortable. Do you think that having two of them  
37 [psychologists] made it any more difficult to talk openly, or easier to talk openly?

38

39 P: It was easier actually.

40

41 L: Can you tell me a bit about how it made it easier?

42

43 P: Yes. Basically it was easier to talk about my Father. Me and my Mum agree about him  
44 not being the best Father. We know that and it hurt. When she had her one to one,  
45 because she had one to one some time ago. It hurt her telling somebody she didn't know  
46 about my father.

*enabled  
talking  
about  
painful  
things*

**Appendix**

**11. Emerging themes example family**

## Family7

### Summary of emerging themes

|  |            |  |
|--|------------|--|
|  | under me.* |  |
|--|------------|--|

#### Views on reflecting team

|                                                                                                                                               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                   |
|-----------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------|
| ② Explanation given for having two therapists                                                                                                 | [psychologist] did the talking and he explained that [other psychologist] would do the listening and take notes. And that he would do the talking and then they went away. I thought it was very well set up.*                                                                                                                                                                                                                                                                                                                     | F7,P4, L16                                        |
| Co-therapist not seen as contributing very much                                                                                               | [psychologist/co-therapist], didn't really do anything.<br><br>She was very much in the background. She was just writing notes. So she didn't distract me at all.                                                                                                                                                                                                                                                                                                                                                                  | F7,P10, L2<br><br>F7,P10, L2                      |
| Value of having variety in therapy team eg, gender of therapists                                                                              | They went away and they discussed their impressions they both got and he quite often said 'I didn't pick up on this, but [other psychologist] noticed' you know. Certain things that a woman does pick up on about my relationship in the home with X that men maybe wouldn't notice so dramatically as maybe a woman would.*                                                                                                                                                                                                      | F7,P4, L18                                        |
| Two therapists                                                                                                                                | It wasn't intimidating it was strange*                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | F7,P3, L42                                        |
| Impact of feedback after team took break for reflections enabled thinking and conversations around issues to continue outside of the therapy. | they sort of did a summary a précis of what had gone on in the room.<br><br>Our feelings, you know, our thoughts, was presented to us in a concise way. So that as we left, going home, waiting for the bus, we could discuss what they had said, what we thought about it and what we were going to do, from there.<br><br>strategies were suggested in these feedbacks. Strategies were worked out, we worked out some, they worked out some, you know and then we amalgamated them when we came home and tried to work on them. | F7,P10, L37<br><br>F7,P10, L39<br><br>F7,P10, L42 |
| Mum's experience of feedback after the break                                                                                                  | It was fascinating actually.*                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | F7,P4, L31                                        |

Family7  
Summary of emerging themes

**Therapists seen as wanting to help**

|                                                                                      |                                                                                                                                                                                                                                                                                                                                 |            |
|--------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------|
| ② Liking your therapist as a person                                                  | At first I found [psychologist] a bit; I thought [psychologist was] very serious and very, slightly formidable. But as I got to know [psychologist] I realised that this was just [their] front, you know [their] face and I realised that [psychologist] wasn't a bit like that underneath. They were both very nice people. * | F7,P4, L35 |
| What enabled client to be open – feeling safe, seeing therapists as wanting to help. | I am pretty forthright, by nature, but first of all I thought they created a very safe place. I got the feeling that they really had our interests at heart. So that enabled me to say anything, you know. *                                                                                                                    | F7,P9, L32 |

**Long term problems**

|                                                              |                                                                                                   |           |
|--------------------------------------------------------------|---------------------------------------------------------------------------------------------------|-----------|
| ① Issues brought to therapy have been around for a long time | its always been there basically. For me it has always been my inability to accept where he is at. | F7,P5, L1 |
|--------------------------------------------------------------|---------------------------------------------------------------------------------------------------|-----------|

**Positive outcomes**

|                                                             |                                                                                                                                       |            |
|-------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------|------------|
| ② Therapy has helped X to use strategies for handling anger | What the therapy has done is given X some strategies for handling his anger.                                                          | F7,P7, L40 |
| How X's relationship with anger has changed                 | It used to be with him all the time.                                                                                                  | F7,P7, L40 |
|                                                             | It used to be constant but now it's only occasionally. *                                                                              | F7,P7, L42 |
|                                                             | The other day he started an argument about something                                                                                  | F7,P7, L42 |
|                                                             | Finally he went into his room                                                                                                         | F7,P7, L46 |
|                                                             | So we were talking yesterday about it and he said, yes but you did notice Mum I did go into my room and think. * (use with one below) | F7,P8, L1  |
|                                                             | that is one of the strategies we discussed with [psychologist], the way we were going                                                 | F7,P8, L2  |

## Family7

### Summary of emerging themes

|                                                                                                                                                     |                                                                                                                                                                                                                                                                                                                       |                                       |
|-----------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------|
|                                                                                                                                                     | to handle these rows, what was going to happen. We were going to try and back away a bit. *                                                                                                                                                                                                                           |                                       |
| Benefits for X – life cycle is moving through transition perhaps more than it was pre-therapy as he has an aim, a focus                             | <p>X Has clarified since we started going, what he want to do. He now has an aim in life. Whether he achieves it or not is irrelevant. The fact is its important to have an aim. *</p> <p>He is focussed finally. I think it was going to the therapy has helped him sort out what he wants to do with his life.*</p> | <p>F7,P15, L12</p> <p>F7,P15, L19</p> |
| Benefits for Mum – for her moving through/ grieving loss of hoped for retirement                                                                    | <p>The point is that when I think of what my plans were for retirement they weren't this.</p> <p>I'm more philosophical about my life.</p>                                                                                                                                                                            | <p>F7,P15, L26</p> <p>F7,P15, L38</p> |
| Therapy as helping to be in a position of balanced perspective- balance between the sadness at what you wanted and happiness for what you have got? | It has made me a little more optimistic and hopeful. It helps me to retain a sense of balance.*                                                                                                                                                                                                                       | F7,P15, L25                           |

### Gaining recognition

|                                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |                                     |
|------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|
| Therapists picked up on strengths about their relationship | <p>Actually [psychologist] did say that they were both very impressed by our relationship. How open it was and how affectionate it was. They thought that considering our history it was quite remarkable that we are both still able to relate to each other in extremely friendly ways.</p> <p>They were congratulatory about the work I had done with X and as I have said the relationship we have. They said that it was quite exceptional, quite unusual for people to be so open.</p> | <p>F7,P8, L11</p> <p>F7,P9, L16</p> |
|------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|

### Different perspectives

|                                                      |                                                                      |            |
|------------------------------------------------------|----------------------------------------------------------------------|------------|
| Client felt pwld and herself were treated equally by | He treated us equally, you know, as equally important. I liked that. | F7,P10, L6 |
|------------------------------------------------------|----------------------------------------------------------------------|------------|

## **Appendix**

### **12. Emerging themes example adults with learning disabilities**

### The room

|                  |                                                                                                                                                                                |              |
|------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|
| Physical setting | <p>P: It was too hot, because I get hot.</p> <p>L: Just thinking about things that you think they could do to make that room better//</p> <p>P: They should have a window.</p> | PLD4, P2, L9 |
|------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|

### Who's idea?

*Need to quote from*

|                            |                                                                                                                                                  |               |
|----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------|---------------|
| How go to systemic therapy | <p>L: When the staff had the idea that you should go, what did you think about that?</p> <p>P: I didn't mind, because we were arguing a lot.</p> | PLD4, P3, L11 |
|----------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------|---------------|

### Pwld experience

|                                                    |                                                                                                                                                                                                                                    |               |
|----------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------|
| Number of people in meetings made her feel nervous | <p>L: Can you remember back to before you went to the first meeting, how you felt about going//</p> <p>P: Nervous, nervous.</p> <p>L: What do you think it was about it that made you nervous?</p> <p>P: There was four of us.</p> | PLD4, P3, L38 |
|----------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------|

### Coping with nerves in meetings

|                 |                                                                                     |               |
|-----------------|-------------------------------------------------------------------------------------|---------------|
| Managing nerves | <p>What do you think helped that to go away?</p> <p>P: I didn't think about it.</p> | PLD4, P4, L17 |
|-----------------|-------------------------------------------------------------------------------------|---------------|

### Experience of team

|                                              |                                                                                                                                                                                                                                                                                                                 |              |
|----------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|
| Unexpected number of people increased nerves | <p>L: So you expected that there was going to be//</p> <p>P: One. I didn't think there was going to be two.</p> <p>L: So what was that like when you walked in and there was two of them sitting in there?</p> <p>P: I was nervous.</p> <p>L: How did that make your nervousness feel?</p> <p>P: Came back.</p> | PLD4, P5, L1 |
|----------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|

### Voice of pwld: Keeping quiet

|                                    |                                                                                                                                                                                                                                                                |               |
|------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------|
| Not talking                        | <p>P: I didn't say nothing. My ex-boyfriend did it all, the talking.</p> <p>L: He did all the talking and you didn't say anything at all. How come you kept quiet?</p> <p>P: That's how I am. I don't really like, I can't say, didn't say anything.</p>       | PLD4, P6, L21 |
| Powerless: dis-ables voice of pwld | <p>P: [partner] punched me and hit me round the face. That's why I think kept quiet in the meetings.</p> <p>L: You kept quiet because of him hitting you? Can you tell me a little bit more about what you mean?</p> <p>P: He wouldn't let me tell anyone.</p> | PLD4, P7, L11 |

*disempower*

## **Appendix**

### **13. Master themes examples family**

## **2. Value of Therapy**

### **2.1 Changes**

#### **Positive outcome**

|                                                  |                                                                                                                                                                                                  |             |
|--------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------|
| Therapy tangible benefit for pwld not really Mum | Not really to me. It was helpful for X.                                                                                                                                                          | F5, P4, L45 |
|                                                  | Well they got him into where he wanted to go. He knew he was just round the corner from here. Mind you it wasn't them that got X in there, but they helped, you know. Never done nothing for me. | F5, P5, L4  |
| Value of talking                                 | I said it was good to talk to somebody. It was really good                                                                                                                                       | F5, P7, L44 |

#### **Gaining recognition**

|                                              |                                                                                                                                                 |             |
|----------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|-------------|
| Picked up on things about their relationship | [therapist] did say that X and I get on very well together and we seem to think alike.                                                          | F5, P6, L38 |
|                                              | I think the way I spoke and X kept telling them he loved me. I think that is where [therapist] got it from. She said you're very close you two. | F5, P7, L1  |

#### **Seeing things more clearly**

|                                                                          |                                                                                                                                                               |              |
|--------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|
| Parents have moved to position of awareness of stuckness – over cautious | was probably being over cautious in a sense. Perhaps the psychologists have probably in the way they have been speaking to us, we probably realised that now. | F1, P18, L24 |
|                                                                          | That we were sort of trying to look after her too much and trying to keep her to ourselves.                                                                   | F1, P18, L26 |
| Through therapy they found a different approach.                         | It wouldn't have happened without [the psychologists]. I don't think we would have approached it in the same way.                                             | F1, P18, L40 |

#### **Leaving feelings**

|                            |                                      |              |
|----------------------------|--------------------------------------|--------------|
| Benefit is in way feel not | It's good. But a lot of points but X | F10, P3, L33 |
|----------------------------|--------------------------------------|--------------|

Family master themes with quotes

|                              |                                                                                                                                                               |              |
|------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|
| change in problems with pwld | never change, you understand. Just like you go in, feeling better, it's very nice<br><br>Feeling better, feeling is good. I leave feeling like that you know. | F10, P7, L21 |
| Express negative emotions    | Hurting feelings has come out in front them, that time it is alright.                                                                                         | F10, P3, L36 |

**No benefits**

|                                                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |              |
|---------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|
| Counselling doesn't help with practical care/support wants for pwld | it is useful, but it is like I don't get no benefits from it. As a point of, I haven't got a problem. The problem is just life in general. It is too much responsibility on my back. I need help with other authorities that should be looking after X, be involved. I said me personally I haven't got a problem with that. I like to go and have a life, but its hard knowing full well no-one else is there to help X. Its like there is only so much you can do. | F4, P10, L7  |
| No change                                                           | It hasn't changed me from day one being there. It hasn't given me confidence with anything, because I have not changed at all. Nothing has changed between anything.                                                                                                                                                                                                                                                                                                 | F4, P10, L25 |
| Going together not introducing possibilities                        | We are sitting there together, then we go out the room, then we go home. Its like did we go somewhere?                                                                                                                                                                                                                                                                                                                                                               | F4, P11, L4  |
| No change in symptoms                                               | he has not changed at all because he still suffers with the [psychological problems], and loads of things that hasn't changed him at all.                                                                                                                                                                                                                                                                                                                            | F4, P13, L31 |

**Nothing gained**

|                                                                                            |                                                                                                                                                                                  |             |
|--------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------|
| Therapy wasn't helpful as it didn't give them anything: new information, advice, progress. | we'd be there at the [family therapy] meeting maybe, what one hour, and you'd come out and think I am none the wiser. I don't feel as though I have achieved anything. You know. | F6, P6, L10 |
| Not wanting more meetings                                                                  | Now there is offers of more meetings, I am, sort of, well what is the point.                                                                                                     | F6, P6, L26 |

Family master themes with quotes

|                                               |                                                                                                                                                        |              |
|-----------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|
|                                               | I'm, you know pretty neutral about going to any further meetings. I thought, what have I achieved going to the meetings? What have I gained? You know. | F6, P6, L43  |
| Wanting a particular kind of help: Practical? | Nothing to help her out or anything, just to talk about her sort of thing                                                                              | F6, P10, L30 |

**Positive Outcomes**

|                                 |                                       |              |
|---------------------------------|---------------------------------------|--------------|
| Benefit of meetings: to move on | They give me more willpower to go on. | F3, P16, L42 |
|---------------------------------|---------------------------------------|--------------|

**Own strength and resources**

|                                                                                              |                                                                                                                                                 |             |
|----------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|-------------|
| Own strength would see her through without therapy (learned over many years without support) | Though I would have done things on my own, because I am one of these people that anything I put me mind to, I do it. With help or without help. | F3, P17, L1 |
|----------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|-------------|

**Gaining recognition**

|                                                         |                                                                                                                                                                                                                                                                                                                                                                                                                    |                                  |
|---------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------|
| Validating, Listening, constructive                     | Well it was helpful because somebody is there, listen to what you have to say or what you are saying, and then comes up with something to say, well I think you are doing the right thing, or you are in your frame of mind that you can sit down and say things like that, because you could be thinking different things and he would come up with something constructive to say, or plan what you are planning. | F3, P8, L20                      |
| Validating                                              | those are things I think about before he said them.<br><br>show that somebody else think like he is on your same wavelength. Thinking the same thing you are thinking.                                                                                                                                                                                                                                             | F3, P11, L28<br><br>F3, P11, L33 |
| Drawing on own strengths; more sure to go with her view | I think about those things for myself.                                                                                                                                                                                                                                                                                                                                                                             | F3, P12, L6                      |

## **Appendix**

### **14. Master themes examples adults with learning disabilities**

|  |                                                                                                                                                                 |               |
|--|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------|
|  | <p>P: Yes.</p> <p>L: When the staff had the idea that you should go, what did you think about that?</p> <p>P: I didn't mind, because we were arguing a lot.</p> | PLD4, P3, L11 |
|--|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------|

## 1.2 What am I here for?

|                                                     |                                                                                                                                                                                                                            |                  |
|-----------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------|
| The problem in their relationship: anger, arguments | Pa: Me. We had a few problems, me and [partner]. We was falling out. So she hitting me and that.                                                                                                                           | PLD6&7, P5, L14  |
|                                                     | Pa: I just want to [pb] get involved, problems with living basically. I wanted [psychologist] to help us out. Sort it all out.                                                                                             | PLD 6&7, P6,L24  |
|                                                     | Pb: Well. I like to help us. Me and [pa] our problem.                                                                                                                                                                      | PLD 6&7, P6, L43 |
| Sees meetings as for talking                        | [psychologist] told me basically. We knew that we were going to a, to talk. She was going to talk to me and my mum. We knew, because she told me when I went to the one to one.                                            | PLD2, P4, L38    |
| Understanding purpose of meetings                   | To talk about things.                                                                                                                                                                                                      | PLD3, P3, L5     |
| Sees family member as wanting to get help for pwld  | <p>What about [relative], did [they] want help with anything, or did [they] want to talk about anything in particular, do you think?</p> <p>P: Yes.</p> <p>L: what kinds of things was [relative] going to talk about?</p> | PLD3, P6, L14    |

|                                                |                                                                                                                                                                                                                                                                                                                                                        |                                                   |
|------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------|
|                                                | Like to get some help like for me.                                                                                                                                                                                                                                                                                                                     | PLD3, P6, L21                                     |
| View of reason for referral                    | P: On, my behaviour.                                                                                                                                                                                                                                                                                                                                   | PLD5, P10, L9                                     |
| Wanted practical help                          | Budgeting.<br>Shopping.<br>and cooking, because I don't like gas cookers. I hate them.                                                                                                                                                                                                                                                                 | PLD5, P10, L23<br>PLD5, P11, L6<br>PLD5, P11, L10 |
| Thinks Mum wanted her to get practical help    | She wants me to help. Cooking, like working on gas cookers and budgeting and shopping                                                                                                                                                                                                                                                                  | PLD5, P11, L21                                    |
| What LD team can offer                         | They could get me therapy, you know talking one to one. They could get me independent living, they could get me a freedom pass.<br><br>I thought, yes why not, because it was another way of getting as I said independent living.                                                                                                                     | PLD2, P7, L15<br><br>PLD2, P7, L23                |
| Wanted help with                               | Getting depressed.<br><br>That's when I started getting panicky.                                                                                                                                                                                                                                                                                       | PLD3, P6, L7<br><br>PLD3, P10, L41                |
| Wanted help with relationships in wider system | L: were there any other things that you wanted to talk about or wanted help with at that time.<br><br>P: Like about [social worker] or something.<br><br>L: What was it with [social worker] that you wanted help with?<br><br>P: Like just to talk about things.<br><br>L: What kind of things?<br><br>P: Like, I found it hard with [social worker]. | PLD3, P8, L27                                     |

|                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |                  |
|---------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------|
|                                 | <p>Pa: I felt upset about my family</p> <p>L: The stuff about your family?</p> <p>Pa: I lost half my family. I was upset for that, but I spoke about that.</p> <p>Pa: We just talked about her [pb's] temper, about the anger what she is having. What she is having in her past with her family. Her family. We just wanted to try and help her get over it.</p>                                                                                                                                                                                                                                                                   | PLD6&7, P12, L1  |
| Hard to see each other upset    | <p>Pa: Alright, but can I say one thing. Some meetings [pb] had a cry didn't you. Some meetings she has been crying.</p> <p>L: Can I ask you a little bit about that [pa]. About what it was like for you in the meeting when [pb] was crying. How did you find that?</p> <p>Pa: Really hard.</p> <p>L: Do you think that seeing [pb] cry like that and her getting upset, do you think that was a bad thing or do you think there were goods things about it?</p> <p>Pa: Because [therapist] stopped meetings, get [pb] some water and some hankies.</p> <p>L: and what did you think of that?</p> <p>Pa: It was a good thing.</p> | PLD6&7, P16, L44 |
| Hard to hear some things        | <p>there was some bits was upsetting, what is my Mum been saying.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | PLD5, P6, L16    |
| Upset about argument in meeting | <p>P: She shouts when, say if someone is blaming something on her. She's</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | PLD5, P8, L36    |

|                                               |                                                                                                                                                                                                                                                                                |                                           |
|-----------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------|
|                                               | <p>either getting upset, or she shouts. Then it's starting to get into an argument.</p> <p>L: Did that happen in the meeting?</p> <p>P: It happened once in the meeting.</p> <p>P: I just got upset.</p>                                                                       | PLD5, P9, L4                              |
| Experience of therapy initially               | <p>it was weird, it was different. There was two of us and two of them. They didn't know us from Adam and we didn't know them from Adam.</p> <p>It made me feel nervous for a while.</p>                                                                                       | <p>PLD2, P8, L27</p> <p>PLD2, P8, L32</p> |
| Hard to hear some things                      | <p>there was some bits was upsetting, what is my Mum been saying.</p>                                                                                                                                                                                                          | PLD5, P6, L16                             |
| Upset about argument in meeting               | <p>P: She shouts when, say if someone is blaming something on her. She's either getting upset, or she shouts. Then it's starting to get into an argument.</p> <p>L: Did that happen in the meeting?</p> <p>P: It happened once in the meeting.</p> <p>P: I just got upset.</p> | <p>PLD5, P8, L36</p> <p>PLD5, P9, L4</p>  |
| Feelings about going to meetings              | <p>I was nervous.</p>                                                                                                                                                                                                                                                          | PLD3, P3, L16                             |
| A stressful situation                         | <p>It was a bit difficult.</p>                                                                                                                                                                                                                                                 | PLD3, P14, L22                            |
| Talking in meetings evoked difficult feelings | <p>It was a bit upsetting.</p> <p>To talk about some things.</p>                                                                                                                                                                                                               | <p>PLD3, P4, L5</p> <p>PLD3, P4, L9</p>   |