

Portfolio including Thesis

Volume 1 of 2

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Mothers with learning disabilities' experience of relationships with their parents, partners and friends:

An IPA study

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Discuss the possible effects of bereavement on the mental health of older people. Compare and contrast two approaches to working with older people who suffer mental health problems following bereavement.

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Ageing and an ageing population are not unique to modern times, but it is only in the last 100 years that the number of people reaching old age has substantially increased. The general cut off point, that is somewhat arbitrarily applied, in both research and clinical practise is 65. In the UK the figures provided by the Office of National Statistics (Social Trends, 1997) suggest that overall, the population over 65 has stabilised with an increasing number of adults in their 70s and 80s. Today, about 12% of the western population is elderly (Stewart-Hamilton, 1993).

This paper addresses the effects of bereavement on the mental health of older people, comparing cognitive behaviour therapy (CBT) and psychodynamic therapy as treatment approaches to mental health problems following bereavement. The paper begins by reviewing older people as a population and the stereotypes, both general and professional that surround this cohort. It discusses the concept of bereavement and the stages of grief that facilitate the process of grieving, possible factors that mediate the development of complicated grief, and the mental health problems that may arise. The focus will be on depression. The paper then concentrates on the growing recognition of psychotherapies within the older adult community and the modifications of therapy that may be beneficial for this cohort. The key structural elements of CBT and psychodynamic therapies, their effectiveness with older people and the limitations within the current research will follow. The paper concludes with recommendations and implications for further research.

Older People

Age is frequently viewed in a polarised fashion and is associated with mental deterioration and increasing difficulties in both physical and mental health. Thompson et al (1991) considered the experience of later life using the accounts of 55 older people. They identified a number of characteristics including loneliness, socio-economic status, inequality, and physical health difficulties among others. They also identified, however, a new degree of freedom and choice and rejected the often-imposed notion that older adults occupy a state of passivity. Erickson (1966) described development as a continuation throughout the life cycle in terms of the person's attitude to and interaction

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with the world and described a series of alternative basic attitudes. He outlined the development task of later life as a negotiation between the two polarities of ego integrity and ego despair. The person who possesses integrity in old age is the person who accepts that this life is the only one he could have had and accepts his personal life as his own responsibility (Garner, 2003). The person without integrity does not accept their life and they despair that life is too short (Garner, 2003). This model has been criticised for proposing successful ageing as a passive preparation for death (Stuart- Hamilton, 1994). Erickson argues, however, that our development is a continuing learning process and the ability to establish a balance between integrity and despair provides a more comfortable old age existence, advocating the utility of psychological interventions in old age.

Therapists, similar to other people, organise their experience by categorising people and events, drawing upon stereotypes and overgeneralising the similarity of those in unfamiliar groups (Yarhouse, 2000). Some of the characteristics imposed on older people by psychotherapists include physical illness, cognitive impairment, and lack of psychological mindedness (James, 2004), causing problems if they are applied to a person without gathering sufficient information about that individual (Strangor and Lange, 1994). The lack of psychological mindedness is generally based on the premise, pioneered by Freud, that older people are 'mentally inflexible' and thereby would not benefit from talking therapies. However, Zeiss and Steffen (1996) suggest that therapists should be mindful of the fact that chronological age will not tell them everything about the individual, particularly as older adults represent the least homogenous of all age groups. Furthermore, research demonstrates that not only can older adults benefit from psychological therapy (Laidlaw et al 2003) but that they may show better outcomes than their younger counterparts (Walker & Clarke, 2001).

Bereavement and Grief

Bereavement is primarily concerned with the loss through death of someone to whom there has been a strong attachment. It is generally recognised as one of the most severe traumas that people cope with during the course of their life (Strobe & Strobe, 1987). Older people are particularly vulnerable to a broad range of loss including relationships,

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accidental injuries, loss of physical or mental abilities, and death. With the latter representing the focus of the current paper. When a spouse dies the survivor in many cases, suffers not only an enormous loss of love, but also most of their support system in terms of life time companion, source of security, co-manager of a home and a lover who provided physical, emotional and sexual companionship (Scrutton, 1995). The emotions generated by bereavement are normally described as grief.

The term normal grief or uncomplicated grief refers to a broad range of feeling and behaviours that generally follow bereavement. Worden (2003) divided these normal grief behaviours into four general categories, feelings, physical sensations, cognitions and behaviours. Much of the literature on the subject of grief views the mourning process in terms of stages. These have been presented by Worden (1991), among others (Parkes, 1972, Bowlby, 1980, Kubler - Ross, 1969). Worden identified the first task of mourning as being able to accept the reality of the loss and acknowledge that a reunion is impossible. The opposite of accepting the reality of the loss is not believing through some type of denial. Secondly, he identified the necessity to work through the pain of grief. Many individuals use thought stopping procedures to help them avoid the pain (Parkes, 1972), thereby preventing completion of the bereavement process. Thirdly is the adjustment to the environment from which the deceased is missing, involving two separate concepts. External adjustments denote every day functioning in the world and internal adjustments consider how death affects one's sense of self. The final phase is the necessity of emotionally relocating the deceased and moving on with life (Worden, 2003).

However, accumulating research illustrates that although stage models are widely accepted there is little empirical evidence to support them (Silver & Wortman, 1980). Furthermore, there is much controversy surrounding the advocated stages of grief and the purported necessity to endure each of these stages to accommodate the loss of a significant other. It has been noted that adhering to the stages of response the individual may expect to proceed from one stage to the next within a particular time frame (Osterweis et al, 1984), perhaps exacerbating the grieving process and leading to a diagnosis of complicated grief. In addition, there is little evidence to support the notion

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that those who do not exhibit distress will show subsequent health difficulties or symptoms (Silver and Wortman, 1990). This highlights the necessity to remain open minded about what constitutes successful mastery of the bereavement process. The key factors must be the person's adjustment, distress and mental health, rather than the path being taken through the bereavement (Woods, 1999).

Factors that mediate complicated grief

Regardless of the grief pathway taken by individuals the death of a significant other generally results in fundamental changes that loss has brought about, often requiring a complete overhaul of the individuals life. In some instances, individuals of all ages fail to grieve appropriately and subsequently experience what is termed abnormal grief reactions. Worden (2003) identifies a number of mediators that influence the type, intensity and duration of grief. These factors influence the individual's capacity to grieve and assist in our understanding of why bereavement in some instances can result in mental health difficulties. It can be suggested that without such mediators, the general theoretical models proposed above will have limited use. Two types of relationship have been focused on in the literature. The most common type of relationship that hinders adequate grieving is the ambivalent one, characterised by lack of trust and conflict, particularly when it encompasses unexpressed hostility (Worden, 2003, Scrutton, 1995). This can result in excessive amounts of anger and guilt, which intervenes with one's ability to grieve appropriately. The narcissistic relationship also can result in the loss being denied because to admit to a loss would then necessitate confronting a loss of part of oneself (Parkes and Weiss, 1983). Alternatively, the death of an individual who was abusive may reactivate residual feelings. Often individuals who have been abused suffer low self esteem and self blaming which can facilitate complicated forms of grief (Scrutton, 1995). In other situations individuals grieve for what they never had and now never will have (Parkes and Weiss, 1983), an element referred to in Erickson's stages of development. Of course many people who lose a significant other feel helpless but not always so helpless that other more positive self-images are omitted (Worden, 2003).

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A second predictor of long term difficulty following loss are the circumstances surrounding the loss such as when loss is uncertain, multiple losses or suicide. Such 'unspeakable losses' deprive the individual of expressing their feeling and may impact in terms of the uncertainty making individuals unsettled about the world we live in (Parkes and Weiss, 1983).

Other factors include personality and social factors. Personality factors relate to the individual characteristics and how it affects his or her ability to cope. This has been cited as the most important factor in the bereavement recovery process (Scrutton, 1995, Slater, 1995). Some individual's are unable to tolerate the emotional distress, withdraw from the feeling, do not complete the process of grieving and develop complicated grief (Worden, 2003). Alternatively, if an individual perceives themselves as the 'strong one in the family', they may not allow themselves to experience the feelings required for an adequate resolution of a loss (Lazare, 1979). Similarly, absence of an adequate social support network (Worden, 2003) can complicate recovery from loss. This may have particular implications for older people who are more likely to have a less family and friends in comparison to other groups. Finally, it is interesting to note that Neugarten (1968) maintained, in relation to the life cycle perspective, that there is a socially prescribed timetable presenting the order in which things should happen. And subsequently the extend to which the death is 'on time' is an important contributing factor to recovery.

Obtaining information regarding these factors is critical in assessing the individual. Many professionals make the erroneous assumption that failure to cope is on the part of the individual. The potential mediating factors of the recovery process are often ignored to the detriment of the client.

Mental Health

Abnormal or complicated grief reaction has been defined as

'the intensification of grief to the level where the person is overwhelmed, resorts to maladaptive behaviour, or remains interminably in the state of grief without progression of the mourning process towards completion' (Horowitz, 1980: p 1157).

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Four examples of complicated grief have been identified including chronic grief reactions, delayed grief reactions, exaggerated grief reactions and masked grief reactions (Scrutton, 1995). This discussion will focus on exaggerated grief reactions because mental health difficulties predominantly appear to stem from this form of grief. In this category the individual experiences the intensification of a normal grief reaction, feelings become overwhelming and debilitating and may lead to maladaptive behaviour (Jacobs, 1999). Exaggerated grief can and often does result in major psychiatric disorders and often receives a DSM (Diagnostic and Statistical Manual of Mental Disorders, APA, 1994) diagnosis (Ott, 2003). Psychiatry disorders that commonly develop include clinical depression, anxiety, interpersonal problems, substance abuse, hallucinations, physical illness, post traumatic stress disorder and even death (Strobe et al, 2001). This paper will focus on depression.

The feelings of depression and hopelessness after a loss happen to most individuals and are usually transient and the development of significant depression is by no means a universal experience. However, in some instances these feelings of hopelessness change into irrational despair and are accompanied by other depressive features resulting in a diagnosis of clinical depression (Worden, 2003). Mediating factors particular to the development of depression include individuals who experienced a relationship where tasks were divided rigidly creating difficulties in acquiring new roles, low social support, enmeshed relationships and avoidance of talking about the loss (Woods et al, 1999). Often the diagnosis is complicated by features of grief but it is now generally recognised that clinical depression exists when it is accompanied by negative self image and feeling a like a failure following the death of a significant other (Woods, 1999). Some of the problems that arise with depression with older adults is mistaking depression for a physical health problem, generalised complaints of fatigue, lethargy and pain may prove difficult to evaluate (Pitt, 1995).

In psychological interventions with bereaved individuals it is often difficult to manoeuvre the fine line between normal grief reactions and the identification of what's 'not normal'. Much of these conceptions are driven by social and cultural influences. It is

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therefore important that psychotherapists are not rigid in their thinking on what constitutes normal grief, and are mindful of individual differences within this area.

Psychological Interventions

Recently there has been growing recognition that psychological approaches developed with younger adults can be successfully adapted for use with older people (Gatz et al, 1985, Knight, 1986, Thompson et al, 1987). There is still, however, the legacy of Freud's view that elderly people lack the flexibility to engage in therapy, commonly referred to as 'mental inflexibility' (Butler and Lewis, 1982). It is recognised that these changes in flexibility do occur in the elderly, but they do not necessarily compromise the therapeutic process (Morris & Morris, 1991). They may however, necessitate adaptations to the approach considering historical experience such as health problems, sensory deficits, cognitive change, and/or family involvement (Edelstein, 2000).

A number of adaptations have been identified. The minor alteration of reducing the speed of conversational flow in each session may be all that is required for the therapy to be effective (Knight, 1986), minimising the possibility of fatigue. Differing cultural experiences over time should be addressed and not confused with developmental changes (Morris & Morris, 1991, Stecker, et al, 2004). For example, an elderly person may not be familiar with talking therapy and be expecting physical treatment in the form of medication and be unprepared for the format of talking therapies and the active role that may be necessary for them to take. It is important to spend a sufficient amount of time socialising the patient to the therapy (Stecker et al, 2004) and not assume that the older individual harbours a preference for medical based intervention. Additional adaptations include keeping the rationale as straight forward as possible, a greater degree of flexibility, bridging the session to address possible memory disturbance and perhaps altering the duration of the session (Stecker et al, 2004). On the other hand, we must be mindful that many older adults are well suited to psychotherapy because they may be more introspective and have a more developed sense of their values and beliefs (Edelstein, 2000).

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Cognitive Behavioural Therapy

Cognitive Behaviour Therapy (CBT) has its origins in both behaviour therapy and cognitive therapy. The conceptualisation of CBT is related to systematic errors in thinking that maintains negative thoughts about oneself, one's expectations and one's future directly influencing one's mood and behaviour (Beck, 1979). CBT emphasises lifelong learning and advocates the optimistic belief that people can make important changes in their thoughts, feelings and actions at any point in their lives (Crowther & Zeiss, 1999). In contrast to psychodynamic therapy, CBT focuses on current conscious thought and is often framed as a learning experience rather than a psychological treatment. This can be useful for the current cohort of older adults, who often are not aware of psychological principles. Rokke and Scogin (1995), encouragingly, showed that older adults rated psychotherapy as more credible and acceptable than drug therapy for depression, in contrast to expectations that older adults would prefer drug therapy and feel stigmatised when psychotherapy is recommended (Crowther and Zeiss, 1999). The therapist must be mindful, however, that older adults may have been raised before CBT gained an established niche in the mental health service and may expect CBT to be similar to that of earlier practice such as psychoanalysis (Secker et al, 2004). Furthermore, the therapist must be familiar with co-hort specific attitudes and stresses that can inhibit the achievement of therapy goals (Zeiss and Lewinshon, 1986). For example, an older male client who believes that women should be responsible for food preparation, may have more practical difficulties adapting to the bereavement of his spouse, and require tailored interventions to re-evaluate this before improvement could be achieved (Secker et al 2004).

There are a number of reviews that describe the application and adaptation of CBT for use in the older adult cohort (Dick et al, 1996, Gallagher- Thompson & Thompson, 1996, Secker et al, 2004). In general it is recognised that very little change is needed to use CBT for depression with relatively healthy older adults (Edelstein, 2000), other than some of the general considerations for psychotherapy work reviewed above. Rybarczyk et al (1992) reviewed five major treatment issues for depressed, chronically ill older adults being treated with CBT. Some of the specific issues raised by this piece of

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research include logistical problems, confrontation of the belief that old age will result in depression regardless of anything, feeling of worthlessness and helping patients cope with increased dependency and fears of being burdensome to others.

CBT and Depression

Research focusing on the treatment of depression with CBT in older people has predominantly illustrated a decrease in depressive symptomatology when compared to no treatment and other treatment modalities (Teri et al, 1994). Much of the research in this area has been conducted by Gallagher, Thompson and their associates primarily involving comparatively healthy adults in their 60's and 70's living in the community. These authors compared individual cognitive behavioural and brief psychodynamic therapy for depression in older people and found comparable remission rates and no difference in the stability of the effects over two years (Gallagher and Thompson et al 1990). At one and two year follow up 77% were depression free, although a number of these patients did experience relapse of depression in the interim. A finding also reported in the younger adult research (Clarke & Walker, 2001). Gallagher and Thompson (1982) suggested that the older people often focus on past faults that cannot now be changed (such as an unfulfilling relationship) and advocate challenging these rigid thinking patterns. The therapist's attention should focus on here and now thinking patterns that when restructured, will result in an improved mood. An innovative behaviour therapy for depression has been described by Lewinshon et al (1982). This approach uses a social learning model to investigate the cause of some depressions. The authors focus particularly on positive reinforcers and the change in their availability, which occurs regularly following the death of a significant other. This approach aims to help the patient re-establish new skills and positive life activities to replace losses that the elderly person may endure. Gallagher (1981) successfully applied this approach to an elderly population. Meta-analysis of the current literature has added weight to the support of CBT with older people. Teri et al (1994) reviewed 20 studies of CBT for older people with depression and revealed that 50% - 75% made substantial improvement and CBT compared favourably with studies of medication for depressed older people. Group CBT,

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which in the current economic climate of the National Health Service is a desirable approach, produced a 70% improvement in depression that was maintained at a one-year follow-up (Leung & Orrell, 1993). Of interest it was noted to be less stigmatising for the older person than individual psychotherapy (Hepple et al, 2002). Also of interest CBT has been found to be highly effective in treating some of the other mental health problems that may arise from bereavement, including anxiety (Stanley, 1996) and panic (Swales et al, 1996).

Psychodynamic Therapy

The history of psychodynamic therapy is rooted in the founding of psychoanalysis by Sigmund Freud. Freud (1905) wrote of the ineducability of people over 50 and indicated that too much material would be presented by older adults to be analysed, which effectively rendered the use of psychodynamic therapy with older adults as futile. Fortunately, Jung (1929) did not follow Freud's example. He considered old age to present a multitude of challenges that differed greatly from those faced by younger individuals and he described the duty of the ageing person to be

'to give serious attention to himself' (Jung, 1929).

However despite this support of psychodynamic therapy for older adults, with a few notable exceptions the application of psychodynamic therapy to older people has only really developed within the last decade (Arden, 2002). The therapy focuses on releasing the patient from neurotic conflicts, leading to symptoms and difficulties in interpersonal relationships (Arden, 2002). This therapy endeavours to develop emotional maturation in the individual. By following the therapy the individual should develop a more mature and less conflicted way to relate (Garner, 2003). The basic underlying assumptions of psychodynamic work considers an area of existence that we are usually unaware. This interacts with our current experiences and impacts on our behaviours and emotional states (Garner, 2002). As we progress through life each of our developmental stages and the experiences they encompass remain with us and may be reactivated at any stage through a variety of factors including new relationships, changes in environment, loss of significant others. (Karel and Hinrichsen, 2000).

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For psychodynamic therapy to be effective, regardless of the age of the client, Arden (2002) identifies the following criteria. Awareness that neurotic symptoms have meanings, motivation to change, a degree of personal responsibility, capacity to understand interpretation and a realism that treatment will require time. A common argument presented regarding the suitability of older people to psychodynamic therapy is that older people have no time in which to change. However, a 25 year old in therapy may feel he has all the time in the world to alter his life while a 75 year old as a result of the short time remaining may accelerate his psychological change (Gatz et al, 1998). When working with the older population the idea of therapeutic change may need to be refocused (Hepple et al, 2002) and possibly different goals set. The required outcome may be for the older adult to accept what they now can no longer change. Perhaps, therefore using therapy to resolve the conflict between integrity and despair identified by Erickson in his stages of development. Similar to the argument mentioned above in relation to CBT, reference has been made to the necessity to be 'psychologically minded' to benefit from this approach. However, this is required for a variety of psychological therapies and unless it has been identified as an innate characteristic it must equally be learned by young and old (Hepple et al, 2002). When working with the older adult population in this way two areas are particularly important. Firstly, therapists must be mindful of biological and social realities of the lives of older adults and the multitude of issues that may not have been addressed in many years or even at all (Garner, 2003). Secondly, despite stereotypes, older adults have a plethora of coping skills that they have developed over a lifetime and an increased capacity for delayed gratification (Karel and Hinrichsen, 2000) which would render them good candidates for the psychodynamic approach.

Psychodynamic therapy and depression

There is a paucity of empirical evidence on the effectiveness of psychodynamic therapy in the treatment of older people. Neiderhe (1994) reviewed the existing empirical literature and concluded that psychodynamic therapy was more effective in treating depression in older people and was as effective when compared to other types of

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(1987) illustrated that brief individual psychodynamic therapy was as effective in treating depressed older people as cognitive and behavioural therapies. These therapeutic gains were maintained at two year follow up (Gallagher - Thompson et al, 1990). Similar results were reported by Steuer (1984) who concluded that psychodynamic and CBT psychotherapies were equally effective in treating depression in older people. Lazarus et al (1987) reported on the outcome of brief psychodynamic therapy with eight older adults. Of this group seven had received a diagnosis of adjustment disorder with depressed mood or dysthymia. Following 10 -12 session's symptoms had significantly improved and there was a resolution of primary psychological problems, although they did not report significant gains in insight. Karel and Hinrichsen (2000) cite this study as a good example of the difficulties inherent in monitoring the outcome of psychodynamic approach with older people (i.e. Symptom change may not always be sufficient to measure the changes that therapy hopes to make).

Limitations

Overall the research suggests that older people are as likely to benefit from psychotherapeutic interventions as are younger adults (Karnel & Hinrichsen, 2000). Currently CBT has the most empirical support relative to other psychotherapies in treating depression in late life. The psychodynamic approach has also received support, albeit limited, due to the paucity of literature in this area. Some of the limitations of the current research in both CBT and psychodynamic therapy include the population of older adults who have participated are generally white, 60 - 70 year olds, living independently in the community. This is particularly relevant as the numbers of older adults above the prescribed age of 70 is rapidly expanding. Furthermore, there is little research available considering mental health problems in minority older adults, frail older adults or indeed in the broad variety of treatment settings including long term inpatients and those being cared for in their own homes (Karel and Hinrichsen, 2000). It would also be beneficial to consider combinations of therapeutic intervention, and to focus on other non-specific factors such as the therapeutic alliance which may have important implications for the outcome for any therapeutic approach. Additionally, one of the fundamental problems of

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the research within this area is the lack of agreement about the measurement of outcome variables, such as what is appropriate to measure and at what point should assessments be conducted (Osterweis et al, 1984). Furthermore, many of the studies mentioned above focus on the short term gains of psychotherapeutic interventions, the long term impact requires further research in addition to the use of maintenance sessions which may increase the effectiveness of interventions (Karel and Hinrichsen, 2000).

CBT v's Psychodynamic Therapy

Despite the limitations of the research base clinicians practising psychological therapies will nevertheless need to make a decision regarding the approach they will implement. Considering the similarities and differences between CBT and psychodynamic therapy in the treatment of older people a number of issues must be addressed. Firstly, the above studies indicate that both CBT and psychodynamic therapy are effective in the treatment of the older adult population in the domain of mental health. However, it is evident that the amount of supporting studies is greater in the area of CBT, thereby providing this approach with a stronger theoretical base from which to work. Perhaps the dearth of research in psychodynamic therapy is due to the difficulties inherent in evaluating outcomes, particularly those not based on symptom severity or diagnostic severity, such as mobilisation following a bereavement (Hepple et al, 2002).

From a more practical based perspective it would appear from the literature that CBT lends itself to the older people in the respect that it can be presented as a psycho-educational program. Removing the potential conflict between older people and the acceptance of psychological concepts. Furthermore, within the current climate of the NHS it may be argued that CBT could be a more time effective approach in comparison with psychodynamic therapy, particularly as the research advocates group CBT approach as effective. The short-term nature of CBT addresses the well seasoned argument that 'older adults have no time to change', although it could be argued that the shorter time available to older people may evoke a more rapid response to psychodynamic therapy than the average younger person. Other issues of note include the underlying conceptualisation of CBT as life long learning, which removes any potential biases from

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the treatment of older people. Alternatively CBT requires collaboration within the therapeutic context and benefits from the implementation of cognitive or behavioural strategies outside the therapy session, a concept older people may find difficult to implement. Although, while ageing brings with it a degree of deterioration in cognitive and physical capabilities, it does not result in an invalidation of the basic laws of learning seen in younger age groups (Levendusky & Hufford, 1997).

Conclusion

Despite the tangible advantages of CBT and the evidence available, a recommendation on the type of therapy to be utilised with the older people perhaps should be guided by the particular circumstances of the individual. It is important to be aware that later life encompasses many changes in the individuals social and biological context and a number of aetiological factors may be present (Hepple et al, 2002). For example, substantial difficulties in accessing long-term memories may make the psychodynamic approach difficult to implement. Or alternatively, an inability to understand and conceptualise the fundamental principles of CBT will render this approach unsuitable for that particular individual. Later life is now beginning to be viewed as similar to all other stages of the life cycle with transitions to be adjusted to and challenges to be faced, generated in many instances by the death of a significant other. What remains to be achieved in the area of older adult mental health is substantial. The dearth of research needs to be addressed, taking into consideration a number of the limitations outlined above. Awareness must be generated about the effectiveness of psychotherapy with the older adult population and ageism, particularly among clinicians, must be challenged. Bereavement and loss represent fundamental life adjustment for older people and successful treatment can and does provide in a better quality of life. We as clinicians have a duty to provide them with treatment that is grounded in theoretical research and adaptable to each individual older person.

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How can attachment theory be used by a clinical psychologist to aid his or her understanding of the relationships and the communications of people with severe learning disabilities and assist in creating therapeutic change within this group?

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Attachment theory is considered by many to be one of the most sweeping, comprehensive theories within psychology today (Rholes and Simpson, 2006). These authors suggest that attachment theory offers a biosocial life span account of how our close relationships form, are maintained and dissolve and how relationships can influence, often permanently, the individuals involved in them (Bowlby, 1979). This discussion will provide a brief overview of the theory of attachment, an introduction to the concept of severe learning disabilities with a focus on relationships and communication, and finally how attachment theory may be useful in both assisting our understanding of this population and in the creation of therapeutic change.

Attachment theory

Attachment theory was initially formulated by John Bowlby (1969, 1973, 1979, 1980) and was later extended by Mary Ainsworth (Ainsworth, Blehar, Waters and Wall, 1978). The basic assumption of attachment theory is founded on the fundamental premise that a young infant has an evolutionary based need to become attached to its parent in order to enhance its chance of survival. This attachment protects the child from danger while they develop the maturational skills to care for themselves (Hollins and Sinason, 2000). As a result of selection pressures it is suggested that infants have evolved behaviours that function to maintain proximity to a protector/caregiver. These are essentially a loosely organised set of behaviours (smiling, crying, following) with the primary function of increasing physical and psychological proximity to the primary caregiver (Rholes and Simpson, 2006). In systemic terms the child and primary caregiver maintain a protective process in which the infants require the consistent and affectionate presence of their parents in order for a secure attachment to occur (Dallos, 1995)

The idea of attachment behaviours was most readily observable in a series of experiments conducted by Mary Ainsworth in 1978, referred to as the strange situation. It is generally accepted that infants exhibit one of two main types of attachment, secure and insecure. This can be further categorised into four main patterns of behaviour described as secure, avoidant, ambivalent and disorganised. The secure pattern is generally expressed by infants who consistently experience the primary caregiver as available and thus are enabled to develop a representation of that person as accessible when needed. They provide a safe haven in times of distress or a safe base from which to explore the world. Insecurely attached infants, in contrast, repeatedly experience the parent as unavailable or insensitive and inconsistent to their needs. This maintains the infant in a state of high arousal or anxiety. This distress is managed by the infant in one of two ways – avoidance or hyper-vigilance. The former may involve the child developing strategies to distract himself/herself from any needs for attachment and attempts to focus on other aspects of the environment. The latter is evident when the child's experience is of inconsistent responses from the primary caregiver. They become hyper-vigilant in order to maximise any possibility of attention and care when it is available. This is generally associated with decreased exploration and play and excessive focus and concern with the primary caregiver (Dallos, 2004). Insecure attachment, from the above implications, would suggest that the attachment needs of these children occupy large proportions of the child's thinking and experience (Kobak and Cole, 1994). They are constantly striving to avoid or elicit care, expending excessive amounts of cognitive and emotional effort leaving them less available to engage in other activities.

The above discussion about attachment is obviously a simplification, in that it essentially focuses on the primary caregiver dyad. Arguably there are multiple attachment relationships throughout our lives particularly within our family, social and romantic sphere. As Bowlby suggests *'every situation we meet with in life is constructed in terms of the representational models we have of the world about us and ourselves. Information reaching us through our sense organs is selected and interpreted in terms of these models... and plans and actions are conceived and executed with those models in mind'* (Bowlby, 1980). We essentially construct and reconstruct ourselves and our relationships from real time interaction with important people in our lives based on our primary attachment figure early in life. This deterministic aspect of attachment has been hotly debated. With the dominant perception currently suggesting that people can and do step out of the cycle of intergenerational transfer through the experience of supportive spouse or emotionally available others (Clegg, 1995).

Learning Disabilities

Learning disability entails significantly sub average intellectual functioning (composite score of two standard deviations below the mean) with related skills deficits in adaptive functioning and a manifestation before the age of 18 years. It is currently estimated that approximately 20 people per 1,000 in the UK have a learning disability (Hatton, 1998). Of this group it is estimated that 80% are in the mild category, 12% in the moderate with 7% and 1% falling into the severe and profound categories (Carr, 1999). It is further estimated that between 25 and 50 per cent of the cases have significant conduct, emotional or pervasive developmental problems (British Psychological Society, 1994).

In terms of aetiology organic, polygenetic and socio-cultural factors have all been implicated (Simonoff et al, 1996). Discrete genetic and organic factors are implicated in moderate and severe learning disability while polygenetic influences and psychosocial adversity underpin mild intellectual disability (Carr, 1998).

Communication

The ability we have to communicate is of fundamental importance if we want to take part in the current social world. Communications span a broad spectrum ranging from simple signalling for basic needs to the powerful and sophisticated use of language – a symbolic and rule governed organisation which enables not only personal expression but also the capacity to influence our environment and those individuals who make up that environment (Ambalu, 1997). All human beings fail to hear what is said to them on occasions, but unlike individuals with severe learning disabilities we are able to let the individuals within our environment know when this has occurred. Very many people with intellectual disabilities encounter extreme difficulties with communication and it is estimated that 80% of those with severe or profound learning disabilities fail to acquire fully affective speech (Garcia and DeHaven, 1974). In a more recent study conducted by McLean et al (1996) reported that 59% of this population showed limited evidence of symbolic communication, 19% show evidence of non-symbolic communication intent and 21% displayed no evidence whatsoever of intentional communication. Ambalu (1997) noted that when communication breaks down because of lack of understanding one individual involved in that breakdown will generally pick up the pieces and try and repair the system. In the lives of severely learning disabled individuals this is generally the care staff in the residential

homes. This can create a number of difficulties, the individual may withdraw as a reaction to years of intrusive interactions that they are unable to comprehend or participate in or alternatively the frustration of being unable to communicate may manifest itself in challenging behaviours with the function of communicating their needs and engaging in social interaction.

Social interaction is recognised as fundamental in the development of the ability to understand other people's mental states (Howe, 2006). As levels of emotional availability on the part of the care receiver appear to affect parent's sensitivity, levels of non hostile and non intrusive behaviour (Howe, 2006) one may question whether an individual who is less emotionally available will suffer the consequences of less social interaction. Research into babies who are born with Down's Syndrome argue that the relatively slow speed that they process information (Anderson, 2001) and the use of fewer internal state words result in mothers or carers also beginning to use fewer internal state words (feel, believe). The consequence is less information been exchanged between the mother and child affecting the quality of communication and joint affect regulation (Howe, 2006). So although individuals with Downs' syndrome similar to individuals with severe learning disabilities can and do understand theory of mind this may be under-developed relative to its potential. An insufficiency in communication, joint affect regulation and theory of mind will have implications on their ability to take part in a reciprocal interaction that forms the foundation of secure attachment.

Relationships

Relationships with other people play an important role in shaping us as individuals – impacting on our personalities, our experiences and how we feel about ourselves. In the case of children who are born with severe learning disabilities relationships can and often are fraught with difficulties. Maternal depression, the parents own childhood experience and their experiences of being parented can all influence parental states of mind and attitudes towards the parenting role (Sheppard, 1997). These factors have a universal ability to impact on our ability to parent adequately. Now consider the component of loss which is inevitable when a child is born with severe learning disabilities. It is very difficult to acknowledge and appreciate the implications of the diagnosis of learning disabilities, since the diagnosis generally violates their expectations of having a completely healthy child (Carr, 1998). Many parents experience a series of shock followed by denial (Carr, 1998) which will often have implications for their ability to care for the child in a way that encourages a secure attachment to form. A number of studies have investigated the attitude parents develop towards their disabled children and have cited a number of factors which appear to have implications on these relationships. These include the severity of the disability, the presence of additional life threatening impairments, and the hopes and expectations of the parents, the way in which the news is delivered, and the reception the infant receives from both the professionals and the extended family (Cunningham and Mittler, 1981, Carr, 1988, Gallimore et al, 1989). This relationship will not always be resolved resulting in a sizable group of insecure learning disabled children (Clegg, 1995).

Despite these difficulties families – not professionals- are the main providers of services to adults with learning disabilities. Over 50% of adults with profound or severe learning disabilities live at home with their families who provide a shadow

welfare service supporting their disabled off spring both materially and practically (Mencap, 1994). However, whether they are accommodated at home or in residential setting individuals with severe learning disabilities can expect to be subjected to constant changes in their environment and relationships – often without any control and/or acknowledgment of the changes occurring (Hodge, 1997). Mattison and Pistrang (2000) looked in detail at the impact these frequent losses of relationships had on this client group. They paid particular attention to the key worker relationships that are now in place in most community settings. The main themes identified by the learning disabled population following the breakdown of such a relationship included loss and grief, helplessness, acceptance and acquiescence. Staff themes identified included attachment, denial, and self devaluation. Although this study was conducted with individuals who had the capacity to participate in a verbal account of their loss and therefore may be limited to those with mild learning disabilities – it nevertheless refers to the same context as many of those with severe learning disabilities. Mattison and Pistrang (2000) describe how the often sudden departure of staff creates a sense of confusion, bewilderment and shock in the individuals with learning disabilities. Often in the case of individuals with severe learning disabilities they are unable to verbally communicate what they are experiencing and it is often more usual for them to present with a change in behaviour or perhaps biological symptoms (Thomson, 1997). This is often a sign that something in their world is not going particularly well and we need to look at their environment and the individuals in it.

Both professionals and care staff alike need to be mindful of the possible ‘functions’ of behavioural or biological changes and it is helpful to think about this in terms of the family or service in trouble to avoid colluding with the idea that it is the person who needs attention and not the system as a whole (Sheppard, 1997). Staffs have often reported a ‘lack of response’ in a client following the breakdown of an attachment relationship between the client and his/her care worker to be replaced later by challenging behaviours. It is often necessary to consider how this particular client has reacted on previous occasions when he/she has been separated from his/her primary link worker. This generally results in the identification of challenging behaviours or withdrawal that coincided with the departure of various link workers. Acknowledging behaviours as a method of communicating distress has immediate implications for staff attitudes. This has important consequences because to have an unresolved state of mind in relation to the individual you are caring for interferes with the capacity to interact sensitively, empathically, accurately and congruently (Howe, 2006).

The theory of attachment in relation to severe learning disabilities

Attachment theory describes care-giving and care-receiving as basic components of human nature and essential for personal and relationship well being (Bowlby, 1969). Caregiving plays a central role in the nature and function of attachment relationships and more importantly it interacts in fundamental ways with other basic components of the human nature – attachment and exploration (Feeney and Collins, 2006). Attachment theory provides an ideal framework for studying social support and care giving processes in adulthood because it identifies the need for security as the most fundamental of all basic needs across the life span (Feeney and Collins, 2006). It also provides us with a basis for understanding the complicated dynamics involved in the three important and interrelated components of human nature: attachment (care

seeking), caregiving and exploration (Bowlby, 1988). From the perspective of the attachment framework caregiving serves two major functions. The caregiver provides both a safe haven for the attached person by meeting his or her needs for security and a secure base for the attached person by supporting his or her autonomy and exploration in the environment (Feeney and Collins, 2006).

Within the context of individuals with severe learning disabilities this care giving procedure is not only fundamental to their physical survival but also to their emotional and psychological well being. An early premise of attachment theory was that patterns of attachment were determined by the characteristics of the care-giving and that the individual factor did not play a significant part in the classification (Howe, 2006). However, a study by Blesky and Rovine (1987) found that although caregiver factors determined whether a secure or insecure attachment developed, temperament did appear to affect the manner in which the security or insecurity was expressed. More interestingly there is evidence to suggest that parents sensitivity to their children might be affected by the innate reactivity, temperamental difficulties, arousability and ability to self regulate (Howe, 2006). So what is suggested here is that children with high irritability place higher demands and increase the level of stress on their parents. Vaughan and Bost (1999) noted that *'when a parents economic, social and/or psychological resources are strained, an irritable or otherwise difficult infant elicits less than optimal care-giving, which in turn potentates the assembly of insecure attachment'* (p.220). Howe (2006) considers the substitution of the word temperament for disability and suggests intuitively that behavioural, interactional and communication characteristics are likely to impact on the levels of stress, the quality of care giving and therefore the security of the attachment for individuals suffering from a disability such as learning disability. The more open, reflective and emotionally tuned the caregiver is about the child's behaviour and mental states, the more the child feels psychologically recognised contained and regulated (Howe, 2006). These continual interactions help the child to make sense of both their own world and over time other people's behaviour and mental states. Thus providing predictability and thereby reducing anxiety and possibly the necessity of challenging behaviours.

Stovall and Davis (1998) consider the developmental outcomes achieved by older aged foster children in terms of the 'transactional model'. They consider a child's 'movement along a particular developmental pathway is determined by the transactions that occur between the child and his/her environment'. It is recognised that children bring to each new relationships their own unique histories, along with specific mental states and associated behavioural and relationship styles formed in their caregiving environments (Howe, 2003). If they have experienced a number of negative care giving environments these strategies are generally related to the deactivation or increased activation of their attachment behaviours and include such behaviours as compulsive compliance, suppression or denial of affect, and power and aggression (Crittenden, 1995, 1997). Stovall and Davis point out that, although these strategies may have been useful in very difficult environments they can also mean that these children are ill equipped to take advantage of good quality and loving and responsive substitute care (Stovall and Davies, 1998). Relating this to the fact that many individuals with severe learning disabilities, similar to fostered children, have been subjected to a number of different types of carers, some parallels can be drawn. In some cases, not always, this continual change in key workers and the necessity to

renegotiate each new relationship in the context of their own unique relationship history (relating to both service user and staff) can create both emotional and psychological difficulties for both parties.

Abuse towards individuals with learning disabilities is unfortunately very common, and can take many forms including physical, sexual, emotional, financial, neglect and discrimination (Emerson et al, 2001). Studies have indicated that 23 percent of individuals presenting with learning disabilities have been physically abused and 47% percent have experienced verbal abuse (Brown, 1999). These types of abuse and environments when considered for children who have been fostered have grave implications and therefore we can tentatively suggest that they will also have implications for the learning disabled population whose vulnerability may be considered similar to that of foster children who do not have the capacity to care for themselves. The experience of having a caregiver as a source of both danger and reassurance creates a major disturbance in the balance between fear and attachment – this can lead to attachment disoriented behaviours or fright without resolution (Fischer- Mamblona, 2000). There are a number of implications of such experiences including freezing or suppression, challenging behaviours, confused avoidance and approach behaviours (Howe, 2003). Thus individuals with severe learning disabilities who have been subjected to distressing care environments may have developed a series of adaptive strategies developed in early years of care. Their experience of being in a care-giving relationship may have been frightening. This can manifest in a number of ways the two most obvious been withdrawal or challenging behaviour. This will place a higher level of demand on their carers which in turn may lead carers without support and expert help to get caught up in a distorted rationale about how relationships work leaving them feeling helpless and often angry. In some cases they will then withdraw from the attachment with that person allowing the same relationship patterns to be repeated again and again maintaining the care receiver distrust in relationships and security.

In addition to the individuals being cared for we must also consider the implications of the carer's previous relationships both within their line of work and also within their personal life. If the attachment demands of a caring relationship unconsciously activate painful memories of rejection and emotional hurt, this can interfere with the individual's ability to interact sensitively, empathically, accurately and congruently with the other (Howe, 2006). In essence, the attachment behaviour of the individual with severe learning disabilities can activate the carer's attachment system, which, due to its unresolved condition results in anxious distressed, uncertain and emotionally unattuned care giving (Howe, 2006). This can lead to an intensified striving on the part of the service user to illicit adequate care and attention which may increase the feeling of anxiety and helplessness in the carer. Therefore at the very time when the service user needs to feel understood and safe the carer may be experienced as distressed and emotionally unavailable. Howe (2003) talks about this in relation to the child-parent dyad but it is also relevant to other caregiver and care receiver relationships. Care givers and care receivers can get caught up in an escalating spiral of mutually fuelled states of dysregulation (Howe, 2006). The literature highlights the fact that parental sensitivity, emotional attunement, congruence and responsivity depends largely on the parent's ability to accurately recognise, understand and interpret the behaviour, body language, facial expression and speech. Individuals who happen to have severe learning disabilities often rely

on their carers capacity to accurately read and understand their behaviour in the absence of verbal ability to explain what they are experiencing.

Therapeutic Change

Heard (1982) addressed care seeking and care giving in older children and adults and considered behaviours that could be readily observed when these are ineffective. He argues that all people have a need to create meaning in their lives and considers this need to be met by exploring both our physical and emotional world. This exploration can be inhibited in two ways, imposing care-giving that prevents exploration or attachment behaviour been aroused in response to physical or psychological threat. This concept can be related to the relationship between a severely disabled adult and their primary caregiver. The care provider has the capacity to facilitate and support by providing both a safe haven to access in times of distress and a secure base from which to explore the environment. This, according to Heard, will assist in the creation of meaning in the lives of these individuals and thereby increase their sense of identify and security. These supportive relationships are essential to people with learning disabilities especially as children and adults with learning disabilities have few relationships (Murphy, 1992). They continue to experience social isolation throughout their lives with the social network getting even smaller as they get older (Grant, 1993). This situation is exacerbated for those individuals who have spent their formative years in an institutional setting with no contact from stable family members and it is now recognised that these institutions were not conducive to emotional development primarily due to the lack of stability. Clegg (1995) identified one study conducted by Stephenson and Robertson (1972) that identified a ward for 20 children with severe learning disabilities who had 89 different members of nursing staff providing care over a three year period. However, fortunately more recent service developments have increased staff stability with an estimated quarter of community residential staff leaving annually (Allan et al, 1990). This is an important development in terms of providing the capacity, for those that need it, to develop personal and secure relationships with staff. This will lead to an appeasement in arrested emotional development and offer the opportunity to step out of the cycle of destructive relationship patterns that may have developed over time and circumstances. However, this type of approach also places staff in these residential homes under substantial pressure both professionally and personally (Clegg, 1995).

Currently an estimated 37 percent of people with learning disabilities live in accommodation supported by members of paid staff (Kavanagh and O'pitt, 1999). A great deal of literature relates to the relationship between staff stress levels and challenging behaviours. Stress, as one of the most important predictive factors in the ability to provide adequate care to this population (Sharrard, 1992) highlights the necessity to put practises into place that reduce the level of stress experienced. The dynamics of residential care homes can sometimes be thought about in terms of the client (or staff!) projecting their feelings related to previous care relationships. Staff can and often do become the recipients of these projections (Sheppard, 1997). Furthermore the staff may vulnerabilities relating back to their own experience of past relationships, as was discussed above, making it very difficult for them to contain their own feelings. Moylan (1994) suggests that when emotional or physical pain is too great for service users they get rid of these feeling by projecting them onto a staff member - this can overwhelm staff who will in turn project the feeling onto someone else. Moylan (1994) suggests that when this occurs the entire organisation can

become embroiled in the distressed state of mind of the service user's experience. It is important that the level of stress projected by the client is understood and accepted by members of staff to avoid locating all of the difficulty in the client without adequate attention being paid to the possible sources of his/her distress. Hastings (1998) investigated staff attitudes and emotional reactions and concluded that providing training for staff helps to modify attitudes – in this study after training staff were less likely to attribute challenging behaviour to personality traits and are more likely to consider environmental factors and past experiences. Sheppard (1997) suggests that the feeling the staff experience can perhaps be used in a therapeutic environment to get a better understanding and provide an insight into what the client may be experiencing. By helping the staff to think about the client's internal world and their psychosocial development through discussion of past history and previous attachment relationships, a deeper understanding of the service users current emotional functioning can be achieved (Sheppard, 1997). This will facilitate effective and appropriate problem solving rather than resorting to avoidance and despair (Sheppard, 1997), which will inadvertently remove the security of a safe haven when perhaps the service user requires it the most.

Interest in interventions which foster emotional development is beginning to grow (Clegg, 1995). Some of these interventions focus directly on the client with the fundamental premise being to educate the individual about his/her early attachment experiences and psychosocial difficulties giving the message 'We understand how you got to be this way and can help you' within appropriate boundaries (Howe, 2003). However this approach poses a number of difficulties. Firstly, comprehension and communication skills within this population may create difficulties in accessing emotions. Secondly, for many of these individuals being alone with one person and been given their undivided attention is such a foreign experience for some individuals that they reject the intensity of the relationship (Clegg, 1995). Therefore, another source of intervention is sometimes used and perhaps is always necessary if real change is to occur. This comes in the form of focusing on helping the carer to change. If carers have the knowledge and capacity to think about and tolerate the pain and reality of the suffering and circumstances, then the client is more likely to take in or introject this capacity (Hodges, 1997) and therefore feel secure and participate in more independent exploratory behaviour. Clegg (1995) points out the importance of identifying someone who is able to change the way they relate to clients and also robust enough to be able to meet distress without defending themselves from it.

Clegg et al (1995) outlined a number of important points in the facilitation of change following the application of the attachment framework to three enmeshed relationships between learning disabled clients and their carers. In addition to the above interventions the authors suggested introducing carers to Rogerian counselling as a vehicle for enacting attachment concepts although the intensity of this approach maybe too demanding for one carer to carry alone. If this is the case, these authors suggest a team approach with a closely shared understanding and a frequently changing support role within the group members so the client can understand and predict the shape of the support being offered. These authors also identify the necessity for new staff to understand the client's potential for becoming enmeshed and to alert them to any signs of an inappropriate attachment developing. By addressing the negative experiences originating in the carers working relationships greater sensitivity to the emotional world of the client and better care is provided.

These authors identified these interventions yielding significant client change in three areas, reduction in anger and distress, increased exploration of physical and intellectual environment and an increase in the number of people in whom the client related.

Finally an obvious point of discussion in the context of repeated relationship transitions and therapeutic input is separation and loss. The level of staff turn over and the movement of service users through a series of residential homes make this a frequent reality. Clegg et al (1995) identified long term responsibilities for professionals who become involved in attachment work. The authors concede that while some staff turn over will be necessary they advocate the clients need for support taking priority when the person who has worked with them is leaving. Care must be taken to provide preparation to both parties and to provide the client with an alternative person who might become an attachment figure. This concept can be similarly used with the frequently occurring difficulty of enmeshed relationships, which become self sustaining and resist all other change Clegg and colleagues suggest a separation that is not permanent but includes informal contact to retain a level of stability.

Conclusion

Relationship difficulties are generally more likely to occur in this population than in the normal population. Clegg (1995) identifies the reason behind this to be multifarious factors which make parent infant bonding difficult in the very beginning and because of patterns of residential services provided in the past were not conducive to emotional development and secure attachments. Attachment theory provides us with a way to understand the past and present interactions between dyads where one member is temporarily or permanently stronger and wiser than the other (Clegg et al 1995). The current climate of change within learning disabilities is moving towards more stable staffing and as a result is creating better opportunities for emotional development and secure attachments. However, this change is also bringing with it a plethora of difficulties for both staff and service users. If these problems are addressed successfully both clients and staff can be assisted towards emotional growth and as indicated above this is likely to benefit the entire service. However, in order to achieve this, time, financial resources and emotional energy will need to be dedicated to this cause. Some implications for therapy have been identified and discussed but further research into this area is required. The clinical implications of attachment theory need to be subjected to more rigorous examination directly within the severely LD population widening the focus to those who are not currently displaying distress.

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Small Scale Service Related Research Project

**Exploring Clinical Psychologists perspective on Continuing Professional
Development: Report of a Focus Group**

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Abstract

Background: In 2000 the British Psychological Society voted to make the undertaking of CPD obligatory for all chartered psychologists who were currently working within the general public (BPS, 2000). The University of Hertfordshire have recently elected to take some of the responsibility for the provision of CPD activities in Hertfordshire and Essex. Following a discussion with a member of the course team it became apparent that no formal data had been identified on the CPD needs within Hertfordshire or Essex resulting in inconsistency in both content and quality of CPD provision

Aim: The was a qualitative study designed to identify current CPD practises and availability and future training needs and priorities for clinical psychologists in Hertfordshire and Essex NHS trusts.

Method: In line with the British Psychological Society guidelines on clinical psychology workforce planning a 'needs based approach' was adopted. Focus Groups were conducted with a selection of clinical psychologists and the transcripts were analysed to identify major categories and key themes

Results: This project generated a significant amount of information about the current and future CPD needs of clinical psychologists in both Hertfordshire and Essex. It produced a number of clear directions for further investigation and highlighted specific information in a number of areas including current barriers to CPD and factors that contribute to good CPD.

Conclusion: The findings of this report have provided a valuable contribution to the current knowledge of CPD. This knowledge will be used to inform both the direction of future research and the planning and implementation of CPD activities in Hertfordshire and Essex.

2.0 Background

Clinical Psychology is a distinct profession involving the provision of healthcare to the general public. In theory clinical psychology addresses the psychological aspects of healthcare with approaches grounded in the Scientist Practitioner Model. This model is invariably talked about as the key to the values, competencies and contributions of the profession and is therefore considered by many clinical psychologists as the golden standard of our profession (Shapiro, 2002). The origins of this model can be traced back to the Boulder Conference on Graduate Education in Clinical Psychology in 1949 (Benjamin & Baker, 2000). This conference emphasised with vigour the value and necessity of applying the findings and methods of scientific psychological studies to clinical practice but offered little information as to the means of bridging the gap between these two poles. The other major model of working within the profession of psychology is the Reflective Practitioner Model which focuses more on Kantian subjectivity and is essentially incompatible with the scientist practitioner model grounded in objective empiricism. This incompatibility highlights one of the key issues in both the training and CPD needs of clinical psychologists—begging the age old question of reflective versus scientific.

We are currently at a point where although neither of these two models of working have been universally accepted by the psychological profession we are slowly acknowledging that 'clinical psychologists have an obligation to the public and to the profession to maintain and develop their professional competence throughout their working lives (DCP Professional Practice Guidelines, 1995). Although this policy had been identified for a number of years it was not until 2000 that the British Psychological Society (BPS) voted to make the undertaking of continuing professional development (CPD) obligatory for all chartered applied psychologists who were currently working within the general public (BPS, 2003). The Department of Health's consultation paper 'Clinical Governance in the New NHS' defines CPD as a 'process of lifelong learning for all individuals and teams which meets the needs of patients and delivers the health outcomes and healthcare priorities of the NHS, and which enables professionals to expand and fulfil their potential' (DoH, 1999). In order for all applied psychologists to receive their annual practising certificate, they have to submit evidence of their participation in CPD. This involves a minimum of

**Exploring Clinical Psychologists perspective on Continuing Professional Development:
Report of a Focus Group**

40 hours per year for clinical psychologists. These guidelines are placing significant pressure on the profession to coordinate the provision and implementation of such activities.

CPD has evolved legitimately as a concept over the past 15 years as the practise and evaluation of CPD seeks to define and quantify the ambiguous concepts of skills, knowledge and ability (Daiches et al, 2006). In the current climate, and in the mist of BPS stipulations of mandatory CPD, meaningfully defining and recording of CPD activities has become fundamental. And although the 'scientist practitioner model' may be reflected in the essence of CPD it encompasses much more then relating science to practise. It aims to map out a professionals growth and change in the context of broadening and development of roles and tasks (Daiches et al, 2006). In an age where accountability and responsibility is core, CPD has '*a reassuring ring to it*' (Golding and Gray, 2006) and must be practitioner based in order to meet the needs of both the individual services and individual professionals.

3.0 Aim of the study

The British Psychological Society's guidelines (2000) aim to provide guidance that will facilitate the CPD of all psychologists. The process must incorporate identification of needs, action, reflection and implementation in a structured and meaningful way (Kiemle, 2006). The University of Hertfordshire have recently elected to take some responsibility for the provision of CPD activities in the Hertfordshire and Essex area. Following a discussion with a member of the course team it became apparent that the CPD needs of clinical psychologists in Hertfordshire and Essex had never been formally identified, reflected upon or co-ordinated resulting in inconsistency in both the content and quality of CPD provision.

The present study was conducted with two primary aims in mind

1. To identify current CPD practises and availability
2. To identify future training needs and CPD priority for clinical psychologists in Hertfordshire and Essex NHS trusts

4.0 Ethical Approval

Ethical approval was sought and obtained from the Hertfordshire 2 REC (See Appendix 1).

5.0 Methodology

5.1 Design

This project was conducted in two parts.

Part 1

Part one was a postal survey. The 'Clinical Psychology Continuing Professional Development Survey', developed by Laura Golding (2003) (see appendix 8). The results of this survey will be presented in another report and will be available from the University of Hertfordshire (Rudge, R. (2006))

Part 2

Following the return of the questionnaires participants were sent a postal invitation. This invited them to attend a focus group. The invitations (See Appendix 4) were sent three weeks prior to the focus group. They were provided with an information sheet (See Appendix 3) outlining the purpose of the study and a stamped addressed envelope to return the slip at the bottom of the page to confirm their attendance. Two focus groups were held in total.

5.2 Participants

Participants for this study were identified through the University of Hertfordshire's Doctorate in Clinical Psychology Course. The doctorate course holds a register of clinical psychologists who provide supervision for the clinical psychology trainees and are located in Hertfordshire and Essex. As the clinical psychology trainees must do core placements in child and adolescent, adult mental health, older adults and learning disabilities it was thought that accessing clinical psychologists through this domain would provide participation representing a varied number of services. 79 clinical psychologist supervisors were identified and invited to attend one of the focus groups. 2 clinical psychologists attended the first focus group and seven clinical psychologists attended the second. They took place on the 8th of February and the 27th of February respectively.

Composition of the focus groups

Focus Group 1	Older Adult Service	Team Manager x 1 A grade psychologist x 1
Focus Group 2	Learning Disabilities Service	Team Manager x 1 B grade psychologists x 3 A grade psychologists x 3

5.3 Focus Group Methodology

A focus group is a carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment (Krueger & Casey, 2000). They typically involve people who possess certain characteristics and provide qualitative data in a focused discussion to help understand the topic of interest. The focus group is mediated by a facilitator who is there to ask questions, listen, keep the conversation on track, and make sure everyone has a chance to share (Krueger & Casey, 2000).

5.4 Focus Group Format

The focus group was scheduled to last approximately one hour and took place in two NHS settings. The aim of this group was to investigate in more detail than the questionnaire permitted in two identified areas:

1. Current CPD practise and availability
2. Future CPD needs

The questions used to facilitate the group were agreed among the research team prior to the group taking place (See appendix 2). Open ended questions were used to encourage explanations and descriptions (Kruger & Casey, 2000).

The two groups were facilitated by a trainee clinical psychologist. Participants were assured that all of their individual comments would be anonymous and that neither they nor their services would be identifiable from the data analysis. All of the participants signed consent forms (See Appendix 5) on the day prior to the group

beginning including their written consent for the group discussion to be audio-taped. In addition another trainee clinical psychologist took notes of the group discussion. The audiotapes in conjunction with the notes were transcribed. The transcript (See Appendix 6) then formed the basis of a qualitative analysis of the data.

5.5 Analysis of Focus Group

The transcript was analysed by a trainee clinical psychologist. Analysis involved reading and rereading the transcripts of the focus groups to identify the main themes emerging. The text was sectioned into categories based on the format used to facilitate the focus group. The key themes were discussed with the chief supervisor before the final decisions were made (See Appendix 7).

6.0 Results

Table one lists the main categories and themes that emerged from the focus group. The main themes arising from the group are illustrated by quotes from the participants in the appendix (See Appendix 7). A selection of these shall be included in the next section.

Table 1 Categories and Themes emerging from the focus groups

Category 1 : Identifying Current CPD Practise and Availability

Theme	Definition
What is CPD	General comments on how people understand CPD
Access to CPD	Procedure involved in accessing/organising CPD
Barriers to CPD	What things are currently preventing individuals from accessing CPD

Category 2: Identifying Future CPD needs

Theme	Definition
Choosing CPD	What's important in choosing CPD activities
Relevance of CPD	What areas in CPD are considered the most important to clinicians
Setting up CPD	What is important in setting up CPD activities

6.1 Current CPD practise and availability

6.1.1 What is CPD

Firstly and interestingly despite the BPS now stipulating that the undertaking of CPD is obligatory for all chartered applied psychologists (BPS, 2003) there were mixed responses on what exactly CPD constituted.

'I suppose the first thing is that I am not entirely sure what CPD means'

Many of the group participants felt that it was something that was integral to the job of clinical psychology. They felt it was imperative to maintaining clinical standards and many of them were pleased that it was now protected by the BPS.

'it must be an integral part of the job and is there to maintain standards...and ensure high quality service'

'I think it is good that it is recognised as part of our job and is protected'

The range of activities that constituted CPD were discussed. There was a general consensus among the group members that it was not made up of a single element (i.e. courses and conferences) but covered a much broader range of activities including reading, supervision, challenges and group discussions.

'there is a tendency to see CPD as courses and it is much boarder then that its about the type of challenges you face and the types of tasks you undertake to develop your own personal skills'

'The way I understand it is that it involves on the one hand supervision and on the other hand the development of knowledge and theories around the work that you are doing'

The current nebulous nature of CPD was also reflected in a focus group conducted with service managers by Golding (2003), throughout this group participants expressed some uncertainty about what CPD is in practise or how it could be structured within their services.

6.1.2 Access to CPD

A number of different methods can be employed to aid the process of identifying CPD needs, such as informal discussion with colleagues or in a more formal relationship, with one's professional line manager. Participants generally felt that the process of accessing and identifying CPD needs were good. They generally occurred in the context of current clinical or professional activity. Many identified formal methods such as appraisals or formal discussions as the most accessible means although informal discussion with managers was also identified.

'another forum you can take this to is the individual performance review which I had at the end of my first year and one of the needs identified at that point was ...'

'in supervision the decision was made...'

'some things are put together within the department and made available to everyone'

This was in contrast to the survey of CPD needs conducted by Golding (2003) where only 31 out of 224 clinicians identified the formal appraisal process as one of the three main factors that encouraged them to participate in CPD activities. While 79% of the respondents were involved in the appraisal process, only 17% were finding that it was a cornerstone in their CPD activity (Golding, 2003). This, in conjunction with the 21% of those who did not have appraisal systems in place suggest that the government emphasis on appraisals has not yet filtered through the profession (Daiches et al, 2006). The evidence suggests therefore, that although formal appraisal systems do have a role to play in the CPD activities of clinical psychologists it is not universally celebrated. Some attention should be paid to the development of a system that reflects both the needs of the service and the individual to make both accessibility and monitoring of CPD activities more accessible.

6.1.3 Barriers to CPD

Participants generally felt that 'lack of time' created substantial difficulties in undertaking CPD. They felt that they could attend the CPD event but this would place more pressure on the individual because the demands of work did not accommodate this.

'my department were very keen for me to incorporate this into my time but individually for me it has been really difficult- my job is very pressured and I have very little time as it is'

'I agree it's a double edged sword on the one hand you really want to do it but on the other hand the job is very unforgiving and its all extra'

There was also the feeling that some trusts made an effort to accommodate this but there was a belief that this was not always the case

'In this service we manage to protect some time for CPD but I think perhaps this may be a novelty'

'some psychologists are managed by CMHT managers who are not necessarily psychologists and they have quite a different view of how much CPD you should be going on'

'the training budget can be the first things to be cut, this is very tempting but this can destroy the business I have certainly seen this before and over five years the entire staff left'

With a further suggestion that clinical psychologists need to be more pro-active and assertive in accessing time and space for CPD

'Maybe psychologists need to get more assertive and negotiate a bit more'

This is similar to the outcome found by Golding (2003) who reported that 40% of the respondents to the CPD survey identified time restraints to be particularly difficult in maintaining appropriate levels of CPD. Furthermore, Knight and Devonshire (1996) found that over the half the respondents to their survey of CPD identified that the time allocated to CPD was 'not adequate' to meet the mandatory amount of CPD.

Interestingly money was not raised as a major issue in accessing CPD with the exception of some concerns that recent cuts in budgets will impact on this.

'the access of money was not a problem for me but this course was not an expensive course'

'We are having this conversation in a climate of a lot of worries about financial situation ... and for me there is a bit anxiety about CPD and how it will be funded'

This is in contrast to the findings by Golding (2003) where over half of the respondents stated that limited funding was available. This is an important issue. In order for CPD needs to be met equally across clinical psychology there is a necessity

for clear structures and plans to be implemented to establish and maintain a standard level of financial support.

6.2 Future of CPD

6.2.1 Choosing CPD

In terms of future CPD there was a strong consensus that individuals would prefer to attend CPD that was delivered by a well known and eminent speaker from a well known institution. This was referred to by some participants as the 'brand of CPD'.

'People have fantasy about where Freud and Klein have gone'

'You buy quality like 'everybody loves the Tavi' it goes on your CV and people know what it means it's a bit like buying a brand'

'for me it's a pain now to go to London so I would probably do something local but I would miss the branded institutions'

The group also raised the idea that these 'branded institutions' were well marketed and presented to the psychological community thus attracting both eminent speakers and psychologists to attend these events.

'Having come from another country and having to establish my credentials in the UK it was more useful to go to courses that were well known – this establishes a certain standard and I suppose makes them very marketable'

'It's important to remember that those courses are marketed really well'

Participants would generally prefer CPD to be available locally but there appeared to be a contention about the convenience of locally over the quality of the courses/conferences being delivered. One team manager made reference to the fact that courses in this area are relatively new and the tendency individuals have towards establishments that are more familiar. This highlights a particularly difficult hurdle for Hertfordshire and Essex to overcome in the immediate future as both the University of Hertfordshire and the University of Essex doctoral courses in clinical psychology are relatively new, five years and one year respectively.

'It would be marvellous for all of us if the courses were available locally'

'I think locally would be a preference but it would depend on who was delivering the course'

'if you have a choice of hearing someone who is well known in the field I am much more likely to attend that but if these people could come locally that would be fabulous'

'courses are very young locally there is not much in terms of courses that have been running for a long time this is one of the attraction of the longer running London courses – like if you were choosing a CBT training course there are lots of them across the country but you tend to gravitate towards the one you have heard about like oxford or the institute'

6.2.2 Relevance of CPD

Many participants identified supervision/mentoring as one of the most important areas in CPD with a general feeling that this was imperative to our job as clinical psychologists.

'Supervision and personal development are the most important things for all individuals – you need to have a way to reflect on your work otherwise you are not doing your job properly'

'in relation to self awareness I think a mentoring programme where you pay a bit and the department pay a bit for external supervision where it is completely independent and you are buying the time in some ways I think this is the best form of CPD'

There appears to be a general consensus nationally that supervision needs are central to the CPD. Carr (1996) identified supervision as a prominent feature of CPD needs following a survey of CPD needs of clinical psychologists in Ireland. Green and Youngson (2003) stated that *'the opportunity that the supervisory relationship offers for systemic and considered reflection with a respected colleague comes the potential to improve practise in other realms'* and is thus imperative to CPD needs. Diaches (2006) highlighted the importance for supervision to be recognised as a key CPD activity and not secondary to workshops and courses. This trend was also echoed in the survey conducted by Golding (2003) with 101 individuals rating supervision as one of their top five CPD needs, while only 38 put attending courses/conferences in the same category. This finding would appear to suggest that the provision of supervision is the most highly regarded form of CBT and as Diaches (2006) noted supervision training is currently only provided in relation to trainee clinical psychologists and only limited regard has been paid to training in supervision post qualification. Perhaps in due course more guidance will be provided in this area responding to the needs identified by the individuals working within this profession.

There was some conflict in the current study about the allocation of CPD time and resources to areas that are applicable to all clinical psychologists to the detriment of

individual special interests. The consensus was that this would make sense in theory but was not a favourable option for all members of this group.

I think a generic updating of key intervention skills and core clinical skills should be focused on'

'Should this take priority? The honest answer is no I want to do my own thing but the PC answer is yes they should but if this means I can't do the courses I select for myself this creates a conflict'

'Ideally yes but this would take the funding away from more specialised areas and that would be difficult'

'there is a difference between essential and non essential CPD because I think we all want to read things and go to one day conferences that might enhance our skills but will not impact greatly on the service we work for'

Historically, the individual's perceived career needs and personal interests would have taken priority in the CPD activities available (Daiches et al, 2006). In 1992 Hayes asked individuals to rate the importance of their own CPD and found that 'the needs of the individual were paramount'. More recently, however, the emphasis appears to have shifted to create a more level playing field. The DoH (1998) defines CPD as a process of 'lifelong learning for all individuals and teams which meets the needs of patients and delivers the health outcomes of the NHS and enables professionals to expand and fulfil their potential'. This was also evident from the focus group with service managers conducted by Golding (2003) who quoted a typical comment being 'I wouldn't pay for my staff to do something if I couldn't see the relevance for the service or the relevance for someone's long term career development'. This highlights the necessity to focus on the development of some formal guidelines to direct the future of CPD in terms of benefits for both the services and the individual.

6.2.3 Setting up CPD

The elements that were identified in the current study as important in setting up CPD activities were quite explicit. The majority of the participants agreed that it needed to be more 'needs lead' with one suggestion of a website that individuals would access to let their particular CPD requirements be known. Additional matters raised included adequate notification, time required and the location of the course, clear programme guides and the possibility of a training calendar.

'a website that may be responsive to whatever the flavour (topic) of the month is, it would be a really good interactive way of planning.... And it would be a reflection of what was needed'

*'good because it would be needs lead as opposed to decisions from a few individuals'
'It might also lead to funding in terms of ... more information regarding needs being available'*

'Notification is crucial and also the amount of time we would devote and the location'

Specific areas identified for CPD have been included in the appendix (See Appendix 7). Generic refresher courses appeared to reach the approval of the whole group as beneficial with emphasis being based on the fact that you become very narrow in your vision/interests if you concentrate solely on one particular area of clinical psychology.

'Refresher course was like a new start for me it reintroduced me to stuff I had forgotten about'

'you tend to get tunnel vision on what your needs are and what the service requires but I agree that you need to know about other areas as well You lose track of this'

7.0 Summary of results

This project produced a number of clear directions for further investigation. It has generated a significant amount of information about the current and future Continuing Professional Development needs of clinical psychologists in both Hertfordshire and Essex. It provided information on:

- How clinical psychologists in Hertfordshire and Essex understand CPD
- The current availability of CPD
- Current barriers to CPD
- The future needs of CPD
- The factors that contribute to good CPD
- The elements that individuals consider important in setting up CPD activities

8.0 Clinical and service implications

The findings of this report in conjunction with the questionnaire will be used to inform future research and the implementation of CPD activities in Hertfordshire and Essex. As up to this point there has been very little information on the CPD needs of clinical psychologists, the information contained in this report and others will be used to guide the CPD policy in this region and to govern the strategy to maximise the support for regional clinical psychologists.

9.0 General Discussion

9.1 Study Limitations

There were a number of difficulties encountered during the process of this research. 79 clinical psychologists were invited to attend the focus group on the 15th of December 2005. The letters were sent to the participants three weeks prior to the focus group taking place. A response was attained from 5 of the 79 individuals contacted informing the research team of their inability to attend. No further responses were received and there a zero attendance rate on the 15th of December. The team discussed this matter and it was suggested that perhaps the timing of the planned focus group had been difficult for many clinical psychologists. Additionally, we also received feedback on one of the returned slips suggesting that sufficient time had not been allowed to incorporate the focus group into their schedule for that week. Furthermore, the planning of this focus group coincided with a crisis within the local healthcare economy, which is one of the most badly affected by the current financial hardship within the NHS. This will naturally reduce morale in the psychology teams affected, with the helplessness of the situation perhaps causing individuals to think that there is no point in thinking about CPD. The lack of attendance required the setting up of additional focus groups which was both time consuming and difficult to organise.

Numbers in the two focus groups varied from 2 to 7 participants and was limited to clinical psychologists representing learning disabilities and older adult services. We must remain mindful therefore, that responses may have differed substantially had a larger more heterogeneous sample being available. Consequently, the findings in the present study, although valuable, require further research involving larger samples and more lengthy discussions should funding become available. Additionally future research projects should also involve newly qualified clinical psychologists. The mythical concept that once trainees are qualified things will be different and they will become 'super psychologists' needs to be addressed (Latham & Toye, 2006). This is particularly pertinent for Hertfordshire and Essex who between them are now qualifying approximately 20 new clinical psychologists each year. Clare and Porter's survey (Clare and Porter, 2000) highlighted the need for doctoral clinical psychology training programmes to address the issues that arise from pre to post qualification.

The increase in autonomy, the supervisory role, the need to maintain and develop generic knowledge and skills in conjunction with the necessity to develop specialist knowledge and skills needs to be addressed and incorporated into any future study involving the investigation or allocation of CPD resources.

9.2 Group Process

Throughout the group there was generally a consensus on many of the issues that were raised. The group process was such that the first opinion to be expressed by an individual generally set the tone for that question, although there were some notable exceptions to this general observation, particularly related to the time management and the responsibility of CPD. Pre-existing group dynamics may have impacted upon disclosure on certain topics. It was noticed that the most junior members of staff were generally quieter, whilst the more senior members dominated the discussion. Attempts were made to draw the quieter members into the discussion or to seek clarification about a consensus reached on a particular topic under discussion. It is also noteworthy to mention that this type of research is subjective in nature in terms of the analysis of the data and pre-existing opinions held by the researcher may influence the results (Smith, 1995). The researcher made a conscious effort to be 'open to multiple realities' and this was likely to lessen any personal bias that may have impacted on reported results (Smith, 1995).

9.2 Conclusion

Despite the above limitations the data yielded in these focus groups is meaningful and will be particularly beneficial when it is used in conjunction with information collated in the questionnaire. This group allowed some of the fundamental themes of the questionnaire to be explored in more depth allowing much richer information to emerge about the key issues. It has provided us with a direction for both future research and practise in the area of CPD. This will ultimately improve the practise and career development of clinical psychologists in both Hertfordshire and Essex.

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Appendix 1: Letter of ethical Approval

Dea.

Full title of study: Evaluation of the Continuing Professional Development Needs of [redacted] and [redacted] clinical psychologists.
REC reference number: 05/Q0204/40

Thank you for your email of 25 August 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised. The data is to be stored for 3 years.

The Committee agreed with your declaration that this is a "no local investigator" study. Site-specific assessment is not required for sites involved in the research and no information about the study needs to be submitted to Local Research Ethics Committees. However, you should arrange for the R&D Departments of all relevant NHS care organisations to be notified that the research will be taking place before the research commences.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application	AB/48151/1	27 July 2005
Investigator CV		(None Specified)

Protocol	1	04 August 2005
Copy of Questionnaire	1	04 August 2005
Copy of Questionnaire	ii	25 August 2005
Participant Information Sheet	1	04 August 2005
Response to Request for Further Information	Email	25 August 2005

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Notification of other bodies

The Committee Administrator will notify the research sponsor that the study has a favourable ethical opinion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/Q0204/40

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project,

Yours sincerely

PP Jenny Austin

Mr David Grayson
Vice Chair

Email: jenny.austin@nhs.net

Copy to:

Enclosures:

Standard approval conditions

Appendix 2: Interview Schedule

Format of Focus Group

Introduction

Good Afternoon. Thank you all for taking the time to attend the discussion today on the Continuing Professional Development needs of clinical psychologists on X and X. My name is X and I am on the doctoral course located in UH. I would like to introduce X who is also on the UH course and will be assisting in our discussion today. The British Psychological Society (BPS) recently established a set of CPD requirements for qualified clinical psychologists which requires all clinical psychologists to submit evidence of their CPD activities on an annual basis to receive their practising certificate. Currently there is very little information on the CPD requirements of clinical psychologists in X and X. The primary function of today's discussion is to guide CPD policy in the region and to govern the strategy that will be executed by the regional CPD trainer (University of X) to maximise support for CPD of regional clinical psychologists. Additionally the focus group is forming part of a course requirement and shall be written up as a small scale research project.

You have all been invited here today because you are all qualified clinical psychologists currently in the position of offering supervision to current doctorate students. The function of this focus group is to gather further information about CPD needs within X and X. We want to consider what is currently available – its quality, accessibility, frequency. We also would like to consider what the CPD needs of X and X are for the future – topics for events, location of events, accessibility, and work attitude to CPD etc...

There are no right or wrong answers. We are interested in as many points of view as possible and would appreciate if you could share your point of view even if you feel it is different from that offered by everyone else. I would like you all to feel free to follow up on conversations of points of view initiated by other people agreeing or disagreeing.

We are recording the sessions because we do not want to miss any of the comments but no names will be included in the report and the comments will remain confidential. I would also like to request that that each member of this group also maintain confidentiality for each other.

My role as moderator will be to predominantly ask questions but also to ensure that everyone has the opportunity to offer their ideas and opinions. Therefore it may be necessary during the course of our discussion for me to halt a conversation in order to accommodate the opinion of other members of our discussion team. I will provide a brief summary of what I have heard at the end and then ask for help just to ensure that we have captured the most important points.

Please feel free to get more refreshments and perhaps we can make a start.

Sequence of Questions

Opening Question

Please tell us who you are and a little bit about how you maintain a work life balance?
I would like each of you to answer this question in turn.

Introductory Question

How did each of you feel when you learned that CPD requirements were going to be mandatory to you career as a clinical psychologist? (Good to identify where individuals stand in relation to CPD as a general theme)

Identifying current CPD Practise and Availability

1. How are the CPD needs of individual staff against CPD needs of their services managed in your service?
2. How are CPD needs identified? Is it a formal process – if so how does it work
3. Tell me about the current standard of CPD that is provided in this area (prompt – accessibility, frequency, applicability to clinical work)
4. Do you know any examples of CPD events either in this area or nationally that were good – (prompt – what was good about this, what was not so good about this)

Identifying Future CPD needs

1. What are the main areas you feel are not currently included in the CPD available? (**Follow up questions/prompts:** Are these areas directly related to your personal areas of work? Are there CPD areas that you consider to be important to all clinical psychologists to attend? Do you think the areas applicable to everybody should be prioritised over more specialised areas? How would you feel about that? What implications do you think that may have your professional life?)
2. What do you think are the important elements in setting up CPD activities in this area? (location, schedule at workplace, notification sooner)
3. How does work and the opinion of others impact on your ability to access CPD needs (managers, work load – how could this be improved, do you think this would work in practise, do time and money play a role in your place of work?)

Ending

Q to determine the final position of the participants
,suppose each of you had one minute to talk to the govern of CPD what would you say'

Provide summary followed by 'did I correctly describe what was said'

Insurance Q

Short overview of the purpose of the study – to facilitate the formation of a CPD programme located at UH to meet the needs of the clinical psychologists working in both X and X

‘is there anything we should have talked about or anything that you feel we should have covered or is there anything you came here today wishing to say but didn’t’

Appendix 3: Information Sheet

**Version (1) 22.08.2005
Information Sheet**

Study Title: Evaluation of Continuing Professional Development needs in X and X

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what the research will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to consider whether or not you wish to take part.

Thank you for reading this.

The British Psychological Society (BPS) recently established a set of CPD requirements for qualified clinical psychologists which will take effect from next year. A standard feature will require all clinical psychologists to submit evidence of their CPD activities on an annual basis to receive their practising certificate. Currently there is very little information on the CPD requirements of clinical psychologists in X and X. This research is required to guide CPD policy in the region and to govern the strategy that X Doctoral Programme as regional trainer provider to maximise support for CPD of regional clinical psychologists.

The research will focus on clinical psychologist supervisors within X and X

It is your decision whether or not to take part. If you do decide to take part you are still free to withdraw and without giving a reason. The questionnaire is anonymous and all information collected about you will be kept strictly confidential.

If you decide to take part you will be asked to complete the enclosed questionnaire. This questionnaire aims to identify the training needs and continuing professional development priorities of clinical psychologists working in X and X.

Objectives

- To evaluate the type and level of CPD currently available in X and X
- To develop recommendations for future CPD activity in X and X

The questionnaire consists of **three sections**.

Section 1: About You
Section 2: Your CPD Needs
Section 3: Your Job

The information collected shall be used to inform the future of CPD within X and X. All participants will be informed of the outcome of the research through an invitation to a meeting based at the University of X. The University of X shall be informed via a presentation given by the researchers. Participants shall be informed if the research is published, including information on how the research can be accessed.

Please complete the questionnaire and return it to the address below in the stamped addressed envelope provided as soon as possible.

XXXXXXXXXXXXX
School of Psychology
XXXXXXXXXX
XXXXXXXXXX

If you have any further questions, please telephone X (07970051449)
or X (07910283073).

Thank you for taking part in this study.

Appendix 4: Invitation

INVITATION

YOU ARE INVITED TO ATTEND A FOCUS GROUP TO DISCUSS THE CONTINUING PROFESSIONAL DEVELOPMENT NEEDS OF CLINICAL PSYCHOLOGISTS IN X AND X.

THIS WILL TAKE PLACE ON THURSDAY THE 15TH OF DECEMBER AT 4.00PM IN ROOM E374 AT THE UNVERISITY OF X, X. THE DISCUSSION WILL LAST APPROXIMATELY ONE HOUR.

PLEASE FIND DIRECTIONS AND A MAP OF THE UNIVERSITY ENCLOSED. REFRESHMENTS WILL BE PROVIDED.

PLEASE RETURN THE SLIP BELOW TO CONFIRM YOUR ATTENDANCE

NAME: _____

WILL BE ATTENDING THE FOCUS GROUP ON THE 15TH OF X AT 4.00PM IN THE UNIVERSITY OF X.

Appendix 5: Consent Form

Consent form

I give my informed consent to participate in this discussion related to continuing professional needs of clinical psychologists in X and X. I consent to the publication of study results as long as the information is anonymous so that no identification can be made. I further understand that the discussion today shall be recorded but the tape shall be confidential and will be accessible by the research team only. I have been informed that I am free to withdraw from the discussion at any point without any penalty of any kind.

If any of the above information is unclear please request clarification prior to signing below.

Name _____

Date _____

Appendix 6: Transcription of Focus Group

Transcription of Focus Group I

Basically what we want to talk about is a little bit about the current CPD practise so just things like needs of individual staff or yourself of the service you are working in at the moment

So am I talking about myself or the needs of the staff in the department as I see their needs

Well which ever you like really I suppose which ever you feel more comfortable talking about, perhaps if we start off thinking about the kinds of things you are accessing at the moment

I suppose as a first thing is that I am not entirely sure what CPD means? It seems to me that it is something that is much more in the frame then it ever used to be in psychology. So when I qualified which was about 18 months 2 years ago CPD was like a buzz word that we had to think about especially when we were looking for jobs in terms of if we wanted that to be part or our job description but certainly what we were understanding from the British psychological society was that CPD was very important and was up with things like clinical governance and stuff like that. The way that I understand it is that it involves on the one hand supervision but on the other hand keeping you hand in the development of knowledge and theories around the work that you are doing and with the knowledge skills framework that has come about that what your doing in your CPD is relevant to the clinical work that your doing in your job. So to that end in my first year of qualifying I was very much focused on getting good supervision in the work I was doing to develop my clinical skills and that was a big part of my CPD in my first year after qualifying and I had individual supervision for the two parts of the job that I did but I also attended a group supervision once a month which was on psychoanalytic theories of development because we got the opportunity to discuss papers about thinking about a client in those ways especially in regards to their development which a lot of people had said that they wanted to know more about especially in terms of the clients we were working with etc

How was that group organised was it a formal process or was it something that the colleagues in your department decided to put together themselves

It was in place when I came into this job and it was put together in the department for colleagues who were interested in that particular area but whom it was also relevant for but it was made available to all members of the department

One of the other things that I am interested in is how you and your colleagues would go about organising CPD that you needed in your job whether there is a formal process set up so you go to the manager or whether there is a system in place

There is yea during the first few months after I had started the job one of the CPD requirements of working in primary care was learning more about brief intervention and solution focused therapy so in supervision we made a decision that it would be of benefit to me to go on a solution focused therapy course and so in order to that I made enquiries to my line manager to find out whether there was the opportunity to do that and she said that there was so then I went off and made an application to addend the course but I think there is a certain level of responsibility for the individual to keep in touch with what courses are around Have a notion of what's around through email get on mailing lists and an idea of which places teach which courses and another forum to bring that to is the individual performance review which I had at the end of my first year and one of my needs that I identified at that point was working with people who had experienced trauma because that was something that was coming up constantly in my work with the CMHT and also in primary care ad so ii had looked around different course I could do. I feel like this was also a very individual thing about feeling very unskilled and not quite knowing what to do with people who were presenting with this and wanting to develop some knowledge about this. I looked around and identified a number of courses like CBT was one and in the end I choose on in the Tavi . this was a weekly course and at the end you get a CPD qualification ad its built into the course is different discussions of cases and learning about different models of trauma and discussing those and also experiential groups and some stuff about the effects of working with trauma in your work. It was very interesting and what attracted me to it was that it was very clinically based and much less about

having to write essays etc which would not have felt right for me in this time in my professional development

So it sounds like there is a pretty good set up there for accessing some of these courses. What about in terms of taking the time off work and accessing money to pay for these kinds of things

The access of money as not a problem for me it was available for the course granted it was not an expensive course and also there is the money for travel etc but it is possible to claim back on some of these expenses . The access of the money was just a case of asking my line manager if that was available and in my case there was not really a problem with that

What about taking the time off work

Taking the time off work was ok my department were very keen for me to incorporate this into my time I think individually it has been very difficult to incorporate this into my time. My jobs are very pressured and I have little time as it is and this really eats into my time especially in terms of the travel that is involved and I don't get back until 8.30 so it has been hard time wise but what I liked about doing the course is that it has forced me to take some time for CPD and make time for reading and academic pursuits which really enhances my clinical work providing me with time to think and reflect which I would not have done before all of my time would be spent on admin and clinical work rather than forcing myself to have that time but you have to squeeze everything in and be a lot more boundaries and it really creates a lot more pressure

I would agree with that it is almost like a double edged sword one the one hand you really want to do it the job requires it but on the other hand if the job is very unforgiving and it is then it is actually extra you are not fully released and different employers have different ways of doing this but you are not mentally released necessarily. It's also difficult you and I have split jobs for example and it's much harder with a split job in terms of who takes the hit and how you manage the effects of this. Sometimes it is easier in a single job because you only have one set of people to relate to as opposed to when its two sets of people what do you do you take two

hours out of here. What I tend to do is to go for the default the bit where you will get the least resistance but you try and balance it. I was wondering as well was whether I choose a CPD course because of its orientation or because it's a Tavi course or its an institute course. You buy quality like 'everyone loves the Tavi' like it goes on your CV and people know what that means it's a bit like buying a brand – just like branding and there is the difficulty between that and having something more local but not as prestigious . Like if there was something available locally like in Harlow higher college of education of UH or APU they all must run courses but would you really think about going or would you be more inclined to go to London for a similar course. I think for me now it's a pain to go to London so I would probably do something local or maybe something electronic but I would miss the group the courses I did at the Tavi the part I really enjoyed was the group discussions and the case discussions were really fantastic there is almost a mantle you adopt partly because it is an institute of learning and you know you are a set of clinicians and its a lot of discussions about the cold face clinical stuff and your discussing it with a group of professionals that are interested in the same thing

But its not necessarily psychologist just a bunch of therapists and when you go in there you kind of lose your role and this is very interesting as well

It seems like one of the things that probably both of you are saying is that time is an issue and having to travel to London do either of you have any experience of CPD requirements being met locally or what is available locally

Not much obviously the courses locally are quite young – there is not much in terms of courses that have been running for a long time for me this is one of the attractions of some of the London courses and oxford – they do a CBT course and there are lots of CBT courses across the country and lots of them are accredited but you tend to gravitate towards the ones you have heard about like oxford or the institute. I think you want to buy an established brand and its not that I think those courses are bad

But its important to remember that those courses are marketed well I mean the Tavi spends loads of money on sending out flyers constantly and that may be something to do with it as well

It's about the brand its not about programs it's the Tavi and its been around for along time and its got this famous history

Yea people have a fantasy about where Freud and Klein were

your right it is about brand and tavi represents a trusted brand hat almost in a sense a lot of the prime characters of CBT or neuroscience are working in these institutions. I was just wondering if someone really famous was working at a Uni I didn't know and it was relatively local I would seriously think about attending if it was someone I really wanted to hear but in the absence of that one tends to go for the recognised institutions

I think that is really true when I was doing my third year research I was really interested in attachment and they had conferences with Chinchitti and Critden and all those kind pf people and you immediately go for that because they are the people that have written papers on that kind of stuff and that was the kind of thing I want to go to at that time

I mean having come from another country and having to establish my credential s in the UK it was useful to go to courses that were well known like the Tavi – people know where it is and specific training it is recognised for. This establishes a certain standard and I suppose this what makes them very marketable

So in an attempt to summarise that a good CPD course would included good theory and practise combination, eminent writers within that field attached to a recognised institute that possibly do a lot of advertising with leaflets and your really aware of it

I think money is also a big factor. Like sometimes the trust put on training days and like if this is free then that would be good although I have found that the days organised by the trust are not very helpful – very general

I think they lack the academic edge that the London courses appear to have and a certain academic standard that is often not provided by the trust

Ok – I would like to move on now to thinking about future CPD needs

I think that goes back to what you were saying earlier about what you choose and the approach there is a lot of pressure on psychologists whether its true or not to develop skills in a particular way of working after they qualify sometimes just qualifying as a clinical psychologist is not enough like there a lot of people now who are working as CBT therapists who have completed the CBT accredited courses and has put into doubt the kind of training we get in clinical training although the DCP has stated that we are categorically sufficient at CBT but never the less there is something around to develop a new skill like in neuropsychology like its really required in this area that you have the specialised skills in this area. But there is limited scope you either become a CBT psychologist, a neuropsychologist,

I suppose the training is pretty generic and not focused on one thing but one of the key things is that you do have more flexibility and not stuck as a CBT therapist for the rest of your life but it is breath without so much depth. But I feel that people have moved from more orientation to more skilled stuff and we see the swap the most common training certainly when I was training was psychotherapy – people would do their three years training and then they would use as foundation for the first year of Tavi training for here to five years and that was the most common but this seems to have swapped to CBT and this has come on line and it is much faster but the row around CBT now was going on between clinical psych and psychoanalytic therapists. Neuro is seen as specialist but this is a little similar to medical training where you do a set of rotations very similar to the doctorate course but then once you start to specialise in one area and I think this is what is happening more in psychology people get interested in CBT or neuro and go off and do training and most of their stuff tends to be around that sort of area but they might go off and do a family training because there is so much family work involved in neuropsychology

Or group or CAT or psychodynamic

I think sometimes its tools for the job and other times I think it's an interest and commitment in particular theoretical orientation and pursuing that in any job. Like

someone who wants to work psychotherapeutically will get various qualifications in this field to use in conjunction with clinical psychologist and works with a number of different groups in this way. Or a neuropsychologist will work closely with MS - highly specialised attends conferences related to this

So you are suggesting that it is often quite niche but people do sometimes go off on tangents to areas that may be beneficial to their niche area or it might just be something that they are interested in

Yea I mean for me I did two short Tavi courses in the two areas of interest for me in LD and older people to get a different perspective because I am not psychoanalytically trained and it was useful to do this even though I was not necessarily going to practise it. But it was good to work with those type of people and also they were the forces I could afford they were cheaper which is very interesting with the Tavi which is a very successful teaching organisation there prices are good

Sometimes but I have been on a couple of one off days or primary care days and they always have a plenary at the end of the day and its complete rubbish like the first bit of the day is good with good speakers etc and then the final two hours of the day is filled with people feeding back and doing this plenary thing and they could have put a couple of more speakers in

Yea I find one day conferences like that really poor quality and some of them are really expensive and I agree I think you do get ripped off because its people talking to each other who would be talking anyway so it would be better to have a couple of extra speakers at the end . Would be better if they had a sum up at the end of some eminent

Moving away from niche areas – areas that are important to all areas of psychologists no matter what area they are in

I would say supervision and personal development are the most important for individuals because you need to find some way of reflecting on the work because otherwise you are not really doing your job properly are you

So do you think that things like supervision and personal development should be given priority because they are applicable to all clinical psychologists as opposed to pursuing more specialised kind of training?

Yea I think the self awareness bit is really important and I also think the applied science like a generic updating because you never do that within any one field but there may be key to skills because one of the problems that we have is that we are all of in our little hutches there are still key intervention skills that are still fairly shared are often talked about at a departmental level and core clinical skills and core things we know about the way people process information for example

In terms of work load and time do you think that those kinds of CPD needs that are applicable to all psychologists should take priority over offering specialised training locally particularly?

The honest answer would be no I want to do my own thing the correct PC answer is yes they should take priority but if it means I can't do my tavi course then this creates a conflict because I am aware of my CPD needs and I want the badge and want to go to do it not half as shiny as some sort of day on self awareness

Also the way presented is like this a day here and a day there and actually they usually haven't got enough time. Actually what I like I the mentoring some of the most valuable conversations I have had have been with colleagues or with senior people I really respect I either have a conversation with them or talk about a case – like self awareness stuff I really miss this – like a mentoring programme where you pay a bit and the department pay a bit for external supervision where it is completely independent and you are buying the time and in some ways I think this is the best form of CPD

Department paying a proportion of that and the individual paying a proportion of that

Yea because its personal development which we should pay for and professional development which the dept pays for and this could be anything from personal

therapy and more often than not almost professional coaching and time you can think about cases your independent like the course advisor confidential and does not leak back to anyone. However senior you are this does not get any less acute its very similar to the coaching models for big companies that sort of model but not so naff - but spending time with a senior experienced supervisor. I found this enormously useful . Much more informal arrangement – just call people up through contacts – old psychoanalytic – lost that much more in your face now – like trying to achieve something in a day. I avoid day courses especially plenary nice to hear about something but I still need the space to think about my patients

It sounds like what is being said is more like personal development and actual personal supervision around cases that you both benefit the most from as opposed to day conference or conferences generally.

Thinking about setting up CBT activity in this area what elements would be important – make it more conducive

Vulnerable adults – dragged out for four days – mandatory everyone has to attend pure rubbish

I am split in the trust sometimes nice to have a mixture of people because I have never really come across other types of therapists so it had been really interesting to listen to the way they work so people who have done therapeutic work but from a different orientation and listening to the way they see things and their experiences I find this quite helpful to do the discussions its interesting the different perspectives makes it more interesting sometimes when we a bunch of psychologists we just go around in circles

What other professions?

Well on the course I am on art, psychotherapists social worker, counselling psychologists and one with no clients at all – a manager

Yea this is good because I tend to be quite snooty about other professionals and I think it is good to have the opportunity to have the contact to build up respect I think

sometimes like with something highly specialised like neuro you need a lot of basic neuro-psychologist knowledge and a psychotherapist on that course would really struggle because there is a lot of technical stuff highly neuro-scientific and its also the gossip to talk about other professions

Like people have different idea of therapy like some people do not have any supervision and they think it's not important and this is us as psychologists what we have been socialised to like boundaries and frequency we see them can be really different

Like trauma see people for four hours – you think really issue but they often have success sometimes you thin what I do is mad other times you think I might take that on board its not a bad idea but its also things like swanning around the NHS and those private therapists are under a lot of pressure the insurance company will only pay for four sessions so therefore you need to cure me in that amount of time. We are pretty lucky we can see people for another couple of sessions in the NHS. We do have a very privileged position in some ways also important to remember. But useless CPD if you go externally you pay 400 quid and the locals pay much less this is really frustrating because they think this is the latest thing from the department of health and it's always the same

I steer clear of the political stuff – policies issues –

More important as you become more senior like QEA days put on CDP but it's because of my training hat other may do a managing course

I am doing a supervision course so that will be part of CPT and will benefit me

I think ~~that~~ raised a really valid point in order to get practising certificate you need to submit forty hours a week. And what I am wondering about are there things in the future around managers and whether they do put pillars I the ways of access to these things or whether you think that some changes can happen to things like workload because obviously there is a necessity for you to meet the targets for CPD

I am not sure how much of that will ever happen the trust is not that into CPD they would just say well you do the work. There is more being placed in our agenda for change contracts

Some psychologists are managed by cmht managers who are not necessarily psychologists and they have quite a different view of how much CPD you should be going on it's a different view. I mean quite lucky where I am because you might not have the same availability as you would have having a psychology manager there is no way of work loads being reduced how could that happen

We do have more formal leave then we used to have it used to be possibly now its related a little bit more to?. Maybe we need to just get more assertive and will have to negotiate a bit more. I have a friend in Staines and they have more time allocated but actually they have to pay a lot more themselves or this because its tough it's a board requirement and they just have to do it some of the lucky ones there are funds set up between groups of psychologists like in private practise and they often join practises and buy people in for the CPD

At any point in this service when it was stipulated that this criterion needed to be reached was it ever discussed formally in terms of organisation of this

No because the trust policy actually conflicts with the BPS policy so they are going to be on the forty hours business

The government have out across this policy that health professionals are meant to be interchangeable like have a set of tools that are interchangeable that is what they basically want . Individual identify is a bit difficult so in terms of the forty hours per week

The general feeling is that you are all going to have to work on it individually and the trust are not going to make huge changes in order to facilitate this

They are very risk aware.. if you stress me out and I go to an employment tribunal and can demonstrate lack of CPD in terms of contract that is actually much more serious –

and they have a minimum standard and a dim view would be taken if this standard was not being met

More lever there if it gets to this point

I speak to friends and colleagues and there is a disparity between trusts some don't do anything at all some just focus on clinical work and I don't think they have thought this through because that will have a potential effect

In London I remember one job being advertised with CPD being totally in house – no lee way.

One colleague on my course her funding was granted for the trauma course and then removed half way through and she had to pay for the other half from her own pocket she had not realised and that was because her trust was a bit like HPT

It seems soft money but this is a very short sighted way of seeing this – like the training budget is the first thing to be cut but it very tempting but it can destroy the business I have certainly seen this before and with over five years the entire staff left so it does not work

One final ending question – think about one minute to talk about the governs of CPD what would you say to them

I think it should be treated as essential the trust can benefit from it

Be flexible with what you advise perhaps

We fully recognise that money is limited but there us money n the budget somewhere but the problem is if you identify a CPD project it gets cut because it doesn't feel particularly equitable. Maybe taking things in turns the bigger the department

One final thought – one of the ways therapist will implement some new information is to send someone to the CPD event and they feedback to the team

In the case of the woman who is going to my trauma case she is the manager of a charity she is seeing clients privately and she has an army of therapists and I think her attend was absolutely disgusting I would say sometimes it would be useful to share it around so that different people go from the department and feedback I guess that would be more

As long as he/she attends decent course handout presentations, references list – like maybe if you could access these things from courses it would help. We have tried this a couple of times and it has worked quite well but the expectation needs to be set up you cannot just jump on somebody and expect them to relay the info they need to know in advance so they go as a representative as such but I think it is also got to do with quality of the course

Anything else

I think the branding I just realise just how commercial but it's true

I think it's the nice thing about courses the issue of branding is not an issues it really does not matter where you train as long as you get qualification and it's nice

Yea particularly for basic training but when you are selecting particular things that you want to pursue further it plays a bigger part – then its either product by the label or product by the institution

Transcript of Focus Group II

What do you understand about continuing professional development and what you thinking about it being mandatory now?

So what we understand CPD and what we think about the compulsory part

I think it must be an integral part of the job and I think it is there to maintain standards and I think in the type of work we are doing CPD plays an active role in ensuring high quality services

I think it is helpful that it is mandatory because it supports in ensuring that we are able to access it

I think it also equality across different psychologists because making it mandatory means there are standards and everyone will need to abide by them. I suppose it's having different standards according to what we think that we need so it's very helpful

It's about ensuring you are up to date with the best practise and the best evidence and so it can be quite wide ranging including research being published but also courses and developing techniques and getting the opportunity to practise those in a structured way supported supervision and that sort of thing. It can be very wide ranging and I think it is good that it is now a recognised part of our job and it is protected and we can out forward it supported bids to continue with this and we can carry this to the work force federation to do particular training and it is helpful that it is now recognised a part of us as professionals

So generally you think it is quite a positive thing that places everyone on a par so that

Ok thinking about how the needs of individual staff are met and how they are managed in this service

I think there is an issue of where the responsibility lies and I have always considered that my professional development is my business and I know it is also related t the organisational workforce to fund and facilitate this and provide money. So yea I think it is a both a personal and professional issue and needs to be balanced between the two. I think now with the emphasis on career needs to fulfilled. But it is also about your own personal development and your drive as a professional

I suppose the context in which it is discussed is between psychologists and their managers and the individual psychologist can then discuss what they are atheistic about and what they develop and can discuss how the service may benefit from this particular therapeutic intervention

I also think there is a procedure available through the working development plan where you can identify with your manager what your training needs are and how they actually link in to the needs of the service as well. I think there is a big balance between pursuing your own personal interests and those that are actually going to meet the needs of the service. And there times when there are course I would love to

go on but I know they are not going to develop my skills for the actual job that I do but my own personal and professional interests would be enhanced by doing this and I think we also need to think about who is responsible for that and I tend to think that if I want to do this I will pay for it so I am much more likely to fund this for myself

There are two sides to it your own personal future, your own personal career path and sometimes the ones you do yourself and the ones you pay for may be more relevant to you in the long run and then there is the bit that is relevant to the organisation that you are working for to promote and its about getting this right and where planning and development works well this should be able to be achieved

And the organisation has an interest in people skills and standards particularly more newly qualified staff as well as specific things where people are going and what their ambitions are the organisation is involved in this it is not a private matter

No its not private matter because if your professional skills are not updated then the quality of service is that much lower and the organisation goals may not be met necessarily that well so therefore CPD is very good for the population as a whole and also for the organisation . So more importantly the population will benefit from CPD

I think as well there is a tendency to see CPD as courses and it's so much broader then that it about the type of challenges you face the type of tasks you undertake to develop your own skills it's not what workshops are about

We are having this conversation in the climate of a lot of worries about the financial situation and the freeze on the trust over the next two years. For me this is a big anxiety about CPD and how it will be funded and what will happen

Yea because we have come out of the period where there was a real generosity on terms of what was available I think we will fell tension because it wouldn't be as generous as it has been

That for me just highlights the difference between essential and non essential CPD because I think perhaps we might all want to read things and go to one day conferences that might enhance our skills but will not impact greatly on the services we are providing but then there is the issue of services we want to set up and how this not happen unless we have an investment in CPD so in that case I think It is quite vital that we have the funding and the CPD is recognised because otherwise the services will not happen

Board spectrum not courses – what are the most important elements of CPD – things in particular that we need to be focusing on CPD

That's a really difficult one because it is different for each person and different for each service

There has always been a focus on CBT and the fact that CBT is the most researched and there is this current difficulty in HPT regarding EFT (emotional freedom technique) for example. Its almost like we know personally form the use of EFT that it has been quite useful with the current clients but it is very difficult to ask for money

v
for EFD training because there is no current recognition for the psychiatrists that it is good even as good as CBT. So to hone in on what is important personally in CPD is hard to pin point personally I feel that I would like to move towards a more recognised approach like CBT and try and solidity that and that is being a coward because it is more recognised by the psychiatrists and in LD we can use it for parents as well as other careers paid or unpaid. But it does take a lot of balance to try and find the best ones

For me it is very difficult to say which types of CPD I think is more important because I think you a balance between all of this and I cannot say which I think is more important

You need both reading and courses not just one or the other

Areas applicable to all clinical psychologists and should they be given priority in terms of the CPD training that would be provided

One of the areas that we have talked about before has been the idea of organisational issues and management issues and stuff like that you don't get a lot of this necessarily in training courses and as you go up the ladder of your career you need more of this

Yes this is a gap that we have identified

This is a thing that is important and understanding about how organisation works and the structure of things is really important and I think this across the board or maybe mental health clin psych do not need this and are just doing therapy but I think that they do because they will have to influence a great deal more then they are doing now

Other Areas

Supervision- we should have on going help and support with this in terms in terms of our own development

But there are quite a lot of courses that do this they courses and work shops for new supervisors

A lot work shop on formulation skills and things refresher core clinical skills I have done a couple of these in the last number of years and they are all really good and full of people who have just qualified and also those who have been around for many years and that worked really well just refreshing skills and making sure they are up to date. They are really good one day courses because it is so difficult to get two days off to do a two day course. Like we tried to do course here in MDIR and very few of us managed to get through the whole thing we need four days to digest and discuss them

A long time ago in my 30's I think I burnt out I was working part time and I had not had any manual input and there was a weeks course and it was termed a refresher and it not only covered your area like not just LD because I had just focused on LD and had sort of got completely cut off from everything else and the refresher course was like a new start for me because it reintroduced me to stuff I had forgotten about and I always

think there is a need for an intensive refresher and it's a bit of a luxury and you go and you hear about things that are happening in other areas but I suppose now it's a bit easier because you have the internet and you can hear about things more easily but that refresher was a really good thing for me in my life and I think a lot of people reach a stage where they are focused and you don't really hear about other things but I suppose its another thing of whether people will get freed up to do it or have the money to do it

I think a refresher would be good for individuals who have been off on maternity leave as well

I think we tend to focus more and more on what the service are and you tend to tunnel vision on what your needs are to what the service requires as well but I agreed that you need to also know about other areas are only last week we were talking bout how you lose track of mental issues and because we are working in the community and there is a lot of social input and how important it would be to have those refresher courses

So not specifically focused on individual niche areas but more of an overview

Time and being able to balance and whether services in general are accepting of this as something you need to go and do

I think in this service we manage to protect some time for CPD and I think perhaps this may be a novelty and we manage to agree to have days not for CPD especially but time in which you can develop your special interest which is great but I m not sure that this is available in other areas of the trust I am not sure that others have that protected time but at least there is an attempt to go in that direction

What about the idea of being able to take off a substantial amount of time like four days to complete a course

I think most people here have been able to complete something two days of psdesky and three days at the learning disability conference you have done your MSc this years and you have dine two - three day workshops so yea its not too bad

It's just quite difficult to get the space you have to be quite disciplined

Internal makes it easier but sometimes if it is internal it is easier to cancel I mean I have cancelled an external course sometimes but not very often

I think this relates back to the protected time for us I mean yea it is protected time but you can always cancel it is your own arrangement I think if it is a formal course it is harder and the same goes for reading and anything really that you don't have to commit to go somewhere else

So if it more internal it is easier to cancel because the boundaries are not so firm so I suppose it is easier to arrange and also easier to cancel

But something internal is harder to keep if it is external the trust may have paid for it or you may have paid or it yourself

There is a much bigger commitment if you are suppose to be going on a course and you have taken money for the trust for it and you get the encouragement to go where if it is a casual arrangement like a day on EMIR three is no loss of money and somebody is breathing down your neck to do the referral or whatever it is easier to cancel

What about what is available locally

Well locally in terms of time or locally in terms of the borough because one of the issues is that UH do courses up near Cambridge and stuff and that is a huge journey especially for someone who is living in the middle of London and is quite difficult to do. So locally needs to be defined

I think what we call locally in the trust is never very local in as much as it is a huge county. Things that concentrate in Hatfield or haberbury tends to be good for us but this concentration here is not necessarily easy for all people depending on where they work

Specialised area – two days designated to go would people go more for the prominent institute or similar courses running in a closer proximity would that influence where you would go

Oh yes that would be marvellous for all of us if the courses were available locally

I think for me I would be more attracted to the established institute

I think they would be a preference but this would depend on who was going to provide the course. I think it would be about who the person was as opposed to the institution

If you have the choice of hearing someone who is well known in the field I think I am much more likely to attend that but if these people could come locally then that would be fabulous

Future – areas that are not currently available through CPD

I would like to see more on social purpose stuff

Organisation stuff, consultancy skills

Training in tools that you need to do the job these training are hideously expensive like £600. Cases where I have not done the training but it would be an ideal tool to use within our service

Therapeutic intervention for individuals with X there is more happening but not great deal around that so we tend to adopt

Another area that is neglected is individuals with profound and multiple disability I have not done any training in this nor have I seen any training in this area

Sensory disabilities

What do you think funding should be prioritised for like niche areas or more generic skills like core clinical skills?

Ideally but this would leave less funding for more specialised

The balance is kind of tricky

Any suggestions for how this information would be collated

Like a website that may be responsive to whatever was the flavour of the month or the most popular option

I think that would be a really good interactive way of doing it planning for the next year and so on and it would be a bit reflective of what was needed

Yea we could identify where the majority of people wanted input like fifty percent of people feel rusty in this core area or an update in a new approach that needs to be addressed

This would be good because it would be more need lead as opposed to decisions by a few individuals

This might also lead to funding in terms of where it is applied depending on peoples needs so if there is more people needing core skills or more people needing specialised input would have more information regarding this

Yes like some of the one day things that have been done at the university have been fairly obscure and take a lot of absorbing. They are new and are stimulating to go to but I am not sure that they are that accessible – some are accessible and others are not like the interacting cognitive subsystems like advanced CBT

I didn't go because of the title

So more interaction in the decision would be good although that is not to say that those one day's are not useful and you get to hear about things that otherwise you may not

In terms of topics something around the law would be useful like defending your decisions in court – like expert witness or even witness of fact

Or another whole area is capacity to consent with the new capacity acts and the role of psychologists in that is massive and is a whole area which is actually developing because we are being asked more and more for capacity and this would be shared thing across a lot of disciplines

The same in terms of child protection like the new child s act states that we have an obligation to participate in child protection so it is another area that we don't know much about but we are going to e more and more implicated in these situations

And also the changing role of psychiatrists and how this will impact on psychologists and is an area we need to know more about it

Important elements in setting up CPD – location, schedule, notification

Notification is crucial the amount of time we have to devote and location bearing in mind that this is such a wide county so where they place courses will be very important

Maybe a training calendar that could be published like annually so you can choose and plan around.

I also thing the aims of the training course should be made really specific so you can decide whether it is relevant to you so that you can avoid things that are not because often titles can be misleading

One minute to talk to CPD what would you say

I think I would like them to know that it is about enhancing the services we provide and it is not about my personal needs as such but more about my professional needs to do my job which would then enhance the services the trust provides. It's about wanting to provide quality services but needing the support to do this

I would like them to recognise the protected time not just the financial time but focus on the fact that in order to provide the service we need the time available in order to do the CPD so it is as important as delivering in that sense

I would like clarification about funding because it is one thing the university giving something for free but it also needs to respond to those needs and it needs to be affordable and there needs to be a liaison with the services and with WDC to make it work properly

And another course that is beyond supervision and is nothing to do with courses it is something to do with mentoring maybe this could be set up so that individuals with skill in the area could mentor people who have that particular interest. Because sometimes you are at a loss to know who might be able to mentor in a particular area. It might be useful to have an outsider to talk to with a particular interest

Yea or its nice to have an external supervisor that you can go to because it helps clinicians that way

Other things

I thought about courses that build on each other instead of a one off perhaps a series of courses around the same area that develop skills

Also the DCP might be useful and perhaps you could organise joint lectures so it would be worth thinking about that

Maybe like a rolling training of different modules that are really substantial that are offered year on year

Appendix 7: Analysis of Focus Group

Analysis of Focus Group I and II – 08.02.06/27.02.06

Section 1

Identifying current CPD practise and availability

What is CPD

'I suppose the first thing is that I am not entirely sure what CPD means'

'The way I understand it is that it involves on the one hand supervision and on the other hand the development of knowledge and theories around the work that you are doing'

'we were understanding from the BPS that CPD was very important and was up with things like clinical governance and stuff like that'

'It must be an integral part of the job and is there is maintain standards..... and ensure high quality services'

'It is about ensuring that you are up to date with best practise and best evidence'

'I think it is good that it is a recognised as part of our job and is protected'

'there is a tendency to see CPD as courses and it is much broader then that its about the type of challenges you face and the types of task you undertake to develop your own personal skills'

'some psychologists are managed by CMHT managers who are not necessarily psychologists and they have quite a different view of how much CPD you should be going on'

'Its about enhancing the services we provide and it is not about personal needs'

Organisation/Access of CPD

'some things are put together within the department and made available to everyone'

'in supervision the decision was made that it would be of benefit to me to go on a solution focused therapy course- then I went off and made the application – there is a certain level of responsibility for the individual to keep in touch with what courses are around'

'Another forum you can take this to is the individual performance review which I had at the end of my first year and one of the needs I identified at that point was...'

'there is an issue of where the responsibility lies and I have always considered that my professional development is my business'

'I think locally would be a preference but it would depend on who was delivering the course'

'if you have a choice of hearing someone who is well known in the field I am much more likely to attend that but if these people could come locally that would be fabulous'

'If someone came to a local uni and it was someone I really wanted to hear I would think about going' (you need either the established institute or a very well known speaker)

'You buy quality like 'everybody loves the Tavi' it goes on your CV and people know what it means it's a bit like buying a brand'

'There is a difficulty between the prestigious and far away and the local but not as prestigious'

'for me it's a pain now to go to London so I would probably do something local but I would miss the branded institutions – the case discussions can be really fantastic there'

'courses are very young locally there is not much in terms of courses that have been running for a long time this is one of the attraction of the longer running London courses – like if you were choosing a CBT training course there are lots of them across the country but you tend to gravitate towards the one you have heard about like oxford or the institute'

'Its important to remember that those courses are marketed really well'

'its about brand its not about programmes'

'People have fantasy about where Freud and Klein have gone'

'Tavi represents a trusted brand'

'Having come from another country and having to establish my credentials in the uk it was more useful to go to courses that were well known – this establishes a certain standard and I suppose makes them very marketable'

Relevance of CPD

'Supervision and personal development are the most important things for all individuals – you need to have a way to reflect on your work otherwise you are not doing your job properly'

'yea I think the self awareness bit is really important'

' I think a generic updating of key intervention skills and core clinical skills should be focused on'

'Maybe psychologists need to get more assertive and negotiate a bit more'

'the training budget can be the first things to be cut, this is very tempting but this can destroy the business I have certainly seen this before and over five years the entire staff left'

'the access of money was not a problem for me but this course was not an expensive course'

'We are having this conversation in a climate of a lot of worries about financial situation ... and for me there is a bit anxiety about CPD and how it will be funded'

'We need clarification about funding because it is all very well the university giving something for free but it needs to respond to needs and needs to be affordable and there needs to be a liaison with the services to make it work properly'

Section 2

Identifying future CPD needs

'there is a lot of pressure for clinical psychologists to develop particular skills of working like there is a lot of people now who are working as CBT therapists who have completed the additional CBT course and this places some doubt on the training you get in clinical psychology doctorate'

'I feel that people have moved from orientation to more skilled stuff – swap from psychotherapy to CBT'

'I think sometimes people want the tools for the job and other times it is just an interest – like a neuropsychologist who specialises in MS will attend highly specialised conferences in this specialised area'

'yea I find one days conferences really poor quality – a lot of time is spent with people talking to one another who would be talking to one another anyway'

When choosing a CPD course – what's important

Local v's branding and prestige

'I think what we call locally in this trust is never very local in as much as X is a huge county'

'Locally needs to be further defined'

'It would be marvellous for all of us if the courses were available locally'

'I would be more attracted to the established institute'

'I think it is a personal and professional issue and needs to be balanced.... Emphasis on career needs need to be fulfilled but it is also about your drive as a professional'

'the context in which it is discussed is between the psychologist and their manager'

'I think there is also a procedure available through a working development plan where you identify with your manger what your training needs are'

'I also need to think about who is responsible for what and I think that if I want to do this (a course that will not develop my skills for the actual job) I will pay for it'

'There are two sides to your own personal future'

'its not a private matter because if your professional skills are not updated then the quality of service is much lower and the organisation goals may not be meet'

'The general feeling is that we are all going to have to work on it individually and the trust are not going to make huge changes to facilitate this'

'I speak to colleagues and there is a disparity between trusts some don't do anything at all just focus on clinical work'

Barriers to CPD

'my department were very keen for me to incorporate this into my time but individually for me it has been really difficult- my job is very pressured and I have very little time as it is'

' I agree it's a double edged sword on the one hand you really want to do it but on the other hand the job is very unforgiving and its all extra'

'its much harder with a split job in terms of who takes the hit and how you manage the effects of this easier in a single job because you just have one et of people to relate to'

'in this service (LD) we manage to protect some time for CPD but I think perhaps this may be a novelty'

'its quite difficult to get the space you have to quite disciplined'

'internal training makes it easier but sometimes if it is internal it is easier to cancel'

'internal is easier to arrange but also easier to cancel there is a much bigger commitment if you are supposed to be going on a course and you have taken money off the trust'

'some psychologists are managed by CMHT managers who are not necessarily psychologists and they have quite a different view of how much CPD you should be going on'

**Appendix 8: Clinical psychology Continuing Professional Development Survey
(Golding , 2003)**

Version ii (25.08.2005)

**CLINICAL PSYCHOLOGY CONTINUING PROFESSIONAL
DEVELOPMENT SURVEY**

This questionnaire aims to collect information about your Continuing Professional Development (CPD) needs. Please complete the form as indicated and feel free to add any additional comments. Please return the completed questionnaire in the enclosed FREEPOST envelope. Thank you.

Section 1: ABOUT YOU

1. Gender Male Female
2. Age _____
3. Specialism (major client group worked with) _____
4. Years working as a clinical psychologist? _____
- 5a. What Grade are you? (please circle) A B Other (please describe)

- 5b. What is your job title? _____
6. Where do you work? (please circle) X
X
- 7a. Are you a member of (please circle if yes) BPS DCP
- 7b. Are you a member of any other professional society? Yes No
If yes, please list

- 7c. Are you a Chartered Clinical Psychologist? Yes No
- 7d. Are you eligible for Chartered status? Yes No Don't know
8. Do you attend any clinical psychology special interest groups? Please state

Section 2: YOUR CPD NEEDS

9. What CPD activities did you undertake during 2004? (tick all that apply and give a description for each ticked category if possible)

- Reading relevant literature Example _____
- Attending training courses/workshops Example _____
- Visiting examples of good practice Example _____
- Research/audit/service evaluation Example _____
- Writing in order to publish Example _____
- Consulting or working with a colleague who has specialist knowledge Example _____
- Delivering courses or workshops Example _____
- Professional activity (e.g., attending SIG meetings, involvement on professional body committees etc.) Example _____
- Being supervised Example _____
- Supervising others Example _____
- Other (please state) Example _____

10. What are your five main CPD needs for the year 2005?

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____

11. Please give examples of any multidisciplinary CPD activity you undertook in 2004

12a. Please give examples of any good practice CPD activity you know about in the region

12b. Please give examples of any good practice CPD activity you know about nationally

13a. Do you have regular supervision?

Yes No If yes, how often? _____

13b. What type of supervision?

Peer Clinical Other

13c. Who do you have supervision with?

Clinical psychologist Other

14a. Do you have a regular appraisal/personal development plan?

Yes No

14b. When was your last appraisal/personal development plan meeting? _____

14c. At your last appraisal, were core competencies discussed?

Yes No Not sure

If yes, please specify _____

15a. Who did your last appraisal?

Clinical psychologist Other (please state) _____

15b. Is this likely to stay the same person over the next 12 months?

Yes No Don't know

16. What are the three main factors that encourage you to undertake CPD activities?

1. _____
2. _____
3. _____

17. What are the three main factors that stop you from undertaking CPD activities?

1. _____
2. _____
3. _____

18a. Approximately, how much money did your employer spend on your CPD needs in 2004?
(Include conferences, courses, books, journals etc.) _____

18b. Was this: Enough money? Needed more money?

18c. Approximately, how much money did you spend on your CPD needs in 2004? (Include conferences, courses, books, journals etc.) _____

18d. How much time did your employer allocate for your CPD activities in 2004? _____ days

18e. How much of your own time was spent on CPD activities in 2004? _____ days

- 19a. At work, do you have access to a PC? Yes No
- 19b. Do you share the PC with others? Yes No
- 19c. Is your PC at work networked?. Yes No
- 19d. At work, do you have access to e-mail? Yes No
- 19e. At work, do you have access to the Internet? Yes No
- 19f. At work, do you have your own e-mail address? Yes No
- 19g. At work, so you have any restrictions on your e-mail access? Yes No
- 19h. At work, so you have any restrictions on your Internet access? Yes No
- 19i. Do you have a printer at work? Yes No
- 19j. Do you use a home computer for work purposes? Yes No

20. Do you have any additional comments that you would like to make about CPD?

Section 3: YOUR JOB

21. How long have you been in your current post? _____

22. How long have you worked in:
 the NHS as a clinical psychologist? _____
 the local area as a clinical psychologist? _____

23. How many sessions are you contracted to work a week? _____

24. How likely are you to stay in your current job over the next 12 months?

1-----2-----3-----4-----5
 (unlikely) (very likely)

25. How likely are you to stay in the local area over the next 12 months?

1-----2-----3-----4-----5
 (unlikely) (very likely)

26. How likely are you to stay in the NHS over the next 12 months?

1-----2-----3-----4-----5
 (unlikely) (very likely)

27. Please rank, in order of importance, the following factors in terms of (a) importance in keeping you in your current job (b) importance in terms of your competence as a professional (1 = most important through to 14 = least important)

FACTOR	STAYING IN JOB	COMPETENCE
Cohesive psychology department		
Cohesive speciality		
Geography		
Good/regular supervision		
Head of department/service with a good reputation		
Head of speciality with a good reputation		
Opportunity for a split post		
Opportunities to work with a good team of professionals		
Post-qualification training opportunities and finance		
Promising/good career opportunities		
Research opportunities		
Speciality		
Spine point		
Other (please state)		

Thank you for completing this survey

Please add any additional comments you would like to make in the space below and then return the completed form in the enclosed FREEPOST envelope.

Parents with learning disabilities: Can they provide 'adequate
parenting'?

A review of the literature

27th October 2006

Word Count: 4838

Tamara Scully

Cohort IV

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Appendices

1. Search Strategy

1.0 Introduction

It is now recognised that people with learning disabilities (LD) share the same needs and desires as other people, the need to form friendships, to engage in sexual relations and in some cases to bear children (McGaw, 1998). However, people with learning disabilities were unable to participate in their full rights as citizens in the first half of the twentieth century (Murphy and Feldman, 2003). They were not considered able to vote, able to consent to sexual relationships or to become parents (Murphy and Feldman, 2003). However, with the introduction of the normalisation movement and the disability rights movement all of this began to change. The public began to accept the view that individuals with LD have equal rights to education, community living, sexual relationships, having children, employment and other aspects of normal everyday living in a democratic society. However, despite this acceptance, even today people with LD are frequently discouraged from entering sexual relationships. This is because of concerns of the families, carers or supporting professionals that the relationship may ultimately lead to pregnancy and children.

2.0 Learning disability

LD entails significantly sub average intellectual functioning (composite score of two standard deviations below the mean), with related skills deficits in adaptive functioning and a manifestation before the age of 18 years. It is currently estimated that approximately 20 people per 1,000 in the UK have LD (Hatton, 1998). Of this group it is estimated that 80% are in the mild category, 12% in the moderate with 7% and 1% falling into the severe and profound categories (Carr, 1999).

The majority of people with a LD who become parents are those with milder degrees of LD (Mufin-Veitch, 2003).

3.0 Epidemiology

The number of people with LD who are forming relationships and having children has steadily increased over the last twenty years (DH, 2001), but there are no precise figures available in the current population. Estimates in the UK continue to be debated but generally it is considered that a minimum of 250,000 parents in the UK may have LD (McGaw, 1996). The most recent statistics come from the first national survey of

adults with LD in England, where 1 in 15 of the 2,898 adults interviewed had children (Emerson et al, 2005).

4.0 Recent reviews and documents

There is now a considerable amount of literature covering the issues related to parenting for parents with LD. Particularly useful overviews included: Goodinge (2000), Feldman (1994), McGaw and Newman (2005), Tharleton, Ward, Howarth (2006), and Mirfin-Veitch (2003).

5.0 Focus of the current review

This review aims to summarise the core issues the research has identified in relation to parents with LD.

1. How do you define 'adequate parenting'?
2. What is the current representation of parents with LD in child care proceedings?
3. Can parents with LD provide adequate parenting?
4. What are the outcomes for children who have one or more parents with LD?
5. Is there a relationship between cognitive impairment and parental capacity?
6. What are the current governmental policies on supporting parents with LD?
7. Are social networks and partnerships important in the provision of 'adequate parenting'?

6.0 How do you define adequate parenting?

Parents with LD are expected to provide their children with the same standards as any individual who becomes a parent. However, it is difficult to provide a precise definition of adequate parenting and the literature highlights a lack of consistency and clarity (McGaw and Newman, 2005, Morgan and Goff, 2004). Although there is reasonably consensus, on what is important for child development, there is no agreement as to minimal standards of what constitutes 'adequate parenting'. Furthermore, there is a clear discrepancy in the literature between parent and professional views on parental adequacy (Llewellyn, 1991, Walton, Allen and Feldman, 1991). As Zetlin et al (1985) pointed out, families have their own standards of adequacy based on 'personal, cultural, and social class experience rather than some general normative criteria'. Booth and Booth (1996) suggest that the lack of

consensus leads practitioners and researchers alike to rely on their own subjective judgements when making decisions. Unfortunately, this echoes the typical tone of much of the anecdotal research in this area; it lacks empirical support and is burdened with value judgements.

Hayman (1990), writing in the Harvard Law Review, addresses the United States Legal Approach to parenting by persons with LD. He noted the absence of any 'legal consensus on the meaning of this term' and identified a number of common denominators when defining 'adequate parenting'. He suggested it is the provision of a safe, healthy, nurturing, and stimulating environment (Hayman, 1990). This definition is useful in terms of the courts who are often involved in child care proceeding involving both non learning disabled and learning disabled parents.

7.0 Care proceedings and parents with learning disabilities

It has been identified that parents with learning disabilities worldwide are anywhere between 40 and 60 times more likely to be the subject of a care order application than their number in the general population warrant (McConnell et al, 2004). 66% of parents with learning disabilities had one or more children taken into adoption as against 38% for all other families in the UK (Booth and Booth, 1994). The National Survey of Adults with Learning Difficulties in England identified 48% of parents with learning disabilities were not looking after their own children (Emerson, 2005).

Following a national review of services to support disabled adults in their parenting role, the SSI report (Goodinge, 2000) shows how parents are undermined by a 'professional knows best culture' characterised by insufficient knowledge, poor assessments, an over zealous attitude to risk, lack of awareness of disability equality issues, fragmented services, and serious shortcoming in service provision. Booth and Booth (2003) describe this as 'system abuse' where people are made worse off by the services that are supposed to help them. These authors describe it as *'rampant, pervasive and destruction of family life and far more prevalent than the child abuse whose prevention is so often cited as the reason for policing the families in the first place'*. The combination of professional assumptions, that presume parenting failure and neglect are inevitable and the lack of a precise definition provide a part

explanation of why the representation of these families is so high in court proceedings.

8.0 How effective is support for parents with LD?

The research clearly suggests that adequate support protects against breakdown (i.e. the family no longer staying together). It also identifies the kinds and durations of support that are effective with families headed up by parents with LD (Booth and Booth, 1996, McGaw, 2000). Basic training programmes have been provided with varying degrees of success in the areas of basic child care skills (Keltner, Wise and Taylor, 1999), safety in the home skills (Keltner et al, 1999, Tymchuk, Hamada, Andron and Anderson, 1993), child behaviour management (Downey and Skuse, 1993) and mother and child interaction of play skills (Downey and Skuse, 1993, Feldman, Sparks and Case, 1993, Keltner et al, 1999, Slater, 1986). In particular the training of mother-child interaction with very young children was shown to have very positive effects on the relationship between mother and child, while training parents to change abusive or neglectful parenting has had limited success (Downey and Skuse, 1993).

Feldman (1994) carried out a comprehensive review of parenting education programmes for parents with LD. The review identified twenty published papers with adequate outcome data. A total of 190 parents with learning disabilities were involved with IQ's ranging from 50-79. Parenting skills trained included basic child care, safety, nutrition, problem solving, positive child care interactions, and child behaviour management. The most common instructional approach was behavioural. The author concluded that initial training, follow up and social validity results were encouraging. The three studies (Feldman et al, 1992, 1993, Slater, 1986) that used between group designs found significant differences between training and no training control groups on parent target behaviours after training. The percentage improvement scores involved 84 parents and 57 different skills. Overall, across the 16 studies providing individual data, 96% of the parents showed improvements in one or more skills and improvements were noted in 66% of skills in training. Of the 19 studies that conducted follow up observations (ranging from 2-82 weeks) improvements were maintained in 92% of the parents and 55% of skills. Concerns remained regarding parents capacity to generalise their newly learned parenting skills

to all situations to which they were needed. Nine studies conducted generalisation probes, five of which reported individualised generalisation data. In these five studies improvements were noted in 14 of the 19 parents but only in 21% of skills. Additional narrative accounts of generalisation were identified in three studies but the author suggested caution given the lack of response generalisation reported by Bakken et al (1993) and Tymchuk et al (1992).

8.1 Effective parent education technology

Overall, Feldman's review illustrated that an effective parent education technology, designed specifically for these families, has emerged. The author illustrated that the best practise parenting education for parents with LD would involve specific skill assessment. This utilised direct observational techniques with an emphasis on performance based behavioural strategies such as task analysis, modelling, feedback and reinforcement. Feldman et al (1989) found that verbal instruction alone was not as effective as a full training package of instruction, modelling, corrective feedback and trainer praise in teaching affectionate and stimulating interactions. Watson-Perczel, Lutzker, Greene and McGimpsey (1988) found that an education procedure with corrective feedback but no praise was not as effective as a package consisting of posted record charts, homework, corrective practise and trainer praise. A study by Llewellyn and Brigden (1995) reported that the training requires the use of highly concreted approaches and methods to ensure generalisation and is more successful if it is carried out in the home (Llewellyn and Brigden, 1995). The goals of the intervention need to be negotiated with the parents (Downey and Skuse, 1993) and long term programmes are often required.

8.2 Additional interventions

Within the current literature it is now recognised that the ability of parents with LD to gain from parent training programmes is only one facet of essential support that this population requires. Research which has investigated parents own perception of their needs has consistently identified the need for a much broader support which moves away from the narrow focus on short term training in specific skills. Booth (1996) identified this as an approach based on a 'deficit model of service delivery' which is crisis driven. The service models advocated by researchers, service providers, and parents themselves emphasis the need to move away from the deficit model and build

on parental strengths rather than focusing on limitations (Spencer, 1998). The literature identifies the necessity to promote parental competence (Booth and Booth, 1996, Espe-Sherwindt and Crable, 1993), by recognising and supporting the resourcefulness of the parents (Zetlin et al, 1985), enhancing parents own decision making abilities (Brechtin and Swain, 1988) and focusing on empowering the parents (McConnell et al, 1997). Furthermore, there is a wide agreement in the literature that support services must be proactive rather than reactive (Ely et al, 1998, McConnell et al, 1997) preferably beginning prior to the birth of the child (Ely et al, 1998, Tymchuk, 1999).

9.0 Possible outcomes for children

The research literature gives credibility to a number of the concerns expressed by professionals and families in relation to parents with LD, particularly in relation to child's safety, developmental, and emotional outcome. By definition, individuals with LD experience problems in learning, particularly in areas involving abstract concepts or complex reasoning. They also experience difficulties in generalising information across time and place (Booth and Booth, 1993, Young, 1997), solving problems (Tymchuk, Yokota and Rahbar, 1990) and poor communication and social skills (Llewellyn, 1997) much of which is a combination of both the LD but also the lack of opportunity that often defines the lives of these individuals (Llewellyn, 1997). This literature further identifies limitations in knowledge, understanding and inadequate skills in parenting. They often have problems in making appropriate decisions (Tymchuck, 1990), ensuring that children's nutritional, health and safety needs are met (Feldman et al 1992), providing a stimulating home environment and interacting in a developmentally appropriate sensitive, affectionate, and responsive manner (Tymchuk, 1992). Parents with learning disabilities also experience a lack of knowledge in areas related to developmental milestones (Tymchuk, 1992), child management, and appropriate discipline strategies.

In the Feldman (1994) review of the literature 10 studies were presented with data on the effects of parent training on the children. With the exception of Slater (1986) and Feldman et al, (1993), deficiencies in experimental design utilised precluded clear cause-effect demonstrations of parent training on child outcomes (i.e. maturational effects were not controlled). Slater (1986) found that increasing the level of positive

maternal interactions significantly increased cognitive skills of preschoolers. Feldman et al (1993) showed that after parental interactional training, toddlers of mothers with learning disabilities spoke their first words sooner, had more vocalisations, and scored higher on language and social items of the Bayley Scales of Infant Development (Bayley, 1969) than did age matched children whose mothers did not have this training. Feldman (1994) pointed out that although the mean improvement scores for child behaviours was low in most of the seven studies providing individual child data these scores reflect, to some extent, the high baseline child measures that impede a clear interpretation of the effects of parent training on the child. Furthermore, when the ambiguous child data are removed, the mean percentage improvement scores increase considerably in both training and in follow up.

Some anecdotal accounts were also provided in a number of studies. A home training safety study (Tymchuk et al, 1990) found that although child accidents increased during the training, none were reported in the four week follow up. Two other studies (Feldman et al, 1992, 1992) provided anecdotal accounts of benefits to the child's health, which were corroborated by the child's doctors and health visitor. A number of studies provided no information on the outcome of the child following parent training. As Feldman (1994) points out '*this omission is most unfortunate because the raison d'etre for parent training for parents with mental retardation is to ensure that the child's welfare is protected and his or her development encouraged*'. Outcomes for older children with one or more parents with a LD were examined by Feldman and Walton-Allen (1997), they identified lower academic achievement and more behaviour problems than children of parents from the same socio economic status with no learning disabilities.

10.0 Some Methodological Issues

As the above sample of research indicates the majority of studies on child development outcome have focused on intellectual development and achievement with a dearth of research detailing emotional and behavioural outcomes in children (Murfin-Veitch, 2003). The sample of parents used in the research studies is generally not representative of the general population of such parents, with very limited samples identified from institutional records, child welfare or mental health services (Murfin-

Veitch, 2003). Furthermore, the lack of consensus across the research on a precise definition for 'adequate parenting' makes it difficult to compare outcomes across studies. Additionally, although we may be able to tentatively conclude that some children of parents with learning disabilities have poorer developmental outcomes the operant word remains 'some'. Perhaps the more important question that needs to be asked is 'why do some children develop normally and some do not'? Increasing attention needs to be paid to the concepts of risk and resilience, to investigate and understand such questions (Mirfin-Veitch, 2003). Currently in this area some studies have focused on asking the children when they are adults of what it was like growing up with parents who happened to have a learning disability. Booth and Booth (1997) carried out a series of in-depth interviews with adults who had one or more parents with learning disability. The authors concluded that those adult children without an intellectual disability '*experienced no problems of a type or magnitude sufficient to distinguish them from other people coming from the same socio-economic background*'(p35).

Interestingly, one of the early studies in child development research carried out by Skeels (1966), which provided evidence for adequate parenting by woman with an intellectual disability, received very little attention in the literature. In this experimental study, a group of very young children in an orphanage were divided into groups at the mean age of 16-19 months. One group showed significantly delayed development and was sent to an institution for children and adults with learning disabilities and was assigned to the care of a woman with a learning disability. The other group of children, who were considered developing normally, remained in the orphanage. The follow up of both groups of children 21 years later showed surprising results. The children who had been parented by the woman with intellectual disabilities had recovered from the early developmental delays in the first two years and were now leading normal adult lives while those who remained in the orphanage showed increasing developmental delay in their early years and very low educational achievement in adult life. Although the findings of this study failed to take a number of important points into consideration and cannot be generalised to the current population of parents it does beg us to ask the question: To what extent is a LD responsible for the ability to provide good enough parenting?

11.0 Relationship between cognitive impairment and ‘adequate parenting’

As a population, these parents have been identified to share many social and psychological characteristics with other at risk parents (Budd and Greenspan, 1984) and almost always have additional problems related to poverty, parental psychopathology, abuse, lack of social support, all of which adversely affect a parent’s ability to provide adequate parenting (Feldman, 1994). In addition to the experience of institutionalisation (Budd and Greenspan, 1985) a significant number of parents have experienced severe deprivation and/or abuse in their own childhood (Downey and Skuse, 1993, Glaun and Brown, 1999, Llewellyn, 1990) resulting in lack of any appropriate role models from which to learn parenting skills (Booth and Booth, 1994, Booth and Booth, 1993, Gath, 1988). This image reflects the increasing body of research that illustrates no clear causal relationship between parental competence and general cognitive functioning (Tymchuk, 1992). A study conducted by Rosenberg and McTate, (1982) identified that the level of intellectual functioning is neither necessary or sufficient for adequate parenting and the ability of the parent to provide good enough child care is not predictable on the basis of intelligence alone. On this point the research evidence is consistent and persuasive and long standing (Mickelson, 1949, Brandon, 1957, Shaw and Wright, 1960, Galliher, 1973, McGaw, 2006).

12.0 Government support policies

Identified in the ‘Finding the Right Support Review’ government policies are beginning to show signs of change. At a policy level ‘Valuing People’ saw the government commit to ‘supporting parents with learning disabilities in order to help them, whenever possible, to ensure their children gain maximum life chance benefits’ (DH, 2001). Furthermore, ‘The Same as You’, the Scottish equivalent, require that local authorities and NHS trusts should make sure that the needs of parents with learning disabilities and their children are identified and met (Scottish Executive, 2000). Further to this the Prime Minister and his Strategy Unit make a commitment in their report to ‘*improving the life chances of disabled people so thathave full opportunities and choices to improve their quality of life and be respected and included as equal members of society*’ (Prime Minister Strategy Unit, 2005). In response to many of these policies the last five years have seen an increase in

parenting support and advocacy services. These services focus on providing parents with learning difficulties with the help, support and interventions they need to keep their children and bring them up in a way that maximises their life chances (Tharleton et al, 2006).

13.0 How important are relationships and social support?

Within the research there is now an increasing focus on other factors besides parental cognitive limitations on parenting. The literature has repeatedly suggested that a significant predictor of child well being is the adequacy of supports that parents have, regardless of their knowledge and skill (Tymchuk, 1992, McGaw, 1998, Feldman, 1994, Booth and Booth, 1996, McGaw, in press, McGaw and Newman, 2006). Social isolation is one of the adversities that threaten the health, safety and well being of parents with learning disabilities and their children (Downey and Skuse, 1993). Papers continue to highlight the primary role an adequate social network plays in protecting the family and keeping them together (Booth and Booth, 1994, McGaw and Sturme, 1994, McGaw, 1998). Support can be provided by a multitude of people but predominantly is provided by a partner, family member, friend or neighbour. However, for many parents with LD the prospect of social isolation is immense (McGaw, 1998, Booth and Booth, 1996). They often lack sufficient opportunities to meet other people and difficulties with social skills make it hard for them to develop and sustain relationships with other people (McGaw, 2002)

In a study conducted by Llewellyn et al (1998) parents identified the need for skill development in areas that would better equip them to participate in the life of their local community. Identified areas included vocational skills and training, knowledge and skills in using community resources and developing assertiveness skills to become part of the community –this was identified by parents as ‘meeting people and making friends’. In response to this growing need McGaw et al (2002) set up a group intervention concentrating on relationship issues (such as recognising and managing emotions, trusting others, using negotiating etc) employing a cognitive behavioural approach. The study found that parents who participated in the group had a more positive self concept and illustrated an improvement in relationships (for example with partners or new friends) in comparison to those who did not participate. The group itself also acted to extend parents social networks with some of the

relationships formed in the group continuing after the group disbanded.

13.1 Partnership relationships

There is the growing number of studies that have identified a long term relationship with a supportive partner as a protective factor in the ability of parents with LD to provide 'good enough parenting' (McGaw, in press, Llewellyn, 2003, Tymchuck and Keltner, 1991). Llewellyn (2003) identified that the risk of having children removed from the family was greater for single LD parents when compared to learning disabled parents in a partnership. Limited social support and an unsupportive partner were identified as negatively influencing 'parental adequacy' by Tymchuck in 1991. Quinton (1984) identified the presence or absence of a supportive spouse/partner to be significantly associated with the quality of parenting in families where the mother has an institutional upbringing (Quinton et al, 1984) and Snodgrass (2000) identified the importance of *'parents having someone who believes in them and can help them to believe in themselves'*. McGaw, Shaw, Scully, & Pritchard (in press) considered high risk versus low risk parents with intellectual disabilities and concluded that the capacity to maintain long term supportive relationship as one of the most protective factors in their capacity to provide good enough parenting.

However as with any research phenomena there is an alternative side. Whitman et al (1990) identified the necessity to be aware of the 'power and influence welded by the men in lives of woman with learning disabilities', and the potential impact this may have. The small amount of research in this area has associated men with sexual exploitation and threat to mothers who have learning disabilities (McCarthy, 1999). They have been identified as shaping the expectations of family life in terms of abuse (Seagull and Scheurer, 1986, Gath, 1988) and targeting mothers to take advantage of their vulnerability or to gain access to their children (Glaun and Brown, 1999). In addition they have been identified as bringing significant problems of their own to the parental relationship (Glaun and Brown, 1999).

Although this research cannot be ignored Booth and Booth (2002) suggested that it did not represent the full picture of men in the lives of woman with LD. In response to this they conducted a qualitative study which examined the view that, mothers with intellectual disabilities were generally used abused and abandoned by the men in their

lives. This study identified a number of interesting findings, the majority of mothers had experienced a long lasting relationship (> 5 years) with a steady partner at some point in their lives and only a small number of woman were involved in successive short term casual relationships as stereotypes of this population may suggest. This report suggested that a number of relationships had been brought together by 'the shared experience of disability, exclusion and discrimination'. Booth and Booth (2002) also made an attempt to identify the main benefits of a mother with LD having a supportive partner. They identified a number of attributes – literacy and numeracy, street savvy, ability to drive, do-it yourself expertise, confidence to deal with public officials, money management and another pair of hands. However, due to the narrative nature of the methodology and the small sample size (n=5), statistical foundation or generalisation cannot be implied.

14.0 Critical Summary

14.1 Overview

The aim of this review was to summarise the core issues identified in relation to parents with LD. The review identified the difficulties associated with the precise definition of 'adequate parenting'. It considered current care proceedings and acknowledged that 48% of parents with LD were not considered capable to look after their own children. This identifies 52% of parents with LD that do in fact bring up their own children. With regard to the abilities of parents with LD to parent adequately, there is strong evidence to suggest, with the right types of support, these parents can and do parent their children adequately. This is particularly evident when we consider the final outcome of children, with research suggesting improvements in cognitive, developmental and emotional aspects. Finally, when comparing parents with little or no social support to parents with a good social network (particularly a supportive partner) it is clear that this is one of the most valuable resources for mothers with LD.

14.2 Methodological considerations

There were a number of inconsistencies in the selection criteria employed in various studies. Researchers (i.e. Watson-Perczel et al, 1988) recruit families already known to services which may not be representative of the population as a whole (Tymchuk, 1992). Many parents are referred because they are identified as risks to the children,

very infrequently do parents refer themselves because they perceive a need for help and support (McGaw, 2006). Other studies, which employed control groups, failed to match them to the population been studied on socio economic and other variables (i.e. Schilling et al, 1982). Furthermore, as mentioned above, there is no precise definition of 'adequate parenting', resulting in lack of comparability across the studies. The quality of measures (i.e anecdotal accounts) used in many of the studies, particularly in relation to child outcome, lacked empirical support. This limits generalisation and consequently lessens the impact of the studies. Moreover, the literature has highlighted the propensity of this type of research to value judgements and emotional accounts of the prejudices encountered by this population, which bias the reporting of the results particularly where anecdotal evidence is used.

14.3 Directions for future research

More research is also needed to investigate specific areas within this population. (1) The current standards and procedures in child protection courts. Focusing on, the documentation, evaluation, and follow up, of the process and outcomes of child protection systems for children and parents. (2) The paucity of research in risk and resilience that concerns the question 'Why do some children with one or more parent with LD develop normally and some do not'? (3) Further understanding of both supportive partnerships and good social support networks, (i.e informal social network, social services) as protective factors in the provision of adequate parenting.

Additional areas that are absent from the current research literature are fathers with learning disabilities and issues for parents with LD from different minority ethnic groups. The former is absent with the exception of small scale study from Iceland (Sigurjonsdottir, 2004) and Tower Hamlets in London (O'Hara and Martin, 2003). As the recent national survey has confirmed that fathers with learning difficulties are heavily involved in parenting their children (Emerson et al, 2005), this requires further research on the role, involvement and adequacy of LD fathers, in relation to parenting. The latter has been ignored with the exception of a small scale study reported by O'Hara and Martin (2003).

15.0 Conclusion

As crucial decisions regarding child custody and the continuance of parenting rights have to be made, based in part, on the availability of programmes and support, these families have a fundamental right to access this type of support. More research is needed to develop cost effective and feasible interventions that reduce risk to the children, address the additional difficulties faced by this population, and have extensive and long term benefits for all family members.

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Appendix 1 Search Strategy Procedure

Overview of Procedure for Conducting the Systematic Literature Search:

Initially ideas for a topic were discussed with supervisors and colleagues. Background information and ideas were sought from books, and an initial list of key authors/works in the area of parents with learning disabilities was put together.

Government documents were also reviewed to gain information on current guidelines and recommendations for working with parents with learning disabilities and their families.

The topic then became more focussed, and a more detailed search ensued. Electronic databases (see below) were systematically searched and the most relevant articles/books/theses identified. These sources were then read and brief summaries written for each. The main aim was to gain an up to date understanding of the current literature and to identify any gaps in the current knowledge base.

Databases searched

The following databases were searched:

PsycINFO, Science Direct, Medline, Cinahl (Cumulative Index to Nursing & Allied Health Literature), Cochrane database of systematic reviews, AMED (Allied and Alternative Health Database) and the NHS National Research Register (acts as a register of ongoing and recently completed research funded by, or of interest to, the National Health Service). Barnardo's (research on parents with learning disabilities)

The following editing/expansion procedures were used:

- a) Boolean operators. The Boolean operators (AND, OR, NOT) tell search engines which keywords you want your results to include or exclude.
- b) The truncation technique. An asterisk is placed at the end of a term to search for all terms that begin with that word (i.e. parent* - Parents, parenting)
- c) MESH terminology. This provides a consistent way to retrieve information that may use different terminology for the same concepts.
- d) The key terms/words/concepts and major descriptors identified by the authors of the most relevant articles, were used as search terms.

Searching was conducted using the following search and MESH terms:

Learning disability, mental retardation, intellectual disabilities, intellectually challenged, learning disabled, mentally retarded, IQ

Parent, mother, father, family, siblings, children,

Parenting, primary caregiver, attachment figure, up bringing, rearing, childhood, outcomes, results

Interventions, support, professional help, guidance,

Care proceedings, court outcomes, standards, measures,

Capacity, ability, capability,

Adequate, satisfactory, acceptable, tolerable, good enough,

Attachment, friendship, support, relationship, partner, husband, men,

Support, relationships,

The names of the most relevant authors were searched

McGaw, Booth & Booth, Feldman, Tymchuk, Lewellyn, McConnell

Clegg

Additional searching techniques

Citation searches

PsycINFO and Science Direct was searched as they enable cited references to be found (e.g. seminal papers) as well as the authors, articles or journals that have cited these references.

Reference searches

The references of all identified articles were searched for further relevant citations. These were then obtained.

Web Searches:

Web searches were conducted using the search engine 'google'. The Internet was helpful in accessing charity funded review papers published on this topic including the 'What works for parents with learning disabilities' (McGaw and Newman, 2006), and Finding the Right Support' (Tarleton, 2006)

Contacting 'experts' in the field:

Contact was made with the authors of the most relevant articles, or those deemed to be expert in the field of parents with learning disabilities. The study was discussed and advice sought about relevant research in related fields.

THESIS: Mothers with learning disabilities' experience of relationships with their parents, partners and friends. An IPA study

Portfolio including Thesis

Volume 1 of 3

TAMARA MARIA SCULLY

A portfolio submitted to the University of Hertfordshire in partial fulfilment of the requirements of the Degree of Doctor of Clinical Psychology including a Thesis entitled:

**Mothers with learning disabilities' experience of relationships with their parents, partners and friends:
An IPA study**

The programme of study was carried out in the Department of Psychology,
University of Hertfordshire

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1. ABSTRACT

Many mothers with learning disabilities experience social isolation (McGaw, 1998; Booth & Booth, 1996) despite the current research clearly delineating the importance of supportive relationships for mothers with learning disabilities. The aim of this research was to investigate the experience of three types of relationships from the mother's perspective. Semi-structured interviews were conducted with five mothers with learning disabilities about their experience of three types of supportive relationships, with their parents, their partners and their friends. The transcripts were analysed individually using Interpretative Phenomenological Analysis (IPA). Superordinate themes were identified for each topic area. These were, for parent relationships, importance of support, and vulnerability; for partner relationships, significance of support, and ambivalence about independence; for friendships, friendships can be dangerous and benefits of friendships. The results were related to existing theoretical frameworks, clinical implications were identified and recommendations for future research were made.

2. INTRODUCTION

The benefits of social support and interpersonal relationships have long been recognised in the literature. Extensive research shows that close relationships are vital to various indicators of well-being including happiness, mental health, physical health and longevity (Berkham, 1995). In particular attention is drawn to the moderating role social support and relationships can play in the adjustment to stressful life events and their link to mental and physical health (Cohen, Gottlieb & Underwood, 2000). This study is interested in the experience of social support and interpersonal relationships for mothers who have learning disabilities, a population that has consistently been identified as one of the most socially isolated groups of mothers in both the UK and Australia (Llewellyn, McConnell & Bye, 1995). The first part of this introduction will consist of a discussion of the current understanding and conceptualisation of social support and interpersonal relationships, focusing on social support within the general population of mothers. Thereafter, the discussion will focus on mothers with learning disabilities, what the existing literature suggests and an introduction to the current research.

2.1 Social support

The term social support has been widely used to refer to the mechanism by which interpersonal relationships can protect people from the harmful effects of stress (Cohen & McKay, 1984). The literature agrees that social support involves the exchange of social resources between individuals (Cohen & Syme, 1985; Thoits, 1985). There is also a consensus that at least three broad categories of support can be

identified, namely, emotional support involving the expressions of caring and esteem created through confiding and reliance on one another, informational support concerning the provision of information and advice, and instrumental support which involves tangible goods or assistance with tasks (Schaefer, Coyne & Lazarus, 1981). For a substantial period of time researchers identified emotional support as the most fundamental of the supports provided in terms of psychological well-being, but several studies now suggest that the provision of instrumental support may be a critical resource for successfully managing many life challenges (Kaniasty & Norris, 1992; Schaefer et al, 1981) and thereby impacting directly on psychological well-being.

The literature also differentiates between 'available support' which is concerned with a person's general perception that people would be available to provide assistance in times of need, and 'received support' referring to exchanges that have actually occurred (Haber, Cohen & Lucas, 2007). In studies that have measured both types of support, expectations of available support were only modestly associated with actual support received (Dunfkel-Schetter & Bennett, 1990) and, in one landmark study of social support, the correlation between received and perceived support was only .01 (Sandler & Barrera, 1984). In a comprehensive review of the literature, Cohen and Wills (1985) concluded that stress buffering is strongest for perceived availability of social support and resources. Furthermore, perceptions of available support have been found to be more closely tied to individual differences than to environmental provisions that exist outside the individual (Sarason, Sarason & Shearin, 1986), suggesting that perception of support may be more influential than the actual support available.

Two major models have been proposed that identify the conditions under which different forms of social support might influence psychological well-being (Cohen & Wills, 1985; House, 1981). The 'direct effect' model claims that greater social resources should have beneficial effects on psychological and physical well-being, regardless of whether or not people are currently experiencing stress. According to this model support affects an individual's psychological state by offering a sense of predictability and understanding that support is available if it is needed. The 'stress buffering' model (Cohen & Wills, 1985) in contrast, contends that the amount and quality of support is related to health and psychological well-being, but only when people are experiencing chronic stress. This view holds that perceived social support is beneficial to those who may be in need of assistance from others. For individuals who are not under stress the availability of social support is desirable but does not necessarily have positive consequences for personal well-being and functioning. Thus the key component of the stress buffering model appears to be the perception that support will be available when needed.

2.2 Interpersonal relationships

For many years several prospective studies have documented the unmistakable buffering effect of close relationships on mortality, physical and psychological morbidity and recovery from chronic illness (e.g. Berkman, 1985). Still the most widely accepted definition of a relationship is that it exists to the extent that two people exert strong, frequent and diverse effects on one another over an extended period of time (Kelley et al, 1983). That is, when people are in a relationship they impact on one another's behaviours and well-being and each action in that

relationship has a bearing on the other person. A number of very different theoretical orientations have been identified in the field of relationship study. Some relationship scientists adopt an interdependence orientation (Thaibut & Kelley, 1959) emphasising the nature of the relationship between two people rather than focusing on the people themselves, which is a characteristic of many other theories. The theory provides a systematic account of the interpersonal properties that shape social interaction. These properties include: 1. Degree of dependence (the extent to which each person's outcome depends on, or is influenced by, the other's behaviour); 2. Mutuality of acceptance (the extent to which two people depends on a relationship to the same degree); 3. Basis of independence (whether the dependence on one another is absolute or contingent); and 4. Correspondence of outcomes (whether the individual outcomes correspond or conflict). This theory differentiates between how attractive or satisfactory we find a relationship and how dependant we are on it. The authors suggest that the level of satisfaction in a relationship is the difference between the outcome level of that relationship and the outcome that we expect from relationships in general (Kelley & Thaibut, 1978). Our dependence on a relationship, on the other hand, is the difference between the relationship and the best alternative relationship that is available, which in some cases may include being alone (Thaibut & Kelley, 1959).

The equity theory, proposed by Elaine Walster and her colleagues (1973, 1978), consists of a number of related propositions. Similar to the previous model, individuals will try and maximise their outcomes. Difficulties arise if one person receives relatively more or less from the relationship than the other person does relative to the level of input. This may result in the over-benefited feeling guilty and

the under-benefited feeling angry and resentful. The more inequitable the relationship, the more individuals will attempt to reduce their distress by restoring either actual or psychological equity into the relationship. The restoring of actual equity refers to changing the actual outcomes and/or inputs in the relationship, while restoring psychological equity concerns changing one's perception of the outcomes and/or inputs (Cramer, 1998).

The capacity to maintain a relationship may depend on the type of relationship. Clark and Mills (1979) theorised extensively about the important distinction between communal and exchange relationships. In communal relationships, the two people in the relationship are concerned first and foremost with each other's welfare and provide benefits (assistance and emotional support) to help fulfil each other's needs. This is the typical relationship between family members. In exchange relationships, on the other hand, each person in the relationship benefits the other either to repay a past benefit or in expectation of a future comparable benefit. A benefit can be anything that a person chooses to give to another person that is useful to that other person (Clark & Mills, 1979). The rules concerning the giving and receiving of benefits are what distinguishes communal and exchange relationships, rather than the specific benefits that are given and received. Research has demonstrated that attraction to a new acquaintance is greater when the provision of benefits is consistent with the type of relationship expected (Clark & Mills, 1979).

2.3 Social support and parenting

The role of supportive relationships for parents generally has been the focus of much research and social intervention over the past two decades. Extensive research has shown that social support has a substantial weight particularly in terms of its protection factor against negative affect and promotion of psychological well-being (Ceballo & McLoyd; 2002, Green, Furrer & McAllister, 2007). The results of a meta analysis of 66 studies investigating the relationship between social support and maternal behaviours and attitudes in the general population suggested that mothers' perceptions of available emotional and material supports were generally positively related to a variety of indicators of mothers' behaviour and psychological well being (Andresen & Telleen, 1992). Social support, if available, is two-fold; it helps parents to feel confident that they can meet demands, and assists in the alleviation of stress and the maintenance of psychological well-being when parenthood is perceived as stressful. Selye's (1976) demand-resources model of stress suggests that stress is the result of the appraisal and coping processes used by individuals exposed to concrete environmental demands associated with their occupation. Thus mothers experiencing their environment as troubling or difficult would be under greater stress and might be at greater risk for negative outcomes such as lowered self-esteem and greater symptomatology. These negative outcomes are significantly more likely to occur for those mothers lacking adequate resources, particularly social support (Koeske & Koeske, 1990).

As expected, social support is identified in the literature as being even more important for women who live in poverty or with other stress-provoking circumstances, owing

to the greater number of daily stressors shown to cause increased psychological difficulties (Simons et al, 1993; Brooks-Gunn & Duncan; 1997, Furstenburg, 1993), and chronic stress (Cutrona et al, 2000; McLoyd, 1998). Simmons et al (1993) found that social support had a positive indirect impact on parenting via its effects on psychological well-being; social support has been found to improve satisfaction and psychological well-being when parents are under stress (Koeske & Koeske, 1990). The latter study involved 125 mothers and established that stress produced debilitating effects and higher psychological and somatic symptomatology almost exclusively for mothers lacking adequate social support. Additionally, and unexpectedly for the authors, the mother's education level seemed to operate in much the same way as social support in alleviating stress and maintaining psychological well-being, suggesting that education plays a role in reducing the level of stress experienced.

Hashima and Amato (1994) investigated the relationships between poverty, social support and parental behaviour. Their findings suggest that low income is problematic for all parents but especially when low income is combined with low level of perceived social support. Studies have shown that economic deprivation combined with a lack of social support creates an especially dangerous situation for children (Garbarino & Kostelny, 1992). Parents with a higher income will be in the desirable position of being able to counter some of the everyday strain by drawing on economic resources that are not available to families in poverty.

Much of this literature, which has studied samples of parents taken from the general population, is relevant to parents with learning disabilities because they too often

experience conditions of poverty and stress (Budd & Holdsworth, 1996; Feldman & Walton –Allen, 1997; Feldman et al, 1993).

2.4 People with learning disabilities

During the first half of the 20th Century people with learning disabilities were subjected to involuntary sterilisation and institutionalisation (Murphy & Feldman, 2003). They were not considered able to vote, able to consent to sexual relationships or to parent (Murphy & Feldman, 2003). With the introduction of the Normalisation Movement (1970s) and the Disability Rights Movement (1970s) this began to change. It was accepted that individuals with learning disabilities have equal rights to education, community living, employment, sexual relationships, having children, and other aspects of normal everyday living in a democratic society. People with learning disabilities share the same needs and desires as other people, the need to form friendships, to engage in sexual relations and in some cases to bear children (McGaw, 1998).

2.5 Definition of learning disability

People with learning disabilities do not constitute a homogenous group. However, in terms of diagnosis and classification there are a number of features of learning disabilities which have gained widespread acceptance across professional boundaries within the UK and America. Three core criteria have been identified: significant impairment of intellectual functioning, significant impairment of adaptive/social functioning, and age of onset before adulthood. The Department of Health, 2001, offers the following definition '*usually described as a significant impairment of intelligence and social functioning acquired before adulthood*'. Two categories of

intellectual impairment have been identified: significant impairment of intellectual functioning (IQ 55-69) and severe impairment of intellectual functioning (IQ<55) (British Psychological Society, 2000).

2.6 Epidemiology of people with a learning disability who have children

The number of people with learning disabilities who are forming relationships and having children has steadily increased over the last twenty years (Department of Health, 2001), but there are no precise figures available in the current UK population. A number of years ago it was identified that in the USA there were over 100 programmes serving an estimated population of 1 million families with children, in which one or both parents had a learning disability (McGaw, 1998). The only UK statistics comes from the first national survey of adults with learning disabilities in England, where 1 in 15 of the 2,898 adults interviewed had a child or children (Emerson et al, 2005).

2.7 Mothers with learning disabilities

Mothers with learning disabilities share many social and psychological characteristics with other 'at risk' populations (Budd & Greenspan, 1984). Apart from the need for greater compensatory learning, poverty, poor housing and limited vocational opportunities, restricted social networks create substantial difficulties in the lives of this population (McGaw & Newman, 2006). They have been consistently identified as one of the most socially isolated groups of mothers in both the UK and Australia (Llewellyn et al, 1995). Environmental stressors generally include a poor standard of living resulting from low income and impoverishment (poor housing, inadequate transport) and general lack of amenities (food, clothing, equipment) (McGaw &

Newman, 2006). Research indicates that approximately 70% of mothers with learning disabilities suffer from depression and/or anxiety disorders (Feldman et al, 2002) with many mothers with learning disabilities exhibiting greater and more severe depression than mothers who do not have learning disabilities (Tymchuck, 1994).

2.8 Parenting by mothers who have learning disabilities

To what extent mothers with learning disabilities can take on the role of parents has been debated for many years (Mickelson, 1947; Brandon, 1957; Skeels, 1966), but it is only in the last decade that there has been a substantial increase of interest and research into this area. As Egerton (1999) pointed out, *'the study of marriage, and parenting by individuals with intellectual disabilities has a long history but it was not until a little over a decade ago that scholarsbegan intensive study of the needs of such parents and children'*. Basic training programmes have been provided with varying degrees of success in the areas of basic child care skills (Keltner, Wise & Taylor, 1999), safety in the home skills (Keltner et al, 1999; Tymchuk et al, 1993), child behaviour management (Downey & Skuse, 1993) and mother and child interaction of play skills (Dowdney & Skuse, 1993; Feldman, Sparks & Case, 1993; Keltner et al, 1999; Slater, 1986). In particular the training of mother-child interaction with young children was shown to have positive effects on the relationship between mother and child, while training parents to change abusive or neglectful parenting has had limited success (Dowdney & Skuse, 1993). Feldman (1994) carried out a comprehensive review of parenting education programmes for parents with learning disabilities. The review identified twenty published papers with adequate outcome data. A total of 190 parents with learning disabilities were involved, with IQ's ranging from 50-79. Parenting skills taught included basic child care, safety, nutrition,

problem solving, positive child care interactions and child behaviour management. The most common instructional approach was behavioural. The author concluded that initial training, follow up and social validity results were encouraging, suggesting that parents with learning disabilities have the capacity to learn, maintain and implement new skills and thereby provide adequate parenting.

However, despite the current body of knowledge, this population still remains largely under-researched relative to the vast impact learning disabilities may have on both parents and children involved. Most noteworthy is the fact that parents with learning disabilities are over-represented in child care proceedings (e.g. McConnell, Llewellyn & Ferronato, 2002). It has been identified that parents with learning disabilities worldwide are between 40 and 60 times more likely to be the subject of a care order application than their number in the general population warrant (McConnell et al, 2002). Sixty-six percent of parents with learning disabilities had one or more children taken into adoption as against thirty-eight percent for all other families with special needs (e.g. mental health) in the UK (Booth & Booth, 1994). The 2004 National Survey of Adults with Learning Difficulties in England identified forty-eight percent of parents with learning disabilities were not looking after their own children (Emerson et al, 2005).

With almost one out of every two families having their children taken into care it is clear that the current interventions for these families may be inadequate or poorly available. Newton et al, 1994, in a review of the general literature on learning disabilities, criticised the lack of attention within the available research to conceptually sound studies of social relationships and support for people with

learning disabilities. Since then there has been an increasing focus on other factors besides parental cognitive limitations on parenting. Researchers now recognise that, in addition to specific parental training input such as parenting education programmes, emotional and social support are as important in determining parental competence (Llewellyn, 1994; McGaw & Newman, 2006). A significant predictor of child well-being is the adequacy of supports that parents have in addition to parenting competencies and skills in parenting (Tymchuk, 1992; McGaw, 1998; Feldman, 1994; Booth & Booth, 1996; Booth & Booth, 1994; McGaw & Sturmeay, 1994; McGaw, in press).

2.9 Support networks for mother with learning disabilities

For many parents with learning disabilities the prospect of social isolation is immense (McGaw, 1998; Booth & Booth, 1996; McGaw, Ball & Clark, 2002) with regular reports of loneliness and relationship difficulties (Llewellyn et al, 1995; McGaw, 1997). Typically, parents are described as socially excluded, experiencing multiple temporary relationships and becoming dependent on statutory agencies for both practical and emotional support (McGaw et al, 2002). Llewellyn et al (1999) and Stenfert Kroese et al (2002) reported that the natural support networks of mothers with a learning disability contained an average of six supportive contacts, made up mostly of family and professionals. The average number of contacts in the normal population is identified as 13 (Levitt et al, 1986). Parents themselves identified the need for help in areas that would better equip them to participate in the life of their local community (Llewellyn et al, 1998), such as vocational skills and training, knowledge and skills in using community resources and developing assertiveness

skills to become part of the community. The latter was identified by parents as 'meeting people and making friends'.

This social isolation has been associated with 'social skill deficits', a lack of social skills which makes forming and maintaining new relationships very difficult (Llewellyn et al, 1995). Parents with learning disabilities often lack sufficient opportunities to meet other people and difficulties with social skills often make it hard for them to develop and sustain relationships with other people. They rely on people such as parents or paid staff for support, 'friendship' and continuity, which inhibits their ability and inclination to achieve a level of continuity in their friendships and social relationships with their peers.

McGaw et al (2002) set up a group intervention concentrating on relationship issues (i.e. recognising and managing emotions, trusting others, using negotiation etc.), employing a cognitive behavioural approach. The study found that parents who participated in the group had a more positive self concept and illustrated an improvement in relationships (for example with partners or new friends) while attending this group in comparison to those who did not participate. The group itself also acted to extend parents' social networks with some of the relationships formed in the group continuing after the group disbanded.

2.10 Social support and psychological well-being in mothers with learning difficulties

As with other parents, lack of social support for parents with learning disabilities is strongly associated with increased stress, and stress reduces competencies (Feldman

et al, 2002). Stenfert Kroese et al (2002) investigated social support networks and psychological well-being of mothers with learning disabilities. The study used a measure of psychological well-being (The Affect Balance Scale, Stenfert Kroese et al, 2000) and identified, consistent with the finding in the literature, strong associations between supportive social networks and psychological well-being. Significant associations were found between the number of reported social contacts and positive affect, the recency of reported social contacts and self esteem, and reported burdens of parenting. The findings of this study were in agreement with Simmons et al (1993), who found that social support affected parenting indirectly via its effects on psychological well-being. Furthermore, mothers in this study lived in very deprived conditions. Economic difficulties were reported as burdensome and material support was seen as very helpful.

In a similar study Feldman et al (2002) examined the relationship between social supports, stress and mother/child interactions in 30 mothers with learning disabilities. The study measured parental stress, parental support network and an interpersonal support evaluation list. The findings clearly illustrated that mothers with learning disabilities experienced high levels of stress, were socially isolated and reported a great need for support. The study found that a satisfactory social support network, identified by parents' perception of support rather than resource size, could mitigate the effects of stress and was therefore related to a positive maternal interactional style. The fact that parents' perceptions of support may be more important than actual support size is similar to findings of other potentially highly stressed parents, such as those that have children with developmental disabilities and chronic illness (Dunst et al, 1986).

For mothers with learning disabilities, when support is provided it is predominantly by a family member, partner, friend or neighbour (Llewellyn et al, 1995; McGaw et al, 2002). Zetlin, Weisner and Gallimore (1985), found that in 13 family units with at least one parent with a learning disability, parents received support from family members first and foremost. Similarly, in a study of 12 couples with learning disabilities, Tucker and Johnson (1989) found that social support from family members was central, but they stressed that this could have both positive and negative outcomes for its recipients. Competence-enhancing support described family members believing that the adults could be good reliable adults thus promoting their confidence in themselves and competence-inhibiting support involved family inhibiting their efforts and undermining their confidence. Llewellyn et al (1995) conducted a qualitative study with parents with learning disabilities focusing on relationships and social support. This was an ethnographic study and involved in-depth interviews and participant observations with six couples over a two-year period. Parental support was identified as central to the parents' support networks, with parents accepting input from family members even when they found it unhelpful. Furthermore, in a review of the literature relating to adults with learning disabilities Mirfin-Veitch (2003) concluded that some individuals clearly valued their parents and relied on them for practical and emotional support, while others felt resentful by what they perceived as an intrusion into their own lives. These conflicting views can result in relationships between the two generations being characterised by mutual incomprehension and interpersonal conflict.

Llewellyn et al (1995) found that friendships were rare for parents with learning disabilities, with eight out of ten having no friends at all, a finding consistently found in the literature. Grant (1993) found that in a group of young (childless) adults with learning disabilities their support networks were distinctly lacking in friends, a finding supported by Atkinson (1986) who found that half of all adults with learning disabilities had no friends. Parents with learning disabilities repeatedly fail to benefit from what is often regarded to be invaluable peer support. Evidence suggests that emotional well-being and assertiveness significantly improved in mothers who attended a support group provided specifically for mothers with learning disabilities (Wayne & Fine, 1986). The Roher Institute (1990) also identified difficulties for this population in making and maintaining friends, inadequate social skills, poor self identity, few opportunities and inaccurate assumptions by services involved with this population. Furthermore people with learning disabilities were frequently reliant on other people (such as paid staff) for support in many different areas in their lives and unintended social barriers could result (Werner, Horner & Newton, 1997).

As early as 1984, Quinton, Rutter and Liddle identified the presence or absence of a supportive spouse to be significantly associated with the quality of parenting in families where the mother has an institutional upbringing. Similarly, Llewellyn et al (1995) concluded that partners/spouses were the most important source of reciprocal support for mothers with learning disabilities. The emphasis was placed on practical assistance and moral support. In a quantitative study conducted by McGaw et al (in press), the authors investigated low risk families (families that were still looking after their own children) versus high risk families (families that were no longer looking after their own children), in families with a parent with a learning disability. The

study identified a long term supportive relationship as the most protective factor in terms of the parents' capacity to provide 'good enough parenting'. Whitman et al (1990) inferred from their research that when working successfully with mothers who have learning disabilities, 'We have to be sure never to underestimate the power and influence wielded by the men in their lives'.

Booth and Booth (2002) suggest, in the absence of clear research, that this 'power and influence' has been estimated by inference and anecdote, and widely portrayed as malign. These authors examined the part played by men in the lives of mothers with learning disabilities. This study drew on the personal stories and experiences of a group of 55 women in order to evaluate the common assumptions that partnerships of mothers with intellectual disabilities tend to be unstable, exploitative and abusive. The authors concluded that although the incidence of psychosocial pathology was relatively high, most of the men were supportive of their families. Supportive relationships were mostly based on the complementary skills of partners. For some of the women their relationship with their partner gave them a valued role in their local community, access to the wider social network and other benefits. Additional benefits included very tangible components such as an extra pair of hands, and knowledge of how the social care system worked.

2.11 The current research

It is clear from the research reviewed above that the learning-disabled population continues to be among the most socially isolated populations. As social support networks have been identified as crucial in terms of their psychological well being and capacity to parent, it follows that professionals working with this population must

pay attention to and facilitate these mothers' social support networks. However, with the paucity of research on how these mothers think about and experience relationships, the best way to support these mothers is not yet known. Much of the qualitative research to date has looked at the relationship between social support and parenting rather than looking specifically at how they experience the relationships in their lives. Further idiographic study, focusing specifically on the experience of relationships and exploring the specific accounts of relationships in depth, would help build upon the work to date. It would explore the manner in which mothers with learning disabilities made sense of their relationships and contribute to our understanding of the intricacies of relationships for this population, aiding intervention.

Booth and Booth (1998) encouraged researchers to move away from the risk paradigm for this population and acknowledge the sources of resilience in these families. In line with this, although the majority of this population are identified in the literature as being socially isolated, this research has elected to focus on mothers who are currently well-supported and looking after their own children.

The term 'parent with learning disabilities' is used in the literature in a generic sense. That is, the term includes two-parent families where one or both parents have intellectual disability and single parents with intellectual disability. However, most studies claiming to be about parents with intellectual disabilities in fact include only mothers with intellectual disabilities (Tymchuck, 1990, Feldman, 1998). Tymchuck noted in 1990, 'Although we always refer to parents ... virtually all information that is available refers to mothers only'. Llewellyn (1990), too, observes that the 'role of fathers, with or without an intellectual disability, has been neglected'. This omission

reflects the reality that mothers within this population are the primary care-givers to their children. This study has elected to continue with this tradition firstly because the literature that is underpinning the current research has focused almost exclusively on mothers, and secondly, within this population mothers have been identified most frequently as the primary care givers. The study acknowledges the limitations of not including fathers.

This research will focus on parent relationships, partner relationships and peer friendships. Parent and partner relationships have been clearly identified in the literature as being central to the support network of these mothers. Friendships are included because all studies, without exception, have reported an almost complete lack of friendships for this population. However, mothers continue to identify this as an area in their lives they would like to change. Including this category of relationship, the research will explore their perceptions and beliefs about friendships and attempt to understand why this area continues to be absent from their lives.

This study endeavours to gain an in-depth understanding of the social networks of mothers with learning disabilities by exploring the phenomenon of a number of adult relationships. The present study was guided by the following research questions.

1. How do mothers with learning disabilities experience their relationship with their parents?
2. How do mothers with learning disabilities experience their relationship with their partner?
3. How do mothers with learning disabilities experience their relationships with friends?

3. METHODOLOGICAL APPROACH

In this section the rationale for choosing a qualitative approach will be outlined. The chosen qualitative approach will be discussed and the rationale will be given for this type of approach with reference to other possible methods of analysing the data. The use of this method with mothers with learning disabilities will be considered and the researchers' own philosophical position on the topic of interest will be outlined.

3.1 A Qualitative Approach

The literature review revealed significant gaps concerning the subjective experiences of close relationships from the perspective of mothers who have learning disabilities. The literature also suggested that the capacity for mothers with learning disabilities to provide adequate care for their children is greatly influenced by the level of social support and close relationships. This creates an immediate interest in the subject 'experience of close relationships'. The complexity of this subject for each individual person suggests that a qualitative rather than a quantitative approach might be more suitable (Barker, Pistrang & Elliot, 2002).

The aim of qualitative research is to understand and represent the experiences and actions of people as they encounter, engage and live through situations (Elliot, Fisher & Rennie, 1999). Given the exploratory nature of the present study it was decided that a qualitative approach was the most appropriate. By contrast a quantitative approach is concerned with testing hypothesised relationships or causal explanations, measuring the degree of generalizability across samples (Roberts, 2000). This

research was designed to use the data to generate ideas, rather than testing the data against the hypothesis, as in quantitative research (Barker et al, 2002).

The aim of this present study was to use in-depth semi-structured interviews to explore the experience of a small, but well defined, sample in detail, whilst remaining cautious about generalising to the general population (Flowers et al, 1997).

3.2 Interpretative Phenomenological Analysis (IPA)

IPA is a recent and still evolving approach to qualitative research developed by Jonathan Smith (1996). It attempts to gather an in-depth, subjective understanding of lived experience and is concerned with how participants make sense of their experience and the meaning they attach to these experiences. It is grounded within the realist ontology in that there is assumed to be a chain of connection between account, cognition and behaviour (Willig, 2001). IPA does emphasise the phenomenological exploration of the participant's experience and is based on the understanding that such experiences will involve the interpretation of, and imposition of, meaning by both participant and researcher of the phenomenon under study.

The approach is phenomenological in that it is assumed that what a participant says has some ongoing significance for them and there is a relationship, although perhaps not a transparent one, between what they say and the beliefs that they hold. It is also interpretative in that it is recognised that meaning is constructed within a social context (Smith, 1995). The IPA approach acknowledges that in 'order to explore the participant's view of the world and to adopt, as far as possible, an insider's perspective' (Smith, 1996), the researcher must engage in an interpretative dialogue

with the data. Thus, the analytic account is thought to be a joint product of reflection and co-construction by both participant and researcher (Smith et al, 1997). Constructivism and social construction have provided further richness to the influences on IPA as experience is viewed as an active process of engaging with the world and is influenced by the person's social and political context. IPA has been used largely to focus on the mental processes of the individual and hence has aligned itself with the psychology discipline (Smith & Osborn, 2003).

IPA was chosen as the preferred qualitative approach for this piece of research for a number of reasons. The researcher was interested in obtaining rich, detailed accounts of the mothers' experiences, in keeping within the aims of IPA. Additionally, in consideration of the theoretical frameworks, the researcher felt that the constructivist and social construction orientations of IPA were well placed within the topic under study. Discourse analysis, which is also rooted in social constructionism, was also briefly considered but that approach suggests that analysis and interpretation cannot move beyond the text and the language of the data (Potter, 1998). IPA, in contrast, advocates more flexibility in the interpretation of data (Larkin, 2004). Considering the language capacities of the learning disabled population this was considered to be important for the current study.

It was felt that narrative analysis, while well-matched with the topic under investigation, similar to discourse analysis, was too rigid in terms of how the data is analysed, in prioritising temporal dimensions of narrative (Murray, 2003), particularly with a population that experiences clear difficulties with the concept of time and maintains a predominantly present orientation. The availability of a supervisor

experienced in the use of IPA and access to detailed accounts of the analytic procedure were also important considerations in the selection of this approach. Moreover, IPA involves purposive samples of a small and homogenous sample, which was considered an advantage over the theoretical sampling of grounded theory (Larkin, 2004) and appeared more achievable within the time frame dictated by clinical training.

3.3 Using a qualitative approach with people who have learning difficulties

Qualitative research generates research in the form of words. Booth and Booth (1996) addressed the difficulties in conducting narrative research with subjects who may find it difficult to answer questions coherently and follow a logical sequence of a conversation. These authors identified a number of particular interview problems, such as inarticulateness, unresponsiveness, a concrete frame of reference and difficulties with the concept of time. Inarticulateness refers to the inability to communicate fluently in words. It is synonymous with restricted language skills, but is often associated with other factors such as low self-esteem, learned habits of compliance, social isolation, or loneliness and the experience of oppressions (Booth & Booth, 1996). Unresponsiveness is the inability to answer some types of questions, such as open ended-questions. The lack of responsiveness to open-ended questions by participants with learning disabilities usually requires the researcher to adopt a more direct style of interviewing. The concrete frame of reference generates difficulties in generalising from experience and thinking in abstract terms. Difficulties with the concept of time are marked by a strong present orientation and difficulties with dates and numbers. However, the paper illustrates, drawing on detailed interview material from an individual with learning disabilities, that too often

the problems of interviewing inarticulate subjects are seen in terms of people with learning disabilities' deficits rather than the limitations of the researchers' methods. The paper then addresses how the problems may be tackled and identified the following:

- Asking more questions and using more probes to fully illicit information
- Focus on the kind of language that is used;
- Take into consideration the conduct of the interviewer – the researcher must figure out a way to establish a level of communication that facilitates rapport without making people feel inadequate;
- Begin each interview without a fixed assumption about people's ability to understand what is being asked of them and must 'refine the interviewing method during the course of the session as the ability of the informant is revealed.
- Sometimes it is necessary to offer a number of different suggestions in order for the participant to think about the area in which their response lies.

(Booth & Booth, 1996)

3.4 The researcher's personal context

Qualitative research is often considered to be the product of an interaction between the researcher and the participants' accounts and stories; it is suggested that meanings are created together (Finlay, 2002). Elliot et al, (1999) and Hammell (2002) argue that it is fundamental for qualitative researchers to be explicit about their own experience, background and theoretical orientations, which, according to the above authors, form part of the research process. Therefore, reflection on one's own

position is seen as necessary in understanding the relationship between researcher and the research and the development of the research. Finlay (2002) suggests that the researcher's position will naturally influence the relationship with the participants taking part in the research, the types of questions that will be asked, and the way the data is interpreted.

The researcher is a young woman in her late twenties of white Irish ethnic origin, living in the UK for the past five years. The researcher feels she is influenced by systemic psychology approaches that focus on the influence of relations, life events and social influence on psychological distress. The researcher does not work from a diagnostic perspective of psychological problems that often label and pathologise individuals and their ability to interact with other people. The researcher considers individuals to be a sum of their relationships, viewing identity as complex, changeable and constructed in the context of relationships. The researcher therefore prefers to work within constructionist and social constructionist ideas.

The researcher's decision to explore close relationships in mothers who have learning disabilities was made for a number of reasons: firstly, the desire to understand the complex nature of relationships and the inevitable impact and influence of social and personal constructs on those relationships. Secondly, the researcher has worked extensively as an assistant psychologist with this population and she became acutely aware, both anecdotally and through direct observations, of the impact relationships can have on these parents' capacity to provide 'good enough' parenting to their offspring. The experience of spending time with this population led the researcher to

wonder about their experiences with their partners and other close relationships within their lives.

The influence of this position will be further considered both in terms of how it impacted on the method of the current research and its data collection and analysis.

4. METHOD

This section will outline how the research was designed and undertaken, including recruitment of participants, consideration of ethical issues, the design and procedure for interviewing and the analytic procedure for analysing the data including measures taken to ensure the quality of the research.

4.1 Design

A qualitative research design was employed. This involved the use of Interpretative Phenomenological Analysis (IPA) to analyse verbatim transcripts of semi-structured interviews.

4.2 Setting of the research

Each interview took place in the participants' own homes. In all cases the interview took place in the living room while sitting on the sofa. The children were at school or were being minded by their father in another room. The television and the telephone were turned off for the duration of the interview. A small digital recorder was placed between the researcher and the participant.

4.3 Sampling

The participant group was recruited using purposive sampling, the aim being to identify a group that possessed specific characteristics in specific circumstances relevant to the phenomena under investigation. A sample of between 5 and 8 was chosen, as is common for IPA studies (Reid, Flowers & Larkin, 2005).

The participants were recruited through three local Community Learning Disability Teams (CLDT) and the local Learning Disabilities Clinical Psychology Team. Members of the CLDT team included community nurses, social workers, clinical psychologists, physiotherapists, speech therapists, and social work assistants. The local learning disabilities psychology team consisted of 5 A grade psychologists and 4 B grade psychologists.

Each team was presented with a comprehensive outline of the research. This included background information on the population in question, current research, the inclusion criteria (see below) and the aims of the present study. A social system perspective (Mercer, 1973) was adopted as the main diagnostic criterion for determining whether parents were eligible for admission on account of their learning disabilities. Parents were considered admissible if they had at some point in their lives, not necessarily currently, been in receipt of specialised services specifically intended for people with learning disabilities. This is the same criterion used by many health authorities for defining the people who are eligible for registration on learning disabilities case registers (Farmer, Rohde & Sacks, 1993) and has been used successfully by a number of previous studies with mothers with learning disabilities (Llewellyn et al, 1995; Booth & Booth, 1995; Llewellyn et al, 1998). Although this approach has obvious limitations, it is the most satisfactory way of dealing with the absence of test data in most cases and with the abandonment by many professional workers of the use of IQ as a classificatory device (Budd & Greenspan, 1984).

4.4 Inclusion criteria

- Participants must have received support from the Community Learning Disabilities Team at some point in their lives;
- Participants must be able to give informed consent to be interviewed;
- Participants must currently be in a long-term relationship (> 5 years);
- Participants must be mothers and their children must be living with them at the time of the study.

4.5 The participants

Five participants took part in the current study. They are given a gender appropriate pseudonym to protect their identity: Emily, Sharon, Rachel, Isabelle and Natasha. A short description of each participant is included here (Table 1). Using IPA as a research method a highly homogenous sample is recommended since IPA is concerned with a detailed understanding of the experience of the sample rather than making more general claims (Smith & Osborn, 2003). This aim was achieved by selecting participants slowly over a five month period.

Participants were provided with written and spoken information about the nature of the research by one of the staff team they were familiar with (Appendix A:2). If they decided to participate at this point the researcher then met the interested participants on an individual basis to enable them to ask further questions and to set up an appropriate time for the interview to take place.

Table 1: A summary of participants

Participant	Age	Ethnicity	SES	Relationship	Relationship duration	Children at home	Age	Children in care	Mental health problems	Substance abuse	Contact with own parents	Employment	Identified friends
Emily	40	White British	Low	Married	26 years	1 girl 1 boy	22 23	0	PND ANX	No	Yes	No	1
Sharon	33	White British	Low	Married	13 years	1 girl 1 boy	3 5	0	PND DEP	No	Yes	No	0
Rachel	35	White British	Low	Married	18 years	1 girl 3 boys	3 7 8 10	0	No	No	Yes	No	0
Isabella	37	White British	Low	Living with partner	9 years	1 girl 1 boy	15 16	1	DEP	No	Yes	No	0
Natasha	38	White British	Low	Living with partner	14 years	2 Girls	13 8	0	No	No	Yes	No	1

SES	Socio Economic Status
PND	Post Natal Depression
ANX	Anxiety
DEP	Depression

4.5.1 Emily

Emily is a 40-year-old woman. At the time of the interview she was living at home with her husband Alan, who was 51. Alan also has a learning disability. Emily met Alan when she was 19 and they have been together for 25 years. They have two grown-up children, Melanie and Mark. Melanie is 22, has a mild learning disability and lives at home with her parents. Mark is 23 and has recently left the family home to move in with his girlfriend. Emily is unemployed and spends most of her time alone in the family home during the day. She enjoys water colour painting and attends a class in the local village once a week. She has one friend who lives 200 miles away whom she visits once a year and speaks to once a week on the telephone. Emily's mother died twenty years ago. Her father's health is deteriorating and Emily now sees him regularly. Emily has been treated in the past for post-natal depression. At the time of the interview she was not receiving any treatment for mental health problems.

4.5.2 Sharon

Sharon is a 33-year-old woman. At the time of the interview she was living in assisted housing with her husband Mike, who is 34. Mike also has a learning disability. Sharon met Mike when she was 26. They have been married for 5 years. Mike and Sharon have two children, David aged 5 and Michelle aged 3. Both David and Michelle are statemented at school and are receiving educational support. Sharon is unemployed but does work for three hours a week in a local charity shop. Sharon's parents divorced when she was 14 years old following years of domestic violence. Her mother is currently living in a nursing home in the north of the country. Her father lives relatively locally and they see each other intermittently. Sharon has no

close friends living locally but does occasionally see her old friends when they travel to visit her mother. Sharon has been treated in the past for both post-natal depression and clinical depression. At the time of the interview she was not receiving any treatment and reported no symptoms of depression.

4.5.3 Rachel

Rachel is a 35-year-old mother of four. She met her husband John when she was 17 and they have been married for 15 years. John also has a learning disability. Rachel has one girl, Amy aged three, and three boys John, Michael and Joe aged 10, 8 and 7 respectively. Three of the children receive 25 hours of extra help a week at school. Rachel is a full-time housewife; she looks after the house and their four children. She was sent to a special needs boarding school at the age of 10 and remained there until she was 18. Her contact with her mother was sporadic during this period but now she has regular contact with both her mother and stepfather. Rachel never met her biological father. Rachel does not have any close friends.

4.5.4 Isabelle

Isabelle is a 37-year-old woman. At the time of the interview she was living with her partner Peter, whom she met when she was 28; they have been together for nine years and have been engaged for two years. Peter was statemented at school. Isabelle has two children from two previous relationships. Her son Mike is 15 and was adopted following child care proceeding when he was 8 years old on the grounds of neglect. Her daughter Jennifer is 14 and is living with Isabelle and Peter on a permanent basis. Isabelle described a close relationship with her mother who lives locally; she does not

consider herself to have any close friends. Isabelle has suffered from depression in the past but was not receiving any treatment at the time of the interview.

4.5.5 Natasha

Natasha is a 38-year-old woman. At the time of the interview she had been living with her partner, Paul, for 14 years. They have been engaged for 7 years. It is not known whether or not Paul has learning disabilities. They have two children, Patricia and Sian, 14 and 8 respectively. Both girls are in full-time education and neither of them have been identified as having learning difficulties. Natasha's father and stepmother live locally and she sees them on a frequent basis. Her mother lives 'up north' but does occasionally visit the family home. Natasha identified one close friend, Sheena, who she sees on a daily basis. Natasha has not suffered from any mental health problems in the past.

4.6 Method and procedure

4.6.1 Ethical Considerations

Ethical approval for the study was granted by the Local Research Ethics Committee (Appendix A.1).

4.6.2 Informed consent

Before any of the participants were approached by the researcher a list of clients was identified by members of the various teams approached for participation in the study (CLDT, Clinical Psychologists). Possible participants were then contacted by a member of the team who they were familiar with and they were provided with both spoken and written information regarding the study and were given an opportunity to

ask questions. The written information sheet explains in detail the confidential nature of the study, what participating in the study would involve (Appendix A.2). It was made clear that their participation in the study was entirely voluntary and they were free to withdraw from the study. It was also made clear that withdrawal from the study would not impact on their status or treatment. If the participant agreed to consider taking part in the study their telephone number was passed to the researcher, who rang them to arrange a suitable time to go and conduct the interview. At the beginning of the meeting the study was once again discussed in detail and they were reminded that they were free to withdraw from the study at any point during the interview or following the interview if they wished to do so. All participants were required to sign a written consent form before participating in the interview (Appendix A.3).

4.6.3 Confidentiality

Data was held securely, in line with the Data Protection Act. In the process of providing consent, participants were informed that the results of the interviews would only be heard by the principal researcher and digital recordings would be kept in a locked cabinet along with written notes and paper copies of transcripts. Transcripts were also kept on a computer and protected with a personal password. Participants were informed that verbatim extracts might be used when writing up the research but ensured that pseudonyms would be used to protect their identification. At the end of each participant's interview they were asked if they wanted to withhold consent for anything that had been discussed in the interview to be used in the project. Participants were informed that all data would be destroyed following completion of the study.

4.6.4 Potential distress to participants

The nature of the study gave rise to the potential distress related to the topic under discussion. Participants were told they could stop the interview at any time or that they could withhold information or decline to answer a question at any time. The researcher also used her clinical judgement to be sensitive to the feeling of participants and avoid causing harm. Following the interview the participants were invited to discuss their feelings about the interview process and were also asked if they would like to discuss the interview further with a member of the CLDT.

4.6.5 Safety of the researcher

The researcher acknowledged that there were risks involved in carrying out interviews alone in the participants' own homes. Risks to the researcher were minimised in the following manner. Before each interview the staff member who had spoken to the client was contacted and informed of the time and duration of the interview and also to ascertain that a home visit could be conducted without identified risk. The researcher carried a personal alarm and a staff member was always aware of her movements whilst she was conducting the interviews.

4.7 Interviews

A semi-structured interview was selected for this research because it is the tool most commonly employed in qualitative research (Barker et al, 2002) and is also considered the best method of collecting data for analysis using IPA (Smith & Osborn, 2003). This is a flexible method that is suited to detailed exploration of the participants' experiences and allows the researcher to focus on particularly interesting areas that emerge (Smith & Osborn, 2003).

Semi-structured interviews are guided by an interview schedule (Appendix B.1). The schedule acts as a framework for the interview and allows a focus on the research questions. The schedule for the current piece of research consisted of a number of open-ended questions with a selection of follow-up probes (Appendix B.2). The schedule was developed using consultation with the research supervisor, the research literature and the literature available on the construction of semi-structured interviews (Smith, 1995; Smith & Osborn, 2003).

4.7.1 Construction of the interview schedule

In the initial preparation stages of the interview schedule a number of articles and book chapters were consulted in order to generate the correct tone and questions for the interview schedule. As the focus of this research was on the experience of adult relationships, the initial schedule attempted to focus on the socially identified fundamental aspects of relationships. In the first draft of the interview schedule, following a discussion with both other professionals working in the learning disabilities field and the thesis supervisor, the questions were identified as too explicit. It was decided that the level of explicitness prevented the participants from engaging in the area of interest in their own manner and was too focused on eliciting what the researcher identified as fundamental to relationships. With redrafting, the questions became less specific; they were designed to let the participants know the area of interest yet allow them to recognize they could say whatever they wanted about it.

To prepare for the possibility that the initial questions would be insufficient to elicit satisfactory responses, a probe sheet was constructed to frame each of the initial questions more explicitly (Appendix B.2). Thus the interview starts with more

general questions which may be sufficient to enable the respondent to talk about the subject. However, if the respondent experienced difficulties, for example in their understanding, or provided short one-word answers, the probe sheet could be used to elicit more explicit answers. Funnelling was identified as a related technique. This involves eliciting the participant's general view on a topic (e.g. partner relationships) and having established that, probes for more specific issues (e.g. trust in a partner relationship). The general premise behind this approach is that participants must be allowed to give their own views before funnelling them into more specific questions that are of particular interest to the researcher.

The interview schedule addressed the following areas (Appendix B.1):

1. Relationship with parents;
2. Relationship with partner;
3. Relationships with friends.

The interviewing techniques were guided by the researcher's experience as a trainee clinical psychologist, using skills such as active listening, rapport building, and reflective techniques. The researcher also adopted the suggestions of Booth and Booth (1996), outlined in the Section 3. Methodological Approach.

Following each of the interviews, an Interview Reaction Sheet was completed (Appendix B.3). The main use of the reaction sheet was to record initial impressions and reactions to the interviews. It included items such the rapport created, potential themes that may have arisen, and the researcher's response to the participant. This

form increases reflexivity and is similar to field notes used in other areas of qualitative research.

The interviews were transcribed verbatim from the digital recording by the researcher.

4.8 Data Analysis

The transcripts from the interviews with the participants were analysed using Interpretative Phenomenological Analysis (IPA) (Smith, 1995). The interviews were analysed on a case by case basis. The analysis followed a procedure delineated by Smith (1995) and Smith and Osborn (2003) and will be described in detail below.

Supervision was sought throughout from the academic supervisor.

The analysis process began by first listening to the digital recording of the interview, then listening again while the interview was transcribed. The resulting transcript was then read several times in order to become as 'intimate as possible with the account' (Smith, 1995). The transcripts were printed with wide margins to allow notes, preliminary summaries and emerging themes to be made on either side. The left margin was used for initial exploratory codes, with the right hand margin used for noting emerging themes. The interviews were first gone through making preliminary notes in the left hand margin followed by the theme titles in the right hand margin (Appendix C.1).

Once no additional themes were generated, the resulting themes were then listed with line numbers of where to find the verbatim extract to which they referred (Appendix C.2). The system used was page number-line. Possible connections between themes

were then made in order to generate theme categories or cluster groups. Each cluster group was given a theme title, which represented a super-ordinate theme for each interview (Appendix C:3). In line with the underlying philosophy of IPA, the analysis process was not conducted in a linear fashion; instead themes and categories of themes were often changed, refined and discarded through a continual interpretative relationship with the data.

All of the interviews were analysed individually using the same procedure for each. After the super-ordinate themes for all of the interviews were identified, they were then clustered and prioritised (Appendix E). The prioritisation was based on the richness of the data presented by the theme and the prevalence of the themes within the data. A final table of themes was then produced for each topic area (Tables 1, 2, 3: Results Section). Throughout the process the researcher continually ensured that the interpretations of the text were checked against the actual words of the participant.

The analysis was aided by the use of the reflective diary (Strauss & Corbin, 1990) and the reaction sheet for the interview was used to record the researcher values and thoughts which may have influenced the analysis. As mentioned previously, the analysis continued throughout the writing-up stage as the themes were explained, illustrated and placed in the context of the theoretical and research literature.

4.9 Reliability and validity

Published guidelines related to qualitative research studies (Elliot et al, 1999; Yardley, 2000) were consulted to help address some issues of reliability and validity in the qualitative aspects of the current study. Although it must be noted that it is often

suggested that qualitative research by its very nature should not be subjected to rigid guidelines (Elliot et al, 1999), a number of strategies can improve the reliability of the research (Lincoln & Guba, 1985). Steps taken to improve reliability include a research diary to keep reflective notes, interview reaction sheets, re-reading the transcripts, and providing evidence of links between final analysis and original data. The steps taken to maximise the validity include training in IPA (Visser, 2006), reflective questions to verify statements, re-reading the transcripts several times (Elliot et al, 1999), looking for exceptions in the data and the use of an IPA support group. An experienced IPA tutor audited the documentation of interviews one and three, examining the themes that had been extracted and the summary documents of themes that had being produced. This involved the tutor reading through interview one and interview three, checking the generated themes, examining the themes that appear to cluster together and providing guidance and expertise on how the themes might be grouped together and checking these against the transcript. The credibility of the final results table was also checked. This validity check was based on a method proposed by Macran et al (1999).

4.10 Personal Bias

The author's personal interest in this area following two years of working exclusively with this population has already being noted. It must be acknowledged that it may be impossible to separate one's own values, assumptions and theoretical biases in the research processes (Smith & Osborn, 2003). This will be addressed in more detail in the discussion.

5. RESULTS

The results involved the individual analysis of the three topic areas identified in the interview schedule; parent relationships, partner relationships and friendships. Each area was analysed following the protocol identified in the method section of this text. Each of these topic areas will be considered individually. Super-ordinate and sub-ordinate themes will be examined with reference to verbal extracts of the interviews.

5.1 Relationships with parents

This section was guided by the following research question: How do mothers with learning disabilities experience their relationship with their parents?

Table 1 Relationships with parents: summary of the analysis

The importance of support	Vulnerability in relationship
<ul style="list-style-type: none">• Importance of practical support• Tangible expression of care	<ul style="list-style-type: none">• Feeling blamed• Sense of not belonging

All of the participants spoke about their relationship with their parents. Their descriptions of their experience were both retrospective and current. The analysis of the interviews produced two super-ordinate themes which can be viewed with the sub-ordinate themes in the table above. Each super-ordinate theme and sub-ordinate theme will be discussed below with reference to verbal extracts from the interviews.

5.1.1 The importance of support

In their relationship with their parents all of the participants clearly identified how important the provision of support was to their relationship with their parents. Support seemed fundamental both in terms of how they experienced the role their parents played in their lives and also in terms of how they experienced and perceived being loved and cared for by their parents.

This theme was composed of two sub- themes:

1. The importance of practical support;
2. Tangible expression of care.

The importance of practical support

For many of the participants, practical support from their parents represented one of the most important aspects of their relationship. Emily identifies the most valuable thing about her relationship with her mother being the time when she offered her practical support following the birth of her baby.

I think the important time was when I had my son and my mum helped me a lot, she came down every weekend and went back on a Monday; she sat in the garden with the baby and helped out. (4: 94-96)

This support was reciprocated in the relationship, suggesting that the system of practical support worked in both directions.

I helped with Nan and when I had my son she always came down,
we went out shopping she helped with the baby. (3:62-65)

Interestingly, with her father it was clear that Emily experienced a better relationship with him when he became ill and the level of practical support necessary in the relationship increased.

...it (the relationship) has been much better since he has not been well. He has had pneumonia and arthritis and we help him, which is good. (4; 103-107)

Natasha, who despite having a difficult relationship with her mother, appreciates the practical support that her mother now provides for her. This practical support appears to be sufficient for Natasha to be able to experience appreciation of her relationship with her mother alongside the difficulties she perceives in the relationship.

She's alright now she brought me a table, kettle, toaster, TV unit,
she bought me this table, she bought me loads of stuff and helped
me out. (7:108-109)

When Natasha is asked what she misses about her mother now that she lives far away she continues to emphasise the practical support in the relationship.

...just miss her being near to me ... she could help me and stuff.

That would be good. (8:134-135)

Similarly Sharon, who struggled to talk about the relationship she had with her mother, identified the importance of practical support in their relationship. Akin to Emily there appeared to be a recognisable reciprocity in the support that was provided between mother and daughter.

I just did things for me mum, did her shopping and things like that for her (3:37) ...When I had my first period at twelve and asked my mum what it was and she said it's your first period and things like that. (4:41)

The provision of practical support for Rachel (from her mother in-law) creates a sense of security and permanency but also highlights the limitations of perceived support she would receive from her own mother in a similar situation.

She's always there for me, if I need anything she will help ... she'll babysit and everything, stuff like that. She will help me out on the phone and stuff like that. My mum would do that but if she is too busy she won't. (21:273)

Tangible expression of care

For many of the participants it was important for them to be able to identify tangible evidence that their parents cared for them as part of making sense of the relationship.

This is illustrated clearly by Natasha, who despite being unable to talk to her father identifies the tangible support provided as sufficient for a good relationship.

...he is good he is always helping, like if I am short on anything he will always come over and help me. We don't really talk about things either but he helps me so that's ok. (7:108-109)

She describes their relationship as good in terms of what her father does for her.

I When you were younger what kind of a relationship did you have with your dad?

N Yea I was alright with my dad, he gave me things and took me places and helped me with school stuff, it was good. (7:114-116)

Sharon found it very difficult to recall the good times she experienced with her parents when she was younger. In the following extract she describes her mother as someone who was special and bought her things. Similarly with her father, she can only recall very tangible means of knowing it was a good relationship.

...she (her mother) was special and that ... buy you things and things like that. (2:19-12) ...Dad took me out to places. (3:33) ...He takes you out and things like that. (3:36)

Although for Rachel tangible expression of care was also evident in her interview,

They use to take me out in the car and stuff. I know that. (10:128)

Unlike the others, Rachel was the only participant who placed much emphasis on the experience of emotional support she experienced in her relationship with her parents. She emphasised the importance of talking in the relationship.

If my mum says something or annoys me or something I'll talk to my father or brother.... Sometimes you have to talk because you will not get any help if you don't. I talk to my mum sometimes, some things, my brother more. (11:138)

5.1.2 Vulnerability in the relationship

Participants spoke clearly about the level of vulnerability they often experienced in their relationship with their parents. They describe feeling blamed and being unable to do anything to make the situation better. There was also a sense for some participants that they didn't belong. For some this was limited to when they were younger, for others it seemed to continue into their adult lives. This theme is made up of the following two sub-themes:

1. Feeling blamed;
2. Sense of not belonging.

Feeling Blamed

For three of the participants interviewed the experience of being blamed by their parents was very strong. In some cases the blame was interpreted and understood in terms of their learning difficulties. This was very poignantly illustrated by Natasha when she was asked about her relationship with her mother.

She used to pick on me all the time and take my sister's side all the time and blame all things onto me (7:117-118). ...She liked her better. She didn't have problems like me so she blamed me for everything and never listened to my side. (7:120)

And also in her relationship with her father:

He blamed me as well all the time and if you had a cold or that and made any noise he would have a go at me and leave my sister making the same noise. (7:124-126)

She eventually accepted this position and felt there was no point trying to change it any more.

...she (mother) never listened to me so there was no point in the end. (7:123)

Sharon also experienced a disparity between her and her brother in terms of the level of blame she experienced from her parents.

...if I did something wrong I would get put to my room. My brother would get... if he (brother) was bad I used to get the blame for it.

(2:23)

Rachel, who grew up in a family with her brother and two step sisters, often felt she was blamed for things unnecessarily.

...he tried to treat us all the same but it was hard. My sisters were sorta hard on him. ...I got the most of it they always blamed me, that is, something...something got broken or something and they blamed me for it and I got in trouble for it and it wasn't me...

(8:108-110)

Similar to Natasha, Rachel initially tried to address this unfairness. Eventually, following a number of unsuccessful attempts, she accepted this position of blame.

I, I did but eventually I just didn't. What's the point if they are going to blame me in the first place. (8:111)

Sense of not belonging

A number of the participants clearly struggled to feel they were an integral part of their families. Their sense of belonging didn't feel secure, with one participant feeling left out, while for another their sense of belonging appeared to be threatened.

Natasha gave a clear example of feeling as if she didn't belong to the relationship

between her mother and her sister and her wish to play a bigger part in this relationship. The following extract relates to an imminent visit from her mother.

...she (mother) might stay here this time I hope because I have the bigger place, but she normally goes to my sister to stay and have dinner and drinks and all that. It really annoys me she only ever spends an hour or two with me. (8:137)

Similarly, Sharon felt left out by her parents in comparison to her younger brother.

I wasn't a spoilt person like me brother. I was usually left out not like my brother ... I was left out more. (2:20-21)

For Rachel her sense of belonging appeared to be something that was very important to her.

...my dad who brought me up, he wasn't my real dad but he was dad to me because he brought me up and he was dad to my brother but my sisters didn't like it. (8:)

This belonging appeared to be threatened by her stepsisters who made it very difficult for her stepfather to maintain this sense of security and belonging.

He tried to treat us all the same but it was hard for him my sisters were kinda hard on him. (8:108)

For Rachel the experience of continual blame may have contributed to her sense of belonging being threatened. She suggests that her parents did believe her sometimes but the power of her two sisters was very difficult for her to overcome.

...they did but what it is the two sisters they all got together, and you know you just can't ... (8:112)

5.2 Relationship with partner

This section was guided by the following research question: How do mothers with learning disabilities experience their relationship with their partner?

Table 2 Relationships with partner: summary of the analysis

Significance of support	Ambivalence about independence
<ul style="list-style-type: none">• Importance of practical support• Importance of reciprocity• Tangible expression of emotion	<ul style="list-style-type: none">• Independence is important• Uncertainty about independence

All of the participants spoke about their relationship with their long-term partner. Their descriptions of their experience were both retrospective and current. The analysis of the interviews produced two super-ordinate themes which are illustrated with their sub themes in the table above. Each theme will be discussed with reference to verbal extracts from the original transcripts.

5.2.1 Significance of support

All of the participants identified support as playing a central role in their experience of partner relationships. Most noteworthy was the value they placed on practical day-to-day support from their partners. Although the perceived importance of support was similar across all the participants, the actual support received varied. Reciprocity also emerged as something participants were very aware of in their relationships, in some cases present and in other cases absent. This theme was composed of three sub-themes:

1. Importance of practical support;
2. Importance of reciprocity;
3. Tangible expression of care.

Importance of practical support

Across all of the participants, with the exception of one, the importance placed on practical help and support in the relationship was evident. When Emily was struggling with post natal depression she experienced support from her partner in a practical sense.

I How was S with you when you had the post natal depression?

E He was great looking after X and feeding him as well

I So he was a good help. What do you think it might have been like if he wasn't there?

E I don't know. I can't imagine it, I wouldn't be able to cope I don't think. (11:377-380)

Similarly, when Emily is asked if she finds it easy to ask her partner for help she answers by highlighting the practical support that he provides.

...like when I am doing a crossword, Melanie (daughter) and Mark (partner) are here they help me. (10:241-243)

Equally for Sharon, when she is struggling with stress and feeling unable to cope she experiences support from her partner in terms of practical activities.

S ...he knows if I am due to come on my period or if I wake up on the wrong side of the bed or just have a bad day or my legs are tired.

I What does he do?

S He does everything for me, the shopping and the taking the kids to school...(10:134)

Natasha also places a lot of value on the provision of practical support. However, in her case she experiences a complete lack of practical support from her partner in her day-to-day living. The following extract represents the frustration this creates in her experience of the relationship.

N I get a bit fed up with him because he doesn't help me that much. Like I go out and I get fed up when I come back to a mess all the time and I keep getting cross like he sits in the bloody front room and does bugger all really.

I How does that make you feel?

N Well sometimes I get a bit fed up. (1:13-15)

Likewise for Rachel, although she is able to identify a number of ways she is practically supported by her partner, she feels let down and disappointed when her

expectations of practical support are not met. This is illustrated in the following extract when her partner doesn't pick her up when she needs him to.

...he helps me cook sometimes and that he does all that sort of stuff. He helps me pick the kids up and when I met John he used to pick me up and drop me off. (2: 30-32) ...He can do that (spend time with his friends) but when I need him I prefer him to come ... I tell him I have been let down by him. (21:270-271)

Importance of reciprocity

Alongside the importance of practical support a number of the participants identified the importance of doing things for one another in the relationship. For most of the participants this reflected the experience of equality in the relationship, for others it highlighted the perceived inequality in the relationship and created resentment and frustration. For Natasha, who felt a clear level of frustration at the perceived lack of practical support from her partner, the principle of reciprocity allowed her to try and rectify the perceived imbalance in the relationship in practical terms. This is illustrated by the following extract when she was asked if the imbalance was always there in the relationship.

It's been on and off, he does the odd thing like he did the hoovering on Thursday and things like that but it's only if I ask him to do it otherwise I have to say to him. ...And often I will say to him, "will you do this if I do that" and things like that. (2:19-21)

Natasha reflects on the importance of reciprocity in a relationship emphasising the practical aspect of reciprocity that appears to be missing in her relationship.

Like Paul should help me more, like I do something he should do something (3:43). ... He could help me more and do things for me when I do things for him. (9:145)

For Emily the level of reciprocity in the relationship was something very important and highlighted in very practical, tangible terms when asked about sharing in the relationship.

Well on Friday I go shopping and when I come home the house is all clean and tidy and I do the washing and the ironing and he does the cooking as well. Two nights I cook and two nights he cooks and then the third or fourth night we have a toss-up about who is going to cook. (7:213-220)

The experience of reciprocity for Sharon represented their capacity to support one another and was discussed primarily in the context of not feeling well or feeling tired.

Alright he does it mostly but when I am feeling OK then I can do it mostly. (10:135) ... We have turns each once in a while. (10:134) ... I do that with him as well if he is tired and he wants to stay in bed a wee bit longer then I do the same things as well. (11:144)

For Isabelle the presence of reciprocity in the relationship was identified in a definite but minimal way.

...we help each other. (4:42)

Tangible expression of emotion

All of the participants, to different degrees, experienced love or care in the relationship through the experience or expression of tangible acts. For some of the participants, Isabelle and Rachel in particular, this was accompanied by a high level of emotional expression and intimacy in the relationship while for others the level of verbal expression and intimacy was limited. For Emily the experience and expression of care and love in her relationship with her partner is illustrated through the following extract.

I ...how do you know he cares about you?

E We go places and go around. We went away for my birthday which if he didn't care he wouldn't have taken you away on your birthday. (6:190-193)

I Why do you think he loves you?

E ...make him tea, cook his breakfast for him and nine times out of ten I cook the tea and if he has not gotten any money I will give him some money to buy stuff like last weekend and I also buy him stuff. (15:514-519)

In a further extract Emily describes only talking to her partner about 'nothing really' and again emphasising the importance of tangible support in their relationship.

E We talk about nothing really, like where will we go out and where will we go shopping and can you take me to.... If I want to go anywhere he will take me, he might moan but he will take me.

I What about times when you're feeling sad or cross about something would you talk to Alan then?

E No. (11:397-403)

Even Natasha, who from previous extracts appears to struggle with the lack of practical and emotional support she receives from her partner, was able to identify some tangible means of knowing that she was cared for and also cared for her partner.

...well he does things for me, he sees that I'm alright and em.... gets me stuff like chicken wings from pizza hut and things like that helping me and stuff. (6:103)

However, unlike Emily, Natasha really struggles with the lack of communication and what she perceives to be emotional support in her relationship.

...the thing is with me I don't do enough talking to Paul, because he is at work and when he is coming in I go out to the pub... so we

don't really sit and talk things over or chat and like my mate says to me if you don't talk to Paul you are not going to have a proper relationship (2:24-28). ... I would really like to talk things over ... a couple of times I have talked to him about the kids he just sits there and says they are just kids ... and I think to myself, what is the point of talking to you. (2:30-32)

Sharon also experienced caring for her partner by doing things for him.

I What kind of thing do you do so that he knows you care for him and love him?

S I do the house work, take the kids to school, things like that.

I What kinds of things?

S His breakfast, all his dirty washing, I let him watch the football... (11:136-138)

Limited but apparent emotional expression was also evident and Sharon did tell her partner that she loved him occasionally.

I do say I love him sometimes. (11:139)

For Rachel when she was asked how she lets her partner know that she cares about him she clearly expressed the importance of tangible acts in the expression of emotion, both in terms of her experience and her expression of care and love.

R How do I let him know that I care about him? Things I think.
Like I buy a trousers for him once in a blue moon. I help with
his petrol every week ... stuff like that.

I All that kind of stuff.

R He took me out. That was. He took me out to the pub once or
twice last year. He did that last time it was good. (5:67-70)

Rachel also experienced a level of intimacy and perceived emotional support from her partner as illustrated from the following extract.

R Things about him! When things come up he is quite
good at helping me put them, not put them straight but
he helps me through it.

I So what kinds of things would they be?

R If the family upsets me or something like that. (1:13-
14)

Similarly for Isabelle, although she also highlighted the tangible expression of care in her relationship with Peter, she placed most of her emphasis on the level of emotional connection, openness and intimacy she experienced in her relationship. In the following excerpt she expresses the presence and importance of both when asked how she shows P that she loves him.

I show it in my heart and he has a heart so we can show it together.

He waits in for me, and if I am bloody tired from work he will run

my bath and gives me time on my own and he takes me out and we have a nice time and its good...because we love one another we share a lot... I do lots of things for him: I do his washing, cleaning. I love it, it's good and it makes me feel good to be caring for him.
(4:30-41)

Isabelle expresses the intense experience of intimacy with her partner, something that Natasha clearly misses from her relationship.

...yea we talk about everything. (5:49) ...When I look at him and he looks at me and I think you're great and the relationship is good.
(5:47)

5.2.2 Ambivalence about independence

All of the participants identified some ambivalence about the role independence plays in their relationship. They recognized independence as something that was important in a relationship, often identified in terms of giving each other some space outside of the relationship. Some of the participants faced a dilemma; their perception of social norms suggested that a relationship should mean doing things together and they therefore struggled with the idea of doing things alone without their partner. For others a clear shift is evident over the course of the interview, where their perception of independence adjusts from something fearful to something important. The theme was made up of two sub-themes:

- Uncertainty about independence;
- Importance of independence.

Uncertainty about independence

Many of the participants expressed a level of uncertainty about independence in their relationship. The concept of independence presented a dilemma for Rachel. Her beliefs clearly suggested that doing things together is what constitutes a relationship, which made it difficult to conceive where independence fits in the relationship. The following extract illustrates this.

I What do you think a really close relationship is?

R Between them is like, ah, if you're doing things together but if you're not you do things by yourself distant from everyone else.

I What do you think about the distance?

R Got to do it for yourself if you are independent on your own. Stuff like that but if you do things together, that's a relationship together.

I And do you think a relationship should be all about doing things together?

R If you want to stay together, yea, it should be together yea.

(23:287-289)

But it was also clear, as the other sub-theme will illustrate, that independence was something that she felt was important in the relationship.

For Emily the idea of having more independence in the relationship didn't represent any possible differences in the relationship, that is, she didn't feel having more independence in her relationship would make any difference.

I Do you think your relationship with Alan might change if you were a little bit more independent?

E It wouldn't be any different – just doing a bit more...
(13:452-453)

Sharon she didn't feel independence was particularly important because her life was already so busy with the two children.

I Do you ever wish that you were a little bit more independent and doing things on your own?

S No not really because I have two children to keep me going and that and I do more with them. (14:180-181)

Importance of independence

All five of the participants at some point in the interview identified the importance of independence in their relationship. For some independence represented space in the relationship while for others independence allowed them to cope better with their partner being absent for periods of time. Isabelle, over the course of the interview, shows a clear qualitative shift from independence being something that is frightening to something that she feels is important to the relationship. In the following extract

she highlights how having some independence leaves her feeling more secure in the relationship.

It is a little bit scary but I get used to it because it is my independence. (6:64) ...I do miss him like but I have a job now so it's better I am not here all the time waiting for him to come home. That was hard for him and for me waiting all the bloody time and getting annoyed. (13:133-135)

Furthermore, for Isabelle the fear of losing her partner was very strong in the interview yet she is able to recognise the importance of allowing her partner to have other people in his life.

He rings other people, too. He has the right to have friends. I asked him the other day if he slept with other woman but he said, no. (9:87)

Emily, despite her ambivalence about the importance or place of independence in her relationship, recognises that having some independence from the relationship allows her to engage in different activities.

On Friday I go to art therapy and on Monday I do an art course... so yea I do go there on me own on Monday. (8:273-274)

She also recognises that if she did have more independence she would be able to cope with things a little bit better.

I Do you think that you would like to rely on yourself a little bit more?

E Yea because I could cope with things if I relied more on myself.

I What would you be doing differently?

E ... just to rely on yourself and to have to think about whom is going to help you with things. (13:445)

Rachel also experienced the importance of having some space in the relationship which is difficult to align with her previous message that for a relationship to work it must involve all things being done together.

Sometimes John would like to go on his own somewhere and I would like myself if there was space... because you get on top of each other and you are arguing and stuff like ... it gives you the break between two people. (23:290-292)

Similarly, Sharon who identified independence as unimportant at one point, later in the interview acknowledged that she and her partner have separate lives as well and recognises the importance of space in the relationship.

S ...but that's his (partner) life. He goes out a lot because he has lots of friends.

I Do you mind him going out all the time?

S Not a lot I don't mind. It keeps me going what I can do in my own house and I can watch what's on TV. If he comes home he can watch football things. (17:210-213)

5.3 Relationships with friends

This section was guided by the following research question: How do mothers with learning disabilities experience their relationships with friends?

Table 3 Relationships with friends: summary of the analysis

Friendships can be dangerous	Benefits of friendships
<ul style="list-style-type: none">• Distrusting close relationships• Friends can be bullies	<ul style="list-style-type: none">• Friendships provide support• Friendships provide sense of belonging

Although only two of the participants who took part in this study were able to identify specific people who they currently called friends, all of the participants shared their experiences, their beliefs and their fears about this area of their life. The analysis of the interviews produced two super-ordinate themes which can be viewed with the themes in the Table above. Each super-ordinate theme with reference to the subordinate themes will be discussed below with reference to verbal extracts from the interview.

5.3.1 Friendships can be dangerous

All of the participants expressed much fear and distrust associated with both their present and past experiences of friendships and peer groups. Most of the participants had experienced some form of bullying over the course of their lives and the experience of exclusion was a common thread running through many of their narratives, often identifying their learning disability as the reason they experience this

behaviour from others. This super-ordinate theme was made up of two sub themes which will be discussed individually:

- Distrusting close friendships;
- Friends can be bullies.

Distrusting close friendships

Some of the participants experienced considerable fear about getting too close to other people. In the following extract from Emily there is a strong sense of the fear she feels towards other people.

It frightens me a little bit; close relationships are a bit frightening.
(13:438-439) ...because I think they go behind your back and slag
you off and that's not nice. (14:481-482)

Later in the interview it emerges that risk and disappointment appear to be some of the reasons why she struggles with most close relationships.

E I don't know I don't think you can ever tell, sometimes you
make friends and you get hurt

I How do you get hurt?

E Well like when they say, 'Oh yea we will do this and do that'
and then they don't do it and you're sorta left thinking, 'oh
well why not'? (18:590-596)

Rachel expresses a similar level of distrust, despite the clear wish she expresses to belong. The following extract depicts a clear narrative of fear of the unpredictability of friendships for Rachel.

I did, ah, tried to make friends, I did it.....to see if I could join in and mix with other people (16:200-202).... It's just too hard plus I don't like it anyway. (16:114) ...I don't want to get too close (18:136) ...I'm afraid (18:137) ...I sorta get very nervous, talking and because you don't know that person very well, and you don't know what they are going to do, what they are going to say and stuff like that. That is why I don't like getting too close to people I don't really know. (18:139)

Isabelle's fear of closeness is clearly associated with distrust. The following extract provides a sense of this after she was asked if she would she like to have some friends.

No not really because I don't want to talk to people about my private business and that and I don't trust people. They talk about you and things like that, don't like it. (11:107)

Isabelle experiences meeting new people as risking getting herself hurt and recognises this as something she is not prepared to do.

I just don't like people knowing my business; you might get hurt and it's just not worth it. (11:110)

Natasha identifies making friends as something that is easy for her; her level of distrust is related to being left out and her sense of being used by other people. Like some of the other participants when they identified their bullying experience, Natasha understands some of the treatment in terms of her special needs as the following extract illustrates.

I'm easy to make friends it's just that the one's I make seems only to want to know... em when they have nothing to do, like use me. When they have other people they will ignore me, maybe because I went to special school or something, like I'm different. (4:62-64)

Later in the interview she seems to understand their treatment of her in terms of her limited social network making her vulnerable.

Some people are just like that they use you when they have nothing better to do and because I don't have much friends and they know that maybe they do it more cos it's me and stuff. (4:71-72)

Friends can be bullies

Rachel was able to remember a number of instances of when she had been bullied when she was younger. In the following extract she identifies her learning difficulties as one of the ways she understands why.

They'd be on my back, they were so rude and nasty, but I know I know what it's like. (14:181) ...I had, um, freckles when I was little, they used to moan about that, or um I actually can't read properly. You know stuff like that. They used to take the mick out of me. (14:183-184)

Similarly for Sharon, her experience of being picked on and being bullied was understood in terms of her own difficulties and her perception of herself as inferior. In the following extract she very poignantly speaks about going to a school for 'people like her' and because of this expecting not to be bullied.

Well I knew there would be other people there the same as me, things were wrong with them like what I'm like but since I have been at school but I was bullied as well. (15:191)

Later in the interview when Sharon speaks again about the level of bullying she experienced it is clear how this experience may have contributed to her current worries about her own children having a similar experience.

I don't get bullied much now and I don't want that to happen to my kids either at school. (15:195)

Similar to Sharon and Rachel, Natasha identifies herself as the reason for the bullying behaviour. That is, she invokes the behaviour as a consequence of her learning

difficulties. In the following extract she is talking about the bullying she experienced at school.

I used to get the blame there as well. I thought it might be because I was different but I don't know. People picked on me a lot, the teachers as well. I don't know. It was really hard. (7:127-178)

5.3.2 Benefits of friendships

Surprisingly, in spite of this very negative experience, all of the participants were able to identify the substantial benefits that friendships were able to offer them, both in terms of personal wellbeing and general life style:

- Friendships provide support;
- Friendships provide sense of belonging.

Friendships provide sense of belonging

Rachel is very clear in her wish to belong to what she thinks friendship may be like and identifies friendships as something she would really like to be part of.

I see them sitting down with their friends. Why can't I have some friends?
(15:196) ...I wish I had someone to sit down with and have a cup of tea
with really. (19:248)

For Emily, who was able to identify one close friend, the sense of belonging that this relationship offered and what not having a friend may be like is illustrated by the following quote.

...going out and having a girly night out for a change (18:605) ...don't know it would be terrible because when we went on holiday we met up with L and her husband and then there was me and Alan and that was so nice we went to the pub. (18:606-611)

For Sharon the sense of belonging relates to friends she had when she was only a small child.

They made me laugh more and made me help more with them as well. (4:45)

This sense of belonging seems to continue into her adulthood where she was able to use this friendship and sense of belonging to move forward in her life. In the following extract Sharon is referring to a time in her life when she was mistreated in one of her previous relationships and she needed to get away.

I That's hard. How did you sort yourself out?

S Moved away from xxxx because it was getting - because it was getting bad.

I Who did you move away with?

S A friend, just a friend I used to hang around the weekends with and we go out.

I What did you like about her?

S She was good company for me and she was a good laugh so we moved to xxxx together and started afresh. (9:116-120)

With Natasha the sense of belonging was very strong. She didn't appear to have a particularly good relationship with her family and therefore the level of importance attached to her one friend was great, perhaps compensating for the difficulties in her other relationships.

It would be very lonely because I only really got her to do things with, I haven't really got anybody else. Yea it would be very lonely nobody to do things with or to talk to things with. I don't really have anybody else to do things with. (4:74-76)

Natasha created a clear distinction between this friend and other people she knew and the clear sense of belonging is evident in the following extract

S is different, like we speak to each other most days, and we see each other most days as well when we go up the village together and have a drink together its nice. (4:59-61)

Friendships provide support

Emily is very clear in her beliefs about the importance of friendship and what friendship has to offer. In the following extract she describes the level of emotional support that can be provided by friends.

I Why do you think it's important that we have people around that we can trust?

E Because if you have a problem you can talk to them and they will not tell anyone else about the problem. They can keep it to themselves.

I Why do you think it's important to talk about the problem?

E To get it aired because it just builds up inside otherwise and makes you feel angry. (15: 493)

In the following extract Emily illustrates the level of support she received from her friend following the birth of her son and her post natal depression.

...yea I did. She was very helpful, she said I could come and stay with her if I liked for a week. I didn't go but it was nice to know and I just got on with it but if it had been really bad that would have been the one place that I would have thought of going for a rest. (17:579-585)

The essential nature of support is further highlighted when Emily speaks about her daughter in the following extract when asked why she thought it was important for her daughter to have friends.

...so she can find a real friend and then if anything upsets her she can talk to that person because she finds it hard as well. (18-19: 621-624)

Isabelle, despite identifying friends as not being important to her, still identified the difficulties she often experienced because she didn't have many friends. For her, friends offer a way of avoiding the loneliness that everyone experiences at some point.

...don't know really. A bit lonely on your own, not talking to anybody,
like friends... like no friends is a bit lonely. (10:95)

Later in the interview Isabelle identifies both social and emotional support as things that are offered by friendship. The following extract relates to a friend who she sees occasionally and follows the question 'What's she like?'

...she thinks I am a nice girl and she helps me with things like that I can't understand and tells me not to worry. (10:101)

For Sharon the support offered by her friends was related to her experience of being bullied and the protective role her friends played in this experience.

People were making fun of me and laughing at me but my friend stuck up for me my friend. (20: 255)

Sharon also experienced the reciprocal support role friendships can offer and identified the support she received from her friends as something that made her feel happy.

They make me feel happy and that, like stop the bully and things like that, because that's what my friends do for me, because she went through the same thing as well. (20:257-259)

For Natasha the support provided by her one identified friend was both emotional and practical. Because her relationship with her partner was limited in terms of emotional support this was a much valued attribute from her friend.

N Cos I hate arguments so I just tend to leave and talk to my friend.

I How does that help?

N She says I get left to do everything here in the house and she says it's not fair on me to have to tidy all the time.

I Sounds like she listens to you. How do you feel after you have spoken to her?

N Like I feel better after I tell her. (3: 41-41)

Natasha receives a lot of practical support from her friendship and illustrates a clear level of reciprocity in the relationship

...well she got me some clothes and helped me that day to do my hair and makeup and things. (3:50) ...she (friend) is all on her own now and I was there for her. I have been looking after her and helping her and inviting her here for dinner and looking out for her and helping her and checking and now we are a best mate, that's what mates do for each other. All my other mates just use me when they have nothing better to do. (4:56-58)

6. DISCUSSION

6.1 Summary of the results

This research aimed to explore how mothers with learning disabilities experience the relationships in their lives with their parents, with their partners and with their friends. Analysis revealed super-ordinate and sub-ordinate themes for each of the three topic areas. In their relationships with their parents 'The importance of support' and 'Vulnerability in relationship' were identified. In their relationships with their partners 'Significance of support' and 'Ambivalence about independence' were identified. In their relationships with friends 'Friendships can be dangerous' and 'Benefits of friendships' were identified. These major findings will be discussed in turn in relation to the existing theoretical and research literature the research findings. This will be followed by some observations across all three areas. Limitations, clinical implications and recommendations for future research will also be considered.

6.2 *Relationship with parents*

A number of studies identified parental support as a central element of parents with learning disabilities' support networks but stressed that this support could have both positive and negative outcomes for its recipients (Tucker & Johnson, 1989; Llewellyn et al 1995; Stenfert Kroese et al, 2002). The current research also identified their relationship with their parents as an important source of support but little emphasis was placed on the negative impacts of this support. In some cases the reciprocal nature of this support was emphasised with participants both giving and receiving help from their parents. Heller, Millar and Factor (1997), in support of this, identified adults with learning disabilities as effective support providers, and highlighted the

importance of opportunities for adults with learning disabilities to reciprocate the care and support they receive in a relationship. For other participants in the current study, the provision of support represented the experience of being loved and cared for by their parents, often in cases where the sharing and expression of emotions was limited or where other areas of the relationship were difficult. For example, Natasha was not able to ask to her father for support but felt supported and cared for through tangible acts, "He will always come over and help me. We don't really talk about things either but that's OK he helps me".

This research also revealed a number of vulnerabilities in relationships with parents (Results: Table 1). In the research literature the term 'social power' refers to the person's ability to influence deliberately the behaviour, thoughts or feelings of another person (Huston, 2000). Some of the participants experienced a lack of mutual exchange of social power within their relationships with their parents. That is, they experienced being blamed by their parents and felt unable to challenge this successfully. Some of the participants also illustrated a sense of not belonging to the family or their sense of belonging being threatened, often feeling pushed out by other siblings within the family. Widmer et al (2008) investigated the way individuals with learning disabilities perceived their family contexts and reported that individuals with learning disabilities perceived themselves as less central in their own families compared to other family members. The authors identified the need for this area to be further understood. In the current study the sense of blame and vulnerability experienced within relationships with parents was often understood as a consequence of their learning disability, particularly where there were other siblings in the house who did not have learning disabilities.

6.3 Relationship with partners

In their relationship with their partners, participants again placed significant importance on support received from their partners (Results: Table 2). In particular they identified the provision of practical support as something they valued, both in terms of something that was offered to them by their partner, and offered by them to their partner. The level of reciprocity experienced in the relationship was often mentioned in the context of their sense of equality in their relationship. A good relationship appeared to be characterised by a substantial level of reciprocity. Reciprocity has been found to contribute to the stability of the relationships with adults with learning disabilities (e.g. Newton, Olson & Horner, 1995), a finding supported in a number of other studies (Stenfert Kroese, 2002; Llewellyn et al, 1999).

All of the participants, to different degrees, experienced being cared for in their relationship with their partners through the 'tangible expression of emotion' (Table 2). For some of the participants, Rachel and Isabelle in particular, this was accompanied by their partners sharing and expressing emotions, while for others this was limited. It was often difficult to separate instances of practical assistance from those of emotional support. This was largely because the participants viewed the acts of tangible support or practical assistance as how they experienced being loved and cared for in the relationship.

Within the partner relationship there was a high level of ambivalence attached to the theme of independence in the relationship. Some of the participants struggled with the idea of a close relationship existing alongside independence of their partners. For

one participant, Rachel, it was clear that she struggled to align the importance she placed on 'space' and independence in the relationship with the clear beliefs she expressed about the survival of relationships being dependent on 'doing things together'. For others, there was a clear qualitative shift in their perception of independence, in the case of Isabelle moving from 'frightening', to 'OK' to 'good' over the course of the interview.

The Interdependence Theory (Thibaut & Kelley, 1959) would suggest that people who are highly dependent on their relationship believe that their needs and goals can be best met in their current relationship. The theory further suggests that the degree of dependence forecasts the likelihood that individuals are motivated to openly express distress and to seek support from their partners when they are upset (see Rusbult & Arriaga, 1997, for a review). Interestingly, despite the fear the participants often expressed about doing things on their own, some did not turn to their partners in times of distress to seek their reassurance and support but sought this generally from people outside of the relationship (i.e. parents and friends). For example, Emily was very ambivalent about more independence in her relationship with and displayed a high level of dependence yet she never spoke to her partner about things she was finding difficult or about emotions which she found overwhelming.

6.4 Relationships with friends

In the participants' experience of friendships there was a clear dichotomy expressed in terms of positive and negative aspects to this type of relationship. It was clear that participants experienced substantial difficulties in making and maintaining friendships.

This supports previous findings that this is one of the greatest unmet needs within this

population (Llewellyn et al, 1995; Atkinson, 1986; Llewellyn et al, 1998). The participants expressed a distrust of other people, with many of their fears being grounded in previous experiences of being let down and in some cases being bullied by their peer group (Results: Table 3). Interestingly, many of the difficulties associated with friendships were perceived as being located within themselves, in that they identified their learning disability as one of the reasons why they experienced problems in their friendships. This supports a study conducted by the Rother Institute (1990) which identified the role of poor self identity/self concept in the making and maintaining of friendships. Particular narratives or schemes such as 'I'm a bit different' appear to hold substantial implications for how people regard themselves in their relationship with potential friends. Participants spoke about past experiences of negative appraisals by others of their learning disability. These experiences had created a fear of friendships, and a sense of the unpredictability of friendships, with participants using words like 'frightening', 'let down' and 'disappointed' dominating their narratives.

However, despite the difficulties and the perceived dangers associated with friendships, the participants also spoke about the benefits that friendships had to offer. Participants emphasised the reciprocal nature of friendships and emphasised support and belonging as something they felt relationships with friends had to offer. There is often an assumption that people with a learning disability cannot have reciprocal friendships because they do not have anything to 'offer' the friendship (Mirfin-Veitch, 2003). However, for a number of the participants in the current study both receiving support and being able to offer support were identified as important and reflected the significance placed on reciprocity. This finding supports the relatively recent research

conducted by the Donald Beasley Institute (2001) which identified the importance of being able to be a 'good friend' for individuals with learning disabilities and linked this with their ability to provide information and practical and emotional support to friends when they were experiencing difficulties. The findings in this study also reflect findings by Lutfiyya (1991) who conducted a qualitative study to explore the meaning of friends with four pairs of friends, one with a learning disability and one without. The findings of this study, similar to the current study, identified sense of belonging, and practical and emotional support as the primary benefits of the relationship.

6.5 The importance of support in relationships for mothers with learning disabilities

One of the key contributions of this study is to highlight the emphasis placed on the importance of support for all of the participants across all three relationships: parent, partner and friendships. The literature, as stated in the introduction, identifies three broad categories of support: emotional, informational and instrumental. Until relatively recently emotional support was identified as the most important of the three types of support in terms of psychological and physical wellbeing. However, this has begun to change and researchers are now beginning to focus on the critical role instrumental/practical support plays in the promotion of successfully managing life challenges (e.g. Kaniasky & Norris, 1992). In the current study all three types of support were evident but there was an emphasis placed on the importance of practical/instrumental support, particularly in the participants' experiences of their relationships with their parents and their partner. This finding supports the study conducted by Stenfert Kroese et al (2002) who suggested that the most important

aspect of social support was 'support with difficulties'. Similar to the present study, this ranged from basic support (e.g. shopping) to transport in an emergency. Similarly, Hashima and Amato (1994) also found that practical support is particularly important for families living in deprived socio-economic circumstances.

The Interdependence Theory (Thibaut & Kelley, 1959) suggests that interactions with other people are experienced as pleasurable to the extent that they gratify one or more important need and are experienced as unpleasant or painful when they fail to gratify important needs for that person (Holmes, 2000). The participants identified support as fundamental, and in cases where support was provided the participants expressed satisfaction with their relationship, even when there were other difficulties within the relationship. Where this need or expectation for support was not gratified, frustration and disappointment were evident. In the case of Natasha the level of frustration in her relationship with her partner centred on the perceived disparity in the relationship. Like the others she emphasised the importance of support, but unlike the others there was a discrepancy between her expectation and the provision of support. The Equity Theory (Walster et al, 1973, 1978) would suggest that difficulties occur when one person receives relatively more from the relationship than the other person does. Natasha felt she was contributing more to the relationship in terms of practical actions and was receiving very little in return in the relationship.

The importance of receiving practical support may be fundamental in the narratives of the present sample for a number of reasons which will be considered here. First, it is possible that some of the participants, as a result of their learning disabilities, did not have the vocabulary to describe the importance of the emotional aspects of their

relationships (Booth & Booth, 1996). On the other hand participants may have preferred to talk about the more tangible aspects of the relationship. Or an alternative explanation may be that participants may have chosen not to discuss what they considered the more private aspects of their relationships. Second, this population often receives specialised and community-based support programmes (Booth & Booth, 1995) from a range of professionals. Such support has been linked with the term 'learned helplessness' (Abramson, Seligman & Teasdale, 1978), which is often used to describe individuals who, due to the level of support they receive from professional services, find it difficult to cope alone. Because services generally offer tangible help and support, individuals may be socialised into a model of relationships that identifies the giving and receiving of material items and tangible support as indicative of love and care in a relationship.

6.6 Stigmatisation

Difficulties in making and maintaining relationships, is not considered an inherent problem associated with having a learning disability. Rather, as the current study illustrates, these difficulties can be caused by a combination of lack of social opportunities, previous experiences, and beliefs about friendship. In addition there is a recognised dearth of educational programmes for people with learning disabilities focused on communication and interpersonal skills (McGaw et al, 2002). As this study illustrates, people with learning disabilities are often faced with stigmatization, discrimination and hurtful experiences, often to the extent that they themselves begin to identify their own deficits as the reason for difficulties in relationships.

Thus, having a learning disability and its impact on women's relational experiences is a key issue. From the present findings a number of themes emerged in the final analysis, particularly 'vulnerability in relationships' and 'friendships can be dangerous'. These were understood and experienced in terms of the learning disability that each of the participants had been labelled with. For many the level of vulnerability they experienced in their relationships with their parents was internalised and understood to be a consequence of their learning disability. This was also evident in their experiences of friends. Some of the participants identified themselves as different from their friends and explanations such as 'I'm different because I have a learning disability' saturated their stories. These results are similar to a study conducted by Gillman et al. (2000) who also identified the stigmatising effects of labelling individuals with the term 'learning disabilities'. Particular explanations or schemes such as these can have substantial implications for how people regard themselves, how others see them, how they are treated, and what hopes and fears are held. In narrative therapy terms, labels such as 'different' and 'responsible' may represent problem-saturated stories that may act to limit the participant's ability to engage in relationships.

6.7 Clinical implications

Mothers with learning disabilities can maintain a long term relationships with a variety of individuals. Support services need to take into consideration the individual family context of each mother in terms of the provision of support already in place, thus emphasising the importance of consulting with and listening to mothers with learning disabilities. These mothers, despite the difficulties they experience in their relationships with their parents, do value parental support and rely on parents

particularly for support in practical matters. This support should be valued and utilised by services supporting these families placing greater focus on a family centred approach.

In this study partners were identified as a source of substantial support in day-to-day living to the extent that many of the participants were unsure about how they would cope without their partners. However, many mothers with learning disabilities are not part of a supportive partner relationship because they are not in a relationship or the relationship they are in is not supportive (Booth & Booth, 2002). Services should be mindful of the further difficulties this creates and consider this when decisions are being made about the competence of mothers with disabilities. The system needs to be able to make provisions to support the gap left by not having a supportive partner. Particularly, as research has suggested that perception of support may be more important than actual support in buffering the effects of stress (Feldman et al, 2002).

It is also essential for those people working with mothers who have learning disabilities to be aware of the importance of friendship and to consider how mothers with learning disabilities can be supported in developing, maintaining and extending their friendship networks. The absence of friends in mothers' support networks is of concern, given their importance as an indicator of quality of life and social integration for other adults with learning disabilities (House, Umberson & Landis, 1988; Newton et al, 1994). If friends have a unique role in helping individuals cope with life's unexpected crises (Duck, 1991), mothers with learning disabilities may be particularly vulnerable considering the paucity of friendships in most of their lives. Mothers with learning disabilities have the capacity to identify what is useful to facilitate

friendships and self-advocacy should be promoted. The current study contributes to a better understanding of what is frightening about friendships; something that perhaps services could focus on to begin addressing the difficulties in this area. The literature suggests that 'community building' is the most current approach to addressing friendship and social support with adults with learning disabilities and involves creating frequent opportunities for meeting other people and may involve groups and organisations that facilitate social interaction (Mirfin-Veitch, 2003). Support in the area of friendship development should not be seen as an optional add-on; as this study has illustrated, as well as providing emotional and practical support, friends can offer protection from bullies and a sense of belonging.

The participants in the current study tended to internalise the perceived difficulties in relationships as a consequence of their learning disability, maintaining a negative self identity that may limit their capacity to engage in meaningful social interactions. The Attribution Theory (Kelley, 1973) distinguishes between the internal and external dimension of attribution and considers the extent to which events are perceived to be caused by the self rather than factors external to the self. The mothers in the current study consistently attributed their relationship difficulties to the self (i.e. 'it's because I have problems'). Researcher suggests that people who attribute negative events to causes that are internal to themselves struggle to think about ways the situation may be resolved. Narrative therapy has developed an approach to helping people to move away from limiting, dominant narratives and to develop new stories of themselves, their experiences and their expectations (White & Epston, 1990). It places people as the experts on their own lives and as having the skills and resources to change the relationship they have with the 'problem stories' (i.e. I can't make friends because I

have a learning disability) that limit their identities (Susko, 1994). Through questioning, the person is encouraged to understand and deconstruct their beliefs. They are also helped to discover preferred stories and positive selves (Morgan, 2000). Narrative therapy's invitation to perceive people as separate from their problems and to give them a voice in constructing preferred stories about themselves and their future seem both relevant and promising for mothers with learning disabilities. It could offer an alternative to the 'different' and 'vulnerable' themes that permeate their view of themselves in terms of their relationships.

Matthews and Matthews (2003) have used narrative therapy with individuals with learning disabilities experiencing difficulties labelling their emotions and coping strategies. The authors reported good progress in the two case studies they presented and suggested that narrative therapy 'complemented well' the behavioural and cognitive behavioural approaches with people with learning disabilities. Up to now, however, the use of narrative therapy with people with learning disabilities has been limited. This is an area that clearly requires further research to validate the approach and thereby make this type of therapy more accessible.

6.8 Limitations of the study

6.8.1 Validity of interpretation

The communication difficulties observed with people with learning disabilities has frequently been documented in published research (Lloyd, et al, 2006). They often struggle with complex grammatical phrases or abstract concepts and can experience some difficulties in verbalising responses (McLean, Brady & McLean, 1996). This can result in expressive language that may be compromised in its content and richness,

although clearly this depends on the level of cognitive impairment. In the current study the participants frequently provided limited responses and probes were often used to facilitate the conversation. The limited responses made the search for meaning in the text more challenging, raising questions of validity and reliability. To ensure that this was done rigorously the researcher undertook a number of measures: the expertise of an IPA researcher, the attendance at an IPA peer support group and a clear audit trail that relates directly to the results. However, the researcher needs to be aware of whose reality they are working within (Stalker et al, 1999). Views expressed by individuals with learning disabilities at any given time, arguably, represent some aspect of their reality and perspective. Researchers should therefore focus on the value of this and avoid doubting the reliability of their accounts.

6.8.2 Generalisability

It is necessary to be cautious in the claims this study makes. The sample is small and it should not be assumed that similar findings would come from all mothers in a similar situation. However, the fact that the participants spoke similarly about their experiences suggests a wider applicability. Furthermore, by examining the data in relation to existing theoretical and research literature, the research has achieved some theoretical generalisability (Smith & Osborn, 2003). The need for a homogenous sample for an IPA approach means the participants in the current study are all in long term stable relationships. Despite the difficulties they have experienced, they are caring for their children themselves. The level of social exclusion they experience, in terms of lack of friendships, is mitigated by other relationships in their lives, both with partners and continuing contact with their parents. Statistically, 48% of parents with learning disabilities are not looking after their own children (Emerson et al,

2005), and although the current study does not represent those mothers it does provide a valuable insight into how relationships are experienced for this population. It would be useful to conduct a subsequent study with carefully selected participants in order to test the possible extent of applicability. A study selected in terms of age, class, ethnicity and circumstances would offer a useful direct comparison with the results in this study.

6.8.3 Reflexive role of the researcher

Issues of vulnerability in relation to the research must be considered. The researcher was aware of being in a position of power by being the one in the interviewing position. Efforts were undertaken in the interviews to reduce the power differentials by prioritising the participants' concerns and reiterating at the start of the interview that they were free to withdraw from the interview at any time. Furthermore, it is inevitable that the researcher influences what the participant reveals by the questions they ask, the way in which interest is shown and the alliance or rapport that is achieved between the two people involved (Miczo, 2003). The research used a number of conversational strategies in order to develop rapport: active listening, frequent eye contact and encouragement. From reading the reflective diaries it was clear that the researcher used these strategies to different levels across participants. When participants were reluctant to speak, more encouragement was provided in terms of nodding and smiling. The researcher noted that the encouragement was more apparent when the participants were speaking about the positives in their relationship. This may reflect the researcher's belief in supporting positive self perception.

6.9 Recommendations for future research

The research revealed a number of ways in which mothers with learning disabilities make sense of their experiences in a number of adult relationships. It has illustrated some clinical implications but has also identified a number of additional areas and questions for further research. Whilst support for the themes identified was located in the research and theoretical literature, it will be important, given the paucity of research in this area, for further research to explore the transferability and dimensions of the themes identified here. Furthermore, it would be worthwhile to explore the differences, if there are differences, between those mothers who can sustain long-term supportive relationships and those in the majority who continue to live in very socially isolated conditions. Moreover, the present study was limited to mothers' views of their adult relationships; their parents, partners and friends may have very different views of these relationships.

6.10 Conclusion

The results of the present study contribute to the small but developing body of knowledge about the support networks of mothers who have learning disabilities and provide a useful stepping stone to understanding the nature of relationships for these mothers. Overall the study confirms the significance of a well functioning support network, highlights the importance of practical support, and also provides an insight into some of the perceived difficulties mothers with learning disabilities experience in their relationships.

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28 July 2006

Ms Tamara Scully
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Dear Ms Scully

Full title of study: **The experience of attachment in the context of relationships from the perspective of parents with learning disabilities: An Interpretative Phenomenological Analysis**

REC reference number: **06/Q0204/66**

Thank you for your letter of 12 July 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application		30 May 2006
Investigator CV	1	29 May 2006
Protocol	1	29 May 2006
Compensation Arrangements		01 August 2005
Interview Schedules/Topic Guides	1	29 May 2006
Interview Schedules/Topic Guides	1	29 May 2006
Questionnaire: Relationship Questionnaire	1	29 May 2006
Participant Information Sheet:	1	29 May 2006
Participant Information Sheet	2	12 July 2006
Participant Consent Form:	1	29 May 2006
Response to Request for Further Information	Letter	12 July 2006
Supervisor's C.V.	1	29 May 2006

Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q0204/66

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Jenny Austin
Committee Co-ordinator

Email: jenny.austin@nhs.net

Enclosures: Standard approval conditions (SL-AC2)

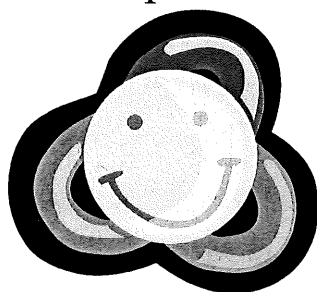
A.2 Participant Information Sheet



Information Sheet

Hi, my name is Tamara Scully. You are being invited to take part in a study. Before you decide it is important for you to understand why the study is being done and what taking part will involve.

Please take the time to read the following information carefully and discuss it with other people if you wish. You can ask me if there is anything that is not clear to you or if you would like some more information. Take some time to think about whether or not you would like to take part.



Thank you for reading this.

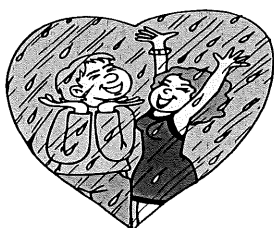
This study wants to find out about how people who have learning disabilities feel about the relationships they have

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in their lives. I want to find out what you have to say about your relationships, what you think about relationships and how they make you feel. We are going to be talking about your relationship with your partner, your parents, and other people who are important to you.



You can decide whether or not you would like to take part. If you do decide to take part and then you change your mind this is ok and you will not have to tell me why.

If you decide to take part you will be asked to sign a piece of paper called a consent form that says you agree to take part. Our conversation will take place at a time and a place that suits you.



It will last about one and a half hours. I will ask you some questions about your relationships. If there are any questions that you do not want to answer that is ok.

If you do decide to take part I will not tell anyone your name or that you decided to take part. Anything that you tell me about yourself will be private and your name or

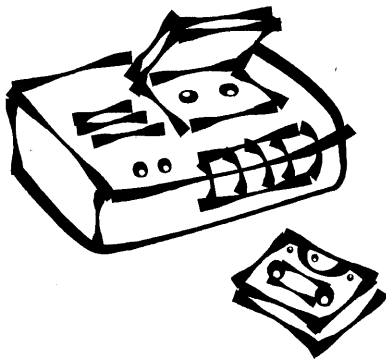
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any information about you will not be given to anybody else. If you tell me something that might be putting any of your children at risk I will first talk to you and then to the learning disabilities team to see what we can do to help.

Our conversation will be tape recorded if that is ok with you. This is to make sure I can remember everything that you say.



Nobody else will be able to listen to the tape.

I am going to meet with 12 mothers' altogether to talk about relationships. After I have spoken to everybody I am going to look at all the things that people have said. By doing this I will try and find the things that you and the other people in the study have in common and the things that you do not have in common.

The stories that I collect from you will be used to tell people more about what you think and feel about relationships.

I will tell you what I have found out after the study has been finished. If you want you can have a copy of the

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conversation we have together. I will let the people I work with know about the study by giving them a talk. Your name or details will never be mentioned in anything that I show to other people.

If you agree to take part can you please tell the person that gave you this information sheet, he/she will give me



your phone number.

I will call you to check that it is still ok and answer any questions that you might have for me.

Thank for taking the time to read this.

A.3 Consent Form

1. I have read and understood the information sheet for this study. I have had time to think about the information and to ask questions. My questions have been answered to my satisfaction

2. I understand that Tamara will keep the information I give her but my name will be removed and replaced by a number so nobody will know that it is me.

3. I know that I do not have to take part in this study and that I can stop at any time. I will not have to tell anyone why I want to leave. I know this will not affect the care/support my family and I receive

4. I agree to take part in this study

Name.....

Signature.....

Witness Name

Witness Signature.....

Researcher's Name

Researcher's Signature.....

B.1 Interview Schedule

General Questions

Name

Age

Children (number and ages)

Partner (length of relationship)

Location

Education

Employment

Physical Health

Mental Health

SES

Child (mental/physical difficulties)

Topic 1: Parent relationships

Key Question

1. Tell me about the relationship you had with your mum/dad

Topic Two: Partner relationships

Key Questions

1. Tell me about the relationship you have with your partner?
2. I wonder, could you tell me a little bit about what its like to be in this relationship?

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3. Could you tell me how you think your children might describe your relationship?
4. What do you think a relationship should be like?

Topic Three: Relationships with friends

Key Questions

1. Can I ask you to tell me a little bit about the friends you have in your life?
2. Can you tell me a little bit more about what it's like to have a friendship with this person?

Future

- Parents
- Partner
- Friends

Key Question

1. How do you see your relationship with X in five years time?
2. Tell me about how you think the relationship will change as you get older?
3. Are there things you would like to be different about your relationships?

B.2: Interview Probe Sheet

Relationship with parents

Growing up

- Who did you live with?
- Did you live here for most of your childhood?
- Were you happy living there, can you remember times when you were happy – what was so special about these times that you were happy?
- Were other times when you were not so happy?

Relationship with mum and dad

- What kind of things did you do together?
- Did you tell them about what was happening in your life?
- Did he/she want to talk about things like that?
- How did your mum and dad respond if you did something naughty – do you think this was fair?
- How about if you did something good?

Qualities

- What about you is like them?
- Are you like your mum or dad?
- Are you different to them?
- Is this a good or a bad thing?

Partner relationships

Tell me about the relationship you have with your partner

- How long have you been together?
- How did you meet?
- Did you go on dates?
- What did you like about him?
- Was there anything you were not sure about?
- How do you let your partner know you care about him?
- How does he let you know?
- What kind of things do you like to do together?
- Are there things you prefer to do on your own?

Support

- Can you tell me what support is like in your relationship with your partner?
- Is it easy to ask him for help?
- How does it make you feel?
- Do you feel like you can tell x anything?
- What do you think makes this easy/hard?

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- Can you give me an example of this – what about it made you feel that way?

Closeness

- Tell me about the closeness in your relationship?
- What do you think might happen if you did get very close to your partner?
- Have you ever tried to get really close to someone else?
- What do you think about someone getting really close to you?
- Do you like this or do you prefer to be a bit more independent?
- Why do you prefer relying on yourself/ on someone else?

Dependence

- Can you tell me a little bit about the dependence in your relationship?
- How would your life be different?
- What do you think would be different about your day?
- Would you still see as many people?
- See more people?
- Do less things?
- Do more things?
- Are there things you can't do because of your partner?
- What kind of things?
- Are there things you might not be able to do if you were on your own?

Trust

- Can you tell me a little bit about trust in your relationship?
- Are there times when you don't trust?
- Why, do you normally trust people or is this hard for you?
- Who do you feel you trust?
- Why do you trust this person?
- Why is it important for you to have someone around that you can trust?
- Can you imagine what it might be like if they were not there to trust?

What do you think a really close relationship is compared to just a normal relationship

- Can you tell me a little bit about the closeness in your relationship?
- Is it in a physical way?
- By telling him things about your life?
- By spending all of your time together?

Relationships with Friends

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Relationships with Friends

- Can you tell me a little bit about your friends?
- Where did you meet them?
- How long have you known them?
- What kinds of thing do you do together?
- What is it about your friends that you like?
- What do they like about you?
- What kind of things do they help you with?
- Do you support each other?

Beliefs/experiences of friendships

- Can you tell me about the experience of friends in your life?
- What is the hardest thing about making friends?
- What is the easiest thing about making friends?
- What is the most important thing about friends?
- How do you think your life might be different if there were more/less friends in it?
- What do you think would help make that happen?
- Would it be easier if you lived somewhere else?
- Why would that be easier ?

Future

- Can you imagine what your relationship might be like with x in five years time?
- Are there things you think might change in your relationships in the next 5 years ?

I don't have any more questions. Is there anything else you'd like to say before we finish, anything we haven't covered that you think might be important?

B.3 Interview Reaction Sheet

Interview number

Date

Duration of interview

Setting

Reactions:

Interruptions

Rapport

Line of questions

Extent questions were understood

General comments on process

Preliminary ideas about themes

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C.1 Example of coded transcript from interview with Emily

		<i>So what I thought we might start talking about a little bit was the relationship that you had with your mam and dad. Maybe start with just telling me a little bit about where you grew up</i>	
	1	Hertford Heath	
		<i>What kind of a place was that?</i>	
Isolated	2 3 4 5 6 7	Out in the countryside – out in the sticks really. You had to get a bus to the nearest town and they are not that regular; they are twenty to each hour. They changed it – it never used to be like that.	
		<i>And did you live there for most of your childhood</i>	
Childhood ends with marriage	8	Yea until I got married.	
		<i>Can you remember were you happy living there?</i>	
	9	I was yea.	
		<i>Can you remember times when you were happy?</i>	
Mum associated with happiness	10	Hmm... yea when my mum was alive	
		<i>What was it about your mum that was so special?</i>	
Closeness to mum Differentiation between mother/daughter relationship and friends Trust Comparison between parents	11 12 13 14	We were really close mother daughter relationship and we were friends as well. You could tell her anything not like my dad, he was very strict.	Close to mum Mother supportive
		<i>What do you think it was about your mum that it was so easy to talk to her?</i>	
No limits Total trust	15 16	Don't know. She was like the salt of the earth – would do anything for anyone.	Mother supportive
		<i>What kinds of things did you tell her?</i>	
Constant presence/support	17 18	Oh all sorts – about boys, school, the lot, she was always there.	Mother supportive
Positive reaction to hearing things Death was a shock /loss	19 20 21 22 23	She would react sorta nice about it and she used to come to our house when I had Mark. He had just been christened when she died so this was quite a shock.	Mother supportive
		<i>I imagine that was a big shock</i>	
Only fifty – relevance of age in death	24	Yea she was only fifty.	
		<i>That was very young</i>	
Impact of losing one relationship on another Looking after him made the	25 26 27	Yea and after that it was very different relationship with my dad, it has just been better in the last couple of years.	Importance of practical support

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relationship better	28 29 30 31 32	He was in hospital with pneumonia and that and I was going back to and fro and looking after his house as well and since then things have been better.	
		<i>Sounds like you have been doing a lot to help at the moment. What was your relationship like with him when you were younger?</i>	
Not great relationship with dad associated with not being able to talk	33 34 35	Not great. You couldn't talk to him he would always fly up in the air.	Dad unavailable
		<i>Was there anything you could talk to him about?</i>	
	36	No not really.	
		<i>So say in a day would you see much of him?</i>	
Perceived as absent	37 38 39	No only in the evening, he would be having tea, watching television, smoking and moaning.	Physically present but emotionally absent
		<i>What about his relationship with your mum?</i>	
Importance of talking in relationship Taking care of parents	40 41 42 43 44	Yea that was alright, they talked to each other. But nine times out of ten she would go up and see my Nan. She spend a lot of time up there because her mum was old.	Lack of closeness in parents' relationship
		<i>What happened in your house when you were really good?</i>	
Dad remote from the family Different parental reactions	45 46 47	My mum would react quite nice about it, but my dad just wouldn't. He just didn't say anything at all.	Mother supportive Dad unavailable
		<i>What about if you were naughty?</i>	
Dad's presence more prominent when discipline required	48 49	You would get a smack from my dad but my mum never smacked me.	Mother supportive
		<i>What if you were naughty with your mum?</i>	
Tell you off – laugh contradictory	50 51	No she would just tell you off and then laugh about it.	
		<i>Can you remember a time when that happened?</i>	
	52	No	
		<i>Did you feel normally that your dad was right?</i>	
	53	No.	
		<i>So if you had been naughty and he slapped you, you think he shouldn't have slapped you, what do you think he should have done?</i>	
Unnecessary	54 55	Just said, you know, that's not right and left it at that.	Helplessness
		<i>Was he the same with your brothers and sisters?</i>	
	56 57	I don't have any brothers and sisters. I am the only child	
		<i>OK I must take a note of that here.</i>	

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		<i>After your mum died... you were married?</i>	
	58 59 60 61	Yea I had just had my son and she came down quite regularly and stayed the weekend – she usually left on a Monday.	Mum supportive
		<i>What kind of things did you do with your mum?</i>	
Helping/support big component of relationship	62 63 64 65	I helped with Nan and when I had my son she always came down, we went out shopping; she helped with the baby.	Reciprocity Importance of practical support
		<i>And when you were younger what kind of things did you do? Do you remember?</i>	
Reliance on family relationships	66 67 68	Nah, just went up my Nan's, that was about all and down the town on a Saturday.	
		<i>And it sounds like you were able to tell your mum stuff about things going on in your life.</i>	
Advice offered	69	She gives you advice.	Mother supportive
		<i>Was there ever a time you felt she wasn't there?</i>	
Permanent support	70	No she was always there, always ...	Mother supportive
		<i>Which parts of you do you think are like your mum and dad?</i>	
View of self as incorporating different parts from parents	71 72 73	Temper I think I got off my dad but the understanding I have about my children I think I got from my mum.	View of self integrating both parents
		<i>Do you like being a little bit like them or would you not like to be like them at all</i>	
Positive identity with mum	74	No I like being like my mum.	Affirmative identity with mum
		<i>What else about your mum would you like to be?</i>	
View of self incorporating 'good' and 'bad' bits from parents	75 76 77 78 79 80	Just very understanding and thinking like my mother, but I have a temper and I either got it from my husband or dad's side, because when things are not going right for him he will flare up just like I do.	View of self integrating both parents
		<i>How do you find that, when your dad flares up</i>	
Practical answer to the difficulty	81 82 83 84	Not very nice and I tell him that it can't be that bad. Now he goes out in to the garden when he is upset to calm down.	
		<i>How do you think you're different from your mum and dad?</i>	
Parts of parents that are not incorporated	85 86 87 88 89	More laid back than mum and dad, don't worry a lot about anything, cos my mum used to worry about lots of things – money – but me I don't really worry.	Perception of self as different from mum and dad

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		<i>How do you manage not to worry about things?</i>	
Worry is not effective - takes the good out of life	90 91 92 93	I don't know. It just comes and I don't let it worry; it can't be that bad, if you worry what have you got in life to look forward to?	Pragmatic approach
		<i>Is there anything else about the relationship with your mum and dad that you think, yea that was an important part?</i>	
Importance of help in the relationship – biggest component Help with child care	94 95 96 97 98 99	No not really. I think the important time was when I had my son and my mum helped me a lot. She came down every weekend and went back on Monday, she sat in the garden with the baby and helped out.	Importance of practical support Mother supportive
		<i>What about your relationship with dad?</i>	
The component of helping makes the relationship more bearable	100 101 102 103 104 105 106 107	It's a lot better now than it was, because he was still being a pain coming here seven days a week and interfering, really moody. It has been much better since he has not been well. He has had pneumonia and arthritis and we help him which is good.	Importance of practical support
		<i>But before that he was here 7 days a week, so sounds like he liked spending time here, why do you think that is?</i>	
Aloneness equated with boredom	108 109	Hmmm..... Don't know. Because he gets bored on his own.	Dad seeks company
		<i>What does he do when he's here?</i>	
Solitary activities	110 111	He has a cup of tea, gives the dogs chews and dozes off to sleep.	Dad unavailable
		<i>What was it about that, which you were finding hard?</i>	
Importance of talking in the relationship – lack of interaction	112 113 114 115 116	Because he wasn't any company for me. He just came here and dozed off and you would be talking to yourself and with Melanie in college it was even harder.	Dad unavailable Feeling alone
		<i>Was it just the two of you here?</i>	
Always talk to you – preference for talking	117 118 119 120 121 122 123	Yea, my husband would be at work and the dog, and Melanie will always talk to you or she will take herself upstairs and read book and that. And I had a little dog who used to sit on your lap and you could stroke it and it was nice.	
		<i>You like animals.</i>	
Connection with family dog Source of esteem/protection	124 125 126 127 128	Yes. My sons dog who bite me had to be put down. He used to follow me everywhere a bit like a guard dog and he loved playing with toys, he wanted to play tag and things like that.	Pet provided company

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	129		
		<i>Did you have animals when you were younger?</i>	
	130	Yea I had a dog and that died.	Loss of company
		<i>Good relationship with that dog?</i>	
Present from father	131	Yea he was my pet dog when I was	
	132	younger. My dad bought it for me.	
		<i>Wow that was a good presen. Did you spend a lot of time with this dog?</i>	
	133	Yea it died suddenly.	
		<i>What about the relationship you have with your partner Alan?</i>	
Impact from extended family on relationship Opposition	134 135 136 137	It's better now than it was when his step dad was alive. His step dad was against us two going ... but his mum wasn't.	Unsupportive family
		<i>You have been together a long time, how did you meet?</i>	
	138	In a pub	
		<i>Tell me about that, can you remember?</i>	
Fear of being left without someone	139 140 141 142 143	Well I was in there with some friends and having a drink and myself and my friends were saying about boys and I was saying to my friends about being left on the shelf sort of thing.	Searching for a partner
		<i>Was that something that worried you?</i>	
Pragmatic – not worried	144 145	Not really, I mean he asked me out and it went from there.	Ability to develop relationship
		<i>Where did he ask you to go?</i>	
Traditional date	146 147	Out for a drink and to the pictures and that's when it started.	Ability to develop relationship
		<i>What was it about him that attracted you to him?</i>	
Lack of importance on why	148 149 150	Don't know I can't remember. He was very nice and gentle and caring and things like that.	Valued supportive attributes
		<i>What kinds of things</i>	
Comparison to others	151 152	Just been nice and that compared to some of the other boys I knew.	Searching for a partner
		<i>So what was different about Alan compared to the other guys</i>	
Comparison to others Pressure to have a significant other	153 154 155 156	Don't know. The other guys, were tormenting me like saying, where's your boyfriend and stuff like that and he wasn't.	Searching for a partner
		<i>Was there anything that you weren't sure about when you met Alan?</i>	
Unimportance of livelihood/status Helping/supporting position	157 158 159 160 161 162	I asked him what he did and he couldn't remember. His dad threw him out and he had to come to live with me and my mum and dad because his own parents wanted him out.	
		<i>Why did they throw him out?</i>	

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	163	Don't know.	
		<i>Did you think it was something to do with you?</i>	
Location of difficulty in self	164	I think so probably about my learning	Self as inferior
Impact of learning difficulties	165	difficulties and the school I went to.	
		<i>So Alan does not have learning difficulties</i>	
	166	He does but I only found out this year .	
		<i>How did you find out?</i>	
	167	We had to go to court and they said he	
	168	had learning difficulties, since he was	
	169	at school his sister said, but I didn't	
	170	know until this year.	
		<i>Were you annoyed he hadn't told you</i>	
		No.	
		<i>Why?</i>	
LD should be kept a secret	171	Because I had learned that, from my	LD should not be disclosed
	172	doctor, not the one I have now the one	
	173	before, that said that I was lucky I had	
	174	managed to cover mine up for 25	
	175	years.	
		<i>You had.</i>	
Carry-around	176	He said it was a long while to carry	Burden of LD
	177	something around for 25 years before	
	178	anyone knew.	
		<i>Why did you think you covered it up?</i>	
Not worried about having LD	179	Don't know. It just wasn't a worry.	Acceptance of self
		<i>It wasn't like you didn't want anyone to know ... you just ...</i>	
LD associated with help	180	Didn't worry me, but I didn't know	Acceptance of self
Importance of help	181	then what I know now, like Melanie	Importance of support
	182	gets help; I didn't know you could get	
	183	help until Melanie got help, like when	
	184	I had it I didn't know you could get help.	
		<i>And how did Alan react to finding out himself?</i>	
No sense of worry about having LD	185	He wasn't too bothered about it really.	
	186		
		<i>Did he tell you?</i>	
	187	He came home and told me but he	
	188	didn't know until last year himself.	
		<i>How do you and Alan let each other know that you care about one another?</i>	
Caring is natural	189	We don't really, it's just natural.	Caring is innate
		<i>How do you know he cares?</i>	
Care associated with doing things	190	We go to places and go around. We	Tangible expression of care
	191	went away for my birthday, which if	
	192	he didn't care he wouldn't take you	
	193	away on your birthday. We went in a	
	194	camper again and took the dog. We	
	195	drove in the terrible rain, Saturday was	
	196	a nice day and Sunday it rained and	
	197	when we were driving home it was a	
	198	nice day again.	

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		<i>And what did you do?</i>	
Sharing	199 200 201 202 203 204 205 206 207 208 209 210 211 212	Just went to the shops, but we had the dog and after she had walked a little way she plonked herself down and wouldn't walk any more so I ended up carrying her and Alan carried the shopping bags. And Alan took over the dog when I wanted to go and look in some shops. We needed an extension cable for the television but we couldn't find one so he made a makeshift one but we couldn't get the digital box working or anything like that because he had gotten the wrong aerial.	Reciprocity Tangible expression of care
		<i>Are you guys quite good at sharing?</i>	
Division of chores Sharing Encouragement Caring Independent mind	213 214 215 216 217 218 219 220 221 222 223 224 225 226 227 228 229	Yea, well on Fridays I go shopping and when I come home the house is all clean and tidy and I do the washing and the ironing and he does the cooking as well. Two nights I cook, two nights he cooks and then the third or fourth night we have a toss-up about who is going to cook. He does a lot of the cooking because I don't like eating food. I am very thinking I am fat. I have had anorexia so everything I eat I think I am going to get fat, so I often say not tonight but Alan says I have got to eat something so he will cook and make sure that I eat something but then if I don't feel like eating I wouldn't eat.	Reciprocity Tangible expression of care Reciprocity Tangible expression of care Difficult to cope alone Importance of practical support
		<i>Is Alan OK with you not eating?</i>	
Very pragmatic description of process	230 231 232 233 234 235 236	Yea but he was the one that took me to Dr L in the beginning and she said I had anorexia and that I had to go and see a counsellor. And then I had these tests and that's when it came back to Dr L that I had learning disabilities.	Importance of practical support
Being cared for/ worried about	237 238 239 240	She said well you hid that well for 25 years', but it was Alan who had taken me to the doctors because he was really worried about me.	Importance of practical support
		<i>So it sounds like he takes pretty good care of you</i>	
	241	He does.	
		<i>What kinds of things do you guys like doing together?</i>	
Similar interest Sharing, compromise Future planning	242 243 244 245 246 247	We like going camping. We bought a tent at first and camped in that and then he decided that he wanted a camper van and we was looking on e-bay and he decided to go for camper van and he said we could go in it in	

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	248 249 250 251 252 253 254 255 256	September to see my friend who lives in the x – which we did. And then next year he wants to go to x because we're having a change because he wants to go to x and then the following year we will go back to the x because, I want to see my friend so we share where we go between us.	Reciprocity Reciprocity
		<i>Sounds like some great compromise going on there. Are there things that you like doing on your own?</i>	
Dependence on relationships	257 258 259 260 261 262 263 264 265 266 267 268 269	I don't. I go out with him or I go with Melanie if she hasn't been well or something and hasn't gone to day centre; we go and have a coffee. Alan goes on the computer – he has learned to use the computer this year but I wouldn't touch the computer. My sister-in-law told him how to play solitaire and he plays this all the time now. She was around one night and she said she would show it to me but I said, 'oh no' but I will learn to work the DVD and video.	Importance of practical support
		<i>That's pretty good going.</i>	
	270 271 272	And, cable but nine times out of ten there's nothing really on television that I really like watching so-.	
		<i>That's sounds good to me.</i>	
Independent activities Pragmatic explanations Financial constraints	273 274 275 276 277 278 279 280 281 282 283 284 285 286 287 288 289 290	And on Friday I go to art therapy and on a Monday I do an art course down in the Court Yard because I was going to painting and water colour at the college. I did two terms there and then told S and went up from £8 to £106 this year for sessions. Because we are on benefits and we don't get that much so S said I should call the Court Yard. And I have only just got in because they just called me after I came back from holiday and I started one week and just did painting and last week, Christmas cards which they sell in the shop or you can have some yourself and I done clay. So yea I go down there on me own on Monday.	Independence from relationship Dependence on professional guidance Independence from relationship
		<i>How do you feel going there on your own?</i>	
Familiarity with people make it ok	291 292 293 294 295	Oh I enjoy it. The lady who runs the course she was having her daughter when I was having Melanie; we went to the anti natal classes together so I know her.	Familiarity makes it safe
		<i>Are you nervous at all going there?</i>	

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Importance of knowing people , proximity	296	No, especially because I know some	Familiarity makes it safe
	297	people and it is within walking	
	298	distance. On a Wednesday when I go	
Encouragement /Support	299	to x my husband has to take me and	Importance of practical
	300	pick me up. Alan told me that if I	support
	301	wanted to do water colours I should go	
	302	and do it. He bought me a case with all	
	303	the brushes and paints in it so I can do	
	304	water colours at home if I wanted to.	
	205		
		<i>So you could do the pictures at home.</i>	
	306	Yea because my son bought me a set	
	307	of colours as well for my birthday.	
		<i>It sounds like they know what you like.</i>	
Pragmatic approach in the family	308	Well I have to tell them. Like my son	
	309	says 'you have to let me know what	
	310	you want for your birthday mum'.	
		<i>What about Alan, do you need to remind him?</i>	
Matter of fact explanations	311	No, he knows but you have to tell him	Pragmatism in relationship
Receiving gifts is important	312	what you want so that he can go and	
	313	buy it. We went on holiday in	
	314	September and the phone that my	
	315	daughter had -one of her hand me	
	316	down's -and I was ringing my son to	
	317	check that he remember to water the	
	318	plants in September and the phone	
	319	wasn't working. It was a stupid phone	
	320	because the sim card was in there and	
	321	everything – and Alan said you need	
	322	to buy a new phone. So well I have a	
	323	birthday coming up soon maybe you	
	324	will buy me a new one and he said he	
	325	would see and then when last Friday	Pragmatism in relationship
	326	came he bought me a new phone and	
	327	my son bought me a tracksuit, and my	
	328	friend bought me chocolates, not like	
	329	I eat a lot of sweets I eat hardly any,	
	330	but she bought me Cadbury's Hereos	
	331	and things for cups with picture of the	
	332	x on them	
	333		
	334		
		<i>It sounds like form what you're saying that Alan does quite a lot like encouraging you and taking you to the doctors. What do you do for him?</i>	
Too much contact can be bothersome	335	Well now he's not working and he's	
Permission	336	under my feet. He likes fishing and	Importance of space
	337	when he goes fishing he usually goes	
	338	all day so, but he hasn't been yet	
	339	because the weather has been really	
	340	bad.	
		<i>Do you find it quite easy to ask Alan for help?</i>	

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Tangible help is easy to ask for	341 342 343	Yea like when I am doing cross-words with my sister-in-law and Melanie and Alan are here, they help me.	Importance of practical support
		<i>When you said that things are much better now with Alan, what were they like before?</i>	
Unpredictable environment	344 345	Very difficult. Alan would flare up in the air as well as me.	Lack of predictability is difficult in relationship
		<i>Why would he flare up in the air?</i>	
Uncertainty /confusion	346 347 348	Don't know bad temper stress related Would it be because of something you had done?	
Help can dissipate problems Difficulties created by trying to do everything by yourself	349 350 351 352 353 354 355 356 357 358 359 360	Well not really, there was a lot of problems with Alan's work and we needed to help each other. Before I used to just do everything because he went to work because I had Mark and he was only a baby so I had to do all the looking after when Alan went to work, even when he was about two years old. And he was always a handful; put a coffee table through the window, knocked me out.	Importance of practical support
		<i>That must have been pretty scar.</i>	
Partner for protection/help	361 362 363	I had to get Alan home from work to let me in because Mark had locked the door and wouldn't let me in.	Importance of practical support
		<i>How did Alan react?</i>	
Pragmatic explanation	364 365 366	Well he came home and unlocked the door and we got a new coffee table.	Importance of practical support
		<i>Did Alan talk to Mark about what had happened?</i>	
	367	Yea but Mark just gave him two fingers.	
		<i>Difficult times.</i>	
Support from mother in law Impact of separation on relationship	368 369 370 371 372 373 374 375 376	When he was born I wasn't with him because my mum-in-law had him because I had depression so it was harder because I didn't have the time to spend with Mark and I think effects our relationship. Melanie was better, more easier I didn't get post natal depression with her and she was better	
		<i>How was Alan when you had the post natal depression?</i>	
Pride Practical help	377 378	He was great, looking after Mark and feeding him as well.	Importance of practical support
		<i>So he was a good help. What do you think it might have been like if he wasn't here?</i>	
Dependence to cope	379 380	I don't know, I can't imagine it. I wouldn't be able to cope I don't think.	Difficult to cope alone
		It sounds like you can ask Alan for	

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		help with pretty much anything. Do you also feel like you can talk to him about anything?	
Changeable	381	Sometimes and sometimes not.	
		<i>When can you</i>	
Consideration – action taken not to cause upset	382 383 384 385 386 387 388 389 390	Don't know, since this dog attack I keep having these really scary nightmares but I can't really talk to Alan about it because when they took the dog to put him down the vet took a really long time to put the dog down – so it had gutted him inside so you can't mention it at all or you upset him.	
Safety associated with talking about things	391 392	Doesn't make me feel very safe but you can't blame the dog.	
		<i>But you can't talk to Alan</i>	
	393 394 395 396	No but it was Alan's decision to have the dog put down. it wasn't mine. But Alan said no because he could have bite a child or something.	
		<i>It's understandable that it might be difficult to talk to him about that because it is obviously very difficult for him to talk about it as well. Are there other things that you find it difficult to talk to him about?</i>	
Absence of talking about intimate things Pragmatic conversations	397 398 399 400 401 402	No but we talk about nothing really, like where we will go out, where will we go shopping and can you take me to If I want to go anywhere he will take me. He might moan but he will take me.	Absence of intimacy Importance of practical support
		<i>What about times when/if you're feeling sad or cross about something would you talk to Alan the?</i>	
	403	No.	Absence of intimacy
		<i>Would you talk to anyone?</i>	
Access emotional support from professional services	404	Usually S (art therapist).	Reliance on professionals
		<i>So more for feeling kind of things you talk to S and with Alan you talk more about going place and things like that.</i>	
Access emotional support from professional services	405	Yea if I'm feeling sad I talk to S or the doctor.	Reliance on professionals
		<i>What about if Alan if feeling kind of sad?</i>	
Partner accesses support from extended family	406	He usually talks to his sisters about his problems	Absence of intimacy
		<i>Does he talk to you?</i>	
	407	Now and again but not really	Absence of intimacy
		<i>When was the last time he talked to you about something sad or whatever?</i>	
Never have discussions about	408	He hasn't.	Absence of intimacy

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emotions			
		<i>How do you know he talks to his sisters?</i>	
Communication of information through others	409 410 411 412 413	Because they tell me, he has one in x and one in x, she is his half sister but the one in x is his full sister and they are pretty close.	Recognition of other close relationships
		<i>How do you feel about him talking to his sisters and not talking to you?</i>	
No resentment – just wants his needs to be met No sense of entitlement Pain at loss	414 415 416 417 418 419 420	Doesn't bother me really as long as he has someone to talk to because he lost his mum to cancer and we all felt that. I felt it quite bad, I broke down loads but he didn't break down even in the car or that.	Independence is OK
		<i>How did he react when you broke down?</i>	
Implications of what someone is called A bond is something made by two people	421 422 423 424	I don't know because me and his mum just had a bond. We made a bond together, I called her mum and really liked her.	Sense of belonging
		<i>When you were crying at the funeral what did Alan do?</i>	
	425 426	Nothing. I was in the car. I couldn't bear to watch anymore.	
		<i>Do you like getting quite close to other people? I am wondering about the bond you had with Alan's mum and it sounds like that was important to you.</i>	
Family frame of reference for someone who is important	427	Yea it was. She was like a sister to me as well.	Sense of belonging
		<i>What might happen if you really wanted to have a close bond with someone and they pulled away? What you think you might do?</i>	
	428	Don't know.	
		<i>Do you think you would like to be closer to Alan?</i>	
Fulfil social expectations Time alone	429 430 431 432 433 434	Yea... We are close like usually on anniversary or birthday we will go out for a meal and that and Melanie goes to respite once a month and then there is only me Alan and the dog.	Tangible expression of closeness
		<i>What's it like when it's just the two of you?</i>	
Nothing different about being alone	435 436	It's alright. We just sit and watch television.	
		<i>Is it nicer when it is just the two of you?</i>	
Time alone together is not prioritised	437	Not really we just watch television and ...	

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		<i>What do you think about someone else getting really close to you, like someone you wanted to have a really good friendship with like someone you met at the art class or someone like that?</i>	
Afraid of closeness	438 439 440 441	It frightens me a little bit – close friendships are a bit frightening – like a friendship is good but not a close friendship.	Fear of closeness in friendships
		<i>What do you think is the difference between just a normal friendship and a close friendship?</i>	
Closeness associated with sexual intimacy	442 443	A close friendship will always lead to something else and I don't want that.	Closeness associated with intimacy
		<i>Even if the other person is a woman</i>	
	444	Well that would be alright but not a man.	Importance of gender in close peer relationships
		<i>Do you think that you would like to be a little bit more relying on yourself?</i>	
Lack of confidence in self	445	Yea – because I could cope with things if I relied more on myself.	Difficult to cope alone
		<i>What would you be doing differently if you were relying on yourself more?</i>	
wish for more independence more confidence to be independent	445 447 448 449 450 451	Doing things differently – The money side of things although I do take care of my own money anyway but just to rely on yourself and not to have to think about whom is going to help you with things.	Difficult to cope alone Importance of practical support
		<i>Do you think your relationship with Alan might change if you were a little bit more independent?</i>	
	452 453	It wouldn't be any different - just doing a bit more I suppose.	Uncertain about benefits of more independence
		<i>Do you think there would be anything different about your day if you were more independent?</i>	
Independence associated with more activities	454 455 456 457 458	It would be more filled with stuff to do. I do the washing and iron at the moment, maybe I would go out more especially if it was nice day.	Uncertain about benefits of more independence
		<i>Do you think you would see more people?</i>	
Isolated Transient connections	459 460 461	I don't know. I see people in passing up the street that I know but no not really that much more people.	Limited social network
		<i>Do you think there is anything you can't do at the moment because of the relationship you have with Alan?</i>	
Relationship does not limit life in anyway	462	No not really.	
		<i>Do you think there are things you might do if you were more</i>	

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		<i>independent?</i>	
Independence not too important	463 464	No not really I don't think my life would change too much.	Uncertain about benefits of more independence
		<i>What would be different if Alan wasn't in your life?</i>	
	465 466 467 468	Well, don't know. Go out a bit more, like now I go out on a Wednesday and sometimes have a coffee on my own.	
		<i>Do you like that?</i>	
	469	It's a treat having a coffee out.	
		<i>Do you trust Alan?</i>	
Variable trust	470 471	Yes except when I have had a bad day then I don't trust him so much.	Distrust
		<i>What kind of things do you not trust about him when you have had a bad day?</i>	
Jealousy Distrust	472 473 474 475	When he pops up to his friend's. I think it's a bit devious. His friend's wife is there as well like and I don't like it.	Distrust
		<i>Why does this make you nervous?</i>	
Paranoid No basis	476 476	Don't know. Just get this idea in my head.	Distrust
		<i>Do you think anything like that has ever happened?</i>	
Paranoid	477	No but I think about it sometimes.	Distrust
		<i>Does he talk about his friend's wife when he comes home?</i>	
	478	No but I just get a thing in my mind.	Distrust
		<i>Do you think it's hard for you to trust people anyway?</i>	
	479	Yea I think so.	
		<i>What kind of people is it hard to trust?</i>	
Distrust people close (based on previous experience?) Behind my back – unknown, let down	480 481 482 483 484 485	People close to me really, because I think they go behind your back and slag you off and that's not nice. I think my son might say that to his girlfriend but I am not sure but I think he does.	Distrust
Rationalise	486 487	But I don't see him that regularly so how would I know really.	
		<i>So who do you think you really trust in your life?</i>	
	488 489	My sister in law in x, she is very nice to talk to.	
		<i>Why is she easier to trust than Alan?</i>	
Suspicious	490 491	I don't know. Just this thing I have at the back of my mind.	Distrust
		<i>But nothing has ever happened</i>	
	492	No not ever with Alan.	
		<i>Do you think it's important to have people around that we can trust?</i>	
Importance of talking	493	Because if you have a problem you	Importance of emotional

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Safe	494 495 496	can talk to them and they will not tell anyone else about the problem, they can keep it to themselves.	support
		<i>Why do you think it is important to talk about the problem?</i>	
Impact of not talking	497 498 499	To get it aired because it just builds up inside otherwise and makes you feel angry.	Importance of emotional support
		<i>It's hard when you don't talk to someone – can you imagine if there was nobody there to trust?</i>	
Role of professionals	500 501 502	It would be horrible. It would all be bottle up inside. I would talk to the doctor I trust her and S.	Importance of emotional support
		<i>You have known them both for a long time – what is it about them that's makes them so trustworthy?</i>	
	503 504	They are very understanding and they help me with the problem.	
		<i>What do you think is a really close relationship is?</i>	
Close relationship means love	505 506 507	The love is there for the person you have the really close relationship with.	Love is natural in a close relationship
		<i>So the love you have with Alan makes it a very close relationship – what is it you love about Alan?</i>	
Understanding Practical tasks	508 509 510 511 512	Understanding, kind, he does lots around the house, he doesn't moan, he's helpful and takes you where you can't to go and doesn't moan about taking you.	Tangible expression of love
		<i>Why do you think he loves you?</i>	
	513	Don't know.	
		<i>Any clues?</i>	
Love experienced by doing things	514 515 516 517 518 519	Make him tea, cook his breakfast for him and nine times out of ten I cook the tea and if he has not gotten any money I will give him some money to buy stuff, like last weekend, and I also buy him stuff.	Tangible expression of love
		<i>Ok thank you. We might talk a little bit about relationships with friends now. What can you tell me about your friends?</i>	
Longevity	520 521 522 523	I have one friend on the x. We went to school together and we have been friends for twenty five years.	Sense of belonging
		<i>Wow! What is it about this person because it sounds like you make a good effort to go and see her and stay in touch?</i>	
Important traits history together – sense of being through a lot together	524 525 526	She is very nice, very understanding, very easy going and we have been through a lot together over the last 25	Sense of belonging

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	527	years.	
		<i>What kind of things?</i>	
Support Survival	528 529 530 531	We went to school together and got through stuff at school and basically from there. Well she went through a broken marriage and marries again.	Importance of support Sense of belonging
		<i>Why did her first marriage break up?</i>	
Empathic to friends difficulties	532 533 534 535 536 537	Don't know. She came home from work one day and found him in bed in their house with another woman which was really hard for her because they had just bought the house in x.	
		<i>What do you think was so different from your relationships with Alan compared to her relationship with him?</i>	
Luck to be married available to support	538 539 540 541 542	That I was lucky because I was married and her marriage was broken up but we were there for her but this one seems to be better. She has two children with him.	Importance of support
		<i>How is he different from her last husband?</i>	
Importance of practical help	543 544 545	Because he seems to be more understanding to her and very helpful and that.	Importance of practical support
		<i>What was the other person like?</i>	
	546 547	Not really nice. She knew him from school.	
		<i>So you knew him.</i>	
Significance of marriage	548 549 550 551 552 553	Yea he was always woman mad at school and I told her that but I never thought he would actually do it once they had actually got married. It was a shame for her to have to go through that.	Significance of marriage
		<i>Yea, I imagine that would have been a really hard thing to go through</i>	
		<i>So the kinds of thing you like about H are...</i>	
Nice/understanding/trustworthy	544	She is nice, very understanding, trustworthy.	
		<i>Good traits.</i>	
	545	Yea.	
		<i>What do you think she likes about you?</i>	
History together	546 547 548 549	Don't know. We have always been friends, we have had laughs together, we have been on holiday together when we were young.	Sense of belonging
		<i>What kind of things does she help you with?</i>	
Importance of talking	560 561 562	Well we always speak – we always have a good old gossip when we meet up which is nice.	Importance of emotional support Sense of belonging

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		<i>And do you speak to her on the phone sometimes</i>	
Routine conversation Predictability	563 564 565 566 567 568 569 570 571 572 573 574 575 576 577	Yea, Tuesday and Thursday nights on the phone. We ask what each other done. She has got her days off because she works in a hotel and she has one day off a week and I say to her 'well what are you doing on your day off'? And she is going into town and I say, 'did you buy anything in town' and she says, 'oh no I just looking'. And I ask her 'what are you doing for the weekend' and she says 'oh nothing I may go down to town or the beach'. And she says 'what are you doing for the weekend' and I say, 'don't know yet'.	Safe Predictability
		<i>That's cool. If, Emily, you were feeling sad or angry would you tell her about that?</i>	
Can speak to her about emotions	578	Yea like what I'm angry about.	Importance of emotional support
		<i>What might that be?</i>	
		Just general day stuff.	
		<i>And after you had Mark and you were having the postnatal depression did you speak to H about that?</i>	
Other options Safe place	579 580 581 582 583 584 585	Yea I did. She was very helpful. She said I could come and stay with her if I liked for a week. I didn't go but it was nice and I just got on with it but if it had been really bad that would have been the one place that I would have thought of going for a rest.	Sense of belonging
		<i>Its nice knowing that there is somewhere to go Is there anybody else that you would consider a good friend other than H?</i>	
Trust in professional worker Acknowledgement of position in life	586	S, I suppose, but I know she is my art teacher.	professionals as friends
		<i>She is pretty important as well, how do you think she supports you?</i>	
Importance of talking	587 588	Well like when you do your art you sit around and talk and she helps you like that.	Importance of emotional support
		<i>What do you think is the hardest thing about making friends?</i>	
'the right one'	589	I don't know. Just finding the right one and the friendship.	Risk
		<i>How do you know when it is the right one?</i>	
Distrust /suspicion reference to previous experiences	590 591 592	I don't know. I don't think that you can ever tell. Sometimes you make friends and you get hurt.	Peer relationships can be dangerous
		<i>How do you get hurt?</i>	

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Let down Disappointment Uncertainty/ lack of understanding	593 594 595 596	Well like when they say 'oh yea we will do this and do that' and then they don't do it and you are sorta just left thinking 'oh well why not?'	Let down
		Why do you think this happens?	
Disappointment Let you down Distrust	597 598 599 600 601	Well when you arrange something they almost nine times out of ten let you down and because you build yourself to looking forward to going out.	Let down Disappointed
		Has this happened?	
Keep safe Avoidance	602	No because I have no friends now except H and S (art therapist).	Avoidance to keep safe
		But before this has happened?	
	603	Hmm..	
		Why do you think they do that?	
Angry Lack of control	604	I don't know. I think it is nasty of them to do it so.	
		What do you think is the most important thing about having friends?	
Female companionship Change from the normal home environment	605	Going out and having a girly night out for a change.	Sense of belonging
		What do you think it would be like if there were no friends – like if H wasn't there?	
Social aspect of friendship	606 607 608 609 610 611 612	Don't know. It would be terrible because when we went on holiday we met up with her daughter and her husband and then there was me, Alan and Melanie and that was so nice. We went to a pub and it was really nice.	Sense of belonging
		Do you think your life would be different if you had more friends like H?	
Social aspect of friendship	613 614 615 616 617 618 619 620	Yes it would because you could go out more. That's what I encourage Melanie to make friends she goes out with her leisure programme. They go out once a fortnight and there is two other girls she has made friends.	Sense of belonging
		Why do you think it is really important for Melanie to have friends?	
Importance of talking Friends are someone you can talk to	621 622 623 624	So she can find a real friend and then if anything upsets her she can talk to that person because she finds it hard as well.	Importance of emotional support
		That's important because like you were saying before about people who bottle it all up. How do you think that	

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		<i>people who have no friends cope?</i>	
Main outlet for difficulties	625 626	Bottle it up. Whatever their problem is they keep it close to their chest.	Importance of emotional support
		<i>Do you think if you lived somewhere other than x it might be easier to make friends?</i>	
	627 628 629	Don't know. I suppose if you live somewhere else you can make friends easier.	
		<i>Why would you make them easier?</i>	
Importance of location	630 631	Because x does not have a lot of people you can talk to.	
		<i>Why is that?</i>	
Keep themselves to themselves	632 633 634	I don't know. They are a little bit strange; they keep their self to their self.	Searching for friends
		<i>Do you know your neighbours?</i>	
Tangible helping relationship	635 636 637 638 639 640 641	No. that one has a little girl called J she lost a baby too but she keeps herself to herself, but K across the road I speak to her because when she went away I looked after her cat. she bought me a plant and sweets for looking after it.	Access people through helping
		<i>And if something went wrong, Emily, do you think you could go over and ask her for help?</i>	
	642	No.	
		<i>Why?</i>	
	643	Don't know.	
		<i>Is there anyone on this street you would ask for help?</i>	
	644	My sister-in-law	
		<i>What do you think your relationship with Alan might be like in ten years time?</i>	
Contentment with relationship with Alan	645 646 647	Don't want to know. Hopefully still the same but we will be old and decrepit.	Content
	648	I suppose we will all get older. <i>Is there anything about it you would like to change?</i>	
	649	No nothing.	Content
		<i>What do you think your relationship with Melanie, in ten years?</i>	
	650 651 652	The same I hope and maybe better. she will have found some friends and things	
		<i>Do you think she might move out?</i>	
	653 654 655	One day hopefully but not at the moment because she can't cook either.	
		<i>But would you like her to move out one day</i>	
	656	No.	
		<i>But do you think it would be good for</i>	

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		<i>her</i>	
Gender differences	657 658 659 660 661 662	It would be I suppose I hope one day she has a family and makes me a grandma because I don't think my son is going to. He is too young to have a family yet. He wants to live his life.	Wish to be a grandma
		<i>And do you think that Melanie will one day have a family?</i>	
		<i>What kind of a person would you like her to meet?</i>	
	663 664	Don't know, one that is gentle and caring...	Importance of supportive attributes
		<i>Someone like her da?</i>	
Alright ones	665	Hmm they're alright ones.	
		<i>Do you worry about Melanie moving out and what your life would be like?</i>	
Importance of relationship with children	666	Yea empty.	
		<i>You think it would be empty. What about Alan?</i>	
	667 668	No he would be there but it would be more empty than it is now.	
		<i>How do you think it might affect Alan?</i>	
	669 670	Don't know I suppose he would miss her.	
		<i>Your not sure though</i>	
	671	No.	
		<i>Did Alan and Melanie interact much?</i>	
	672	No	
		<i>Do they talk?</i>	
Difficulty in understanding	673 674 675	Yea they talk but he has a job to understand what she has said and he has to ask me what she has said.	
		<i>Does that annoy you when he does that?</i>	
	676	Yea now and again.	
		<i>Why do you think he does it?</i>	
	677	Because he says he can't understand her .	
		<i>Is there anything else you can think of when we are talking about relationships that you think 'oh we haven't talked about that'?</i>	
	678	No.	
		Because I think we have covered pretty much all of this stuff and you have given me piles of information. Thank you so much for all of the information that you have given me.	

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C.2 List of emerging themes from interview with Emily

Relationships with parents

Close to mum
Mother supportive
Importance of support
Physically present but emotionally absent
Lack of closeness in parents' relationship
Mother supportive
Helplessness
Reciprocity
Importance of practical support
Affirmative identity with mum
View of self integrating both parents
Perception of self as different from mum and dad
Pragmatic approach
Dad seeks company
Dad unavailable
Feeling alone
Pet provided company
Loss of company
Unsupportive family

Relationships with partner

Searching for a partner
Ability to develop relationship
Valued supportive attributes
Self as inferior
LD should not be disclosed
Burden of LD
Acceptance of self
Importance of support
Caring is innate
Tangible expression of care /Tangible expression of love
Reciprocity
Importance of support
Independence from relationship
Pragmatism in relationship
Importance of space
Lack of predictability is difficult in relationship
Importance of practical support
Absence of intimacy
Recognition of other close relationships
Independence is ok

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Sense of belonging
Difficult to cope alone
Importance of support
Uncertain about benefits of more independence
Tangible expression of closeness
Distrust
Love is natural in a close relationship
Significance of marriage
Content

Relationships with friends

Familiarity is safe
Reliance on professionals
Fear of closeness in friendships
Closeness associated with intimacy
Importance of gender in close peer relationships
Limited social network
Distrust
Importance of emotional support
Sense of belonging
Importance of support
Safe
Predictability
Risk
Peer relationships can be dangerous
Let down/disappointed
Avoidance to keep safe
Searching for friends
Access people through helping

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C.3 Clustering of emerging themes for Emily

Relationships with parents

- Importance of support
- Importance of practical support
- Reciprocity

- Close to mum
- Mum supportive
- Dad unavailable/physically present emotionally absent

- View of self integrating both parents
- Affirmative identity with mum
- Perception of self as different from mum and dad

Super-ordinate themes

1. Significance of support
2. Variability of parental support
3. Self as same and different

(C.3 Continued)

Relationships with partner

- Importance of support
- Importance of practical support
- Reciprocity
- Value supportive attributes

- Tangible expression of care
- Absence of intimacy
- Caring is innate/love is natural in close relationship

- Independence from relationship
- Space is important
- Difficult to cope alone
- Uncertain about benefits of more independence

Super-ordinate themes

1. Significance of support
2. Tangible expression of emotion
3. Ambivalent about independence

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(C.3 Continued)

Relationships with friends

- Peer relationships can be dangerous
- Distrust
- Fear of closeness
- Risk
- Let down/disappointed

- Importance of emotional support
- Sense of belonging
- Importance of support

Super-ordinate themes

1. Peer relationships can be dangerous
2. Benefits of peer relationships

C.4 Table of clustered themes supported by quotes from the text for Emily
Relationships with parents

Themes	Indicators	Page and Line number
Significance of support <ul style="list-style-type: none"> - Importance of practical support - Reciprocity 	'I think the important time was when I had my son and my mum helped me a lot' 'I helped with Nan and when I had my son she always came down'	4:94-96 3:62-63
Variability of parental support <ul style="list-style-type: none"> - Close to mum - Mum supportive - Dad unavailable - Physically present emotionally absent 	'we are a really close mother daughter relationship' 'she was like the salt of the earth , would do anything for anyone' 'you couldn't talk to him he would just always just fly up in the air'/he just didn't say anything at all 'he would be having tea, watching television, smoking and moaning'	1:11-12 1:15-16 2:34-35/2:46-47 2:37-39
Self as same and different <ul style="list-style-type: none"> - View of self integrating both parents - Affirmative identity with mum - Perception of self as different from mum and dad 	'temper I think I got off my dad but understanding I have about my children I think I got from my mum' 'no I like being like my mum' 'more laid back than mum and dad'	3:71-73 3:74 3:85

C.4 Continued

Relationships with partner

Theme	Indicator	Page and line number
Significance of support <ul style="list-style-type: none"> - Importance of practical support - Reciprocity - Value supportive attributes 	'we needed to help each other. Before I used to do everything because he went to work'/ 'he was great looking after S and feeding him as well' 'two night I cook, two night he cooks'/ 'on Fridays I go shopping and when I come home the house is all clean and tidy' 'he was very nice and gentle and caring and things like that'/one that is gentle and caring'	10:351-353/11:377-378 7:217-218/7:213-215 5:148-150/20:663-664
Tangible expression of emotion <ul style="list-style-type: none"> - Tangible expression of care/love - Absence of intimacy - Caring is innate 	'We went away on my birthday, which if he didn't care he couldn't take you away on your birthday'/he does lots around the house/make him tea, cook his breakfast 'no we talk about nothing really' 'we don't really, it's just natural'	6:190-193 15:509/15:514 11:397-398 6:189/15:
Ambivalent about independence <ul style="list-style-type: none"> - Independence from relationship - Space is important - Difficult to cope alone - Uncertain about benefits of more independence 	'on Friday I go to art therapy and on Monday I do an art course' 'well now he's not working and he's under my feet' 'I could cope with things if I could rely more on myself' 'it would not be any different just doing a bit more I suppose'	8:273-274 10:335-337 13:445 13:452-453

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C.4 Continued

Relationships with friends

Theme	Indicator	Page and line number
Peer relationships can be dangerous		
– Distrust	'I think they go behind your back and slag you off'	14:481-482
– Fear of closeness	'it frightens me a little bit. Close relationships are a bit frightening'	13:438-439
– Risk	'I don't think you can ever tell. Sometimes you make friends and you get hurt'	18:590-592
– Let down	'they say, 'oh yea we will do this and do that' and then they don't do it'	18:593-595
Benefits of peer relationship		
– Importance of support	We were there for her/we went to school together and got through stuff at school	16:540/16:528-229
– Importance of emotional support	'Because if you have a problem you can talk to them'/it just builds up inside otherwise and makes you feel angry'	15:493/15:497
– Sense of belonging	'we have been through a lot together over the past 25 years'	16:525-526.

D.1 Table of clustered themes for Sharon (interview 2)

Relationship with partner

Themes	Indicator	Page and line number
Support is central		
– Practical support	‘he does everything for me, the shopping, the taking the children to school’	10:134
– Emotional support	‘he says ‘don’t worry’ and I feel better...’	11:141
– Reciprocity	‘...sometimes I do that with him as well if he is tired...’	11:144
Emotion is experienced through concrete acts		
– Tangible expression of love	‘I do the housework, take the kids to school and things like that’	11:136
– Tangible expression of care	‘think he just felt like buying me something like a treat’	14:183
– Closeness is tangible	‘go out once a week’	14:179
The importance versus the insignificance of independence		
– Independence in relationship	‘that’s his life because he goes out a lot because he has lots of friends’	17:209-210
– Independence not important	‘not really because I have two children to keep me going’	14:180-181
– Importance of space in relationship	‘it keeps me going what I want to do in my house and I can watch what I want on the TV’	17:211-212
The past versus the present		
– Unsatisfactory past relationship	‘I wish I never met him ...he stole all my stuff and said he would come back for me...’	8:103-104
– Role of comparison in relationship	‘one I used to go out with before’	8:104
– Content	‘happy with what I have at the moment’	8:112

D.1 Continued

Relationship with parents

Themes	Indicator	Page and line number
Support is important <ul style="list-style-type: none"> - Importance of support - Importance of practical support - Tangible expression of care 	'it's much better now because they help each other out and us' 'I just did things for my mum, did her shopping and things like that for her' 'going out on the boat, taking us out in the car, things like that'	7:82-83 3:37 7:81
Differences in relationship with mum and dad <ul style="list-style-type: none"> - Mum was special - Mum supportive - Close relationship with mum - Dad unavailable - Difficult relationship with dad 	'she was special and that' 'she said it's your first period and things like that' 'my mum. I always wanted to be with my mum' 'my dad wasn't living with us at the time' 'it was fine when dad was at work but then when he comes home it goes the other way around...'	2:19 4:41 18:228 5:54 6:71-73
Not fitting in <ul style="list-style-type: none"> - Left out - Blamed - Lack of support 	'I was usually left out, not my brother' 'If I did something wrong I would get put to my room my brother would get... if he was bad I used to get the blame for it' 'it wasn't good. I had rough days with her partner'	2:20 2:23 5:55

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D.1 Continued

Relationship with friends

Themes	Indicator	Page and line number
Desire for friends		
– Limited support network	'I only ask from D's mum or aunties'	11:142
– Isolated	'we did have friends up there but not much. It was lonely'	5:59
– Wanting more friends	'I had to move because I didn't have any friends then'	5:58
Advantages of peer relationships		
– Support	'a friend, just a friend I used to hang around the weekends with'	9:118
– Sense of belonging	'she was good company and a good laugh so we moved and started afresh... and started working'	9:120
– Protective	'people were making fun of me and laughing at me but my friend stuck up for me, my friend'	20:255
– Friends regulate mood	'I would be down if they were not there'	20:256
Feeling unsafe		
– Self as inferior	'things were wrong with them like what I'm like'	15:191
– Bullied	'two people, a boy and a girl, they just picked on me don't know why but it was always me'	15:192

D.2 Table of clustered themes for Rachel (interview 3)

Relationship with partner

Themes	Indicators	Page and line numbers
Value of support in relationship		
– Importance of practical support	A does things for me/ he helps me cook sometimes... he does all sorts of other stuff	2:29/2:30
– Tangible expression of care	'things I think ...like I buy a trousers for him/he took me out ... I know he took me out to the pub'	5:67/5:70
– Importance of emotional support	'when things come up he's good at helping me To get through them./when I have read something he says, 'ah you have read that really well'	1:13-14/20:259
Close relationship versus independence		
- Relationship is doing things together	If you do things together that's a relationship together/if you want to stay together, yea, it should be together yea'	23:288/23:289
– Independence is OK	Sometimes A would like to go on his own somewhere and I would like myself	23:290
– Space is important	'because you get on top of each other and you're arguing and stuff like that'	23:291
Now and Then		
– Unsatisfactory past relationships	'I had one before him and he used to hit me and that's no good/it was a bit hard because he wouldn't leave me alone	4:61/4:63
– Expectation in relationship	'When I need him I prefer him to come'/I tell him I have been let down by him'	21:270/21:271
– Safe/predictable	'he only shouts... he won't lay a hand on me'	4:60
– Content	'No not really I wouldn't change much of it. No.'	24:204

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D.2 Continued

Relationship with parents

Themes	Indicators	Page and line number
Feeling vulnerable in relationship		
– Blamed	Because they always blamed me ... they blamed me for it It wasn't me'	8:110
– Sense of belonging threatened	'what it is, the sisters all got together, and you know you just can't'	8:112
– Powerless	'I, I did but eventually I just didn't. Wants the point if they are going to blame me in the first place'	8:111
– Lack of support	'when I first met him they didn't accept him/he's not for you, you can do better, that's what they kept saying to me'	2:20/2:21
Presence of support		
– Tangible expression of care	They used to take me out in the car and stuff'	10:128
– Importance of emotional support	'if my mum says something or annoys me or something I will talk to my father/I talk to my mum sometimes too'	10:234/11:138
– Importance of practical support	'she's (step mum) always there for me , if I need anything she will help....she'll babysit and everything'	21:273

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D.2 Continued

Relationship with friends

Themes	Indicator	Page and line number
Feeling excluded		
- Limited support network	'If I can't get hold of my brother it would be my mum'	14:174
- Want to belong	'I see them sitting down with their friends, why can't I have some friends /nice to have a cup of tea and a chat and that and there are times to go out and that, you know I don't do a lot'	15:196-197/15:193
Distrusting close relationships		
- Distrust	'Afraid of being hurt and of trusting them'/'Talking behind my back and stuff like that'	16:205/17:117
- Risk	'you don't know what they are going to do and what they are going to say and stuff like that'	18:139
- Fear of closeness	'I'm not too keen on getting too close to friends because what it is... you make friends and they got breaking up'	14:177-178
- Bullied/let down	'They (friends) would sometimes let me down – they'd be on my back they were so rude and nasty... I know what it's like'	181

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D.3 Table of clustered themes for Isabelle (Interview 4)

Relationship with partner

Themes	Indicator	Page and line number
Uncertainty about independence in a relationship		
- Independence	'I have a library card and I do computing'	6:62
- Independence if frightening	'It is a little bit scary but I get used to it, it is my independence'	6:64
- Independence is ok	'he rings other people too he has the right to have friends'	9:87
- Independence is good	'I have a job now so it's much better I'm not here all the time now waiting for him to come home'	13:134-135
Importance of emotional expression		
- Intimacy	Because we love one another we share a lot/we talk about everything'	4:39/5:49
- Emotional expression of care	'I show it in my heart and he has a heart so we can show it together'	2:12-13
- Emotional support	'he doesn't like me getting upset, and he always says 'are you sure' and tells me to cheer up'	1:7-8
- Importance of love	'he loves me a lot and that is what is important'	7:67-68
Caring is tangible		
- Tangible expression of care	'he takes me out. I'm going out tonight'/if I am bloody tired from work he runs my bath and gives me time on my own'/I do lots of things for him. I do his washing, cleaning'	1:8/2:14/4:41
- Reciprocity	'We help each other'	4:42
Feeling insecure in the relationship		
- Fear of losing partner	'they are not going to split us up, it's not my fault I met someone like him'/someone might just come and take him'	4:35/9:90
- Relationship is private	'our relationship has got to be between us and nobody else should be allowed in'	5:53
- Distrust of others	'it's private and that's good for us because it keeps us safe from other people'	5:50
- Marriage offers security	'I will be sitting here and he will be here too and it will be bloody good having a new name'	7:72

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D.3 Continued

Relationship with parents

Themes	Indicator	Page and line number
Parent provides support		
- Importance of support	'me and my mum have been through a lot. I want you to understand that – support'	8:81
- Mother supportive	'you know I got my mum so I am not on my own'	8:79
- Emotional support	'my mum was there for me to talk to and talking helps me to calm down a bit'	13:124

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D.3 Continued

Relationship with friends

Theme	Indicator	Page and line number
Friends offer support		
- No friends is lonely	'Bit lonely on your own not talking to anyone - like friends, no friends is a bit lonely'	10:95
- Emotional support	'she... tells me not to worry'/we meet to talk about things'	10:101/11:103-104
- Practical support	'she helps me with things like that I can't understand'	10:101
Fear of friends		
- Fear of closeness	'don't like people knowing my business, you might get hurt'	11:110
- Distrust	'it's hard, very hard to meet people and trust them'/other people I don't like is because they are too much jealous'	12:109/10:94
- Risk	'sometimes people are cruel.....I only want to keep it to myself'	11:111

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D.4 Table of clustered themes for Natasha (Interview 5)

Relationship with partner

Theme	Indicator	Page and line number
Role of support in the relationship <ul style="list-style-type: none"> - Importance of practical support - Value supportive attributes - Importance of reciprocity 	'sometimes I get a bit fed up ... me doing everything'/he doesn't help me that much.. He sits in the bloody front room and does bugger all really' 'he was a good personality, just caring and loving and funny' 'often I say to him 'will you do this if I do that''.	1:15/1:13-14 1:10 2; 20-21
Tangible expression of emotion <ul style="list-style-type: none"> - Tangible expression of care - Absence of intimacy - Absence of communication 	'he likes dinners. I can do some nice meals and washing and things like that – helping him I suppose'/he does dinner now and again and ... buys me things and helps me sometimes/ 'we don't really talk, to be honest/we don't really sit and talk thing over or chat/I would really like to talk things over/ 'a couple of times I have tried to talk to him and he just sits there... and I say to myself "what's the point talking to you"?'	6:102/6:103 1:12/2:27/2:30 2;31-32

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D.4 Continued

Relationship with parents

Theme	Indicator	Page and line number
Feeling powerless in relationship		
– Blamed	‘she used to pick on me all the time and take my sister’s side all the time and blame all things on me’	7:117-118
– Self as inferior	‘she liked her (sister) better. She didn’t have problems like me’	7:120
– Sense of not belonging	‘she might stay here this time I hope because I have the bigger place, but she normally goes to my sister to stay and have dinner and drinks’	8:137
Parents provide practical support		
– Importance of practical support	‘she’s alright now she bought me a table, kettle, toaster, TV unit, she bought this table, she bought me loads of stuff and helped me out’/‘he is good, he is always helping me, like if I am short on anything he will come over and help me, we don’t really talk about things either but he helps me out so that’s ok’	8:131-132/7:108-109
– Tangible expression of care	‘he gave me things, he took me places and helped me with my school stuff’	7:114-115

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D.4 Continued

Relationship with friends

Themes	Indicator	Page and line number
Friends provide support		
<ul style="list-style-type: none"> - Emotional support - Practical support 	<p>'like I feel better after I tell her'</p> <p>'she got me some clothes and helped me to do my hair and makeup and things'</p>	<p>3:43</p> <p>3:50-51</p>
<ul style="list-style-type: none"> - Sense of belonging 	<p>'we speak to each other most days and see each other most days as well when we go up the village together and stuff'</p>	4:59-60
<ul style="list-style-type: none"> - Lonely without friends 	<p>'I would be very lonely because I only got her to do things with. I haven't really got anybody else'</p>	4:74-75
Fear of friends		
<ul style="list-style-type: none"> - Distrust 	<p>'don't know. People are just like that, they use you when they have nothing better to do'</p>	4:71
<ul style="list-style-type: none"> - Let down/Left out 	<p>'when they have other people they will just ignore me'/'they don't invite me around their houses to have chats or that. I have one of their numbers but she never calls'</p>	4:63/4:65-66
<ul style="list-style-type: none"> - Risk 	<p>'like it's hard to find the right people'</p>	5:86
<ul style="list-style-type: none"> - Bullied 	<p>'I used to get the blame there as well. People picked on me a lot'</p>	7:127-128

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E.1 List of super-ordinate themes across all five interviews

Relationship with Partner

Significance of support
Tangible expression of emotion
Ambivalent about independence
Support is central
Emotion is experienced through concrete acts
The importance vs. insignificance of independence in relationships
The past versus the present
Value of support in the relationship
Close relationship versus independence
Now and Then
Uncertainty about independence in a relationship
Importance of emotional expression
Caring is tangible
Feeling insecure in the relationship
Significance of support
Tangible expression of emotion

Relationship with Parents

Significance of support
Variability of parental support
Self as same and different
Support is important
Differences in relationship with mum and dad
Not fitting in
Feeling vulnerable in the relationship
Presence of support
Parent provides support
Feeling powerless in the relationship
Parents provide practical support

Relationships with Friends

Peer relationships can be dangerous
Benefits of peer relationships
Desire for friends
Advantages of peer relationships
Feeling unsafe
Feeling excluded
Distrusting close relationships
Friend relationships offer support
Fear of friends
Friends provide support
Fear of friends

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E. 2 Clustered super-ordinate themes for all interviews

Relationship with Partner

- Significance of support
- Support is central
- Value of support in the relationship
- Role of support in the relationship
- Tangible expression of emotion
- Emotion is experienced through concrete acts
- Caring is tangible
- Tangible expression of emotion

- The importance vs. the insignificance of independence in a relationship
- Close relationship versus independence
- Uncertainty about independence in the relationship
- Feeling insecure in the relationship

Representative super-ordinate themes

1. The significance of support
2. Ambivalence about independence

E.2 Continued

Relationship with Parents

- Significance of support
- Support is important
- Presence of support
- Parents provide support
- Parents provide practical support
- Variability of parental support

- Not fitting in
- Feeling vulnerable in the relationship
- Feeling powerless in the relationship

Representative super-ordinate themes

1. The importance of support
2. Vulnerability in relationship

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E. 2 Continued

Relationship with Friends

- Peer relationships can be dangerous
- Feeling unsafe
- Feeling excluded
- Distrusting close relationships
- Fear of peer relationships
- Fear of friendships

- Benefits of peer relationships
- Advantages of peer relationships
- Peer relationships can offer support
- Friends provide support

Representative super-ordinate themes

1. Friendships can be dangerous
2. Benefits of friends

F: Abstract

Many mothers with learning disabilities experience social isolation (McGaw, 1998; Booth & Booth, 1996) despite the current research clearly delineating the importance of supportive relationships for mothers with learning disabilities. The aim of this research was to investigate the experience of three types of relationships from the mother's perspective. Semi-structured interviews were conducted with five mothers with learning disabilities about their experience of three types of supportive relationships, with their parents, their partners and their friends. The transcripts were analysed individually using Interpretative Phenomenological Analysis (IPA). Superordinate themes were identified for each topic area. These were, for parent relationships, importance of support, and vulnerability; for partner relationships, significance of support, and ambivalence about independence; for friendships, friendships can be dangerous and benefits of friendships. The results were related to existing theoretical frameworks, clinical implications were identified and recommendations for future research were made.

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Mothers with learning disabilities' experience of relationships with their parents, partners and friends: An IPA study.

Mothers with learning disabilities' experience of relationships with their parents, partners and friends: An IPA Study

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Abstract

Many mothers with learning disabilities experience social isolation (McGaw, 1998; Booth & Booth, 1996) despite the current research clearly delineating the importance of supportive relationships. The aim of this research was to investigate the experience of three types of relationships from the perspective of mothers with learning disabilities. Semi-structured interviews were conducted with five mothers about their experience of three types of supportive relationships, with their parents, their partner and their friends. The transcripts were analysed individually using Interpretative Phenomenological Analysis (IPA). Super-ordinate themes were identified for each topic area. These were, for parent relationships, importance of support, and vulnerability; partner relationships, significance of support and ambivalence about independence; friendships, friendships can be dangerous and benefits of friendships. The results were related to existing theoretical frameworks, clinical implications were identified and recommendations for future research were made.

Introduction

The benefits of social support and interpersonal relationships have long been recognised in the literature. Extensive research shows that close relationships are vital to various indicators of well-being including happiness, mental health, physical health and longevity (Berkham, 1995). In particular attention has been drawn to the moderating role social support and relationships can play in the adjustment to stressful

life events and their link to mental and physical health (Cohen, Gottlieb & Underwood, 2000). This study is concerned with the experiences of social support and interpersonal relationships for mothers who have learning disabilities, a population that has consistently been identified as one of the most socially isolated groups of mothers in both the UK and Australia (Llewellyn, McConnell & Bye, 1995). The interest in this area is underpinned by the fact that 48% of mothers with learning disabilities are not looking after their own children, despite the now vast array of research that suggests that mothers with learning disabilities have the capacity to learn, maintain and implement new skills and thereby provide adequate parenting (for a review see Feldman, 1994). Researchers are now beginning to recognise that in addition to specific parental training input, emotional and practical support are as important in determining parental competence (Llewellyn, 1994; McGaw & Newman, 2006).

For many parents with learning disabilities the prospect of social isolation is probable (McGaw, 1998; Booth & Booth, 1996; McGaw, Ball & Clark 2002) with regular reports of loneliness and relationship difficulties (Llewellyn et al, 1995; McGaw, 1997). Typically parents are described as socially excluded, experiencing multiple temporary relationships and becoming dependent on statutory agencies for both practical and emotional support (McGaw et al, 2002). Llewellyn et al (1999) and Stenfert Kroese et al (2002) reported that the natural support networks of mothers with a learning disability contained an average of six supportive contacts, made up mostly of family and professionals.

Stenfert Kroese et al (2002) investigated social support networks and psychological well-being of mothers with learning disabilities. The study used a measure of psychological well-being (The Affect Balance Scale, Stenfert Kroese et al. 2000) and identified, consistent with previous findings, strong associations between supportive social networks and psychological well-being. Simmons et al (1993) research findings suggest that social support affects parenting indirectly via its effects on psychological well-being. Feldman et al (2002) examined the relationship between social supports, stress and mother/child interactions in 30 mothers with learning disabilities. The findings indicated that mothers with learning disabilities experienced high levels of stress, were socially isolated and reported a great need for support.

Much of the qualitative research to date has looked at the relationship between social support and parenting rather than looking specifically at how these mothers experience the relationships in their lives. Further idiographic study, focusing specifically on the experience of relationships and exploring the specific accounts of relationships in depth, is needed to explore the manner in which mothers with learning disabilities make sense of their relationships and contribute to the understanding of the intricacies of relationships for this population, thus informing and aiding intervention.

The aim of this study is to gain an in-depth understanding of the social networks of mothers with learning disabilities by exploring the phenomenon of a number of adult relationships. This research will explore how mothers with learning disabilities experience relationships with their parents, their partners and friends. Booth and Booth (1998) encouraged researchers to move away from the risk paradigm for this

population and acknowledge and utilise the sources of resilience in these families. In line with this, although the majority of this population are identified in the literature as being socially isolated, this research has elected to focus on mothers who are currently well-supported and are looking after their own children.

Method

Procedure

Information about the study was distributed via presentations to two community learning disability teams. They were provided with information sheets to share with individuals who met the following criteria:

1. Participants must have received support from the Community Learning Disability Team at some point in their lives;
2. Participants must be able to give informed consent to be interviewed;
3. Participants must be currently in a long-term relationship (> 5 years);
4. Participants must be mothers and their children must be living with them mother at the time of the study.

When informed consent was obtained, the researcher discussed with each participant the time and place they wanted to be interviewed.

Participants

5 mothers agreed to be interviewed for this study. The following table provides profiles of the participants.

Table 1: A summary of participants

Participant	Age	Ethnicity	SES	Relationship	Relationship duration	Children at home	Age	Children in care	Mental health problems	Substance abuse	Contact with own parents	Employment	Identified friends
Emily	40	White British	Low	Married	26 years	1 girl 1 boy	22 23	0	PND ANX	No	Yes	No	1
Sharon	33	White British	Low	Married	13 years	1 girl 1 boy	3 5	0	PND DEP	No	Yes	No	0
Rachel	35	White British	Low	Married	18 years	1 girl 3 boys	3 7 8 10	0	No	No	Yes	No	0
Isabella	37	White British	Low	Living with partner	9 years	1 girl 1 boy	15 16	1	DEP	No	Yes	No	0
Natasha	38	White British	Low	Living with partner	14 years	2 Girls	13 8	0	No	No	Yes	No	1

SES	Socio Economic Status
PND	Post Natal Depression
ANX	Anxiety
DEP	Depression

Data collection

The author used a semi-structured interview schedule and a probe sheet. The interviews were audio taped and transcribed.

The interview schedule

A semi-structured interview was developed using the guidelines presented by Smith (1995). The interviews were semi-structured in that the researcher was informed by the schedule but the participants were encouraged to talk in detail about their particular concerns. The resulting interview schedule proceeded through the following three topics:

- Relationships with parents;
- Relationship with partner;
- Relationships with friends.

Data analysis

The data analysis of the individual interviews using IPA was conducted following the guidelines outlined by Smith et al (1999). The data was analysed separately for the three topic areas, parents, partner and peer friendships. The transcript was read from start to finish twice. The transcript was then analysed line by line and comments were made in the left hand margin. In the right hand margin emerging themes were noted. Emerging themes were then listed and connections made to find clusters of themes. This process was repeated for each case and a table of themes was produced for each interview and later compared to create an overall master table of themes. Another researcher reviewed and audited the themes to ensure that they were grounded and

well represented in the transcripts. The master table of themes was then transformed into a narrative account; the analytic account is supported by verbatim extracts from each participant.

Results

Relationship with parents

Table 1 Relationships with parents: Summary of the analysis

The importance of support	Vulnerability in relationship
Importance of practical support	Feeling blamed
Tangible expression of care	Sense of not belonging

The importance of support

All of the participants, without exception, clearly identified how important the provision of support was to their relationships with their parents. Support seemed fundamental, both in terms of how they experienced the role their parents played in their lives, and also in terms of how they experienced and perceived being loved and cared for by their parents. For many of the participants, practical support from their parents represented one of the most important aspects of their relationship. Emily identifies the most valuable thing about her relationship with her mother being the time when she offered her practical support following the birth of her baby.

I think the important time was when I had my son and my mum helped me a lot. She came down every weekend and went back on a Monday, she sat in the garden with the baby and helped out. (4: 94-96)

For many of the participants it was important for them to be able to identify tangible evidence that their parents cared for them as part of making sense of the relationship. This is illustrated clearly by Natasha, who despite being unable to talk to her father, identifies the tangible support provided as sufficient for a good relationship.

...he is good. He is always helping, like if I am short on anything he will always come over and help me. We don't really talk about things either but he helps me so that's OK. (7:108-109)

Vulnerability in relationship

Participants spoke clearly about the level of vulnerability they often experienced in their relationship with their parents. For three of the participants interviewed the experience of being blamed by their parents was strong. In some cases the blame was interpreted and understood in terms of their learning difficulties. This was poignantly illustrated by Natasha when she was asked about the relationship with her mother.

...she used to pick on me all the time and take my sister's side all the time and blame all things onto me (7:117-118)... She liked her better she didn't have problems like me so she blamed me for everything and never listened to my side. (7:120)

She eventually accepted this position and felt there was no point trying to change it any more.

...she (mother) never listened to me so there was no point in the end. (7:123)

A number of the participants clearly struggled to feel they were an integral part of their families. Their sense of belonging didn't feel secure, with one participant feeling left out, while for another their sense of belonging appeared to be threatened. Natasha gave us a clear example of her feeling of not belonging to the relationship between her mother and her sister and her wish to play a bigger part in this relationship. The following extract relates to an imminent visit from her mother.

...she (mother) might stay here this time I hope because I have the bigger place, but she normally goes to my sister to stay and have dinner and drinks and all that. It really annoys me she only ever spends an hour or two with me.
(8:137)

Relationship with partner

Table 2 Relationships with partner: Summary of the analysis

Significance of support	Ambivalence about independence
Importance of practical support	Independence is importance
Importance of reciprocity	Uncertainty about independence
Tangible expression of emotion	

Significance of support

Across all of the participants, with the exception of one, the importance placed on practical help and support in the relationship was evident. When Emily was struggling with post-natal depression she experienced support from her partner in a practical sense.

- I How was Alan with you when you had the post natal depression?
- E He was great looking after Mark and feeding him as well.
- I So he was a good help. What do you think it might have been like if he wasn't there?
- E I don't know. I can't imagine it. I wouldn't be able to cope I don't think. (11:377-380)

Natasha also places a lot of value on the provision of practical support. However, in her case she experiences a complete lack of practical support from her partner in her day to day living. The following extract represents the frustration this creates in her experience of the relationship.

- N I get a bit fed up with him because he doesn't help me that much. Like I go out and I get fed up when I come back to a mess all the time and I keep getting cross. Like he sits in the bloody front room and does bugger all really.
- I How does that make you feel?
- N Well sometimes I get a bit fed up. (1:13-15)

For most of the participants support reflected the experience of equality in the relationship, for others it highlighted the perceived inequality in the relationship and created resentment and frustration. The experience of reciprocity for Sharon represented their capacity to support one another and was discussed primarily in the context of not feeling well or feeling tired.

Alright he does it mostly but when I am feeling OK then I can do it mostly.
(10:135)..... We have turns each once in a while. (10:134)... I do that with
him as well if he is tired and he wants to stay in bed a wee bit longer then I do
the same things as well. (11:144)

Natasha, who felt a clear level of frustration at her perceived lack of practical support,
reflects on the importance of reciprocity in a relationship emphasising the practical
aspect of reciprocity.

‘Like Paul should help me more like I do something he should do something.
(3:43).... He could help me more and do things for me when I do things for
him. (9:145)

All of the participants, to different degrees, experienced love or care in the
relationship through the experience or expression of tangible acts. For some of the
participants, Isabelle and Rachel in particular, this was accompanied by a high level
of emotional expression and intimacy in the relationship while for others the level of
verbal expression and intimacy was limited. For Emily the experience and
expression of care and love in her relationship with her partner is illustrated through
the following extract.

I How do you know he cares about you?
E We go places and go around. We went away for my birthday, which if
he didn't care he wouldn't have taken you away on your birthday...
(6:190-193)

I Why do you think he loves you?

E ...make him tea, cook his breakfast for him and nine times out of ten I cook the tea. And if he has not gotten any money I will give him some money to buy stuff, like last weekend, and I also buy him stuff.
(15:514-519)

Ambivalence about independence

All of the participants identified some ambivalence about the role independence plays in their relationship. They recognized independence as something that was important in a relationship, often identified in terms of giving each other some space outside of the relationship. Some of the participants faced a dilemma: their perception of social norms suggested that a relationship should be doing things together and they therefore struggled with the idea of doing things alone without their partner. For others a clear shift is evident over the course of the interview where their perception of independence adjusts from something fearful to something important.

Isabelle, over the course of the interview, shows a clear qualitative shift from independence being something that is frightening to something that she feels is important to the relationship. In the following extract she highlights how having some independence leaves her feeling more secure in the relationship.

It is a little bit scary but I get used to it because it is my independence. (6:64)

... I do miss him like but I have a job now so it's better I am not here all the time waiting for him to come home that was hard for him and for me waiting all the bloody time and getting annoyed. (13:133-135)

For Rachel the idea of independence presented a dilemma. Her beliefs clearly suggested that doing things together is what constitutes a relationship. The following extract illustrates this.

I What do you think a really close relationship is?

R Between them is like, ah, if you're doing things together but if you're not you do things by yourself distant from everyone else.

I What do you think about the distance?

R Got to do it for yourself if you are independent on your own. Stuff like that but if you do things together, that's a relationship together.

I Do you think a relationship should be all about doing things together?

R If you want to stay together, yea, it should be together yea. (23:287-289)

Although Rachel did also identify the importance of having some space in the relationship, which is difficult to align with her previous message that for relationships to work they must involve all things being done together.

...sometimes John would like to go on his own somewhere and I would like myself if there was space... because you get on top of each other and you are arguing and stuff like ... it gives you the break between two people (23:290-292)

Relationship with friends

Table 3 Relationships with friends: Summary of the analysis

Friendships can be dangerous	Benefits of Friendships
Distrusting close relationships	Friendships provide support
Friends can be bullies	Friendships provide sense of belonging

Friendships can be dangerous

All of the participants expressed fear and distrust associated with both their present and past experience of friendships. Most of the participants had experienced some form of bullying over the course of their lives and the experience of exclusion was a common thread running through many of their narratives, often identifying their learning disability as the reason they experienced this behaviour from others. In the following extract from Emily there is a strong sense of the fear she feels towards other people.

....it frightens me a little bit, close relationships are a bit frightening. (13:438-439) ...because I think they go behind your back and slag you off and that's not nice. (14:481-482)

Later in the interview risk and disappointment appear to be some of the reasons why she struggles with most close relationships.

E I don't know. I don't think you can ever tell, sometimes you make friends and you get hurt.

I How do you get hurt?

E Well like when they say, 'oh yea we will do this and do that' and then they don't do it and you're sorta left thinking, 'oh well why not'.
(18:590-596)

Natasha identifies making friends as something that is easy for her; her level of distrust is related to being left out and her sense of being used by other people. Like some of the other participants, Natasha understands some of the treatment in terms of her learning disabilities, as the following extract illustrates.

I'm easy to make friends it's just that the ones I make seems only to want to know... em when they have nothing to do, like use me. When they have other people they will ignore me, maybe because I went to special school or something, like I'm different. (4:62-64)

Rachel was able to remember a number of instances of when she had been bullied when she was younger. In the following extract she identifies her learning difficulties as one of the ways she understands why.

They'd be on my back, they were so rude and nasty, but I know, I know what it's like. (14:181) ... I had am freckles when I was little, they used to moan about that, or am I actually can't read properly. You know stuff like that. They used to take the mick out of me. (14:183-184)

Similarly for Sharon, her experience of being picked on and being bullied was understood in terms of her own difficulties and her perception of herself as inferior.

In the following extract she poignantly speaks about going to a school for ‘people like her’ and because of this expecting not to be bullied.

...well I knew there would be other people there the same as me, things were wrong with them like what I’m like. But since I have been at school but I was bullied as well. (15:191)

Benefits of friendships

Surprisingly, in spite of this very negative experience, all of the participants were able to identify the substantial benefits that friendships were able to offer them, both in terms of personal well-being and general lifestyle. With Natasha the sense of belonging was very strong. She didn’t appear to have a particularly good relationship with her family and therefore the level of importance attached to her one friend was great.

It would be very lonely because I only really got her to do things with, I haven’t really got anybody else. Yea it would be very lonely, nobody to do things with or to talk to things with. I don’t really have anybody else to do things with. (4:74-76)

Natasha created a clear distinction between this friend and other people she knew; the clear sense of belonging is evident in the following extract.

S is different, like we speak to each other most days and we see each other most days as well when we go up the village together and have a drink together. It's nice. (4:59-61)

Rachel is very clear in her wish to belong to what she thinks friendship may be like.

I see them sitting down with their friends. Why can't I have some friends. (15:196) ...I wish I had someone to sit down with and have a cup of tea with really. (19:248)

For Sharon, the support offered by her friends was related to her experience of being bullied and the protective role her friends played in this experience.

People were making fun of me and laughing at me but my friend stucked up for me, my friend. (20: 255)

Discussion

Relationships with parents

A number of studies have identified parental support as central to parents' with learning disabilities' support networks (Tucker & Johnson, 1989; Llewellyn et al 1995; Stenfert Kroese et al, 2002), and stressed that this support could have both positive and negative outcomes for its recipients. The current research, also identified their relationship with their parents as an important source of support but placed less emphasis on the negative aspects of this support. In some cases the reciprocal nature of this support was emphasised, with participants both helping and receiving help

from their parents. Heller, Millar and Factor (1997), in support of this, identified adults with learning disabilities as effective support providers, and highlighted the importance of reciprocal care-giving roles for adults with learning disabilities in terms of their experience of relationships. For other participants in the current study the provision of support represented the experience of being loved and cared for by their parents, often in cases where the sharing and expression of emotions was limited or where other areas of the relationship were difficult.

This research also revealed a number of vulnerabilities in the mothers' relationships with their parents. In the literature the term 'social power' refers to the person's ability to influence deliberately the behaviour, thoughts or feeling of another person (Huston, 2000). Some of the participants experienced a lack of mutual exchange within their relationships with their parents and experienced their relationships as rather one-sided. That is, they experienced a lot of blame from their parents and felt unable to challenge this successfully. Some of the participants also illustrated a sense of not belonging to the relationship or their sense of belonging being threatened, often feeling pushed out by other siblings within the family. Widmer et al (2008) investigated the way individuals with learning disabilities perceived their family contexts and reported that individuals with learning disabilities perceived themselves as less central in their own families compared to other family members. In the current study the sense of blame and vulnerability experienced within their relationships with their parents was often understood as a consequence of their learning disability, particularly where there were other siblings in the house who did not have learning disabilities.

Relationships with partners

In their relationships with their partners the provision of practical support in particular was identified as something they valued, both in terms of something that was offered to them from their partners, and offered by them to their partner. A good relationship appeared to be characterised by a substantial level of reciprocity in the relationship. Reciprocity has been found to contribute to the stability of the relationships with adults with learning disabilities (e.g. Newton et al, 1995). A finding supported by a number of other studies (Stenfert Kroese et al, 2002; Llewellyn et al, 1999). All of the participants, to different degrees, experienced being cared for in their relationship with their partner through 'tangible expression of emotion'. For some of the participants, Rachel and Isabelle in particular, this was accompanied by their partners sharing and expressing emotions, while for others this was limited.

Some of the participants struggled with the idea of a close relationship existing alongside independence of their partners. The ambivalence towards independence may reflect the general feeling of contentment in their current relationships. The Interdependence Theory (Kelley & Thibaut, 1978) would suggest that people who are highly dependent on their relationship believe that their needs and goals can be best met in their current relationship. Interestingly, despite the fear the participants often expressed about doing things on their own, some did not turn to their partners in times of distress to seek their reassurance and support, but sought this generally from people outside of the relationship (i.e. parents and friends).

Relationships with friends

It was clear that for the most part these participants experienced substantial difficulties in making and maintaining friendships. This supports previous findings that this is one of the greatest unmet needs within this population (Llewellyn et al, 1995, Atkinson, 1986; Llewellyn, McConnell & Bye, 1998). The participants expressed a distrust of other people, with many of their fears being grounded in previous experiences of being let down and in some cases being bullied by their peer group. Interestingly, many of the perceived causes associated with friendship difficulties were located within themselves, in that they identified their learning disability as one of the reasons why they experienced problems in their friendships. This supports a finding by the Roher Institute (1990) which identified the role of poor self identity/self concept when making and maintaining friendships. Particular narratives or schemes such as 'I'm a bit different' appears to hold substantial implications for how these participants regard themselves in their relationship with potential friends. However, despite the difficulties and the perceived dangers associated with friendships, the participants also spoke openly about the benefits that friendships had to offer, identifying reciprocal support and belonging. This challenges the assumption that people with a learning disability cannot have reciprocal friendships because they do not have anything to 'offer' the friendship (Mirfin-Veitch, 2003).

The importance of support

The importance of receiving practical support across all three types of relationships may have occurred for a number of reasons, which will be considered here. First, it is possible that some of the participants, as a result of their learning disabilities, did not

have the vocabulary to describe the importance of the emotional aspects of their relationships (Booth & Booth, 1996). On the other hand the participants may have chosen not to discuss what they considered the more private aspects of their relationships. Second, this population often receives specialised and community-based support programmes (Booth & Booth, 1995) from a range of professionals. Such support has been linked with the term 'learned helplessness' (Abramson, Seligman & Teasdale, 1978), which is often used to describe individuals who, due to the level of support they receive from professional services, find it difficult to cope alone. Because services generally offer tangible help and support, individuals may be socialised into a model of relationships that identifies the giving and receiving of material items and tangible support as indicative of love and care in a relationship.

Stigmatisation

From the results it is clear that a number of the themes that emerged in the final analysis, particularly 'vulnerability in relationships' and 'friendships can be dangerous', were understood and experienced in terms of the learning disability that each of the participants had been labelled with. Some of the participants identified themselves as different from their friends and narratives such as 'I'm different because I have a learning disability' saturated their stories. Similarly, for many the level of vulnerability they experienced in their relationship with their parents was internalised and understood to be a consequence of their learning disability. These results are similar to a study conducted by Gillman, Heyman and Swain, (2000) who identified the stigmatising effects of labelling individuals with the term 'learning disabilities'. Narratives or schemes such as these can have substantial implications for how people regard themselves, and what hopes and fears are held. In narrative

therapy terms, labels such as 'different' and 'responsible' may represent problem-saturated stories that may act to limit the participant's ability to engage in relationships.

Clinical Implications

Parents, partners and friends were all identified as sources of support for the participants in the current study. Support services need to take into consideration the individual context of each mother, emphasising the importance of consulting and listening to mothers with learning disabilities. The absence of friends in mothers' support networks is of concern given their importance as an indicator of quality of life and social integration for other adults with learning disabilities (House, Umberson & Landis, 1988; Newton et al, 1994). If, as general friendships research suggests, friends have a unique role in helping individuals cope with life's unexpected crises (Duck, 1991), mothers with learning disabilities may be particularly vulnerable with the paucity of friendships in their lives. The current study facilitates an understanding of what is frightening about friendships; something that services can focus on to begin to address the difficulties in this area. Many mothers with learning disabilities are not part of a supportive network and services should be mindful of the further difficulties this creates and consider this when decisions are being made about the competence of mothers with disabilities.

Furthermore, the participants in the current study tended to internalise the perceived difficulties in relationships as a consequence of their learning disability, maintaining a negative self identity that may limit their capacity to engage in meaningful social interactions. Narrative therapy has developed an approach to helping people to move

away from limiting dominant narratives and to develop new stories of themselves, their experiences and their expectations (White & Epston, 1990). It could offer an alternative to the 'different' and 'vulnerable' themes that permeates their views of themselves in terms of their relationships.

Limitations of the study

The communication difficulties observed in people with learning difficulties has been frequently documented in published research (Lloyd, Gatherer & Kalsy, 2006). They often struggle with complex grammatical phrases or abstract concepts and can experience some difficulties in verbalising responses (McLean, Brady & McLean, 1996). In the current study the participants frequently provided limited responses and probes were often useful to facilitate the conversation. This made the search for meaning in the text more challenging. However, the researcher needs to be aware of whose reality they are working within (Stalker, Gillard & Downs, 1999). Views expressed by individuals with learning disabilities at any given time, arguably represent some aspect of their reality and perspective, something that should be valued and not distrusted.

It is necessary to be cautious in the claims this study makes. The sample is small and it should not be assumed that similar findings would come from all mothers in a similar situation. However, the fact that participants spoke similarly about their experiences suggest a wider applicability. Furthermore, by examining the data in relation to existing theoretical and research literature, the research has achieved some theoretical generalisability (Smith & Osborn, 2003). It would be useful to conduct a

subsequent study with carefully selected participants in order to test the possible extent of applicability.

Conclusion

The results of the present study contribute to the small, but developing, body of knowledge about the support networks of mothers who have learning disabilities and provide a useful stepping stone to understanding the nature of relationships for these mothers. Overall the study confirms the significance of a well functioning support network; highlights the importance of practical support and also provides an insight into some of the perceived difficulties mothers with learning disabilities experience in their relationships.

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