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**Jane C. Edmonds BSc Hons MSc**

**A qualitative study looking at the experiences of mothers with  
learning disabilities and their school aged children.**

**A thesis submitted in partial fulfilment of the requirements of the  
Open University for the degree of Doctor of Clinical Psychology**

**September 1998**

**Salomons**

**Canterbury Christ Church College**

**(20,000 words)**

**DATE OF WORD: 16 SEPTEMBER 1998**

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## **Acknowledgements<sup>1</sup>**

I would like to express my thanks and gratitude to all the mothers and children who took part in this study, and who were so generous with their time and commitment. I would also like to thank the children, and teacher, of class 4E who took part in the pilot interviews. Additionally, I am indebted to the members of the community team who made initial contact with the families on my behalf, and who so willingly provided support.

My thanks also go to Jan Burns, for supervising the project and for providing encouragement, support and some invaluable thoughts and ideas.

This research was also ably supported by some wonderful family and friends, who provided sanity and reassurance throughout. Special thanks to (et) Al for his constant weather updates!, my own mum for constant phone calls and Sarah for numerous cups of tea.

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<sup>1</sup>The research has been written up to preserve the anonymity of all the participants.

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## **Abstract**

This study looked at the experiences of mothers with learning disabilities and their school aged children. The participants comprised a) 8 mothers with learning disabilities, with school aged children (5-18 years old), who had received services from a community team for people with learning disabilities, and b) 4 children from these families whose permission had been obtained to participate. In-depth, semi-structured interviews were conducted to explore the experiences of the mothers and children in relation to key aspects of family life and the psychological consequences of these experiences. Grounded theory was used to analyse the text generated from the interviews. Findings suggested the importance of identity, difficult relationship and attachment styles, psychological vulnerability and lack of control. This led to a formulation of how different aspects of the mother's and children's experiences interact to produce the overall experience for this group. The model tentatively suggests an interaction between external factors (poverty, support networks, life events) and factors within the individual (role identity, lack of control, attachment patterns and vulnerability) which results in psychological distress and need for support. The model is expanded and validated via recourse to existing theory, namely social identity theory (Tajfel, 1981) attachment (Bowlby, 1969) and object relations theory (Guntrip, 1971), a life events model (Brown and Harris, 1978) and a model of locus of control (Cohen, 1980). The findings are evaluated and ideas for future research are discussed. Clinical implications are also addressed.



## **Chapter 1: Introduction**

A growing number of women with learning disabilities<sup>1</sup> are becoming mothers and services are now being faced with the challenge of providing effective service for this client group (McGaw, 1996). These mothers are frequently involved with a number of agencies concerned with their own welfare and those of their children. Increasingly, clinical psychologists are working with mothers with learning disabilities, often being asked to assess adequacy of parenting and to help design comprehensive service provision (McGaw, 1996).

In response to this, there is also a growing body of literature looking at assessing the parenting skills of parents with learning disabilities and developing intervention strategies to improve parenting skills (McGaw, 1996; McGaw and Sturmev, 1993; Tymcuck, 1992). However, there are a limited number of studies looking at the experiences of mothers with learning disabilities, despite the fact that it has been noted that it is important to understand people's perceptions of their experiences if services are to offer comprehensive help (Chinn, 1996).

The few studies which have looked at the experiences of being a mother with learning disabilities often focus upon early transition to parenthood or have been conducted without recourse to psychological models of understanding (Llewellyn, 1991). Little is said about the psychological and emotional impacts of mothers' experiences, which in turn may significantly affect their capacity to function effectively as a parent. Moreover, scant regard has been paid to the contribution of the child to the functioning of the family unit. This study aims to address some of these issues by focusing on the experience of mothers and their school aged children.

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<sup>1</sup>The term 'learning disabilities' is used throughout the text, reflecting current usage within U.K. service provision. Alternative use of terminology quoted from the wider literature reflects philosophical, historical and cultural differences in the use of labels.

Thus this research starts from a point of agreement with Traustadottir (1990) who noted:

Mothers with mental retardation (sic) have not been represented in the literature, and as a result these mothers are even more invisible than other mothers with disabilities and very little is known about their lives and struggles. The limited information available has been written by professionals who tend to discuss mothers with mental retardation in terms of the problems they pose for the welfare services that encounter them. Few, if any, resources are available that present their own point of view and how they experience motherhood'. (Traustadottir, 1990 p.7).

This study aims to begin to redress this balance and to use its findings to inform psychological theory and clinical practice.

## **1.2 Population**

There are no reliable estimates of the number of parents with learning disabilities. The true prevalence is unknown, and probably unknowable (Booth and Booth, 1994). As Whitman, Graves and Accardo (1986) have noted, they represent an invisible population and conducting a population survey is practically impossible, as at the margin they merge into the general population. However, most sources agree that they constitute a growing population, and will continue to do so as a result of hospital closure, decreased segregation, a wider opportunity for independent living and participation in the community, and an acceptance of the rights of people with learning disabilities to become parents (Whitman and Accardo, 1990; Feldman, 1986). Brantlinger (1988) notes that many people with mild to moderate learning disabilities wish to become parents, and many have already done so.

Regardless of actual numbers, the fact that such families often become known to services at points of crisis and often present with a multiplicity of problems, mean they are extremely demanding of service resources and time (McGaw, 1996).

### **1.3 Historical and current context**

There are a number of salient factors which can be seen to have shaped the experience of parents who have a learning disability and the services which are provided to support them. Firstly, is the impact of the principles of normalisation (Ward, 1993). The normalisation movement has resulted in the acceptance of the view that people with learning disabilities have equal rights and freedom of access to education, community living, employment and other aspects of normal everyday living (Wolfensburger, 1972). As a result there has been a move away from the tradition of segregation, towards community living and participation (McGaw, 1996). A number of authors highlight how the principles of normalisation should extend to the rights of people with learning disabilities to become parents, and experience one of the most valued roles in society (Ward, 1993). It also highlights the role of services to support and enable parents with learning disabilities to be supported in the community (Booth and Booth, 1994). Unless this is done, it seems unjustified that professionals should have the right to deny these parents the opportunity to raise their children (Booth and Booth, 1997).

However, there is a continuing ambivalence within society and for professionals working within learning disabilities, towards sexuality and people with learning disabilities (Booth and Booth, 1996). This is most obviously seen in relation to the rights of people with learning disabilities to become parents. A long history of enforced sterilisation and concern with eugenics attests to this (Murphy, 1996), as does continuing concern about vulnerable children and their right to protection from neglect and abuse, often presumed to be an integral part of parenting from learning

disabled parents (Whitman and Accardo, 1990). This is manifest in a perceived difficulty amongst many professionals to accede to the philosophy and values of normalisation in relation to sexuality and parenting. Professionals often appear over-prescriptive or parental in their styles of relating to families, and are often only able to focus upon the negative experiences of the parents' lives (Chinn, 1996).

Additionally, services for this population have largely been informed by a limited body of research (Booth and Booth, 1994; Chinn, 1996). Much of the research is concerned with issues of adequacy of parenting and efficacy of skill acquisition training, with most of the evidence for this coming from experts, official, clinical or professional sources (Booth and Booth, 1994). Booth and Booth (1996) argue that this illustrates what has been termed the 'hierarchy of credibility', which gives professionals with power and status the right to define the way things really are. This leads to an in-built bias within the research which accords greater weight and legitimacy to the views of certain people. Booth and Booth (1996) note that those who occupy important positions are also vested with moral authority; they are assumed to know best. As with the majority of research concerning people with learning disabilities, the perspective of parents' themselves has largely been disregarded (Booth and Booth, 1993).

It has also been argued that such a 'hierarchy of credibility' may also explain the high number of court cases and subsequent removal of children from families where one or both parents has a learning disability (Booth and Booth, 1996). It is claimed that custodial procedures are often based upon unjustifiably high criteria, with an in-built assumption about the danger of cognitive delay when the parent has a learning disability (Booth and Booth, 1996). Thus, the removal of the child occurs and the family has indeed 'failed' as the professional world view would expect. Little is written about the consequences of separation from these families. Reports tend to be anecdotal, but generally attest to the high levels of distress and incomprehension

experienced. Ironically, many mothers may respond by wishing to have another child to replace the child that has been lost (Ward, 1993).

Another set of factors influencing the context in which parenting takes place is the current discourse which exists within western society concerning parenting. There is little agreement amongst cultural commentators as to what mothers should be, what children need and how these needs conflict with the needs of parents. The result is a polarised debate about parents rights versus children's rights, discourse which both blames and idealises mothers and where the individual and society are juxtaposed as mutually exclusive explanations (Featherstone, 1997). Little is said about what kind of help and support is required by mothers to cope with emotional, material and psychic difficulties. Such omission has implications for the most needy and vulnerable groups of parents in society. Featherstone (1997) argues that what is needed are accounts which take into consideration maternal subjectivity, meaning of motherhood and which look at the reciprocal nature of the mother- child relationship. In this way she argues that more sensitively tailored services can be developed to meet clients' needs.

Some of the issues highlighted above are discussed in more detail in relation to a review of the current research literature.

#### **1.4 The experience of motherhood**

A body of psychological literature attests to the difficulties, demands and rewards of motherhood; the majority of work being presented from psychodynamic, attachment, and feminist perspectives (Rollins, 1996). There has been a general move away from viewing motherhood as characterised by a set of measurable and acquirable skills, which unfortunately still dominates much of the work with mothers with learning disabilities (Chinn, 1996). From the former perspectives it is acknowledged that the

role of motherhood is one of the most valued roles in society (Rollins, 1996). Social identity theorists, such as Tajfel (1981) note that it brings with it role and gender identity, which affords the individual a positive self image and forms the basis of behaviour, belief and feelings about being a woman and allows an important aspect of social connectedness.

Chodrow (1978) explores the reasons why many women wish to become mothers. Combining aspects of psycho-analytic, sociological and feminist theory, she suggests that early socialisation experiences have a major part to play in this decision. She notes that 'because women are themselves mothered by women, they grow up with the relational capacities and needs and psychological definitions of self-in-relationships which commit them to mothering' (Chodrow, 1978, p. 209). Morahan-Martin (1991) further highlights that children are seen by many women as providing continuation, tradition and security.

The above reasons for becoming a mother in relation to the enhancement of positive social identity are particularly relevant to women with learning disabilities, as they are often denied positive self images (Booth and Booth, 1996). It has been noted that having the label 'learning disability' automatically confers stigma and a series of negative consequences (Szivos and Griffiths, 1992). Waitman (1992) notes some of the consequences of a negative identity for people with learning disabilities. They are vulnerable to low expectations and opportunity, rejection, isolation from socially valued people, insecurity, lack of freedom and control. Booth and Booth (1995) suggest that one of the rewards of parenthood for people with learning disabilities is the adult status it confers, increasing their sense of common identity with other parents and thus increasing positive perceptions and self-esteem. Booth and Booth (1995) further note that personal fulfilment, opportunities for integration and loving relationships were seen as positive consequences of parenthood.

Conversely, transition to motherhood in the general population has been associated with high levels of stress, family discord, anxiety and depression (Rollins, 1996). Protective factors associated with positive transitions to motherhood include confidence in ability to parent, high self-esteem and a robust sense of self-agency (Rollins, 1996). Factors predicting difficult transition to motherhood include poverty, lack of social support, past history of mental illness, a difficult childhood and poor self-esteem. Booth and Booth (1996) note how many of the factors associated with problematic transition to motherhood are experienced by mothers with learning disabilities. They note the prevalence of poverty, lack of support, difficult childhood experiences and mental health difficulties. Also of note, is the fact that these factors have been intrinsically linked to parenting style and 'good-enough mothering' (Winnicott, 1964; Dunst, 1986). These in turn have been found to effect the subsequent emotional, social and cognitive development of children in the family (Dunst, 1986).

Transition to motherhood has also been explored in relation to theories of attachment and psycho-analytic ideas, which lead away from the idea of essential harmony between the mother and child (Rollins, 1996). It is important to note the central role of the relationship between the mother and child that these theories propose in exploring experiences of motherhood.

From a psycho-dynamic perspective, it is suggested the experience of motherhood involves experiencing ambivalent and contradictory feelings towards the child. The child's projections may elicit a variety of painful emotions such as terror, anxiety, anger and concern (Parker, 1997). Thus the experience of motherhood becomes one of managing these feelings. This may be particularly painful when the goal of mothering is to try to overcome some of the negative experiences associated with one's own childhood or within the context of needing to prove proficiency as a parent to others (Maynes and Best, 1997). Moreover, motherhood may trigger the mother's

own dependency needs which were not met in her infancy. For the mother the task thus becomes balancing her own needs with the child's needs (Parker, 1997).

Object relation theory suggests in more detail why such problematic relationships may develop, based on the development of relationship patterns in early infancy. Several authors, including Guntrip (1971), note that how the adult responds to a new infant will determine the child's identity in adulthood. It is argued that if no sense of 'us' develops between the adult and child, if there is no sense of being held by another in a relationship, there is a sense of 'I' versus 'they' which leads to pain, vulnerability, a fragile sense of self and difficulty in subsequent relationships.

Guntrip (1971) describes several responses to subsequent relationships: reacting with anger or becoming excessively needy in relationships, or needing love but fearing dependency and so withdrawing. Additionally, Guntrip (1971) suggests that for some people their internalised object relations make dependency almost unbearable. They feel shamed to be dependent on people they perceive as hating and resenting their dependency. Thus, it may be these mothers struggle on alone denying themselves the support they so badly need.

Stokes and Sinason (1992) highlight the kind of early relationships people with learning disabilities may experience. They suggest that these may be experienced as rejecting and abandoning, as the adult mourns the loss of the hoped for perfect child. Thus a predicted pattern of difficulty parenting one's own children occurs (Gath, 1988). The work of Maynes and Best (1997) clearly highlights the difficulty for parents whose own childhood was characterised by neglect and abuse, both in relation to mothering their own children and in being able to seek support. These parents themselves became over-enmeshed or rejecting of their children, and could not allow themselves the much needed support of other adults.



Attachment theory (Bowlby, 1969), further highlights issues of how early relationship experiences profoundly effect the patterns of attachments that people make throughout life. Secure attachments in childhood lead to ability to explore and establish secure relationships. Where the child is unsure if the parent will be available or responsive, attachment becomes marked by ambivalence and fear of separation. The third type of attachment is anxious avoidant attachment, where the infant has no confidence that their needs will be met. Later this individual may attempt to live life without love or support of others. Again, for many people with learning disabilities early attachment experiences have been characterised as problematic (Stoke and Sinason, 1992) and help to explain later difficulties experienced in relationships (Gath, 1988).

Little is known about how mothers with learning disabilities experience and negotiate the development of the mother-child relationship over time. Often they become known to services at the point of crisis and as Booth and Booth (1997) note, it is often assumed that having a learning disability is enough to allow the assumption that they are inadequate parents. However, it has been noted that many parents experience a range of experiences that make them particularly vulnerable to some of the difficulties outlined above, namely poverty, lack of support, unemployment and difficult childhood experiences (Booth and Booth, 1994). Booth and Booth (1994) note that not only are parents with learning disabilities likely to experience parenting under conditions of adversity, they are also more likely to be vulnerable to its strains due to poor coping skills. They suggest these mothers are particularly vulnerable to the traumatic effects of stress, decreased functioning, depression, withdrawal, anger and fear. It would seem important to understand how salient aspects of a mother's experience are viewed, managed and how they interact with each other.

## **1.5 Research looking at parenting and learning disability**

Most of the research in this area has focused upon four areas of interest, (Booth and Booth, 1994). These are concerned with issues of genetics and hereditary impairment of intellectual functioning in children, parental competence and parent training, risk of maltreatment and abuse, and the intellectual functioning of children in relation to their experiences of being parented. Most of the research has been undertaken from a clinical, developmental or behavioural perspective, which has tended to treat parents more or less as independent variables, rather than giving them integrity as individuals (Booth and Booth, 1993). Parents are seen as failing almost exclusively as a result of the consequences of having a learning disability, despite the fact that there is acknowledgement that they share many of the same experiences of other disadvantaged groups of parents (Booth and Booth, 1996). Moreover, many of these studies build models of 'parenting skills' and then measure the behaviour of mothers with learning disabilities, with these mothers coming off badly in the process (Chinn, 1996). Chinn (1996) warns against such an ahistorical approach and characterising the state of motherhood as a set of measurable and transferable skills.

Although this study does not seek to directly address issues of competency or adequacy, there are a number of factors effecting levels of competency which are suggestive of the stresses experienced by these women and which makes a review of this literature pertinent.

### **1.5.1 Conclusions of failure of parenthood**

There are many conclusions drawn in the literature that parents with learning disabilities will inevitably fail to provide adequate parenting (Whitman and Accardo, 1990). Whitman and Accardo (1990) note that 'with regard to parenting failure of significantly retarded adults it would seem to be not whether, but when' (p. 28).

The number of incidents of child abuse and neglect, and children being taken into care is taken as evidence for this (Crain and Miller, 1978). Studies have reported high levels (40 - 60%) of removal of children from family homes (Whitman and Accardo, 1990; Scally, 1973). However, much of the research in this area is representative of a skewed population who have come to the attention of services because they are already in crisis. Moreover, it is noted that findings remain equivocal, with much of the data cited only indirectly addressing the question of child maltreatment (Schilling, Schrinke, Blythe and Barth, 1982).

It is also widely believed that children are at risk of developmental delay and retardation (Feldman, 1986; Schilling et al., 1982), especially in relation to language development (Feldman, Case, Rincover, Towns and Betel., 1989; Feldman, Case, Town and Betel, 1985). This concern presumes inadequate parental stimulation for the child's cognitive development (Llewellyn, 1991). Although effects of absence of parental stimulation in the infant years are known (Bowlby, 1969), what constitutes necessary or sufficient levels of infant stimulation is unclear. It is also difficult to assess, with contradictory evidence being made available. For example, Feldman (1986) found no evidence of paucity of stimulating home environments in relation to parents with learning disabilities. Moreover, he noted that a wide range of different parenting styles were associated with developmental delay.

Thus, it is increasingly acknowledged that not all studies attest to parent failure (Tymchuk, Andron and Unger, 1987). More specifically, the literature suggests that parents with learning disabilities can provide love and affection (Hertz, 1979), acquire and perform housekeeping skills (Tymchuk, 1992) and attend to physical needs (Feldman, 1986; Mickelson, 1947). Several authors have been keen to highlight the incredible resilience of many families to adapt to the overwhelming number of stresses experienced (Booth and Booth, 1997; Feldman, 1986). It would thus seem

important to understand some of the factors that may be mediating between successful and unsuccessful parenting.

### **1.5.2 Factors determining competency**

The literature suggests that there are general predictors of poor parenting competence such as early bonding experiences, family difficulties, mental ill health, unresolved loss, social problems and number of children (Ward, 1993). In addition, there are general predictors of parenting competency which apply more specifically to people with learning disabilities. These include level of learning disability, previous institutionalisation, level of support and characteristics of the spouse (Dowdney, Skuse, Rutter, Quinton and Mrazek, 1985; Feldman et al, 1985; Mickelson, 1947; Tymchuk et al, 1987).

#### **Poverty**

A number of authors have suggested that inadequate child care may be seen as the product of poverty (Brantlinger, 1988; Mattinson, 1970). Mickelson (1947) highlighted some of the consequences of poverty that impede the ability to parent: inadequate incomes, unemployment, poor vocational skills, disadvantaged childhood, isolation from extended family, insufficiency of social supports, stressed marital relationships and lack of ordinary life experiences. These factors are highlighted in the study by Booth and Booth (1994) which used a life review methodology to explore the characteristics of family life for this client group.

#### **Poor childhood experiences**

Gath (1988) has also noted that parents will have been more unlikely to have had experiences in childhood that offered any model of good enough parenting. She suggests they will have experienced poor parenting themselves or led a protected and sheltered family life. Seagull and Scheurer (1986) found that most 'low functioning'

parents (75%) came from chaotic and abusive backgrounds, a finding that has been replicated in other research including that by Turk and Brown (1992), who noted the high prevalence of sexual victimisation. Thus many people with learning disabilities enter adulthood bereft of the benefit of adequate training.

### **Support networks**

It has also been noted that a person's support network may compensate for the shortcomings in the skills of the parents to ensure satisfactory care for the children. Indeed, a significant predictor of child well-being is the adequacy of supports that parents have, 'regardless of their own level of knowledge and skill' (Tymchuk, 1992). It has also been noted that the lack of support seems to be the best predictor of child neglect (Tymchuk, 1992), whilst protective factors include the presence of one or more 'other adults' able to offer support beyond the parents own coping capacity (Floor, Baxter, Rosen and Zisfein, 1975; Quinton, Rutter and Liddle, 1984; Seagull and Scheurer, 1986). The high number of single mothers in this population (Booth and Booth, 1993) is an important factor when considering the importance of support in relation to mothers with learning disabilities. The presence of the father is also significant (Booth and Booth, 1994). Unfortunately this remains outside the remit of the current study, as it was felt to constitute a separate study in its own right.

Further exploration of the relevance of these factors in relationship to mothering and how they are perceived to impact on ability to cope with the demands of family life and psychological well-being is thus a primary aim of this research.

### **1.5.3 Interventions**

As with the research looking at competency of parents, the work looking at interventions for these families highlights the main professional focus within this area. Skill acquisition and concern with the child's developmental well-being are the prime target for intervention, and again are often at the point of crisis. Few, if any,

intervention studies look at psychological aspects of mothering or family dynamics which may be influencing ability to parent.

However, research has shown that parents with learning disabilities have the potential to develop new skills, and parenting ability can be improved by training (Budd and Greenspan, 1985; Thompson, 1984; Tymchuk, Andron and Rahber, 1988; Whitman and Accardo, 1990, Whitman et al, 1989). In a summary of this work, Tymchuk, Andron and Tymchuk (1990) concluded that the interactions between mothers and their children 'can become more positive and less punitive through some form of systematic intervention'. Gains were consistently noted in relation to interaction and caretaking skills (Feldman, 1986; Tymchuk et al, 1990). Behavioural methods are deemed the most effective intervention in relation to this skill acquisition (Murphy, 1996).

Although findings appear positive, Booth and Booth (1994) argue that they need to be appraised in context. Most of the reported work in this field has focused on training in personal and interactive skills, such as how to talk to children, play, use reinforcers, adopt methods of discipline. There is less work looking at practical issues such as housekeeping and time management, health and home safety. Again, this reflects a primary concern with children's development, rather than with support of the family and perhaps is also indicative of the fact much of this research was carried out in America, where there is a greater emphasis upon behavioural intervention programmes generally. The training needs of the parents have mainly been determined by practitioners with the parent's own perspective largely being overlooked (Llewellyn, 1991; Walton-Allen and Feldman 1991). Programmes have tended to use behaviour modification techniques and to concentrate on training in the clinic rather than in the home. Additionally, little is known about the longer term outcomes for children. It is often assumed that problems will magnify as children get older (Whitman and Accardo, 1990; McFadyean, 1995). More needs to be learnt

about the changing training and support needs of families with school aged children and adolescents (Booth and Booth, 1997).

Within the wider context of literature looking at the experience of parenting, there is increasing emphasis on the adoption of a multi-element model of understanding of how psychological well being is related to parenting. A body of research shows how mother-child interaction changed as a result of psychological well-being of the mother, levels of support available and stress levels (Dunst, 1986). For example, Dunst (1986) showed that maternal sensitivity to infant behaviour decreased as psychological distress increased. Dunst (1986) argues that the way parents approach the task will be influenced by the model of child care the mother experienced as a child, and whether they continue to be troubled by conflicts around identity, self-esteem and self control. Few of these variables have been systematically investigated as possible areas for intervention in improving parenting skills. This is perhaps linked to both professional biases and also the lack of research looking at how these factors contribute to the stress experienced by the families currently under consideration.

### **1.6 Service provision**

Although it would seem that providing specialist service support is often essential to these mothers, such services are virtually non-existent (Murphy, 1996). Moreover, professionals can often impose considerable stress on families (McConackie, 1991, Booth and Booth, 1994). Booth and Booth (1994) recognise that the 'at risk' label often ensures that most parents are kept under close and constant supervision, and may often have many different workers involved, all taking up time, offering advice and encroaching on family life. It has been noted that this often leads to resentment and reluctance to seek help when it is required (Whitman and Accardo, 1990). Moreover, services may not always present a very good fit with parents' views of their own needs (Booth and Booth, 1994; Chinn, 1996). Services tend to alienate parents

and reinforce parents' perceptions of themselves as 'failures' (Booth and Booth, 1994; Murphy, 1996).

A number of factors have been identified which determine the success of services for these parents (McGaw, 1996). These include adequate funding to provide a wide ranging, integrated service. Crisis driven, short-term services often result in frustration, burnout and blame on the part of the worker and mistrust despair and cyclical crisis episodes for families. McGaw (1996) argues that long relationships lead to greater mutual trust and respect, a maturation in the ways families use support, more prevention and early intervention and more opportunities for workers to develop a more holistic approach. It has also been acknowledged that there is a need to educate professionals about the issues for parents with learning disabilities (Booth and Booth, 1993).

The different responses by services to families has been noted by Booth and Booth (1993). They note the usefulness of distinguishing between competence promoting and competence inhibiting models of intervention. They suggest that the adoption of these models depends on an interaction between the level of environmental strain (poverty, bad housing, illness, personal crisis etc.), actual level of competence of the parent and the support service's perception of parental competence.

It has also been acknowledged that there are a number of important issues involved for professionals working with these families. Chinn (1996) notes that the conjunction of motherhood and learning disabilities is problematic. Families are often seen as exceedingly needy and demanding, and yet ultimately unable to use support to engender change and thus become less needy. Here the primary consideration is the nature of learning disability and reflects a deficiency discourse in relation to families. However, Chinn (1996) notes that professionals involved will often identify with the client as a mother, where their difficulties are viewed as normal given the



circumstances, and therefore workers adopt a competency perspective. This raises questions as to how such ambivalence can be managed. This is often painful for workers in the field, especially where their reports may have implications for custodial care of children.

### **1.7 Children of mothers with learning disabilities**

In relation to the assessment of families, it has been acknowledged that this is incomplete without a contribution from the child's perspective (Reder and Lucey, 1995). It is essential that the children's views about their family experiences are fully represented. Mayall (1996) notes the increasingly central role of children in research, not merely as 'objects' of study, but as actors participating in and constructing social worlds. However, previous research in this area has only explored the child's experience from the point of view of the professional determining what constitutes good or bad experiences, or from the retrospective stance of adults who have been brought up by parents with learning disabilities (Booth and Booth, 1997). This study aims to look at what the children themselves say about their experiences as they live and work through them.

As already noted, children brought up in these families are often assumed to be vulnerable to cognitive delay, problems with emotional and social development and abuse and neglect (Whitman and Accardo, 1990). Resilience is often thought to be accompanied by pseudo-maturity, isolation or psychological distress (Mrazek and Mrazek, 1987). Indeed it is important to note the high number of adults brought up by parents with learning disabilities who subsequently report psychological problems. One study quotes a figure as high as 85% (Gillberg and Geifer-Karlsson, 1983). However, it can not be concluded that all children suffer as a result of being brought up in families where parents have a learning disability (Tucker and Johnson, 1989). A

number of factors are associated with better outcomes for children including support from others, integration with school and peers and intellectual ability (Werner, 1989).

### **1.7.1 Explanations for different outcomes for children: Resilience and vulnerability**

It is argued that children can play an active part in seeking out and constructing environments that sustain their needs. The resilience of some children to poor parenting and damaging, negative environments has been commented on by Mrazek and Mrazek (1987) and Lynch (1988). While reliable predictions are not possible on individual cases, these authors suggest that children are less damaged by adverse care when they are above average intelligence, have few placement changes and are able to form friendly and trusting relationships. Additionally, rapid response to danger, precocious maturity, dissociation of affect and information seeking have been cited as fostering resilience (Mrazek and Mrazek, 1987). Rutter (1985) suggests that a secure relationship with one parent can substantially mitigate effects of an insecure relationship. Also important is the extent to which children can distance themselves from self perceptions of failure, shame, helplessness or hopelessness about the future. This may be a function of the temperament of the child, the timing of the event or the availability of support. A capacity to distance emotionally from unalterable situations is also protective, as is the ability to find a coping strategy and to act rather than react. Success in one area of life, such as good experiences at school, lead to enhanced self-esteem and a feeling of self-efficacy (Rutter, 1985).

Werner's (1989) proposed a model of resilience that is similar to the work of Rutter (1985). Werner (1989) suggests that vulnerability is predicted by social deprivation, environmental inadequacy and poor relationships. Resilience is determined by three protective factors. The first of these is dispositional attributes of the individual (activity level, sociability, cognitive skills and autonomy), the second is affectionate

ties in the family (providing emotional ties in times of stress) and the third factor is available external support.

This study aims to look at children's current experiences of being in their families and the way they manage these experiences.

### **1.8 Summary, aims of the study and research questions**

The above discussion has begun to highlight some of the problems and difficulties faced by mothers with learning disabilities and their school aged children. Factors mediating the effects of some of these problems have been noted, as have the potential consequences for psychological well-being and service utilisation. The current research developed from an acknowledgement of the need to explore the experience of these mothers and their children in context, and from their own perspective.

Thus the study has two main aims:

- to develop an understanding of the individual experiences of the mother, and of her experiences in relation to her children and her support networks, and to explore consequences in relation to psychological well-being and utilisation of service provision.

- to look at children's current experiences of being in their families and the way they manage these experiences.

### **1.8.1 Research questions**

Research questions were developed to address the aims of the study, as outlined above.

- 1a. What characterises the women's individual experiences of being a mother?
- 1b. What characterises the women's experience in relationship to their children?
- 1c. What characterises the women's experiences in relationship to the other people who form their support networks?
- 1d. What are the psychological consequences of the women's experiences?
- 2a. What are the women's perceptions of their children's experiences?
- 2b. What factors do the women see as helpful and unhelpful to their children's well-being?
- 3a. How do children experience family life?
- 3b. How do children manage family difficulties?

### **1.9 Choice of method**

#### **1.9.1 Reason for choosing a qualitative methodology**

The aim of this study was to provide a detailed account of what mothers with learning disabilities have to say about their experiences of bringing up children, and how their children experience this process. The choice of method can be seen to reflect what

Elliot, Fischer and Rennie (1993) terms the 'appropriate method strategy'. This reflects the idea within psychological research that choice of method should reflect the theoretical rationale behind the study, the needs of the subject population and general ethical issues.

The existing theoretical literature in this area highlights a number of important issues which have informed the choice of methodology for the current study. These are:

1. The paucity of research in this field (Chinn, 1996)
2. The need to understand the issues from the point of view of the families, and not to adopt a professional world view (Booth and Booth, 1996)
3. The need to move away from a simplistic construction of parenting and learning disability (Booth and Booth, 1997)

In response to these issues, a qualitative methodology was chosen, as it has been acknowledged that qualitative research is most suited to investigating an area where research is at an early stage of inquiry (Pope and Mays, 1995) and to the uncovering of meaning and understanding (Henwood and Pidgeon, 1995). As discussed in the introduction, in this study the focus is not upon testing a priori hypotheses, but about discovering how mothers and children view their experiences of parenting.

The choice of a qualitative methodology also reflects epistemological issues. Points two and three above highlight the need to avoid recourse to pre-determined assumptions about what the central issues are. This reflects a significant departure from quantitative research paradigms, which are based upon existing assumptions, which are tested out empirically in the search for universal truths and laws (Henwood and Pidgeon, 1995). Qualitative methods aim to build theory which is grounded in the

personal experiences of participants', rather than a reflection of the researchers a priori assumptions (Henwood and Pidgeon, 1995). Additionally, qualitative research paradigms assume a constructivist epistemology, reflecting a view that all knowledge is socially constructed (Henwood and Pidgeon, 1995). In other words, multiple meanings are assumed to exist, as opposed to objective notions of truth. This reflects expectations that mothers and children may each express different understanding of their experiences and attribute different meanings to these experiences.

### **1.9.2 Type of qualitative method chosen**

Tesch (1996) notes that the type of data, and the analytic aims of the researcher, should influence the type of analysis undertaken. For the purpose of this study interviews were felt to allow collection of the most relevant data. Fielding (1993) argues that interviews allows the researcher to focus upon the individual's understanding of events and experiences. This method generates textual data for analysis. Tesch (1996) notes 26 possible qualitative methods for analysing textual data, and thus this study needed to select its analytic method congruent with the analytic aims of the study. As noted before, the research questions were related to understanding the participants meanings and understanding of their experiences. The research also aimed to identify commonalities that existed in the data - looking for patterns and relationships in the texts. Thus, the study was not primarily concerned with the characteristics of the language used (which is perhaps most closely associated with discourse and content analysis (Tesch, 1996)) or the comprehension of the meaning of the text (more closely associated with phenomenology and case study research, (Tesch, 1996)).

It was decided that grounded theory (Glaser and Strauss, 1967; Strauss and Corbin, 1990), best suited the type of data collected and the analytic aims of the study. This approach allows phenomenology to speak for itself and it is concerned with looking

for patterns and relationships in the data, via a general method of constant comparison.

### **1.9.3 Choice of the semi-structured in-depth interview: rationale for use.**

A semi-structured, in-depth interview was felt to address the issues outlined above for a number of reasons. The use of the term 'in-depth' refers to the fact that this type of interview seeks to attain a detailed understanding of the research area from the point of view of those being studied. Jones (1985) suggests that by using open ended questions the in-depth interview allows the interviewees to answer the question using their own framework of language and understanding, rather than those imposed by the researcher. Thus, in line with the characteristics of qualitative research, the in-depth interview focuses upon viewing experiences from the point of view of those being studied in an unprescribed way. It is concerned with the detailed, contextualised description and understanding of events and experiences, the process being characterised by openness and flexibility (Fielding, 1993).

This flexibility is achieved by the fact that in a semi-structured interview (as opposed to more structured approaches) the interviewer is freed from asking each respondent the same questions in the same order. This, along with the fact respondents are allowed to answer in their own terms, unhindered by a rigid framework, means that the in-depth interview is as close an approximation as possible to a natural setting where individuals communicate and interact with each other (Brenner, 1985; Taylor and Bogdan, 1984). Thus, it can be argued that the data gathered from the interview as described here are representative of real experience and the individual's reality.

The in-depth interview is also characterised by the use of suitable probes to assure detailed, but non-directive, expansion of the issues raised by the interviewee (Fielding, 1993). The careful use of open ended questions and probes, that avoid

recourse to the personal views of the interviewer, was important, as this goes some way to meeting the criteria proposed for in-depth interviews by Brenner (1985). He argues that the interviewer should not bias the accounting process by being directive. To guard against bias, and to ensure continuity of approach across subjects, it is considered ideal to video tape interviews and to have them independently rated for bias and directiveness. However, it is usually felt that this hinders open and honest rapport, and presents insurmountable practical considerations (Brenner, 1985).

The in-depth interview has also been acknowledged as being particularly appropriate for gathering data on sensitive topics (Fielding, 1993; Lee, 1993). Coyle, Good and Wright (1994) acknowledge the ability of the in-depth interview to utilise the rapport created by the one-to-one interaction between the interviewer and interviewee to promote honest and comprehensive reporting. Additionally, this interactive element allows the interviewer to be sensitive to the distress that the participants may be experiencing, and thus can also address the ethical considerations related to research (Coyle et al, 1994).

#### **1.9.4 Judging quality in qualitative research**

Hinds, Scandreff-Hibdon and McAullay (1990) have noted the prevalence of criticism levelled at qualitative research by those who argue that its methodologies are less rigorous than those used in quantitative research. Qualitative studies have often relied on the relevance of their findings and their intuitive appeal to reassure critics that findings are reliable and valid. Conversely, Hinds et al. (1990) argue that with all ill designed research and analysis, qualitative studies have the potential to be 'evocative, illuminating, masterful and wrong' (p. 88).



Thus, whilst remaining within a post-positivist paradigm, which argues for acknowledgement of multiple realities and the cogent use of subjectivity and reflection (Bannister, Burman, Parker, Taylor and Tindall, 1994), this study seeks to explicitly address issues of rigour. Assuring reliability (the apparent consistency and replicability of observation) and validity (the generalised truths of statements), are the two central tenets of scientific rigour (Silverman, 1993). However, these are problematic in relation to qualitative research, as the aim is not to assure objectivity and truth, but to assess degree of trustworthiness. Thus the following principles were selected to evaluate this research.

#### **i) Auditability**

This refers to making explicit the process of conducting the research to the scrutiny of others (Stiles, 1993). A research diary was kept throughout the research which documents the decisions made about the research process and which provides a reflective account of the researchers thoughts and ideas about the analysis and presentation (Appendix 1). A detailed account is also presented in the method section outlining how the analysis was conducted and decisions made about relevant categories and themes.

#### **ii) Respondent validity**

This refers to the degree to which findings represent participants' realities and is important in judging the quality of the researcher's interpretations (Silverman, 1993). To achieve this, the emerging analysis was fed back to the mothers who took part in the study and their level of agreement and comments were noted. Their comments were then used to inform the analysis and provide additional data.

### **iii) Generativity**

Generativity refers to the extent to which the research facilitates further issues and questions for research (Henwood and Pidgeon, 1995).

### **iv) Rhetorical power**

Rhetorical power refers to the effectiveness of the results in persuading others to accept them and can be judged in terms of participant's feedback on the findings and the reader's reactions to the results (Henwood and Pidgeon, 1995).

### **v) Providing enough information to allow consideration of alternative interpretations.**

This allows the reader to judge the reliability of the analysis, in other words to act as the author's inter-rater of reliability (Coyle et al., 1994).

### **vi) Consensus of themes noted by a second coder**

It is suggested that this serves to further ensure reliability of analytic process (Coyle et al., 1994): In this study the research supervisor read three of the transcripts and noted salient themes that appeared across the data.

## **Chapter 2: Method**

### **2.1 Design**

As discussed in section 1.9 above, a qualitative design, using a grounded theory methodology was deemed appropriate in relation to the aims of this study. Data was gathered using in-depth interviews based upon a semi-structured interview schedule which was designed to facilitate exploration of the research questions. Two interviews took place with the eight mothers recruited to the study. The first interview

schedule (Appendix 2) was administered and then a second interview (Appendix 3) was arranged to explore the concepts that had emerged from the first set of interviews. This approach is based on the Delphi Technique (Linstone and Turoff, 1975), which advocates the use of feeding back the results of initial data gathered for further scrutiny, development and refinement by key respondents. Four children from the participating families were also interviewed on a single occasion, using the interview schedule outlined in Appendix 4.

## **2.2 Participants**

### **2.2.1 Mothers with learning disabilities**

Eight mothers were recruited to the study. Inclusion criteria required that the participants had at least one school aged child (5 to 18 years), currently living at home. It was also necessary that the mothers could understand the rationale behind the study in order to give their consent to participating. For the purpose of this study, learning disability was defined using a social systems perspective (Mercer, 1973). This reflects a move away from reliance upon IQ scores as being sufficient to reflect a person's level of functioning, and by the current trend by many health professionals to abandon IQ as a classificatory system (Dowdney and Skuse, 1993). Additionally, formal IQ scores are not available for the majority of service users. Thus for the purpose of this study mothers were considered admissible if they had at some stage been in receipt of specialist services for people with learning disabilities. For all the participants this service was an inner city community mental health team for adults with learning disabilities.

### 2.2.2 Children of mothers with learning disabilities

All the mothers who participated were asked if their children could also be approached to take part in the study. There was a total of 17 children in the 8 families, 13 of whom were over 5 years of age and thus fitted the criteria for being interviewed. Three children were subsequently excluded due to severe learning disability. Of the remaining children, 3 mothers did not wish 5 of the children to be interviewed. Six children from 4 families were identified to take part in the study. Four children from 3 families agreed to be interviewed.

### 2.2.3 Characteristics of participants

Individual participant details are summarised in table 1 and 2.

**Table 1. Participant details: mothers**

Participant	Age	No. children	Ages	Marital status	Accommodation	Ethnicity
1	36	3	3, 4, 17	Single	Council property	White
2	45	3	11, 15, 20	Married	Council property	White
3	47	2	15, 23	Divorced	Hostel (24 hr support)	Black
4	38	1	6	Married	Council property	White
5	51	1	15	Single	Warden hostel	White
6	47	2	17, 20	Married	Private rent	White
7	37	3	4,6,18	Single	Council property	White
8	35	2	2, 12	Single	Council property	White

**Table 2. Participant details: children**

Participant	Age	Sex	Ethnicity
1	11	Female	White
2	15	Female	White
3	17	Female	White
4	15	Male	Black

## **2.3 The Semi-structured interview Schedule**

Initial semi-structured interviews were designed for the two groups (Appendices 2, 3 and 4). The schedules were designed to address the research questions, which had been developed following the review of the literature outlined in the preceding section. The interview questions were constructed to allow participants to talk at length about their personal experiences. In relation to the needs of the client group, it was felt important that terminology was easy to understand and that there was a progression towards topics that were conceptually or emotionally more demanding. Participants were encouraged to use their own language, and to develop ideas and concepts as they arose. This was done by careful use of prompts and asking participants to provide examples of issues that were discussed.

The structure and rationale for each of the three interviews is presented below.

### **2.3.1 Mothers' interview (I)**

#### **Section 1: General information**

Participants were asked general questions about the demographics of their family, and their current home situation. This provided general information about each participant and was also felt to help develop rapport between the interviewer and interviewee.

#### **Section 2: Personal experiences associated with motherhood**

This section aimed to identify feelings about family life, the emotional impact of being a mother and how these feelings are handled.

#### **Section 3: Relationships with other people**

In line with the literature attesting to the importance of social support for people with learning disabilities (Booth and Booth, 1994; Llewellyn, 1991), the questions here

sought to explore involvement of other family members and how this support was perceived and experienced. The advantages and disadvantages of this support were explored.

#### **Section 4: Relationships with services / professionals**

The section related to support services and sought to examine the strengths and weaknesses of service support and how it was perceived by these mothers. How difficulties were managed was also an important area of exploration.

#### **Section 5: Perceptions of children's abilities and difficulties**

This section sought to explore mothers' perceptions of her children's experiences, both within the family and outside this environment. Recognition of the child's needs in relation to academic and social aspects of schooling were also explored.

#### **Section 6: Debriefing**

Participants were asked if there was anything else they felt was important, but that had not been covered by the interview. They were also asked if they felt anything had been discussed that they would like others involved in their care to know. Finally, the purpose of the research was reiterated and participants were asked if they were still happy for what they had said to be used in the research. Participants were then given the researcher's contact number if they wished to discuss anything raised by the research at a later date. Participants were also asked if they would like to be involved in the next part of the study, which would be looking at the findings of the study, and asking them to comment on the findings.

#### **Section 7: Researcher's impressions**

After the interview the researcher made extensive notes regarding the emotional impact of the interview both for the interviewer and interviewee. General impressions were also noted. These are noted in the researcher's diary (Appendix 1).

### **2.3.2 Mother Interview (II)**

The second interview (Appendix 3) required participants to comment on the categories that had emerged from the initial interviews. The categories were presented on cards, which were subsequently sorted into piles representing agreement and disagreement. Each participant was asked if they felt the statement on the card applied to them. In some cases the categories used psychological terms unfamiliar to the participants. Where this occurred, the codes forming the categories were presented to aid understanding. Although, the majority of mothers could not read the cards, the sorting task was thought to allow clear acknowledgement of their overall agreement with the studies findings. The categories agreed with were then explored further using a set of elaborative questions, which looked at the women's ways of thinking about these concepts, and subsequent feelings and attempts to cope with them.

Debriefing followed the same protocol as for the first interview.

### **2.3.3 Child Interview**

The same approach was adopted in relation to the child interview, as was outlined in relation to the mother's first interview. The same structure was followed in terms of introduction of complexity and subsequent debriefing. However, there was a need to individually tailor the interview so that it was appropriate to the age of the child or adolescent being interviewed. This was achieved by simplifying the language used, reducing the complexity of the concepts and reducing the length and time of the interview.

### **Section 1: Background information**

Information was gathered concerning who was in the child's immediate family, and other people who were involved in looking after them. This aimed to collect

background information to inform the rest of the interview schedule and to help establish trust and rapport with the child.

### **Section 2: Perceptions of family life**

This section aimed to explore the experience of being in a family, and perceptions of the good and bad things about their family life. Participants were questioned about how they saw themselves as the same and different from other families. The impact of these differences were also explored as a way of further elaborating on the difficulties faced within the family. How children responded to these difficulties were also explored.

### **Section 3: Debriefing**

A similar protocol was followed as outlined for the adult interview schedule.

### **2.4 Ethical considerations**

A number of ethical issues relating to research with people with learning disabilities have highlighted the need to carefully consider issues of consent and support (Stalker, 1998). Accordingly, a series of procedures were designed to ensure that participants were able to make an informed choice about participating in the study, and to provide adequate debriefing and support after the interview.

An information sheet (Appendix 5) was presented to each participant which explained the purpose of the research and what would be involved if they took part. Issues of confidentiality and anonymity were explained. It was verbally highlighted that any issues that were of concern to the interviewer or interviewee would be returned to at the end of the interview and a decision about the appropriate person to tell discussed. This limited absolute confidentiality but was acceptable to all the participants in the study. Participants were also assured that they could withdraw at any stage without



giving a reason, and that this would not affect the services they received. Care was taken to ensure that language used was understood by participants, and the consent form (Appendix 6) was modified to ensure accessibility and clarity of language. Similar issues were also considered in the presentation of information sheets and consent forms for the children taking part (Appendix 7 and Appendix 8).

Debriefing procedures were also explicitly followed. At the end of each interview participants were asked if they wanted to talk to anyone in more detail about any of the more difficult issues that had arisen in the interview. A member of the community team was identified before each interview who could be contacted to provide such a follow up. Any issues that had caused the interviewer concern were also discussed. This occurred on one occasion, but with further discussion it was clarified that nothing new had been discussed in the interview that was not already known to services, who were known to be providing adequate support.

Prior to the research being undertaken, the above procedures were presented to the local ethics committee covering the community team used for recruitment. Full ethical approval was granted on 1 December 1997 (Appendix 9):

## **2.5 Procedure**

### **2.5.1 Piloting the interview schedule**

The parent interview schedule was adapted in response to comments made by two professional colleagues working with adults with learning disabilities and their families. The interview was further piloted on the first participant who was asked to comment on the interview and make recommendations for further changes. As a result more carefully worded prompts were introduced to help facilitate exploration of feelings and concerns.

The child interview was initially piloted on 4 groups of 5 school children who did not have a learning disability and who were aged 10 to 11 years. The research questions were asked to each group and this was then followed by a general group discussion about families. Following on from this, it was acknowledged that children differ in their ability to conceptualise family dynamics and talk about their experiences of family life. It was felt necessary to be more specific about difficulties experienced in families by presenting a number of potential emotions such as hurt, anger, worry, that may be experienced in the family. The need to adapt the interview to take account of the age of the child and level of comprehension was also indicated.

### **2.5.2 Contacting participants**

Potential participants were identified via members of a community team for people with learning disabilities. The team member who was currently involved with the identified person was asked to make initial contact and to explain briefly the purpose of the research. Of 11 mothers identified who met the selection criteria, 8 were interviewed. One mother did not wish to take part and 2 of the mothers were experiencing current difficulties, which team members felt would make their participation inappropriate and potentially anxiety provoking. The team member also agreed to provide follow up support that as required following the interview. Following this initial contact, the researcher contacted each respondent directly to arrange a time to meet with the participant to explain the research in more detail and to conduct the first research interview.

At the initial meeting the contents of the information sheet (Appendix 5) was read through and discussed. Participants were encouraged to ask questions about the research. Participants were then asked to sign the consent form (Appendix 6). The interview was then conducted. All interviews, except one, were tape recorded and additional notes made during the interview to aid recall. Where the interview was not

recorded (as permission was not attained), detailed hand written notes were taken during the interview.

The interviews lasted between 40 minutes and 2 hours, and were characterised by open rapport, which developed as the interview proceeded. Several of the mothers initially appeared anxious, and a number commented on how they felt uncomfortable discussing certain topics. At the end of the interview participants were also asked if they would be happy to be visited a second time to be interviewed about the findings of the study. All agreed. They were also asked if their children could to be approached to take part in the research.

The second interview was conducted between 4-8 weeks later. The mothers appeared more relaxed, and the increased structure of the interview appeared to allow more detailed exploration of the women's experiences. Issues which had initially been difficult to talk about in the first interview, were also returned to in a number of the second interviews.

Where permission was granted, the child interview was then conducted, using the same approach to gain the child's consent as outlined for the mothers. An information sheet was made available to the children (Appendix 7) and a consent form was signed by both the mother and the child (Appendix 8). The interviews lasted between 30 minutes and 2 hours. Unlike the parent interview, children were more candid in their replies and reluctant to explore difficult family issues.

## **2.6 Data management**

Several authors have suggested that a distinctive feature of qualitative research and data analysis is that enquiry and analysis are simultaneous activities (Taylor and Bogdan, 1984; Krueger, 1994). This was the case in this study, with the initial interviews being used to identify emerging themes and to focus research interest.

All the interviews were transcribed verbatim, using the conventions shown in Appendix 10. The interviews were then analysed individually using aspects of grounded theory methodology as outlined by Strauss and Corbin (1990). The analytic sequence is described below and a working example of the process provided in Appendix 11.

### **2.6.1. Immersion**

Analysis commenced with carefully reading and re-reading of the data to allow for familiarisation with the transcripts. Parts of the interviews were also listened to, ensuring that the emotional significance of the data was considered.

### **2.6.2. Coding**

The data was divided into units of meaning and initial indexing, referred to as 'coding' began. This involved labelling of units of meaning in order to identify and account for relevant features of the participants accounts. As further transcripts were analysed, the codes were gradually modified and extended and new codes developed.

### **2.6.3. Categorisation**

In the next stage of the analysis, basic codes which, when compared, appeared to pertain to a similar phenomenon were grouped together under more general headings. These groupings were then used to develop preliminary conceptual categories to describe the main features of the data.

The categories were continually refined, extended and checked against further data and related to each other. Each category was then defined and illustrated by selecting exemplary quotations from the transcripts.

#### **2.6.4. Respondent validity**

Each of the mothers were re-interviewed and were asked to comment upon the codes and categories generated from the data. Results of this exercise are shown in Appendix 13. Their comments were incorporated into the final analysis, strengthening proposed links between aspects of the data.

#### **2.6.5. Thematic analysis**

The final stage of analysis involved moving from description to interpretation with the aim of constructing a theoretical framework. Themes were identified across the data by carefully examining the emergent categories for each group and looking at links and connections between categories. Thus, in addition to the identification of core categories, a parallel process was undertaken with the writing of theoretical memoranda which generated and developed explanations of the emerging concepts and discerned some of the inter-relationships which exist between them (Henwood and Pidgeon, 1995). Henwood and Pidgeon (1995) note that this is the core analysis stage of grounded theory. The links between categories were derived on the basis of two criteria: either the participant themselves had identified the connection or the link between them was established because data appertaining to one concept could also be recorded under the related category. In this way it is possible to begin to integrate emerging categories into a coherent theory (Taylor and Bogdan, 1984). Core aspects of themes were then used in the final stage of the analysis to develop an explanatory, theoretical framework to understand the data.

#### **2.7 Research diary**

A research diary (Appendix 1) was kept throughout the research to allow documentation of the decisions made in the conducting of the research and the analysis of the data. Its inclusion highlights the theoretical and personal stances taken throughout the study which has influenced the final presentation of the data.

## **Chapter 3: Results**

### **3.1 Outline**

The emerging conceptual categories are presented for each research question. A full description of the categories and codes are provided in Appendix 12, thus allowing the results section to focus on how these categories relate to the thematic analysis and generation of themes. However, the result section alone presents a thorough overview of all the findings in this study without necessary recourse to this appendix. The quotes from the data which appear in the results sections have been chosen to represent all the participants in the study and are presented using the conventions outlined in Appendix 10. Outcomes of the respondent validity exercise are also noted.

The results, in terms of conceptual categories, are initially presented in relation to the relevant research questions. However, thematic analysis cut across all these questions to explore and explain the key elements of the complete experience of motherhood for these women.

### **3.2 Presentation of categories**

Initial coding of the mother interviews generated 242 basic codes related to the experience of being a mother with a learning disability, and led to 58 conceptual categories. They are presented in the table according to broad groupings which were used to begin to develop the thematic analysis. Categories are subsequently discussed in relation to these groups. The number in the bracket beside each category in the tables refers to the number of mothers who gave at least one response appertaining to the category.

**3.2.1 Question 1: What characterises the women's individual experiences of being a mother?**

Table 3, shows those categories which emerged to describe the women's individual experience of being a mother. Thirteen categories emerged in relation to this research question, and they are presented according to broad groupings. Underneath the table these categories are discussed and exemplary quotes are provided for each grouping. The number in the square bracket by the category refers to the numbering in the table.

**Table 3. Identified categories relating to the characteristics of the women's experiences of being a mother.**

<b>Broad Grouping (informing development of themes)</b>	<b>Conceptual Category (Number of respondents)</b>
Threats to self identity	1. Criticism (6) 2. Being monitored (7) 3. Victimisation (6) 4. Feeling self is to blame (5) 5. Problems attributed to having a learning disability (4) 6. Being different (6) 7. Lacking necessary coping skills (5)
Identity as a mother	8. Same as other mothers (5) 9. Same as other mothers with difficulties (4) 10. Being a good mother (3) 11. Caring more than other mothers (4)
Isolation	12. Isolation (8)
Poverty / powerlessness	13. Lack of control (5) 14. Socio-economic deprivation (8)
Attachment difficulties	15. Early traumatic experiences of transition to motherhood (6) 16. Problems attributable to own deficiencies of being mothered (6)

### **i) Threats to self identity**

Many of the mothers described threats to their self identity. These came from external sources; from the criticism the majority received from others [1], from the fact that they were constantly having their abilities and psychological well-being monitored [2], and from victimisation in the form of physical or verbal abuse [3]. Threats to self also came from the mothers themselves. Some of the mothers described feeling that they were in fact to blame for their problems [4], that their learning disability was causing the problems experienced [5] and some had subjective feelings of being different from other people [6]. Mothers also noted the fact they also lacked some of the skills necessary to be competent [7].

One participants comment was particularly salient in relation to this grouping:

*'They [neighbours] call you a pig, they call you a slut ... they say you should be in a mental home' [3]*

Another mother noted the criticism she received:

*'People can be unkind, V.[sister] criticises my cooking, she says she wouldn't feed it to the cat' [2]*

### **ii) Identity as a mother**

All the participants talked about their role and identity as a mother. This was evidenced in their descriptions of the fact that they were the same as other mothers [8], or the same as mothers who were also experiencing difficulties - such as problems with difficult children, lack of support or lack of money [9]. Three of the mothers also noted that they were good mothers [10], whilst half the mothers



suggested that they were in fact better mothers as they cared about their children and how their children were with other people [11].

A typical comment was:

*'I don't let them [children] do that, I don't let them get away with it, other mothers do'* [11].

### **iii) Isolation**

The category was constituted from descriptions of isolation [12], which was noted by all the mothers interviewed. Isolation was related to lack of opportunity to go out, or resulted from the decision of the women to withdraw and remain invisible.

Comments included:

*'I'm invisible, no one sees me.'* [12]

*'I could be dead and no one would know. Sometimes no one knocks on my door or rings for days'* [12]

### **iv) Lack of control**

The category of lack of control was noted by some of the women, in relation both to other people [13] and in relation to their circumstances which meant that they were dependent on the state for housing and income.[14]:

*'I see my social worker to try to get some money, and he say 'I can't give you money to take them out'. The money I get from social security, I got to pay all the bills, money for food. I just can't do it see, and they say you could take them to the park for nothing, but at their ages you can't take them to the park'.*[14]

### **v) Attachment difficulties**

Attachment difficulties were evidenced in the majority of interviews. Mothers noted difficult early experiences of being a mother and not bonding with their children [15]. Mothers described the results of post natal depression, caesarean births and breakdowns, as well as inability to cope with a very small baby. There was also description of poor early relationships with their own mothers, which were either neglectful or abusive [16]

One woman commented:

*'When I was 24, I took an overdose, they found me on the streets with my baby a few weeks old, I couldn't cope with the stress of a little one'. [15]*

Another stated:

*'My mum has done me harm, she used to say I try to take her new husband away from her, I never did. [16]*

### **3.2.2 Question 2: What characterises the mothers' experiences in relation to children?**

Table 4 presents the categories that describe the mothers' experiences in relation to their children. 10 categories were identified.

**Table 4. Identified categories relating to the characteristics of the women's experiences in relationship to their children**

Broad Grouping (informing development of themes)	Conceptual Category
Identity as a mother	1. Satisfaction with mother hood (6) 2. Pride in children's achievements (6) 3. Central focus upon children (3) 4. Need to protect children (8) 5. Worry about children (8)
Threat to identity as a mother	6. Abused by children (3) 7. Feeling stupid in comparison to children (4)
Lack of control	8. Children who are difficult to control (7)
Ambivalence re dependency	9. Partnership with children (4) 10. Children needing to be taught independence (6)

**i) Identity as a mother**

Comments highlighted the importance of the role of being a mother to these women. The majority noted satisfaction with motherhood in terms of enjoyment and reward [1] and pride in children's achievements [2]. The central role that children played in these women's lives were discussed by a number of the mothers [3]. All noted the role they took in protecting their children from difficulties [4], and the fact that children were a constant worry to them [5]. As one woman noted:

*'I would die without my children' [3]*

**ii) Threat to identity as a mother**

The interviews also evidenced the threats that mothers experienced in relation to being a mother. Comments hinted at the fact they were often abused by their children,

both verbally and physically [6] and found themselves as less able than their children [7].

*'I can't help him [son] with his homework. All I can say is 'is that right E.?' He's brighter, he should be the mum' [7]*

### **iii) Lack of control**

Those who commented about their lack of control in relation to their children, noted the problems associated with controlling children's difficult behaviour and because children were too old to be told what to do [8].

*'I've never been able to control his[son's] temper, and you know his staying away and not coming back [8]*

*'I say 'you [children]'are not going to walk all over me all the time [8]*

### **iv) Ambivalence between dependency and independence**

There was a notable amount of evidence from the interviews that the mothers perceived the relationship between children and adults as a partnership [9]. This was noted in relation to both helping in the home and in solving problems that arose. A considerable number of the women also noted that they felt it was their role to teach children to be independent, so they could cope outside the family environment [10].

*'I think we have tried, because it's up to the children as well' [9]*

**3.2.3 Question 3: What characterises the mothers experiences in relationship to other people who form their support networks?**

**A) Informal support**

Table 5 presents the five categories that were noted in relation to the research question. They fell into two broad groupings - good support and problematic support.

**Table 5. Identified categories relating to the characteristics of the women's experiences in relationship to the other people who form their support networks - A) informal support**

Broad Grouping (informing development of themes)	Conceptual Category
Good support	1. Having enough support from key people within the family (4)
Problematic support	2. Family supporters who are vulnerable (5) 3. Family discord (6) 4. Isolation from extended family (7) 5. Difficult relationships with friends (3)

**i) Good support**

Only half the mothers described having enough support from within the family [1]. This support came from either husbands or the women's own mother or siblings:

*I see a lot of my brother, we're very close. When I get ill, he comes to take E. [son]. [1]*

*We didn't have any difficulties, we had his [husband's] mother to help us all the time. [1]*

## **ii) Problematic support**

Support was perceived as problematic in relation to the vulnerability of the supporters [2]. This vulnerability related to supporters own disability, psychological well-being and ability to protect themselves from others. Family discord [3] and isolation from extended family [4] were also common. In addition to difficult relationships within the family, participants also commented upon the difficult, even abusive, friendships that they had [5].

Typical comments included:

*'my mum [...] had mental health problems, it's hard to talk about her. I wouldn't trust her to look after my kids' [2]*

## **B) Formal support**

Seven categories are presented in relation to formal support. In addition to good support and problematic support, the categories were also suggestive of ambivalence in relation to formal support being received.

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**Table 6. Identified categories relating to the characteristics of the women's experiences in relationship to the other people who form their support networks - B) formal support**

Broad Grouping (informing development of themes)	Conceptual Category
Good support	<ol style="list-style-type: none"> <li>1. Support enabling better coping (5)</li> <li>2. Social support from education system (5)</li> </ol>
Ambivalence re support	<ol style="list-style-type: none"> <li>3. Reticence about service involvement (8)</li> </ol>
Problematic support	<ol style="list-style-type: none"> <li>4. Practical problems with support (5)</li> <li>5. Not enough of the right kind of support (3)</li> <li>6. Support over intrusive (6)</li> <li>7. Support causing additional problems (7)</li> </ol>

**i) Good support**

The interviews were suggestive of good support being that which enabled better coping [1]. In relation to the education system good support was related to low level of involvement with formal aspects of schooling such as homework, but available social support for the family in terms of respite for children or advice for family difficulties [2].

*'I need help with reading and writing, they've<sup>1</sup> helped me with that'*

**ii) Ambivalence about dependency**

All the interviews evidenced the apparent ambivalence that the mothers experienced in relation to having services involved [3]. Many expressed the fact that, although they knew services were helpful, they also wished they did not have to be involved. As noted by one of the participants:

*'People come in everyday, I wish they didn't have to' [3].*

<sup>1</sup> In this section the mothers are specifically talking about professional support workers.

### iii) Problematic support

Categories associated with problematic support included practical problems with support, such as when it was available and times when no services were provided [4]. Additionally, comments hinted at the fact that support was often inappropriate in relation to the problem, or age of the child [5]. Support was also described as over intrusive and causing extra problems [6].

*'We had a lovely social worker, but when she left we had another 6 months without anything' [4]*

*'I don't like being told what to do, it drives me mad, they won't leave me alone' [6]*

### 3.2.4 Question 4: What are the psychological consequences of these women's experiences?

**Table 7. Identified categories relating to psychological consequences of the women's experiences.**

<b>Broad Grouping (informing development of themes)</b>	<b>Conceptual Category</b>
Internalisation of emotions	1. Withdrawing (4) 2. Feeling anxious (6) 3. Feelings of depression (2) 4. Lowering of self esteem (4) 5. Causing illness (6)
Externalisation of emotion	6. Feeling angry (3)
Psychologically/emotionally vulnerable	7. Feeling constantly stressed (6) 8. Emotionally vulnerable (4)



### **i) Internalisation of emotions**

Categories that emerged from the data which are suggestive of internalisation of emotion included talk of withdrawal into ones self to avoid emotionally difficult situations [1], feelings of anxiety [2], depression [3] and low self esteem [4]. A number of the women also talked about how their life experiences had caused them to become physically ill [5].

*'If anything happens to them [children], I think 'social worker'. If E [son] falls, I think 'I'd better phone the social worker. I panic. I'm so frightened of social workers' [2]*

*'I sit inside all day, I never go out. It makes me depressed. I get depressed easily, I take tablets and that [3].*

### **ii) Externalisation of emotion**

A small number of the women talked about getting angry [6]

*'I lose my temper, I even slam the door. They [neighbours] have got dogs that bark all day' [6]*

### **iii) Psychological/emotional vulnerability**

In addition to specific emotional consequences of life experiences a number of the emerging categories reflect the overall vulnerability of these women to psychological distress. Talk of feeling constantly stressed was common [7]. Vulnerability to emotional stress [8] was also hinted at by the women, in terms of easily becoming upset over little things, and having a constant battle to remain able to cope.

*'I have to fight to cope all the time'. [7]*

*'I get upset really easily, people say I'm too sensitive' [8]*

### 3.3 Children's experience.

Children's experiences are presented in terms of the mothers' perceptions of their children's experiences (Table 8.), followed by what the children themselves said (Table 9).

#### 3.3.1 Question 5: What are the mothers' perceptions of their children's experiences?

Table 8 presents the 8 categories that emerged from what the mothers said about their children's experiences.

**Table 8. . Identified categories relating to women's perceptions of their children's experiences**

Broad Grouping (informing development of themes)	Conceptual Category
Vulnerability of children	1. Children as vulnerable (7) 2. Children as emotionally affected by previous experiences (5) 3. Children as isolated (3)
Difficult relationships	4. Children having difficult relationships with other children (6)
Resilience	5. Children as succeeding (5) 6. Children as resilient (6) 7. Children having to grow up as a result of difficulties (3)
Helping factors	8. People who care (5)
Hindering factors	9. Lack of concern from others (3) 10. Lack of understanding (5) 11. Slipping in societal standards (3)

### **i) Vulnerability of children**

A number of categories emerged which were suggestive of the vulnerability of the children. Vulnerability [1] in relation to inability to defend self against attack (physical or emotional) was noted by the majority of mothers. Vulnerability was also demonstrated in relation to the emotional distress caused by previous experiences [2] and the fact that children were withdrawing from those around them and becoming isolated [3].

*'Bed wetting she [daughter] did, and all stuff' [2].*

*'I think he<sup>2</sup> feels angry and he takes it out on things as well, he's broken things in temper' [2]*

### **ii) Difficult relationships**

Children were also seen as experiencing difficult relationships in relation to other kids, including siblings [4]. Relationship difficulties were seen in conflict with other children and also in the inability of children to set appropriate boundaries. Thus two comments have been selected to illustrate.

*'He kept getting suspended for fighting and bullying, he shows off with the other kids' [4].*

*'K. [daughter] is good at mixing with people, but she gets too involved' [4]*

---

<sup>2</sup> 'He' and 'she' in this section refer to the sons and daughters of the mothers interviewed.

### **iii) Resilience**

As well as suggesting the difficulties the children were experiencing there was also emerging evidence suggestive of resilience. Categories here included children that were succeeding, both academically and socially [5], children who were resilient [6] in that they could defend themselves and cope with demands made of them, children were also seen as mature in relation to dealing with problems [7].

*'There are things my daughter will do and will not do; she is strong with her daddy, she will have a go at him' [6]*

### **iv) Helping factors**

Mothers suggested that factors helping children were based on the fact that people cared about what happened to them [8]. Thus the category emerged from comments associated with attempts from others to stop victimisation of children, provide emotional support and 'be there' for them.

*'So the bullying started again, but they [the school] did something about it, now she's happy as ever'. [8]*

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### **v) Hindering factors**

Several categories emerged which were suggestive of factors hindering children. These included lack of concern from others [9], lack of understanding of the children's needs and difficulties [10] and, as noted by a few mothers, a slipping in societal standards, so that no action was taken against offenders or bullies [11].

*'People just don't understand her difficulties' [10]*

### 3.3.2 Children's own perceptions of their experiences - initial findings

Table 9 includes the 15 conceptual categories noted in relation to the children's perceptions of their own experiences. As a result of the small sample size it was felt important to add weight to the validity of the categories that emerged from the child interviews. Some of the issues that appeared in relation to the child's experiences mirrored those perceived by the mothers. Therefore, (where appropriate) two numbers appear in brackets beside some of the categories. The number in bold represents the number of children (c) giving at least one response appertaining to the category. The second number are the number of mothers (m) who noted these concepts. These are related to external circumstances, which are potentially open to observation by all family members.

**Table 9. Identified categories relating to the children's own experiences.**

Broad Grouping (informing development of themes)	Conceptual Category
Good relationships	1. Closeness of family ( <b>4c</b> ) (8m)
Need for support	2. Acknowledgement of need to help in family (2) 3. Need for extra help (3) 4. Limitations of own helping capacity (3)
Problematic relationships	5. Difficult relationships in family ( <b>4c</b> ) (8m) 4. Victimization ( <b>3c</b> ) (8m) 7. Difficult neighbours ( <b>4c</b> ) (4m)
Lack of autonomy	8. Problems of autonomy (3)
Resilience	9. Presentation of self as able (4) 2. Externalise cause of difficulties (3)
Psychologically/emotionally vulnerable	11. Emotional stress in family ( <b>4c</b> ) (6m) 3. Chaotic home life (3) 13. Defending against painful feelings (4) 3. Acknowledgement of own stress as a result of the family (3) 15. Anxiety about loss (3)

### **i) Good relationships**

Children all perceived their families as a place where they experienced warmth and affection. Thus the main category is of closeness of these children's family as being a positive experience [1].

*WHAT ARE THE GOOD THINGS ABOUT YOUR FAMILY?*

*'we love each other' [1]*

*'Here [home] mum and dad talk to children, they talk to children in a calm way' [1]*

### **ii) Need for support**

A need to provide support was hinted at by half the children who noted the need to provide mothering to the family, or provide practical help [2]. The need for extra help from other people [3] and limitations of their own helping capacity was also noted [4]

*'She'[mum] is like a child. I have to look after my brother and sister [2]'*

*'I phone my social worker to say that I need a break. That my mum needs a break too'[3].*

### **iii) Problematic relationships**

All respondents talked of experiencing difficult relationships with family members [5], in respect to victimisation from others, both verbal, physical and sexual [6] and in contact with neighbours [7].

*'We [family] have too many arguments' [5]*

#### **iv) Lack of autonomy**

Three of the children spoke of their lack of autonomy within the family, having to tell parents where they would be and what they were doing and not being listened to [8].

*'no one listens to me, I always get into trouble at home, but it's not fair'* [8]

#### **v) Resilience**

Categories in this grouping represent the children's ability to cope and present themselves as able [9], in relation to their academic and social achievements. Attributing the causes outside the family [10], blaming neighbours or environment, was seen as resilient as it can be viewed as protecting them from having to acknowledge the limits of their family.

*'I passed my exams yesterday'* [9]

#### **vi) Psychological/emotional vulnerability**

Categories in this group attest to the high levels of emotional difficulty and distress being experienced by these children. Emotional stress in the family was noted [11], as was the chaotic nature of home life [12]. The home environment was seen as muddled or mad by these children. There was also evidence of the children defending themselves in the interview against painful feelings, questions were inappropriately answered, or could not be thought about [13]. Direct expressions of their own stress was also seen in the interviews, referring to stress, self-harm, anger and becoming easily upset [14]. Finally, a recurrent worry, was the loss of animals or important supporters or mothers themselves [15].

*'I worry about my mum getting ill, and having to go away.'* [15]

*'I wanted to kill myself, stress, too much stress.....'* [14]

### **3.4 Respondent validity**

The level of agreement that participants noted in relation to the categories presented in this result section are shown in Appendix 12. This exercise was completed in relation to the data for mothers only. A high level of overall agreement is suggested. Highest agreement is noted in relation to positive attributes of motherhood, such as 'pride in children's achievements'. Lower agreement was noted in relation to negative aspects such as lack of control.

Typical comments from the mothers in this interview included:

*I agree with a lot of what the other mum's said, didn't I*

*I think it would be good for us all to get together and talk, and help the children like. We could meet in a group, we need to co-operate. We all got problems with our kids and that, we could give each other help like.*

### **3.5 Thematic analysis**

Themes were identified for both groups interviewed to understand the experiences of family life for the two groups. Themes were influenced by the broad groupings used to present the categories in the tables above.

#### **Themes identified in relation to the mothers**

##### **i) Importance of identity as a mother**

This theme reflects the ideas presented in relation to the groupings of identity and threat to identity of being a mother, especially a good mother (Table 3 and 4). Conceptual categories referring to the satisfaction and pride associated with



motherhood highlighted the importance of this identity. Moreover, the category of being the same as other mothers, or in some cases better than other mothers, highlights the attempts this group of mothers made to present themselves as able in relation mothering. Comparison and denigration of other mothers appeared an important technique for conveying their own relative competence. Talk of worry and concern about children also highlights the importance of the role of mother to this group, as did the central role that the children appeared to play in the women's lives. Ability to care was highlighted and seemed to be an attempt to over-ride other less important deficits in their ability.

As one mother noted:

*I really love S [son], he means everything to me. I really have to fight for him. I don't know what I'd do if anything happened to him. Having him has made everything so much better, I've got a reason for getting up in the morning."*

## **ii) Threats to self identity**

The groupings referring to threats to identity suggested the importance of this theme in the overall analysis of the data (Tables 3 and 4). Threats to identity were seen in this analysis as being indicated by the victimisation, criticism, and monitoring experienced by the mothers. Threats to identity were also perceived as coming from the mothers themselves who talked of feeling that they were to blame for their problems, that they lacked necessary skills, and that problems were caused as a result of their learning disability.

Having difficult children and feeling stupid in relation to their children and being abused by children were understood in terms of threats to their identity as a competent mother. The ideal mother would also perhaps expect to have the ideal child, who doesn't threaten this perception!

The relevance of this theme is illustrated by a comment from one mother, who noted:

*You have to try really, really hard to be an extra mum. All mums are extra mums [...] but they tell you you should have done this or that. You feel awful about yourself, and start thinking you shouldn't be a mum at all'.*

### **iii) Problematic support networks**

This theme cut across all the research questions. Broad groupings in the tables highlight difficult relationships both within the family and with formal support networks. Support was variable in relation to the whole of the women's support network. Some support existed, but this was also problematic, being offered by people who were themselves needy or vulnerable. Additionally support was causing problems, relationships were often volatile and in some instances abusive. Formal support was seen as over intrusive, unreliable and in some cases inappropriate to what was actually required.

*'It's OK when my husband is out [of prison] like but when he's in I just can't cope. I go up to the school and I say I can't cope. He's in and out of prison like. He promises he'll stay out this time, but I don't believe him.....*

### **iv) Ambivalence re dependency**

In relation to support the women described both dependency needs and need for independence (Table 6). Mothers acknowledged need for support from within the family and from services. However, this was also accompanied by reticence about service involvement. Moreover formal support was perceived as problematic and intrusive.

In relation to children, there was also an ambivalence about their dependency needs. Mothers acknowledged a need to protect them and control them, but also a need to teach them to be independent and for the mother-child relationship to be one of 'partnership' (Table 4).

#### **v) Attachment difficulties**

An over-riding theme from the data was the number and consistency of difficult life experiences that the women were encountering in relationships. Women had experienced traumatic childhood's, traumatic transitions to motherhood, continuing relationship difficulties. Additionally, they were living with current victimisation and abuse (Table 3). This theme is used to suggest that these are all consequences of attachment difficulties with people around these mothers.

#### **vi) Internalisation of difficulties**

As evidenced in Table 7, all the women experienced internalisation of feelings, only 3 mothers spoke of anger, which was directed at others. All the women spoke of withdrawal, anxiety, depression, stress and illness in response to life's difficulties. The propensity towards internalising difficulties was thus apparent, and this theme therefore reflects the psychological difficulties experienced by these women as a response to life events. The positioning of the emotion in relation to life experiences was particularly relevant in relation to the development of this theme. Links had to be clearly made between an event, or circumstance and a feeling. For example, in relation to her feelings of anxiety one mother noted:

*'I feel like I've been brain washed or something, the social worker comes round to see me and S [son], to see how we are, then all I can think about is whether they'll take him into care. I worry and I get panicky. I ring my mum up all the time, sometimes she can't take anymore and she starts to worry too [...] We both worry'.*

### **vii) Vulnerability.**

This theme emerged to link the categories that were suggestive of psychological vulnerability. High and constant stress forms the central tenant of this theme (See table 7). Additionally, inability to defend themselves from attack from others was also an important concept in the emerging analysis, evidenced by continuing victimisation and threats to self (Table 3).

### **viii) Powerlessness**

Powerlessness or lack of control was also felt to constitute an important theme across the research questions. It was seen in relation to finance and other people (Table 3) and to children (Table 4)

## **3.6.1 Super-ordinate themes**

In order to allow the themes to inform the development of a theoretical framework to begin to understand the data, it was decided that several of the themes could be subsumed under super-ordinate themes, as in many ways they reflected similar theoretical concepts. Therefore, four super-ordinate themes were constituted. These are presented below:

### **i) Identity**

Combines:    i)identity as a mother  
                  ii)threats to identity

### **ii) Relationship difficulties**

Combines:    iii)problems with support networks,  
                  iv) ambivalence re dependency.  
                  v)attachment difficulties

### **iii) Psychological vulnerability**

Combines: vi) Internalisation of difficulties  
vii) Vulnerability

### **iv) Lack of control**

vii) Issues of powerlessness

## **3.7 Themes identified in relation to the children**

It is again important to reiterate that the small sample size makes the formation of themes tentative. However, four themes are presented as beginning to propose a way of theoretically analysing the data, and suggesting an emergent theoretical framework.

### **i) Warm and supportive, but problematic family relationships**

This theme reflected the experience of families as both warm and protective, but also the source of conflict and emotional distress. This dichotomy was evidenced in all the interviews and suggested complex and demanding families, which were often difficult to adapt to. On one side they could look to the family for support and nurturance, on the other hand it was the source of upset, abuse, chaos and difficulty.

### **ii) Seeking out support**

This theme seemed to highlight the children's doubt about their ability to cope alone with the fragility of their environment. It was evident that extra help was needed and there was fear that this would be lost and that this was outside the children's control.

### **iii) Fragile autonomy**

Autonomy here is used to refer to the children's ability to be in control, seek out help, socialise and offer support to the family. It was set against difficulty establishing autonomy and needing other people.

#### **iv) Coping with vulnerability to psychological distress**

This theme refers to the fact that children noted their own emotional difficulties and those of the rest of their family. The theme reflects the coping that children showed in relation to this emotional distress (seeking support, respite or withdrawing from the situation). Coping appeared difficult and children were often overwhelmed by the distress they encountered in the family.

### **Chapter 4: Discussion**

#### **4.1 Outline**

This discussion begins by proposing a tentative theoretical framework to explain the respondents experience of motherhood. The theory is grounded in the data and the themes that have already been presented. The framework proposed utilises a number of existing models to suggest links between the different aspects of the women's experiences, thus highlighting the fact that no one existing theory can be expected to fully represent the individual's experience. A theoretical framework for explaining the children's experience is then presented. A critique of the study and clinical implications for service delivery are discussed. Recommendations are made for future research.

Before venturing a theoretical framework by which to explain the current findings, the categories that emerged are considered in relation to previous research findings to begin to highlight any differences between this study and other work with similar families. At a basic level, it appears that conceptual categories emerging from this study are congruent with previous research findings. The work of Booth and Booth (1995) concluded that the following factors contributed to the difficulties experienced by families where one or both parent has a learning disability: constant surveillance, inadequate support, poverty, isolation and victimisation and system abuse (the

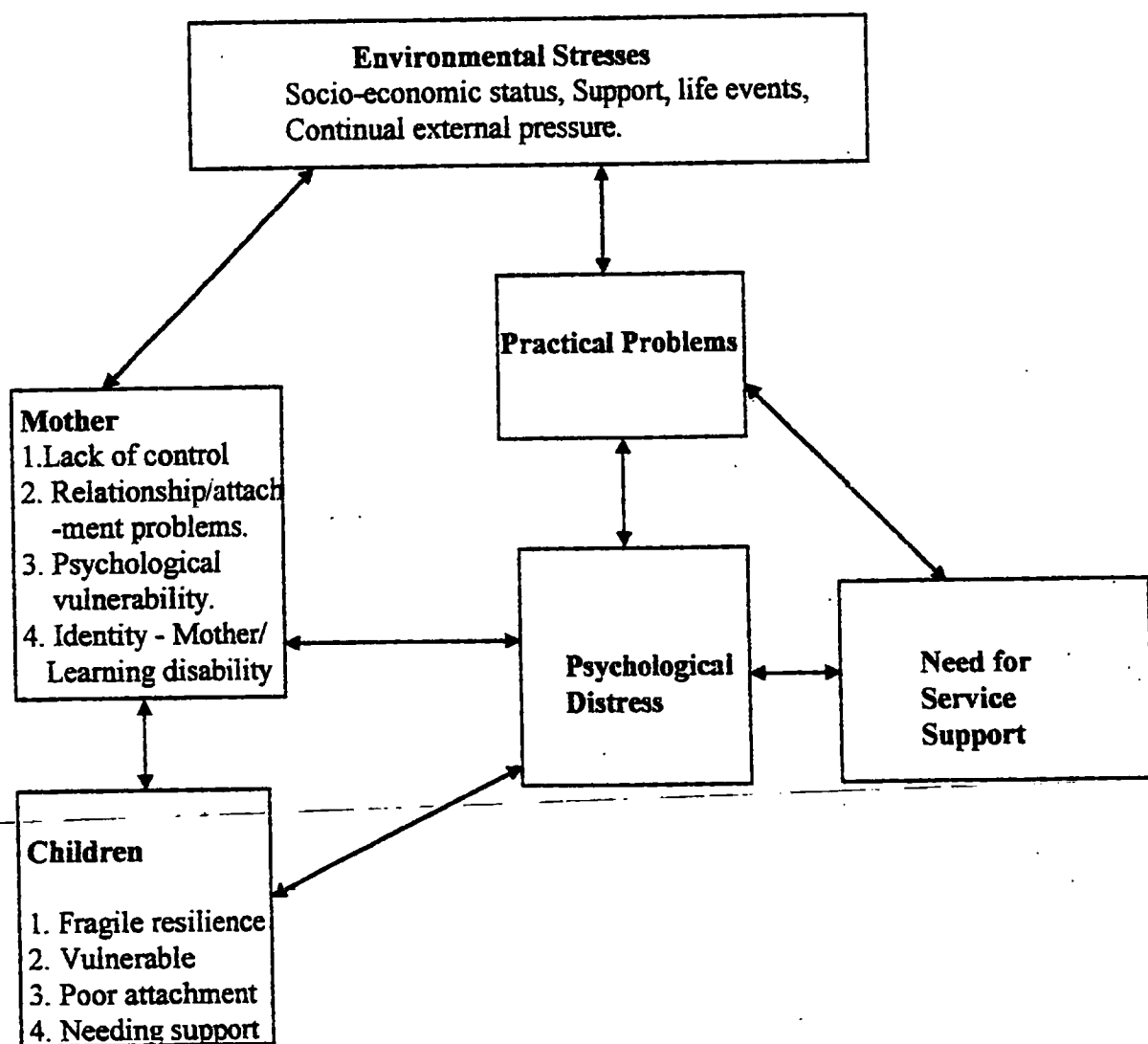
processes that damage the family that is meant to be protected). These findings are similar to those reported by Mickelson (1947), one of the earliest reviewers of this area. Booth and Booth (1995) also noted the importance of the role of parenthood in relation to personal fulfilment, adult status and loving relationships. Gath's (1988) work also highlighted difficult support relationships and poor models of mothering available to these women. A review of the current findings suggests all of the above are evidenced in this study.

However, this study also highlights the importance of perceptions of motherhood identity and difference, threats to identity, lack of control, difficult relationship histories and partnership with children. Additionally, more is said by the current study about the psychological distress experienced by the mothers as a result of their experiences. This can be attributed to the research questions and aims of the study, which were informed by psychological models of understanding. For example, Booth and Booth's (1994) study used a life review methodology, which perhaps precluded the detailed exploration of some of the issues in a way that the interview schedule allowed for in this study.

#### **4.2 Emerging theoretical framework**

The super-ordinate themes of identity, difficult relationships, psychological vulnerability and lack of control have been used to structure a formulation of how the different aspects of the mothers' (and children's) experiences interact to produce the overall experiences for this group of mothers (Figure 1). The formulation is tentative, but as discussed below, it can be understood and validated with recourse to existing theoretical models.

The formulation presented in Figure 1. is a multi-element model, which fits with current thought that the understanding of family dynamics should consider the interaction between the child and mother, individual characteristics of the individuals involved and external factors such as support, economic status, life events etc. (Dunst, 1986).



**Figure 1.**  
**Clinical formulation.**



The model suggests that there is an interaction between external environmental factors (poverty, housing, support networks, life events) factors within the individual (role identity, lack of control, attachment patterns and vulnerability to psychological stress) and resulting psychological distress and need for support. Of particular note in this model, is the reciprocal role that services play in mediating the impact of other factors in the model and the interaction between the child's needs and those of the mother.

### **4.3 Supporting theory and research**

It is suggested that four existing theoretical models can be used to expand the ideas presented in Figure 1, and to provide supporting evidence for their significance. These are models of social role identity (Tajfel, 1981), models of relationship development (namely Object Relations Theory (Guntrip, 1971) and Attachment Theory (Bowlby, 1969)), the life events model of Brown and Harris (1978) and a model based upon theories of control and power (Cohen, 1980).

#### **4.3.1 Social role identity**

The themes relating to identity and threat to identity were evidenced by all the women interviewed. In the main formulation (Figure 1.), identity is suggested to be an important individual characteristic for the mother, which effects interaction with environmental stresses and leads to psychological distress and need for help from services and other people positioned to provide support.

A number of theoretical models have been proposed to explain the role of identity in relation to psychological well-being. Tajfel (1981) suggests that a positive social identity is important for sense of worth and self-esteem. He notes that negative social role identities cause individuals to respond in several ways. They may withdraw into

their negative sub-culture and risk threat to self-esteem, or they may seek to change the negative stereo-types of their identity or they may embrace these differences in a positive and empowering way.

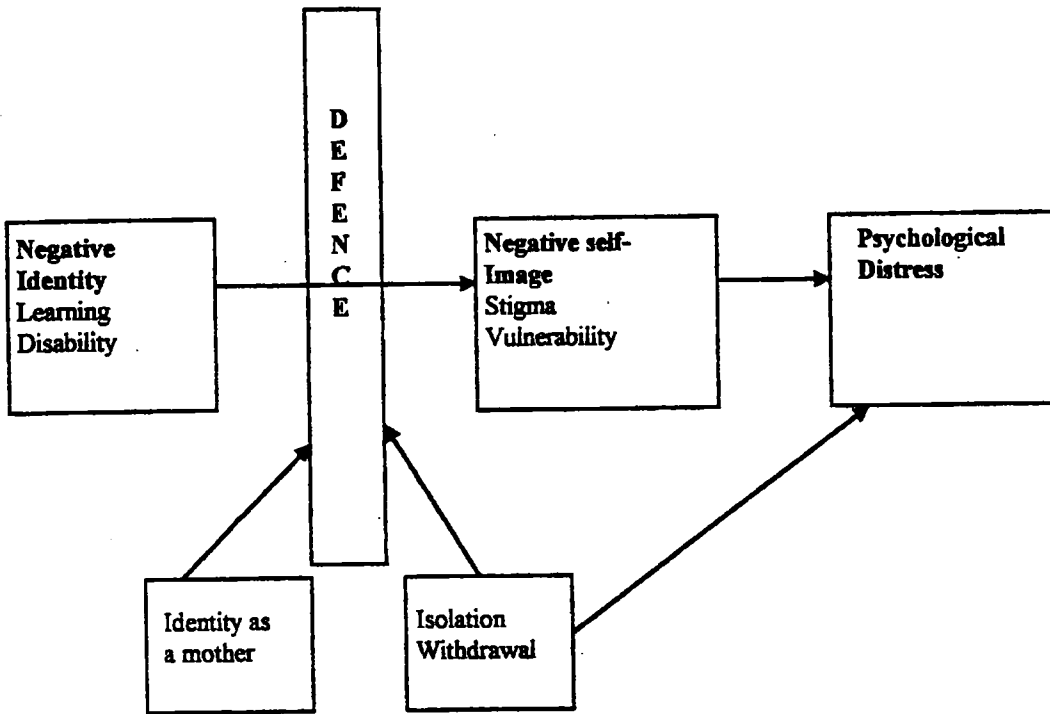
The work by Szivos and Griffiths (1992) and Stokes and Sinason (1992) goes some way to explain the additional complexes that exist in this process for people with learning disabilities, whose prime identity is as a person with a 'disability'. These authors note the negative and painful associations that exist in relation to the label 'learning disability', both for the holder of the label and those around them. Szivos and Griffiths (1992) note the associated stigma that leads to victimisation and lack of power for this group. Additionally, it appears almost impossible for people with a learning disability to re-construct learning disability as a positive experience (Szivos and Griffiths, 1992). Booth and Booth (1995) suggest the identity of motherhood is one way of achieving this, but that this is still problematic and open to attack. It can perhaps be hypothesised that withdrawal, isolation and vulnerability become the only option available when defence against the label 'learning disability' fails. Unfortunately, withdrawal has been associated with further lowering of self-esteem and power (Tajfel, 1981).

A model representing Tajfel's work is shown in figure 2, with the demonstration of where the identity of mother and learning disability would appear to fit into this.

#### **4.3.2 Models of relationship development**

A number of themes from the data have suggested the central role of difficult relationships for this client group. The themes related to early childhood difficulties further suggest the need to employ developmental models focusing on early relationships to explain the current difficulties these women face. Object relation theory (Guntrip, 1971) and attachment theory (Bowlby, 1969) are proposed to aid

understanding of these issues. These theories also suggest the way early experiences may be influencing current levels of psychological vulnerability and distress.



**Figure 2: Identity and psychological well-being**

In the model suggested to understand this studies findings (Figure 1), relationship difficulties are hypothesised to be related to psychological distress, interaction with family, children and support services.

Both attachment theory and object relations theory note the importance of early relationship experiences. As was noted in the introduction, difficulties in early attachment are seen as the corner stone for later experiences (Bowlby, 1969, Guntrip, 1971). A number of consequences of problematic early experiences are proposed by object relation theories, they include ambivalence towards accepting supportive relationships (Guntrip, 1971) and ambivalence, or rejection, towards people who are

emotionally demanding, for example young children or partners (Guntrip, 1971). Also, of significance is the resulting psychological vulnerability that Guntrip (1971) discusses as a result of relationship difficulties. Attachment theory further highlights the propensity to distance one self from relationships and to become anxious about separation and loss.

#### **4.3.3 Life events model**

A third explanatory model to help explain the findings of this study is based on the work of Brown and Harris (1978). The model seeks to explore relationships between amount and quality of support, life events (and daily stresses such as poverty, poor housing), self esteem and psychological distress (Brown and Harris, 1978). Their findings suggest that low levels of social support, poor quality of relationships and high levels of stressful life events lead to low self esteem and subsequently vulnerability to psychological distress. The results from this study document both lack of support and poor quality of key relationships and perhaps explains the accompanying poor self esteem and psychological vulnerability described by the mothers interviewed. In relation to the model proposed in this study, it helps to validate proposed links between the mothers internal state and environmental stresses.

#### **4.3.4 Control**

A number of studies attest to the relationship between perceptions of control and levels of stress and anxiety (Cohen, 1980; Taylor, 1984). In this study the effects of lack of control and powerlessness are perceived throughout the experience for the women interviewed. It is hypothesised that lack of control is heightened for these women due to their socio-economic situation, as a result of having a learning disability and ensuing stigma and the lack of support and protection they receive from others. The experience of the lack of control involved in being a service user has also been documented (Cohen, 1980; Llewellyn, 1991). All these are salient in the lives of these women as documented throughout this study.

Not only has lack of control been associated with increased stress, it has also been associated with making people more vulnerable to attack and abuse from others (Cohen, 1980). Thus it is a useful concept to explain why this group may be more vulnerable to external stresses. Lack of control has further been associated with internalisation of negative affect and poor self esteem (Brown and Harris, 1978). This is another validation of the factors associated with the mother and subsequent psychological distress.

#### **4.4 Children's experiences**

The apparent difficulty for the children in exploring problematic aspects of family life and the small sample size precludes detailed theoretical frameworks being advanced in the way that was possible in relation to the mothers' experiences. However, a review of the categories that emerged from the data show congruence with other studies that have been conducted with children from disadvantaged families (Booth and Booth, 1997; Mzarek and Mzarek, 1987). The positive and negative aspects of family relationships are also documented by Booth and Booth (1997). They note the coexistence of happy childhood experiences, as well as experiences of abuse and victimisation. The importance of external support is also noted by Booth and Booth (1997) and Werner (1989).

##### **4.4.1 Theoretical framework**

A vulnerability and resilience model (based on the work of Rutter, 1985 and Werner, 1989) is proposed to begin to explore the main issues for these children. This study confirms that the children were facing major demands on their ability to cope; as evident in their experiences of abuse, difficult relationships and psychological distress. It is suggested that children are required to be resilient and cope with these

difficulties, but they remain vulnerable for a number of reasons. Two main hypotheses are tentatively suggested to explain this vulnerability:

1. Lack of social support and family ties reduce ability to cope with demands encountered
2. Inappropriate attachment styles reduce the children's ability to negotiate family relationships, cope with ambivalence in relationships, cope with potential loss and maintain psychological strength.

The first hypothesis is relatively uncontentious and is supported by previous findings in the literature. Werner (1989) suggests that family ties and external support are both protective factors, a finding replicated by Booth and Booth (1997).

The second hypothesis is more difficult to substantiate, but accounts for some of the themes that emerged in a way that other theories do not. Werner (1989) highlights the importance of dispositional attributes of the child such as sociability and internal locus of control. However, this does not explain the children's anxiety about loss which was evident, or the difficulty the children had containing their own anxiety. Neither does it explain their vulnerability in relation to setting boundaries with other people that was noted by their mothers. In the course of the interviews with the children it was also striking that the children lacked appropriate boundaries in relation to strangers and other members of the family.

Although it may be that previous experiences in relation to informal and formal support may result in children feeling anxious about separation, or being taken away by services, anxiety may also be determined by more formative attachment experiences (Bowlby, 1969). Bowlby (1969) notes that problems of early attachment can result in over-anxious behaviour or partial or total deactivation of attachment.

Given the experiences of other family members, notably the mother's relationship patterns, such explanations may be given greater credibility. The mothers own relationship patterns would be expected to impact on their children (Gath, 1988). This tentative hypothesis needs further investigation, substantiation and thought. However, it may implications for the type of therapeutic interventions offered to families, suggesting potential efficacy of work looking at family relationships.

#### **4.5 Evaluating the study's findings**

Several criteria for evaluating the reliability and validity of the study are reviewed.

##### **4.5.1 Auditability**

For the research to be open to audit it must explicitly highlight the research process and the interpretations made, so that they can be evaluated by the reader.

The analytic process was outlined in the method and results sections. Whilst the first stage of analysis remained close to the data, the emerging theoretical frameworks required interpretation of the central issues. It is was therefore important to document the assumptions and interpretations made, so that the researcher's bias can be evaluated by the reader in relation to the final account provided (Bannister, 1994). This was achieved in two ways. The introduction outlined the preliminary ideas and theoretical considerations that shaped the research questions. Additionally, the research diary provides a full account of the ideas and interpretations that shaped the research process (Appendix 1).

##### **4.5.2 Respondent validity**

An attempt was made to validate the study by visiting the mothers on a second occasion, and asking them to comment on the emerging analysis from the initial interviews. There was a high degree of agreement with the categories generated

(Appendix 12). Comments served to enrich the themes and theoretical development, rather than suggesting need for revision to the initial stages of analysis. It has however been noted that such exercises need to be approached with caution. Henwood and Pidgeon (1995) suggest that participants may not challenge the results as presented by an expert. However, in the study all the mothers noted some disagreement as well as agreement with the categories presented to them.

#### **4.5.3 Generativity**

This refers to the extent to which the research facilitates further issues and questions. A number of clinical implication and further research questions attest to initial generativity of findings.

#### **4.5.4 Rhetorical Power**

In the final evaluation it is important to consider whether the ideas presented provide a convincing account of the issues explored. As the study progressed supervision was used to test out initial credibility of findings, the rest must be left to the reader to decide.

### **4.6 Methodological and conceptual issues**

This section considers issues of generalisation, the variability of interviews, and research with people with learning disabilities.

#### **4.6.1 Generalising research findings**

The aim of qualitative study is not to recruit large numbers of participants, but rather to develop an in-depth understanding of specific experiences (Silverman, 1993). However, this has implications for generalising the research findings. Several points need to be considered in terms of generalisation from this study. The first concerns recruitment. All of the families interviewed were known to services, and therefore



represent families in need of specialist support. Conversely, they were all functioning despite difficulties and none of the families had children currently in care, despite the statistics showing prevalence of children being removed from such families (Whitman and Accardo, 1990). It may be that caution should be shown in transferring findings both to families with no involvement with services or to more chaotic families where children are in care. Additionally, all the mothers had agreed to take part, perhaps indicating some resilience and feelings that they could cope with scrutiny and intrusion! Finally, all the families interviewed were currently living in inner-city economically deprived areas. Studies looking at families in rural, or more affluent areas are perhaps required before generalisation of findings is assured.

Generalisation of findings from the children interviewed is more problematic. Numbers were small and 3 of the mothers refused permission to let their children be interviewed. Interestingly, children where permission was refused appeared more integrated in terms of attending main stream education and employment. It may have been that these children were not only better integrated, but they had parents who were able to protect them from intrusion and potentially anxiety provoking situations, such as interviews. All four children were in schools for children with behavioural and emotional difficulties, or for people with mild learning difficulties. The remainder had more severe learning disabilities which precluded inclusion in the study. Thus the group interviewed were perhaps representative of those most vulnerable to family stress.

#### **4.6.2 Variability of interviews**

The type of interview adopted precludes necessary recourse to exact standardisation of all the interviews conducted (Silverman, 1993). However, standards of quality and areas covered needs to be assured. The most robust way of achieving this would have been to video tape all the interviews and open them up to scrutiny by independent raters. Time and ethical considerations precluded such an approach. Instead,

supervision allowed for discussion of the interviews conducted and review of the transcripts made. More generally, although the interviews often moved away from the ordering in the schedule all areas were covered in all the interviews and in depth, thus allowing each interview to contribute equally to the subsequent analysis. Variability served to provide richness of data rather than raise questions of reliability.

#### **4.6.3 Issues of learning disability and research interviews: ethics and methodology.**

A number of ethical and methodological issues have been noted in relation to research with people with learning disabilities (Atkinson, 1988; Booth and Booth, 1994; Stalker, 1998). It is widely accepted that people with learning disabilities have a central role to play in research and are the best authorities on their own lives, experiences and views (Booth and Booth, 1994). However, they still occupy a vulnerable role in the research process (Stalker, 1998).

Stalker (1998) notes that the high levels of acquiescence displayed by people with learning disabilities is important in relation to research with this client group. Thus, in the current study careful consideration was given to whether participants were able to decline to take part in the study and whether they had the power to terminate the interview, refuse to discuss certain topics or to disagree with the researcher's ideas in the second interview. The authors impressions was that this was achieved to some extent, participants asked questions of the research and contacted the author to change the time and place of meetings.

Other issues concerning the power relationship between the researcher and people with learning disabilities are also important. Due to the limits of time and resources this study was not able to actively empower the participants in the research process. On reflection this could have been achieved by starting the research with focus groups so participants helped to shape the research questions. A second approach to

empowerment would be to involve participants in feeding back the research to professional groups. This is being considered as an option in conjunction with a newly appointed 'People First' representative within the community team which hosted the research.

Previous research projects have also highlighted the time that is needed to get to know participants before the research commences (Stalker 1998). There is a need to acknowledge communication skills of participants and to sensitively pitch research questions to meet communication needs. Some researchers have also noted the fact that interviews often involve having to elicit elaboration of monosyllabic responses from participants (Booth and Booth, 1994). However, in this study, after the initial opening questions, fluent and expansive replies characterised all the interviews conducted.

#### **4.7 Clinical implications**

The current study further highlighted previous conclusions that support is problematic for parents with learning disabilities (Booth and Booth, 1994, Ward, 1993). However, this study suggests some of the dynamics that may be responsible for these difficulties and thus suggests potential ways of facilitating support and providing appropriate services. Figure 1 clearly demonstrates some of these areas and thus the model is used to structure suggestions for clinical practice.

##### **4.7.1 Addressing environmental stress**

- In order to reduce environmental stress services may need to address practical issues such as housing and finance. Additionally, this may involve improving access to resources such as respite care, leisure facilities or baby-sitting services.

#### **4.7.2 Understanding and responding to mothers' psychological needs**

Services need to be aware of relationship issues and psychological vulnerabilities which may make it difficult for families to engage with support networks, both within the family and with external support agencies. As a result the following suggestions are forwarded:

- Specialist counselling may be appropriate to address current and past relationships to allow the family to function more effectively. This entails a recognition of all the needs of family members, not just children at risk or parents in crises.
- Services need to adopt frameworks for understanding the ambivalence towards, and sometimes rejection of, service support, via an understanding of the way previous relationships may be influencing current relationship behaviour. This may reduce the risk of service responses becoming abusive or abandoning (Chinn, 1996). Chinn (1996) has further highlighted the need for services to acknowledge their own assumptions and anxieties when working with these families. This also suggests the need for backup both for families and workers alike.
- It has been noted that support may serve to confirm the negative identity of the mother as someone who has a learning disability, thus increasing stigma and lowering self esteem (Booth and Booth, 1993). Services need to be non-threatening and non-labelling of these families and should avoid highlighting the limitations of the mother. This may be achieved via the utilisation of mainstream services, which may in turn involve working with these services to develop understanding of the special needs of this client group.
- Several authors have noted the need to empower this client group, thus improving feelings of self worth and self efficacy (Szivos and Griffiths, 1992). Mothers, and

indeed all the family, need to feel strengths are being built upon and to feel good about achievements made.

#### **4.7.2 Addressing psychological distress**

- In line with the findings of this study, it would appear that the psychological distress encountered by these women can be understood via recourse to mainstream models of understanding psychological well-being. It would therefore seem appropriate to utilise 'mainstream' service provisions to address issues of mental health. This will also serve to reduce involvement with specialist learning disability teams, which as already noted may further serve to confer the stigma of disability.

#### **4.7.3 Understanding and responding to children's needs**

This study attests to the importance of families being able to be the firm foundation for their children, whilst having external support available to them.

- Services need to encourage families to feel confident about their ability to provide emotional support to their children whilst providing additional practical support (Booth and Booth, 1994). Schools in this study were often seen as providing good support in that they supported children, without making extra demands on the family.
- family work, which builds on the resilience of children, but which also helps them negotiate difficult emotional problems and contradictions within the family may also be efficacious for this group of children (Cooklin, 1998).

The implications outlined above fit with the models of community based services that characterises the majority of services for people with learning disabilities in Britain (Murphy, 1996). However, this is a particularly difficult area of work, where need for

financial resources, service collaboration and co-ordination is evident (McGaw, 1996). This collaboration seems particularly relevant in working with other services which may be better positioned to help these families, most notably the education system and child care services. Services need to have a knowledge of these women's needs, but also avoid placing extra pressures on families.

#### **4.8 Recommendations for future research**

Due to limited resources the current research stopped short of testing the emerging theoretical framework through new theoretically driven sampling or through looking for negative cases which do not fit the framework. The validation procedure suggested the credibility of the initial themes generated, but further testing is still required. For example, in looking at the effect of early relationship experiences it might be useful to ask further questions about attachment behaviours (perhaps borrowing questions from the adult attachment schedule, object relations test), or to ask respondents what they think about their childhood experiences in relation to current difficulties.

In addition to testing out the emerging theoretical framework, a number of other interesting areas of research are highlighted by the current study. It seems important to know more about how professionals working with these families view the ambivalence of mothers to receiving help, and what anxieties and difficulties they experience in their work. Research looking at therapeutic interventions addressing issues of identity, stigma, vulnerability and lack of personal control also appears relevant. In relation to children, more needs to be known about children's attachment styles and how their experiences may reflect the mother's experiences. Finally, the role of fathers is obviously of significance (Booth and Booth, 1995), and research in this area would add an important dimension to the current formulation. Additionally,

interesting research could be conducted to compare the current findings to other disadvantaged groups of parents and children.

### **Chapter 5: Conclusion**

This research aimed to provide an understanding of the experiences of mothers with learning disabilities and their school aged children. A number of salient factors were acknowledged in relation to these experiences and were used to begin to form a tentative theoretical framework to explain the interaction between these factors. Although tentative, the theoretical framework drew on established theory to begin to suggest the ways these factors interacted. Further research is needed to confirm the formulation and expand upon this theoretical understanding. However, this current understanding has several implications for clinical practice and service delivery, which may serve to improve services to a client group who find it difficult to engage effectively with current services.

## References

Atkinson, D. (1988). Research interviews with people with mental handicaps. Mental Handicap Research, 1 (1), 75-90.

Banister, P., Burman, E., Parker, I., Taylor, M. and Tindall, C. (1994). Qualitative Methods in Psychology. Buckingham: University Press

Booth W. and Booth T. (1993) Learning the hard way: practice issues in supporting parents with learning disabilities. Social Work and Social Sciences Review, 4 (2) 148 - 62.

Booth, T. and Booth, W. (1994) Parenting Under Pressure: Mothers and Fathers with Learning Disabilities. Buckingham: Open University Press

Booth T. and Booth W. (1995) Unto us a child is born: the trials and rewards of parenthood for people with learning difficulties. Australia and New Zealand Journal of Developmental Disabilities, 20 (1) 25-39.

Booth, T. and Booth, W. (1996) Parental competence and parents with learning difficulties. Child and Family Social Work, 1, 81-86.

Booth T and Booth W. (1997) Exceptional Childhood's, Unexceptional Children: Growing Up with Parents who have Learning Difficulties. London: Family Policy Studies Centre.

Bowlby, J. (1969) Attachment. London: Hogarth.

Brandon, M. (1957). The intellectual and social status of children of mental defectives. Journal of Mental Science, 103, 710 - 38.

Brenner, M. J. (1985). Introduction. In J. Brown and D. Canter (eds.) The Research Interview: Uses and Approaches. London: Academic Press.

Brantlinger, E. (1988). Teacher's perceptions of the parenting abilities of their secondary students with mild retardation, Remedial and Special Education, 9, (4), 31-43.

Brown, G. and Harris, T. (1978). Social origins of depression: A study of psychiatric disorder in women. London: Tavistock.

Budd, K. and Greenspan, S. (1985). Parameters of successful and unsuccessful interventions for parents who are mentally retarded'. Mental Retardation, 23 (6), 269-73.

Chinn, D. (1996). All mothers together: talking about mothering and learning disabilities. Changes, 14 (3) 213-217.



- Chodrow, N. (1978). The Reproduction of Mothering: Psychoanalysis and The Sociology of Gender. Berkley, C.A: University of California Press
- Cohen, S. (1980). After effects of stress on human performance and social behaviour: A review of research and theory. Psychological Bulletin, 87, 578-604.
- Cooklin, A. (1998). Making connections through talking with children: from the 'return of the repressed' to 'dialectics'. Journal of Family Therapy, 20 (2) 153-164.
- Coyle, A. Good, A., Wright, C. (1994). The Counselling Interview as Research Method. Paper presented at the British Psychological Society's Annual Conference. Brighton.
- Crain, L. and Miller, G. (1978). Forgotten children: maltreated children of mentally retarded parents. Paediatrics, 61, (1) 130-32.
- Dowdney, L. and Skuse, D. (1993). Parenting provided by adults with mental retardation. Journal of Child Psychology and Psychiatry, 34 (1) 25-47.
- Dowdney, L., Skuse, D., Rutter, M., Quinton, D and Mrazek, D. (1985). The nature and quality of parenting provided by women raised in institutions. Journal of Child Psychology and Psychiatry, 26 (4) 599 - 625.
- Dunst, C. J. (1986). Looking beyond the parent-child dyad for determinants of maternal styles of interaction. Infant Mental Health Journal, 7, 1, 69-80.
- Elliot, R., Fischer, C. and Rennie, D. (1993). Proposed criteria for evaluating clinical research. Paper presented at the Society for Psychotherapy Research. Pittsburgh, P.A.
- Featherstone, B. (1997). Introduction: Crises in the western family. In W. Holloway and B. Featherstone (eds.). Mothering and Ambivalence. London: Routledge.
- Feldman, M. (1986) Research on parenting by mentally retarded persons. Psychiatric Clinics of North America, 9 (4) 777-96.
- Feldman, M., Case, L., Rincover, A., Towns, F. and Betel, J. (1989). Parent education project III: Increasing affection and responsivity in developmentally handicapped mothers. Journal of Applied Behavioural Analysis, 22 (2) 211-22.
- Feldman, M., Case, L., Towns, F. and Betel, J. (1985) Parent education project 1: Development and nurturance of children of mentally retarded parents. American Journal of Mental Deficiency, 90 (3), 253-58.
- Fielding, N. (1993). Qualitative interviewing. In N. Gilbert (ed.). Researching Social Life. London: Sage.
- Floor, L., Baxter, D., Rosen, M., Zisfein, L. (1975). A survey of marriages among previously institutionalized retardates, Mental Retardation, 13 (2) 33-7.

- Gath, A. (1988). Mentally handicapped people as parents. Journal of Child Psychology and Psychiatry, 29 (6), 739-44.
- Glaser, B. and Strauss, A. (1967). The Discovery of Grounded Theory. Chicago: Aldine
- Guntrip, H. (1971) Psychoanalytic Theory, Therapy and Self. New York: International University Press
- Henwood, K.L. and Pidgeon, N. F. (1992) Qualitative research and psychological theorising. British Journal of Psychology, 83, 97-111.
- Henwood, K.L. and Pidgeon, N.F (1995). Grounded theory and psychological research. The Psychologist, 8 (3), 115-118.
- Hertz, R. (1979). Retarded parents in neglect proceedings: Erroneous assumptions of parental inadequacy. Stanford Law Review, 31, 785 - 805.
- Hinds, P.S., Scandrett-Hibdon, S. and McAulay, L.S. (1990). Further assessment of a method to estimate reliability and validity of qualitative research findings. Journal of Advanced Nursing, 25, 430-435.
- Jones, S. (1985). The analysis of depth interviews. In R. Walker (ed.) Applied Qualitative Research. Vermont: Gower Publishing
- Krueger, R. A. (1988). Focus Groups: A Practical Guide for Applied Research. California: Newbury Park
- Lee, R. M. (1993). Doing Research on Sensitive Topics. London: Sage.
- Linstone, H. A. and Turoff, M. (1975). The Delphi Model: Techniques and Applications. Reading: Addison Wesley.
- Llewellyn, G. (1991). People with intellectual disability as parents: perspectives from the professional literature. Australian and New Zealand of Developmental Disabilities, 16 (4), 369-80.
- Mattinson, J. (1970). Marriage and mental handicap. London: Duckworth
- Mayall, B. (1996) Politics and practice in research with children. Changes, 14 (3) 199-203.
- Maynes, P. and Best J. (1997). In the company of women: experiences of working with the lost mothers. In W. Holloway and B. Featherstone (eds.). Mothering and Ambivalence. London: Routledge.
- McConackie, H. (1991). Families and professionals: prospects for partnership. In S. Segal and V. Varma (eds.) Prospects for People with Learning Difficulties. London: David Fulton Press.

- McGaw, S. (1996). Services for parents with learning disabilities. Tizard Learning Disability Review, 1 (1) 21-28.
- McGaw, S and Sturmev, P. (1993). Identifying the needs of parents with learning disabilities: A review and a model of good practice. Child Abuse Review 2.
- Mercer, J. (1973). Labelling the Mentally Retarded: Clinical and Social System Perspectives on Mental Retardation. Berkely and London: University of California Press.
- Mickelson, P. (1947). The feebleminded parent: a study of 90 family cases. American Journal of Mental Deficiency, 51, 644-45.
- Morahan-Martin, J. (1991). Consider the children: Is parenthood being de-valued? The Psychological Record, 41, 303-314.
- Mrazek, p and Mrazek, D. (1987) Resiliece in child maltreatment victims: a conceptual exploration. Child Abuse and Neglect, 11, 357-66.
- Murphy, G. (1996). Services for people with learning disabilities. Tizard learning Disability Review, 1, (1) 29-32.
- Parker, R. (1997). The production and purposes of maternal ambivalence. In W. Holloway and B. Featherstone (eds.). Mothering and Ambivalence. London: Routledge.
- Pope, C and Mays, N. (1995). Qualitative research. British Medical Journal, 311, 42-45.
- Quinton, D., Rutter, M. and Liddle, C. (1984). Institutional rearing, parenting difficulties and marital support. Psychological Medicine, 14, 107-24.
- Reder, P and Lucey, C. (1995). Significant issues in the assessment of parenting. In P. Reder and C. Lucey (eds.) Assessment of Parenting: Psychiatric and Psychological Contributions. London: Routledge.
- Rollins, J. (1996). Women's Minds, Women's Bodies: The psychology of women in a biosocial context. New Jersey: Prentice Hall.
- Rutter, M. (1985). Resilience in the face of adversity: protective factors and resistance to psychiatric disorder. British Journal of Psychiatry, 147, 598 - 611.
- Scally, B. (1973). Marriage and mental handicap: some observations on Northern Ireland. In F. de la Cruz and G. LaVeck (eds.) Human Sexuality and the Mentally Retarded. New York: Brunner/Mazel.

Schilling, R., Schinke, S., Blythe, B. and Barth, R. (1982). Child maltreatment and mentally retarded parents: is there a relationship? Mental Retardation, 20 (5), 201-209.

Seagull, E. and Scheurer, S. (1986). Neglected and abused children of mentally retarded parents. Child Abuse and Neglect, 10 (4), 493-500.

Silverman, D. (1993) Interpreting Qualitative Data: Methods for analysing talk, text and interaction. London: Sage.

Stalker, K. (1998). Some ethical and methodological issues in research with people with learning disabilities. Disability and Society, 13 (1) 5-19.

Stiles, W. (1993). Quality control in qualitative research. Clinical Psychology Review, 13, 593-618.

Stokes J. and Sinason, V. (1992) Secondary mental handicap as defence. In Conboy-Hill S. and Waitman A. (Eds.) Psychotherapy and Mental Handicap London: Sage

Strauss A. and Corbin J. (1990). Basics of Qualitative Research: Grounded Theory Procedure and Techniques. London: Sage.

Szivos, S. and Griffiths, E. (1992) Coming to terms with learning difficulties: The effects of group work and group processes on stigmatised identity. In Conboy-Hill S. and Waitman A. (eds.) Psychotherapy and Mental Handicap London: Sage

Tajfel, H. (1981). Human Groups and Social Categories. Cambridge: Cambridge University Press

Taylor, S. J. and Bogdan, R. (1984). Introduction to Qualitative Research Methods (Second Edition) New York: John Wiley and Sons.

Tesch, R. (1996). Qualitative Research: Analysis types and software tools. New York: Falmer Press.

Thompson, A. (1984). The assessment and remediation through play therapy of parenting competencies of mentally retarded mothers. Dissertation Abstracts International, 45, 01, July 379.

Traustadottir, R. (1990). Women with disabilities: A double discrimination. TASH Newsletter, October, 7-8.

Turk, V. and Brown, H. (1992). Sexual abuse and adults with learning disabilities. Mental Handicap, 20 (2), 56-58.

Tymchuk, A. (1992) Predicting adequacy of parenting by people with mental retardation, Child Abuse and Neglect, 16 (2), 165-178.

Tymchuk, A., Andron, L. and Rahbar, B. (1988). Effective decision making/ problem solving training with mothers who have mental retardation. American Journal of Mental Retardation, 92 (6) 510-16.

Tymchuk, A., Andron, L. and Tymchuk, M (1990) Training mothers with mental handicaps to understand behavioural and developmental principles, Mental Handicap Research, 3, 51-59.

Tymchuk, A, Andron, L. and Ungar, O. (1987). Parents with mental handicaps and adequate child care - a review. Mental Handicap Research, 3, 51-59.

Waitman, A.. (1992) Demystifying traditional approaches to counselling and psychotherapy. In Conboy-Hill S. and Waitman A. (eds.) Psychotherapy and Mental Handicap London: Sage

Walton-Allen, N. and Feldman, M. (1991). Perception of service needs by parents who are mentally retarded and their social workers. Comprehensive Mental Health Care, 1, (2) 137-47.

Ward, L. (1993). Partnership with parents. In A. Craft (Ed.) Parents with Learning Disabilities. Kidderminster, BILD.

Werner, E. (1989) High risk children in young adulthood: A longitudinal study from birth to 32 years. American Journal of Orthopsychiatry, 59 (1), 72-81.

West, W. (1998) Passionate research: heuristics and the use of self in counselling research. Changes, 16 (1) 60-66.

Whitman, B and Accardo, P. (1990) When a Parent is Mentally Retarded. Baltimore, MD, Paul H. Brookes.

Whitman, B, Graves, B. and Accardo, P. (1986). The mentally retarded parent in the community: An epidemiological study, Developmental Medicine and Child Neurology, supplement, 53, 18.

Winnicott, D. (1964). The Child, The Family and The Outside World. Harmondsworth: Pelican.

Wolfensberger, W. (1972). The Principle of Normalisation in Human Services. Toronto: National Institute on Mental Retardation

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## **APPENDIX 1: Research Diary**

### **Early 1997**

Start to consider research ideas.

I am keen that the area of research is clinically relevant and reflects current service concerns. I am also keen to base my research in relation to my third year elective, which is in learning disabilities. I keep returning to women's issues and parenting in particular. I know this also reflects an interest in 'survival on the edge of society'.

The services I am currently working with are also concerned with providing a service to parents with learning disabilities and feel it is not something they are currently addressing adequately. Perhaps a study looking at the difficulties faced by mothers with learning disabilities would fulfil the above criteria.

### **April 1997**

Discuss preliminary ideas with a member of the course staff, who also agrees to supervise me.

My thoughts return to a young mother with learning disabilities I worked with, looking at anxiety management and social skills. It had been felt necessary to help her attend college courses. I wasn't sure we were actually reducing the stress she experienced. Also, service involvement was acknowledged to be threatening to her partner. I acknowledge feelings that we did not understand what the main difficulties were that this family face. Research subject still continues to be relevant clinically and personally.

Begin to work on my dissertation proposal. A lot of work in this area is not relevant to the angle I propose to take - a lot of the previous research has evaluated skills training courses for parents, and is American in origin. I'm more concerned with psychological impact of experiences of mothering for this group.

Also, aware of the polarisation in society of how mothers are viewed. No sign of Winnicott's 'good enough mother' - mothers either idealised or denigrated, can either be a good mum (married and staying at home) or a bad mum (single and poor). Also, theories related to experiences of motherhood seem to be either social or analytic. Feel I need to approach this study with a balance.

### **July 1997**

Proposal accepted by examining board. Now to be taken to NHS ethics committee for approval.

### **September 1997**

Met someone who is on the ethics committee. Took me some time to convince them that it was possible for someone with a learning disability to be a parent! My research proposal in their hands!.

## **1 December 1997**

Get ethical approval, without conditions. Relief.

## **January 1998**

Begin to talk to the community team I am working with about the study. Will they know of enough parents who fit the criteria for inclusion or will I have to approach other community teams in other trusts? I think everyone is surprised by the number of families that the team is in contact with. I have a list of 15 families, of these 13 fulfil my proposed inclusion criteria. Realistically I know that not all of these families will wish to take part.

## **February 1998**

Meet with people who have said that they will ask families they are working with if they are willing to be interviewed. Discuss the process of these people providing any necessary support after the interviews have been conducted.

## **March 1998**

Complete the first pilot interview. This went well, and some of the issues raised made me think this will be a rewarding and worthwhile study. I am impressed with the mothers ability to reflect on her experiences in relation to motherhood. I think her keyworker is surprised when I feed this back to her.

Issues of labelled as 'handicapped', problems of child being brighter than mother, isolation and anxiety were highlighted in this first interview. Pertinent question asked of me 'What does it mean label jars not people?' With regard to feeling labelled, I have revisited my interview schedule to make sure I am not labelling the mothers via the bias of the questions. Feel most of the questions are neutral and don't assume learning disability first, person second.

Writing introduction. I find I swing between idealising the mothers in my study, and being reminded of the painful experience of both mothers and their children. How do I reconcile these feelings with principles of normalisation that implicitly advocates the rights of all women to be mothers? Dislike the intruding thoughts that I have that sometimes the pain outweighs the gains. I still think we have a lot to learn about how pain can be minimised. (Do I need to consider my own ambivalence in relation to people working with these families? Seems relevant to consider how I would manage these anxieties).

## **March 23**

Second interview. This interview lasted longer. Covered a wide range of issues. Some similar issues as appeared in the first interview - issues of isolation and victimisation are particularly pertinent. Mother initially anxious, short replies, however became more relaxed and able to talk in detail about issues - similar to first issue. Does this reflect high performance anxiety for this group, Am I perceived as monitoring, checking up on them? Need to make my role more explicit in future.

## **March 25**

Third interview. Highlighted issues of suspected abuse of children by family member. Highlighted how difficult this is to handle, and how quickly services become



alienated. Discussed with participant if we had talked about anything that needed to be known by others providing service to the family. Participant's key worker fully aware of all the problems and issues involved.

Third interview has taken over 18 hours to transcribe - primarily due to language used by participant. I can only hope not all the interviews will take so long!

Supervisor has read through a couple of my transcripts noting salient themes. With a little re-wording they are in line with my own thinking. Makes me feel more confident in my analysis. Also, I was worried my interview skills would be visible and found wanting, despite the fact the interviews always produce almost too much data!

#### **April 9**

Continue to interview - further two interviews completed. Aware that these women are coping on a day to day basis. All 'mild' learning disability, and some very insightful about the reasons for their difficulties.

Lack of support and history of difficult relationships are discussed in most interviews. Study beginning to feel less about learning disability and more about parenting under adversity - need to carefully consider this balance, and to expand the literature I am currently reading.

#### **16 and 17 April**

Two more interviews completed. Also, interviewed 2 children. These interviews were difficult and exploration of issues was minimal. I think this was a mixture of the children's reluctance to explore painful issues and my reluctance to push this. However, on returning home and re-reading what I wrote, I realise that I have actually been told a lot about family life, some powerful statements about distress and confusion.

#### **May 14**

Final interview with mother. Now need to arrange second interviews, to get feedback on analysis.

#### **May 28**

Second interview with 2 of the mothers. The interview was easier, rapport much better. Seemed pleased to meet with me again! Open relief, and pleasure (?), that their experiences were the same as other mothers. I think this has made the research process slightly more valuable to them personally. I hope so. So far, good agreement with the categories presented. Allowed elaboration of more difficult issues. These interviews will take longer than I had first anticipated.

#### **May 29**

Two more interviews, and a third child interview.

#### **4 and 5 June**

Complete 2 more interviews.

### **June 6**

Six weeks to go. It's as if someone has suddenly pressed a panic button for me. How can I create more time?

### **A little later,**

Read The Guardian (despite the guilt). Reading an article about a photographic biography of 'new age' travellers in Britain. Main discourse was of what happens to people who won't or can't conform. Pictures a group of people marginalised, denied freedom and who are reacting by withdrawing and engaging in destructive / hopeless behaviour. I'm drawn to comparisons with the women I have interviewed.

Next morning decide to remain hopeful about the role of clinical psychology in enabling people with learning disabilities to have a better quality of life. Also aware of need to avoid grandiose, emotive images, language and behaviour NB Guardian!!!!.

### **June 8**

Continue refining data analysis. Wish I'd asked more questions about ambivalence and anxiety, as these appear to be important issues. Also, wish I'd asked more questions about roles of fathers. Perhaps this will have to be a separate study! Also, feel the final study needs to reflect the balance between generalities and particularities of the data.

### **June 12**

Supervision. Discussed what still needs to be done. Do I have the time to continue contacting the two remaining mothers who I've not yet visited a second time? Practically this feels too time consuming, and rewards in terms of addition material limited. However, feel it would feel neater and complete. I will try to see them. In terms of my analysis the categories that are emerging are suggestive of clear models of how the women's experiences are effecting them psychologically. Need to shift analysis to incorporate these causal links. Feels this then moves study on from description and hypothesis generation. Also, makes the study more clinically meaning and relevant.

### **Later,**

At home trying to work supervision into what I've already done.

### **June 19**

Finally complete all the second interviews. Relief.

Also complete final child interview. This interview was much longer than the other 3. Took place at the college. Teachers very aware of problems within the family, and have spent a lot of time discussing these issues and seeking solutions. Of all the children appeared most integrated into her own support network - mainly formal. Teacher tells me of difficulties they have had, and lack of co-ordinated services. Certainly no service plans.

**June 22**

Introduction and method are both nearing final drafts. Feel I need to have the whole dissertation in draft form and then return to each section for re-working and refinement. Wish I was at this stage.

**June 23**

Return to the data analysis. Beginning to consider how to write it up. I hope my framework is clear enough.

**June 24**

I was worried that the child interview had not produced the richness of data I had hoped for, I felt the children interviewed had defended against exploring difficult issues, however I now feel I was defending against the painful stories they have actually been telling. The scripts are actually very rich, painful and difficult to analysis. I need supervision to help me think through the issues these 4 interviews raise.

**July 2**

Supervision. Discuss theoretical models which are relevant to my thematic analysis. I have been trying to be all inclusive and my theory has become diffuse. Need to develop several theoretical 'lenses' to reflect my data, returning to theory related to identity, self esteem and attachment. Also, consider how this relates to use of services and failure of services to meet clients needs. Services as providing help but also being part of the problem. Supervision provides lots of ideas, and confirms what I had been thinking about relevance of certain theories. I now need to do some more reading and time is running out.

Also, discuss my continuing reluctance to have to do an inter-rater reliability exercise. I feel this is paying lip service to a positivist paradigm I have chosen not to adopt. Moreover, my results have good face validity, the mothers themselves have a high agreement with the categories I have extrapolated. I also think I am presenting enough examples from my interview to allow the reader to be suitably critical and reflective. However, this amount of justification reflects my fear that the examiner will be critical.

**July 10**

Final supervision. Useful - but unfortunately has generated the workload I was hoping to avoid. Return to my computer.

**July 11/12**

Making final revisions for submission deadline. End in sight ..... (and the mistakes are all mine!)

## **APPENDIX 2: Interview (I) for mothers**

### **INTERVIEW 1 - MOTHER INTERVIEW**

*I'd like to ask you some questions about what it's like to be a mum and to bring up children.*

#### **A. General information**

*Q. Can you tell me about your family?*

**Areas to be covered** - demographics of family members  
who currently lives at home  
who helps to look after the children

**Prompts:** *How many children do you have?*

*How old are your children?*

*Who lives at home with you?*

*Who helps to look after the children? / helps around the house?*

*Can you tell me a little more about that?*

*Can you give me an example of that?*

#### **B. Parenting**

*Q. What are the good things about being a mum?*

*Q. What are the difficult things about being a mum?*

*Q. What helps you to look after your children / child?*

*Q. What stops you from being a better mum?*

**Areas to be covered:** feelings about family, emotional impact, how these difficulties are handled, involvement of other family members, involvement of professionals.

**Prompts:** *Can you tell me more about that?*

*Can you give me an example of that?*

*How did you feel about that?*

*What did you do about that?*

### **C. Relationships with other people**

*Q. Who provides you with support in your family?*

*Q. What are the good things about this support?*

*Q. What are the difficult things about this support?*

*Q. Can you tell me about the difficult relationships in your family?*

*Q. Do you have anyone else who helps you?*

**Areas to be covered:** feelings about family support and relationships, emotional impact, how difficult relationships are handled, strengths and weaknesses of family support.

**Prompts:** *Can you tell me more about that?*

*Can you give me an example of that?*

*How did you feel about that?*

*What did you do about that?*

### **D. Relationships with services / professionals**

*Which services help you?*

*What else would help?*

*What is good about the help you get?*

*What is difficult about the help you get?*

**Areas to be covered:** feelings about service support, emotional impact, how difficulties are handled, strengths and weaknesses of service support.

**Prompts:** *Can you tell me more about that?*

*Can you give me an example of that?*

*How did you feel about that?*

*What did you do about that?*

### **E. Perceptions of children's abilities and difficulties**

*Q. How do your children get on at school?*

*Q. What do they do at school?*

*Q. What are the things they enjoy at school?*

*Q. What do they find difficult at school?*

*Q. What other problems do they have at school?*

*Q. What would help them at school?*

*Q. What problems do they have at home?*

*Q. What do you think would help them at home?*

*Q. How do your children get on with other children?*

**Areas to be covered:** children's experiences at school and home, difficulties and rewards, children's relationships with others, mother's feelings about children's experiences, emotional impact, how difficulties are handled.

**Prompts:** *Can you tell me more about that?*

*Can you give me an example of that?*

*How did you feel about that?*

*What did you do about that?*

**End of interview**

*Thank you very much for telling me about your family and what it's like to be a mother. What you have said to me will be kept private and I'll wipe clean the tapes when I've written down what you said. Do you have any questions you'd like to ask me? I will leave you a card with my name and telephone number on it, so you can phone me if you would like to talk to me later about anything we have talked about today.*

Any issues of concern that have been highlighted will be talked about at this stage - with discussion on who might be able to help, or who might need to know.

### **APPENDIX 3: Interview (II) for mothers**

#### **A. Initial introduction to categories and agreement:**

*I'd like you to think about some of the things that many of the mothers have said about their experience of being a mother. If we can go through these to begin with, can you tell me which you agree with?*

[The categories generated from analysis, as listed in Appendix 12 were written on index cards and sorted into 2 groups depending on whether or not the mother agreed with the category noted]

[Anticipation of difficulty of some of the language used to describe the categories led to referral of codes to elaborate the meaning of each category for the participant]

#### **B. Elaboration and discussion of categories**

*I'd like to go back to each of the categories you've agreed with, and ask you a few questions about them.*

Questions and prompts were used to generate a picture of the thoughts, feelings and behaviours associated with the categories. Questions included:

*How did that make you feel?*

*What do that make you do?*

*What do you think about that?*

*What does that make you think?*

*What helps with that?*

*Can you give me an example of that?*

#### **End of interview**

*Thank you very much for helping me with the second part of the study. I'm hoping that what you've told me can now be used to help other mothers in similar families. What you have said to me will be kept private. Do you have any questions you'd like to ask me? I will leave you a card with my name and telephone number on it, so you can phone me if you would like to talk to me later about anything we have talked about today.*

**Any issues of concern that have been highlighted will be talked about at this stage - with discussion on who might be able to help, or who might need to know.**



## **APPENDIX 4: Interview for children**

### **Child Interview**

*I'd like to talk to you about what it's like to be in your family*

#### **A. Background Information**

*Q. Can you tell me about your family?*

*Q. Who lives at home with you?*

*Q. Who helps to look after you at home?*

*Q. How do you help at home?*

**Areas to be covered:** family demographics, support from extended family, other support available, professional support

#### **Perceptions of family**

*Q. Can you tell me the good things about your family*

*Q. Can you tell me about the nice or funny things in your family?*

*Q. Can you tell me about the worst things in your family?*

*Q. What makes you cross in your family?*

*Q. What makes you upset in your family?*

*Q. What worries you in your family?*

*Q. What is difficult in your family?*

*Q. How is your family the same as other families?*

*Q. How is your family different from other families?*

**Areas to be covered:** feelings about family, difficulties with families, who provides emotional and practical support in their family. Perception of different circumstances in the family, perceived consequences of this.

#### **Prompts:**

*Can you give me an example of when you've felt like that?*

*Can you tell me more about that?*

*What do you do when you feel like that?*

*Does anyone help you when that happens?*

*What do other people in your family do when that happens?*

**End of interview**

*Thank you for telling me about your family. What we have talked about today will be kept private. have you any questions to ask me?*

At this stage any issues that caused worry or distress will be talked about, and the person who might need to know or could help will be identified.

**INFORMATION SHEET FOR MOTHERS**

**This is a study looking at what it is like to be a mother and to look after children.**

**What is the study about?**

This study looks at what it is like to be a mother.  
You will be asked what the good things are about being a mum.  
You will be asked what the difficult things are about being a mum.

**What will happen if you take part?**

You will be visited by Jane Edmonds. She works with people who are mothers like you.

You will be asked to talk about your family, and what it is like to be a mum.

You will have as much time as you need to talk about this.

If you would like to take part, Jane will contact you and arrange a time to meet you.

If you agree, the conversation will be taped, using a tape recorder.

This is to make sure nothing you say is forgotten.

The tape will be wiped clean afterwards, so what you say is kept private.

**What will happen if you don't want to take part?**

If you don't want to take part, or decide not to later, this does not matter.

It will not effect the service you receive.

You do not have to say why you don't want to take part.

**Will the information I give be kept private?**

What you say will be kept private. The study makes sure you cannot be recognised.

If during the interview anything is talked about that is upsetting for you, this will be talked about at the end of the interview.

A person who you can talk to about this, or who can help, will be identified. This will be someone you already know. It will probably be the person who first asked you to help with this study.

If you talk about anything that causes the person talking to you any concern, this will be talked about at the end of the interview.

If necessary, they will tell someone else involved in your care about this problem.

**Part two of the study**

You may be asked if your children can take part in the study. You can say no. If you agree, they will also be interviewed. They will also be asked what it is like to be part of a family. All the same rules apply for this study.

**Who can I talk to about the study?**

Please phone Jane Edmonds. Tell her your name and that you want to talk about the family study.

Signed

Jane Edmonds

The local Research Ethics Committee has approved the above statement.

Signed by the chair of the Committee ..... Date .....

Index Number of Protocol:

**APPENDIX 6: Consent forms for mothers**

**CONSENT FORM**

Name: \_\_\_\_\_

1. I have read (been read) the information sheet.
2. I understand what the information sheet says.
3. The study has been explained to me.
4. I know what will happen if I take part.
5. I know that the study will be written up afterwards.
6. I know what I say will be kept private.
7. I have asked about the things I don't understand.
8. I have had enough time to decide if I want to take part.
9. I am entering this study of my own free will.
10. I can say 'no' at anytime, without saying why.
11. My future care will not be effected.

Signed \_\_\_\_\_

Date \_\_\_\_\_

**APPENDIX 7: Information sheet for children**

**INFORMATION SHEET FOR CHILDREN**

**This is a study about families**

**I'd like to talk to you about:**

**The good things about your family**

**The difficult things about your family**

**The special things about your family**

You do not have to take part if you do not want to. You don't have to say why.

What you say will be kept private.

The Local Research Ethics Committee has approved the above statement.

Signed by the chair of the committee \_\_\_\_\_ Date \_\_\_\_\_

**APPENDIX 8: Consent form for children**

**CONSENT FORM FOR CHILDREN**

I \_\_\_\_\_ have agreed to take part in this study.

I have been told about the study

I have been told what will happen when I take part.

I know the study will be written up afterwards

I know what I say will be kept private

Signed \_\_\_\_\_ Date \_\_\_\_\_

Parents signature \_\_\_\_\_

## **Appendix 9: Letter of ethic committee approval**

Dear Ms Edmonds,

A qualitative study looking at the experience of parents with learning disabilities who are parenting school aged children. Parent's and children perceptions of the difficulties and differences faced - 97.96.19

The Local Research Ethics Committee of 26 November 1997, considered your application and based on the information provided to the Committee gave ethical approval for the study to proceed.

Yours sincerely

**Acting-Chair  
Local Research Ethics Committee**

**Please Note:** All research should be conducted in accordance with the guidelines of the Ethical Committee and the Committee should be informed:

- (a) when the project is complete.
- (b) what stage the project is at one year from today's date.
- (c) if any alterations are made to the treatment or protocol which might have affected ethical approval being granted.
- (d) all investigators whose projects have been approved by this Committee are required to report at once any adverse experience affecting subjects in the study.



## **APPENDIX 10: Conventions for transcribing tapes and presenting results**

### **Transcription notation**

The notation used when citing respondents comments (adapted from Coyle et al (1994) ), was as follows;

1) Material in closed brackets is classificatory information

E.g. *People can be unkind, V. [sister] criticises my cooking*

2) Pauses in conversation are indicated by a series of dots

E.g. *they call you a slut, pig ..... they say you should be in a mental hospital*

3) Empty square brackets indicate the omission of text which was unrelated to the rest of the exemplary quotation

E.g. *my mum [...] had mental problems*

4) Material in small brackets indicates when the interviewer is speaking.

E.g. *DID YOU FIND ANYTHING DIFFICULT ABOUT BEING A MUM?*  
*No, because we had his mum around*

## APPENDIX 11: Worked example of a coding sequence

The following is a direct extract from an interview conducted with one of the mothers in the study. The analytic process is demonstrated by showing the initial codes that were identified, the categories which they subsequently formed and the themes that were identified following analysis:

The codes given to the units of meaning are shown in (brackets):

*The workers [support workers] give me advice, it has helped me with U [son], what to do to get rid of his friends and that (code: support giving good advice), and what to do to control him [son] (code: support giving good advice, children difficult to control). Some advice is good, some isn't good It's in between. (code: support sort of helping, sort of not). Some advice has been bad for me and has made me feel awful (code: feeling bad about self) (code: support making you feel bad)but then they come round and told me not to worry and that which helps me (emotional support). How to control him is good (code: support giving good advice) (code: children who are difficult to control). They've said he can have three friends round and after that you've got to get rid of them. Just be more firm - I'm sort of doing it (code: difficulty being assertive). I'm standing up to them, even if it frightens me all the time (code: difficulty being assertive)(feeling fearful).*

### Data management

#### 1. Coding

'the data was divided into units of meaning and initial indexing, referred to as coding began. This involved labelling of units of meaning in order to identify and account for relevant features' These are shown in column one in the diagram below.

### **Codes identified:**

1. support giving good advice
2. children difficult to control
3. support sort of helping, sort of not
4. support making you feel bad
5. emotional support
6. difficulty being assertive
7. feeling fearful
8. Feeling bad about self

### **2. Categorisation**

In the next stage of the analysis, basic codes which, when compared, appeared to pertain to similar phenomena were grouped together under more general headings' (column 2).

### **3. Thematic analysis**

Themes were identified across the data by carefully examining the emergent categories and looking for the links and connections between categories (themes are shown in column 3)

<b>(1)</b>	<b>(2)</b>	<b>(3)</b>
<b>Codes</b>	<b>Categories</b>	<b>Themes</b>
1.Support giving advice	Support enabling coping	Ambivalence re dependency
2.Emotional support	Support enabling coping	"
3.Support, sort of helping	Reticence about service involvement	"
4.Support making you feeling bad about self	Support causing additional problems	"
5. Feeling fearful	Emotionally vulnerable	Psychologically vulnerable
6. Children difficult to control	Children diff. to control	Lack of control
7. Difficulty being assertive	Lacking control	"
8. Feeling bad about self	Low self esteem	Internalisation of affect

## **APPENDIX 12 Codes and categories**

### **Categorisation of basic codes into conceptual codes.**

#### **1. What characterises the women's individual experience of being a mother?**

##### **1. Criticised (6)**

- Told what to do (3)
- Told done things wrong (2)
- Told it's their fault (2)
- Laughed at when done something wrong (3)
- 'Put down' by other people (1)

##### **2. Being monitored (7)**

- Meetings to discuss housekeeping issues (2)
- Meeting with key workers to discuss what has been happening (1)
- Children on protection list (3)
- Visits from health visitors (1)
- Daily input to look at development of child (1)

##### **3. Victimisation (6)**

- Called names (5)
- Physically threatened (2)
- Reported to authorities, when done nothing wrong (3)
- Personal property disregarded (1)
- Personal property destroyed (1)

##### **4. Feeling to self blame (5)**

- Used wrong way of controlling children (2)
- Didn't do enough reading with the children (1)
- Not assertive enough with children (2)
- Shouldn't have hit children (1)
- Should have coped better when husband away (1)

##### **5. Problems attributed to having a learning disability (4)**

- Not being accepted by society because of disability (3)
- Causing child's disability (2)
- Causing children's difficult behaviour (2)

##### **6. Being different (6)**

- Other people not so isolated (5)
- Feeling labelled as other (3)
- Other people not victimised (4)
- Other people listened to (2)

**7. Feeling of lacking necessary coping skills (4)**

No relevant experience (2)

No relevant training (1)

Not knowing what to do with children (1)

Not being able to keep up with practical needs of children (1)

**8. Same as other mothers (5)**

See no difference between self and others (2)

Difficulties due only to difficult circumstances (2)

Difficulties due only to difficult children (3)

All mothers have a tough time (2)

All mums need to be extra mums (1)

**9. Same as with other mother's with difficulties (4)**

Other people who have children who want to leave home (1)

Single mothers have same problems (1)

Busy mothers have same problems (1)

Other mothers have difficult children (2)

**10. Being a good mother (3)**

'I'm a good mother' (2)

Look at the mess other mothers are making (1)

**11. Caring more than other mothers (4)**

Caring more what happens to people (3)

Providing better care (3)

Caring what own children do to others (1)

**12. Isolation (8)**

No friends to go to visit (6)

Lack of places to go to (6)

No child care, so have to stay at home (3)

Lack of acceptance by others into social activities (3)

Few close relatives to go to visit (2)

**13. Lacking control**

Other people won't do as you say (4)

Children not doing as they tell them (6)

Difficulty being assertive (2)

Circumstances always against them (1)

Other people having more say in decisions directly affecting the family (3)

Children not respecting you (3)

Not being listened to (4)

**14. Social Economic Status (8)**

Dependent on the state (2)

Poverty (2)

Lack of employment (1)

Poor housing (3)

Bad neighbourhood (4)

**15. Early experience of being a mother emotionally traumatic (6)**

Not having a proper birth (1)

Post-natal depression (1)

Psychotic breakdown (1)

Birth induced because of stress (1)

Lack of early bonding (2)

**16. Problems attributable to own deficiencies of being mothered (6)**

Neglected (2)

Over protected (1)

Physically abused (1)

Verbally abused (3)

**2. What characterises experiences in relation to children**

**1. Satisfaction with motherhood (6)**

Enjoyment (5)

Reward (3)

**2. Pride in children's achievements (6)**

Children doing well at school (4)

Children who have overcome difficulties (1)

Children who have got jobs (3)

Spontaneous talk about what children are doing (1)

**3. Central focus upon children (3)**

No time for anything else but looking after children (2)

Life would be meaningless without children (1)

**4. Need to protect children (8)**

Children who have no personal boundaries (2)

Children who are physically weak (1)

Children against an uncaring society (2)

From being given too much family responsibility (2)

Children vulnerable to abuse (3)

Children who are emotionally vulnerable (1)

Children insecurely attached (1)

**5. Worry about children (8)**

Ability (2)

Behaviour (1)

Due to vulnerability (2)

Something will happen to them (3)

**6. Abused by children (3)**

Money taken (1)

Sworn at (1)

Home abused (1)

Physically assaulted (1)

**7. Feeling stupid in comparison with their children (4)**

Stupid as can't help with school work (2)

Child should be the parent (1)

Children brighter than themselves (3)

**8. Children who are difficult to control (7)**

Won't always do as told (5)

Unable to do as they are told (3)

Too old to listen (5)

Methods ineffectual (4)

**9. Partnership with children (4)**

It's up to them as well to solve problems (1)

Sharing household chores (2)

mum and children having rights (1)

Mothers shouldn't have to do everything (3)

Mothers need help (3)

**10. Children needing to be taught to be independent (6)**

Children need to know for when they have own house (4)

Children need to know for when they have own family (4)

Need to learn (2)

Old enough to learn (3)

Fear of vulnerability in adult world if can't cope alone (1)

3. What characterises the experience of the mothers in relation to other people providing support?

i) Informal support networks

**1. Having enough support from key people within the family (4)**

Husband provides enough support (2)

Own mother providing enough support (1)

Other key family members providing enough support (3)

**2. Family supporters who are vulnerable (5)**

Can't protect themselves from others (1)

Physical disability, not able to help around the house (1)

Learning disability, not able to help against authority (2)

Repeated conviction for petty crime, being seen as weakness (3)

Mental health problems, so can't be trusted (1)

**3. Family discord (6)**

Arguments with family members (5)

Break down in other family units (3)

Divorce (1)

**4. Isolation from extended family (7)**

Extended family not maintaining contact (3)

Geographical distance of family (4)

No extended family (3)

Difficult relationships (3)

**5. Difficult relationships with friends (3)**

Friends distancing themselves (1)

Friendships being abused (1)

Friends pre-occupied with own family (1)

Friends being too critical (2)

ii) In relation to formal (service) support?

**1. Support enabling coping (7)**

Emotional support (2)

Taking the children (3)

Allowing mother to go on holiday for a rest (2)

Giving good advice (2)

Day to day help with housekeeping (1)

**2. Social support from education system (5)**

Providing children with respite (2)

Supporting mothers with family problems (2)

Providing practical advice (4)



### **3. Reticence about service involvement (8)**

- Can now see use of extra help (3)
- Needed but intrusive (2)
- Needed but causing extra work (2)
- Needed but adding restraint to family life (2)
- Wishing they didn't have to come (2)
- Can't choose type of support (2)
- Can't choose when support given (2)
- 'Sort of helping, sort of not' (1)

### **4. Practical problems with support (5)**

- Not always available (1)
- Understaffed (1)
- Changes in workers (3)
- No one available to take over from previous workers (3)
- No continuity between child and adult services (2)

### **5. Not enough of the right kind of support (3)**

- Need support for mothers not just children (3)
- Needing different support now children older (2)

### **6. Support over-intrusive (6)**

- Don't want to discuss business with others (2)
- Doing a good job anyway (3)
- Need to do it your own way (2)
- Coming round every day, so can never plan other things (1)
- Want to know too much (3)

### **7. Support causing additional problems (7)**

- Inappropriate advice (3)
- Breaking up family (1)
- Inconsistent support (2)
- Accusing and blaming (4)
- System abuse (2)
- Raising anxiety (4)
- Feel bad about self (4)
- Being told what to do (2)

What are the psychological consequences of the experiences of these mothers?

**1. Withdrawing (4)**

Making self invisible (2)

Social situations too demanding, so stay alone (1)

Fear of trusting others so keep self to self (1)

Keeping self quiet (2)

**2. Feeling anxious (5)**

About how seen by others (4)

About how performing (4)

About losing children (1)

About what others will do to them (1)

About what children are doing (3)

About what children will do in the future (4)

About getting into trouble with the authorities (3)

**3. Feelings of depression (2)**

**4. Lowering of self esteem (4)**

Feeling bad about self (3)

Feeling can't do anything right (2)

Feeling awful (3)

**5. Causing illness (6)**

Others making them feel ill (2)

Life events making you ill (2)

Stress making you ill (3)

**6. Feeling angry (3)**

With other people who have treated them badly (3)

Angry with people who have been abused (1)

Angry at being labelled as incompetent (1)

Angry at being labelled as a bad mother (1)

**7. Feeling constantly stressed (6)**

No respite from problems (5)

Always having problems (2)

Always having to be coping with adversity (1)

**8. Emotionally vulnerable (4)**

Upset by other peoples behaviour (2)

Upset by other peoples vulnerability (1)

Over sensitive to others needs (2)

Feeling constantly fearful (3)

#### 4. What are the mothers perceptions of their children's experiences?

##### **1. Children as vulnerable (7)**

- Too trusting (2)
- Sexually abused (2)
- Can't defend self (4)
- Physically abused (3)
- Bullied (4)
- Abused by people who should protect them (2)
- Intellectually vulnerable (4)

##### **2. Children as emotionally effected by previous experiences (5)**

- Anger as a result of victimisation (2)
- Children becoming emotionally withdrawn (1)
- Children destroying property (2)
- Children unable to control temper when upset (2)
- Bed wetting (1)

##### **3. Children as isolated**

- Withdrawing from school (3)
- Withdrawing from friends (2)
- Not accepted (1)
- Not having friends around the house (2)

##### **4. Children having difficult relationships with other children (6)**

- Bullying other children (4)
- Not establishing friendships easily (1)
- Friendships abused (1)
- Sibling rivalry (1)
- Lack of boundaries with other children (4)

##### **5. Children as succeeding (5)**

- Getting work (2)
- Doing well at school (4)
- Exceeding at sport (1)
- Moving on to college (2)
- Learning to be independent (1)
- Learning to be responsible (2)

##### **6. Children as resilient (6)**

- Stick up for self (5)
- Well integrated (3)
- See others as in the wrong (10)
- Ask for help (3)
- Independent (1)
- Bright (3)

## **7. Children having to grow up as a result of experiences (3)**

Learning to look after other younger children (1)

Becoming an adult early (2)

### **External factors helping children**

#### **1. People who care (5)**

Meet children's needs (3)

Nurture children (3)

Take time to offer support (1)

### **Factors hindering children**

#### **1. Lack of concern from others (3)**

Other parents not preventing victimisation (2)

teachers not acting on behalf of children (3)

#### **2. Lack of understanding (5)**

Not understanding children's difficulties (3)

Not understanding mother's perspective and concern (2)

People getting the wrong information about children (2)

People not understanding the impact of the child's disabilities (2)

People not understanding the impact of the child's vulnerabilities (3)

#### **3. Slipping in societal values (3)**

No discipline of children (3)

Police not reinforcing the law (1)

Schools getting rougher (1)

### **Children's results**

#### **1. Closeness of family (4)**

Give things to each other (3)

Talk together (2)

Being looked after (2)

Love each other (3)

Do things together (3)

Enjoyment of being a family (2)

## **2. Acknowledgement of need to help in family (2)**

Limitations of mothers practical ability (2)

Limitations of mothers self care ability (1)

Limitations of social competence (1)

## **3. Need for extra help (3)**

Missing people who used to help (2)

Need aunts (1)

Need dad (1)

Need neighbours (1)

Need respite and holidays from family (2)

Need friends to visit (2)

## **4. Limitations of own helping capacity (3)**

College commitments (1)

School commitments (1)

Age (2)

Peers don't have to help all the time at home (1)

## **5. Difficult relationships in family (4)**

Arguments (4)

Fights with siblings (3)

Fights between parents (2)

## **6. Victimization (3)**

Bullied by mother (2)

Bullied by sister (1)

Abuse from aunts (10)

## **7. Difficult neighbours (4)**

Violent (2)

Noisy (3)

Lack of discipline (2)

## **8. Problems of autonomy (3)**

Not being listened to (2)

Lack of control (1)

Lack of personal space (3)

Having to do what told by parents (4)

## **9. Presentation of self as able (4)**

What doing at school (3)

What doing at college (2)

Exam results (3)

Household responsibilities (2)

What will be cooking for tea (1)

Social life being full (2)

Number of friends (2)

**10. Externalisation of difficulties (3)**

Difficulties caused by neighbours (2)

Difficulties caused by cigarette smoke (1)

**11. Emotional stress in the family (4)**

Mum getting stressed (1)

Stress not being handled properly, dwelling on it (2)

Sister getting stressed and self harming (1)

Mum getting violent because of stress (1)

Mum needing a break from the family (1)

Mum trying to commit suicide (1)

**12. Chaotic home life (3)**

Muddled (1)

Feeling of madness (2)

Being good and bad at the same time (1)

**13. Defending against painful feelings (4)**

Not being able to think about painful emotions (3)

Can't take anymore (1)

Inappropriate responses to questions (1)

Inappropriate emotional response (1)

**14. Acknowledgement of own stress as a result of the family (3)**

Problems getting on my nerves (1)

Suicidal feelings as a result of mother's behaviour (1)

Self injury when feeling angry with sister (1)

Feeling stressed (2)

**15. Anxiety about loss (3)**

Worry about ill health of parents (3)

Death of animals in the family (1)

Dad going away (2)

## **APPENDIX 13**

### **Participants feedback on the emerging analysis.**

The numbers in the first, bold, brackets indicates the number of participants who agreed with the category as presented. The second bracket contains the number of participants who appeared to note the category in their first interview.

#### 1. What characterises the women's individual experience of being a mother?

1. Criticised (6) (6)
2. Being monitored (7) (6)
3. Victimisation (5) (6)
4. Feeling to self blame (4) (5)
5. Problem attributed to having a learning disability (4) (4)
6. Being different (4) (6)
7. Feeling of lacking necessary skills (3) (4)
8. Same as other mothers (5) (5)
9. Same as with other mother's with difficulties (7) (4)
10. Caring more than other mothers (4) (4)
11. Feeling that they are a good mother (5) (3)
12. Isolation (8) (8)
13. Lacking control (4) (7)
14. Social Economic Status (7) (8)
- 15 Early experience of being a mother emotionally traumatic (4) (4)
16. Problems attributable to own deficiencies of being mothered (4) (6)

#### 2. What characterises experiences in relation to children

1. Satisfaction with motherhood (6) (6)
2. Pride in children's achievements (8) (6)
3. Central focus upon children (6) (3)
4. Children who need protecting (6) (8)
5. Worry about children (6) (8)
6. Abused by children (3) (3)
7. Feeling stupid in comparison with their children (3) (4)
8. Children who are difficult to control (6) (7)
9. Partnership with children (4) (4)
10. Children needing to be taught to be independent (7) (6)

**3. What characterises the experience of the mothers in relation to other people providing support?**

**i) Informal support networks**

- 1. Having enough support from key people within the family (4) (4)**
- 2. Family supporters who are vulnerable (3) (5)**
- 3. Family discord (6) (6)**
- 4. Isolation from extended family (5) (7)**
- 5. Difficult relationships with friends (3) (3)**

**ii) In relation to formal (service) support?**

- 1. Support enabling coping (5) (7)**
- 2. Mother socially supported by education system (5) (7)**
- 3. Reticence about service involvement (6) (8)**
- 4. Practical problems with support (5) (5)**
- 5. Not enough of the right kind of support (6) (3)**
- 6. Support over-intrusive (5) (6)**
- 7. Support causing additional problems (6) (7)**

**What are the psychological consequences of the experiences of these mothers?**

- 1. Withdrawing (2) (4)**
- 2. Feeling anxious (6) (5)**
- 3. Feelings of depression (4) (2)**
- 4. Lowering of self esteem (4) (4)**
- 5. Causing illness (5) (6)**
- 6. Anger (3) (3)**
- 7. Feeling constantly stressed (6) (6)**
- 8. Emotionally vulnerable (5) (4)**

**4. What are the mothers perceptions of their children's experiences?**

- 1. Children as vulnerable (6) (7)**
- 2. Children as emotionally effected by previous experiences (4) (5)**
- 3. Children as isolated (5) (3)**
- 4. Children having difficult relationships with other children (5) (6)**
- 5. Children as succeeding (5) (5)**
- 6. Children as resilient (6) (6)**
- 7. Children having to grow up (3) (3)**

**External factors helping children**

- 1. People who care (5) (5)**

**Factors hindering children**

- 1. Lack of concern from others (3) (3)**
- 2. Lack of understanding (4) (5)**
- 3. Slipping in societal values (3) (3)**