

UNIVERSITY OF SOUTHAMPTON

**Maternal Expressed Emotion Towards Children
With And Without Learning Disabilities.**

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ABSTRACT

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MATERNAL EXPRESSED EMOTION TOWARDS CHILDREN WITH AND
WITHOUT LEARNING DISABILITIES.

by Alexandra Eve Beck

Parents who have children with learning disabilities are often reported, in published literature, to be more stressed than parents of typically developing children. However, there is much variation in parental levels of stress. As yet, there has been no analysis to identify predictors of negative emotional relationships or intrusive over concern in mothers of children with learning disabilities and, how a negative emotional relationship might influence child outcome. The aim of this thesis was to begin such an analysis.

Firstly, this thesis assesses reliability of the measures to be used within families of children with learning disabilities. Previous research has identified a lack of reliability when transferring the use of measures to parents of children with learning disabilities. Secondly, this thesis explores what variables are associated with negative maternal Expressed Emotion (a measure of the emotional relationship between mother and child) and whether there are any differences in maternal Expressed Emotion between siblings with and without learning disabilities. Thirdly, an exploration is undertaken to identify factors that may account for the differences found between siblings. Lastly, this thesis identifies some tentative predictors of the relationship between parenting behaviour, parenting stress and child outcome.

The research within this thesis finds that there are several variables associated with negative Expressed Emotion in mothers of children with learning disabilities. Crossed lagged correlations challenge previous predictions of parent-child relationships. The implications of these results are discussed.

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PREFACE

Heaven's Very Special Child

A meeting was held quite far from earth
 'It's time again for another birth'
Said the angels to the lord above
 'This special child will need much love
 His progress may seem very slow
Accomplishments he may not show
 And he'll require much extra care
From the folks he'll meet down there
 He may not run or laugh or play
His thoughts might seem quite far away
 In many ways he won't adapt
And he'll be known as handicapped
 So lets be careful when he's sent
 We want his life to be content
Please, lord, find parents who
 Will do a special job for you
 They will not realise right away
The leading role they're asked to play
 But with this child sent from above
Comes stronger faith and richer love
And soon they'll know the privilege given
 In caring for this gift from heaven
Their precious charge, so meek and mild
 Is Heaven's very special child'.

This poem was given to me from a dear friend. I do not know where it originated.

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I am going to keep it short as there are too many individuals to thank, I hope I do not offend anyone. So, I would like to thank all those who have contributed to my smiles and those who have wiped away the tears. I would not be sitting here without the help I have received from every single one of you, **thank you**.

I would also like to thank all the families and schools who helped me throughout this research.

List of Definitions

CA	Chronological Age
CC	Critical Comments
DS	Down Syndrome
EE	Expressed Emotion
EOI	Emotional Over Involvement
FMSS	Five Minute Speech Sample
FSS	Family Satisfaction Scale
GRIMS	The Golombok Rust Inventory of Marital State
HADS	Hospital Anxiety and Depression Scale
ICC	Intraclass Correlations
IS	Initial Statement
LD	Learning Disability
MA	Mental Age
PSI	Parenting Stress Index
PSOC	Parenting Sense of Competence
SB	Sibling
SDQ	Strength and Difficulties Questionnaire
SES	Socio-Economic Status
TD	Typically Developing
VABS	Vineland Adaptive Behaviour Scale

CHAPTER ONE

Parents who have Children with Learning Disabilities

Children with learning disabilities and their families can be faced with a number of ongoing stressors such as poor communication skills, physical disabilities and behavioural problems that affect many dimensions of their lives. Parents may also experience increases in demands on their time, energy, resources and an altered parental role (Aldwin, 2000). This chapter reviews the literature on families and particularly parents who have children with learning disabilities (see Appendix A for definition of a learning disability). Researchers who focus predominantly on parents of children with learning disabilities have been interested in how having a child with learning disabilities affects the parent. This chapter explores the effect of children with learning disabilities on parental psychological well-being. In particular, this chapter addresses the impact on parents within a general stress and coping framework, as researchers have asked how parents adapt to children with learning disabilities.

1.1. What Influence does a Child with a Learning Disability have on Parental Psychological Functioning?

The aim of this section is to provide an overview of research addressing parental adaptation to children with learning disabilities. In particular, researchers studying parents of children with learning disabilities predominantly focus on stress and most researchers find that within families of children with learning disabilities there are elevated levels of parental stress. This first section asks why there are elevated levels of stress in parents of children with learning disabilities and what may account for these stress levels. It is also clear that some parents do cope extremely well with the demands of raising a child with learning disabilities. The final section of this review outlines theoretical models that conceptualise why some families cope and why some families fail to cope when raising a child with learning disabilities.

1.2. Initial Reactions to the Birth of a Child with Learning Disabilities

In the late 1960s and early 1970s developmental research began to examine the impact of a child with learning disabilities on the family. The initial research findings were bleak as research focused on negative parental reactions to the birth of a child with learning disabilities.

In 1978 Rod Ballard wrote a personal review describing his feelings of 'loss' of a child that he thought would be 'normal'. He described his feelings of rage, guilt, despair, worthlessness and frustration particularly in the early weeks after the diagnosis.

These feelings are not unusual as initial findings from research on parents of children with learning disabilities suggested that parents felt uncertain about what the future held, guilt, disappointment and ambivalence (Eden-Piercy, Blancher & Eyman, 1986).

A review of this literature identified three categories of reaction:

1) Shock-Confusion-Guilt-Anger- Despair-Depression-Disorganisation; 2) Refusal-Denial; and 3) Adjustment-Recovery-Acceptance (Eden-Piercy et al., 1986).

The acquisition or onset of a disability by a family member has been described as intrusive to family life (Larson, 1998). That is, the family may have to redefine its collective goals, its life circumstances, the meaning of life and the identity of the affected family member. Frequently, questions are raised by parents who want to know how their child became disabled, who was responsible and why it happened to them, when confronted with the news that their child had a disability (Larson, 1998).

A qualitative survey design was used by Mallow and Bechtel (1999) to identify patterns of feelings and emotions among parents who have a child with learning disabilities. Nine couples, independently, completed a questionnaire about their feelings of raising a child with learning disabilities. The questionnaire contained 16 open-ended questions that were designed to elicit experiences of caring for a child with learning disabilities. Parents reported feelings of chronic sorrow when reflecting upon their child's disability. Initial feelings of sadness and grief existed between both mothers and fathers, the mothers' emotions most often radiated into chronic sorrow while fathers' reactions moved into resignation. When parents were asked what triggered feelings of grief mothers' responses were related to the health of their child (related to the child's disability), whereas fathers' responses were related to comparisons with social norms.

More recent evidence suggests that parents still report instances of being immobilised by their despair, and of feeling utterly helpless and powerless when they learn they have a child with learning disabilities (Kearney & Griffin, 2001). This reaction is not surprising as research suggests that people with disabilities have long been viewed, and are still viewed (in some circumstances), as burdens on society (Turnbull & Turnbull, 1990). Kearney and Griffin (2001) used a qualitative research design which focused on nine parents' individual experience of raising a child with learning disabilities. Discussions with parents took place over an 18 month period and were face to face conversations. Interviews typically lasted between two and three hours. Each interview began with the interviewer asking the parent "Can you tell me about

your experiences of living with (the name of the child)". Parents had the freedom to speak from their own perspective and all told their story as a temporal narrative from either the birth of their child or from when the impairment was apparent. A model of the main themes and interrelationships was developed. The two anchors were joy and sorrow and according to Kearney and Griffin (2001) should not be viewed in isolation. Instead, joy and sorrow should be viewed as parts of a dynamic whole which shift and merge. The main findings suggest that, although all situations were individual, there was an initial consensus of sorrow among parents who were told they had a child with learning disabilities. Many parents said that they felt a perplexing and complex grief, fears and worries were related to the parent's current situation and to the future of their child. All of the parents spoke of messages of 'no hope' being imposed on them and were angry about a professional approach which left no room for hope. Parents believed that many of these feelings of grief and sorrow were thought to come from their dealings with other people's frequent messages of negativity and hopelessness.

Research into families raising a child with learning disabilities has attempted to understand some of the problems faced by these parents as they come to terms with the challenges of raising a child with learning disabilities. One of the most researched areas is the issue of parental stress and the idea that parents of children with learning disabilities may be more stressed than parents of typically developing children. The next section identifies parenting stress and its implications for these families.

1.3. Elevated Parenting Stress

Parenting stress has been described by Deater-Deckard (1998) in his review paper on parenting stress and child adjustment, as a complex process linking the task demands of parenting, the parent's psychological well-being and behaviour, the quality of the parent-child relationship and lastly, the child's psychosocial adjustment. Parenting stress, according to Deater-Deckard, is experienced as negative feelings towards the self or child and these feelings are directly attributed to the demands of parenting. Parenting stress is linked to adult functioning, the quality of the parent-child

relationship and child functioning (Deater-Deckard, 1998). Parenting stress is thought to be a distinct reaction to the demands of parenthood (Deater-Deckard, 1998).

Parenting stress, regardless of socio-economic status, social support and child characteristics, exists in every family. It can be thought of as a normal consequence of being a parent (McCubbin & Thompson, 1991). Yet, McCubbin and Thompson (1991) point out that parenting stress has the potential to vary considerably between families, within families and within individuals.

Generally, research suggests a relationship between raising a child with learning disabilities and parental psychological well-being. These studies find for example that children with more problematic behaviours, more unusual care giving demands and less communication skills have parents who report higher levels of parental stress (Beresford, 1996; Cahill & Glidden, 1996; Chavira, Lopes, Blacher, & Shapiro, 2000; Chetwynd, 1985; Crnic, Friedrich, & Greenberg, 1983; Deater-Deckard, 1998; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Floyd & Gallagher, 1997; Hodapp, Fidler & Smith, 1998; Krauss, 1993; Ong, Chandran, & Peng, 1999; Stores, Stores, Fellows, & Buckley, 1998; Wanamaker & Glenwick, 1998; Weiss, 2002).

Research has also identified within condition effects. For example, Stores, Stores Fellows and Buckley (1998) found that mothers of children with Downs Syndrome were more stressed than mothers of children from the general population, but less stressed than mothers of children with other learning disabilities. This finding has also been replicated by Smith, Oliver and Innocenti (2001).

Having demonstrated that raising a child with learning disabilities is associated with heightened parental stress it should not be automatically assumed that families who have a child with learning disabilities are dysfunctional. Although families who have children with learning disabilities tend to report more stress than families who do not have children with learning disabilities, there is a substantial variation in the nature and extent to which individual families report stress (Beckman, 1983).

1.4. Variability in Parenting Stress

Research within families of children with learning disabilities has demonstrated that parental stress fluctuates. The resources available for meeting the demands of parenting children with learning disabilities include knowledge about day to day tasks, as well as long term parenting tasks. Both of these have been shown to influence parental stress (Deater-Deckard, Pinkerton, & Scarr, 1996; Goldstein, 1995).

Parenting has therefore been described as more stressful for parents who have less knowledge and fewer emotional and instrumental supports. Furthermore, research identifies how parental stress may fluctuate over the course of the family's life cycle. Critical points include when a sibling overtakes the child with learning disabilities development; during consideration of school placement; onset of puberty; discussion about guardianship; and the consideration of residential alternatives (Wilker, Wasow, & Hartfield, 1981).

Variation in stress may also be related to dimensions of the child's disability. For example, parents have reported how they feel more stress when their child's communication skills are relatively low compared with typically developing children (Frey, Greenberg, & Fewell, 1989). In Frey et al's. (1989) study participants were 48 parental pairs and 48 children. Children had a mean age of seven years. Sixty percent of the children had Down Syndrome, 16% had Cerebral Palsy and the remaining children had a variety of mild and moderate learning disabilities. Mothers and fathers independently completed a number of questionnaires. Results showed that parents reported more stress when their child's communication skills were relatively low. Interestingly, Frey et al. (1989) showed that the lack of communication in children had a greater impact on the father's psychological distress than on the mother's psychological distress. Fathers also had more difficulty adjusting to appropriate expectations for their sons as opposed to their daughters. This result is suggested to be due to mothers taking on a caring role which is over emphasised when a child has learning disabilities whereas fathers take on more of a recreational role i.e. playing with their children. Fathers may find raising a child with learning disabilities (who cannot

participate in what would be considered typical recreational activities) harder to interact with than typically developing sons. Thus, this study illustrates interactions between child and family variables which affect variability in parental stress responses.

More recently, Smith et al. (2001) initiated a study of 880 parents of children with moderate to severe learning disabilities. Fifty-nine percent of the children were male, and 78% were Caucasian. Children had a mean age of 2 years 11 months. The measures included the Parenting Stress Index short form (PSI/SF; Abidin, 1990) and the Battelle Development Inventory which assesses adaptive and cognitive development. The study found that severity of disability (as indexed by developmental delay) related to increased parent stress and increased problems with the parent-child relationship. The child's social skills were found to be a stronger predictor of parent stress than motor skills, communication, adaptive behaviour or cognitive ability.

Family problems are also elevated when children with learning disabilities have a greater number of unusual care-giving demands, are less socially responsive, have more difficult temperaments, display more repetitive behavioural patterns, and have more severe disabilities (Beckman, 1983; Chavira et al., 2000). Parents of children with certain biological disorders may be faced with additional parenting burdens that include maintaining a child's physical health, such as changing the child's diet to allow for particular dietary needs (e.g. children with autism are at an increased risk of having Celiac's disease). Parents may also need to maintain physiotherapy sessions at home (especially with children who have motor skills problems), and help the child to achieve certain developmental milestones, (e.g. walking, talking, and self-care that typically would occur without much parental effort). Parents have additional worries about long-term care for their child and the impact of the required care particularly on the mother's personal life. This may include giving up work to look after their child with learning disabilities.

Researchers have often held negative or pessimistic views of the ability of families to cope with raising a child with learning disabilities (Gutman & Eccles, 1999; Marfo, Derick, & Barbour, 1998, Taanila, Jarvelin, & Kokkonen, 1999). However, dissatisfaction with this negative approach to families has recently led to alternative ways of examining family responses to raising a child with learning disabilities.

Although there is a limited amount of research into the positive aspects of raising a child with learning disabilities, initial research has discovered that families do adapt and cope successfully with the challenges of raising a child with learning disabilities (Blacher & Hatton, 2001; Grant, Ramcharan, McGrath, Nolan, & Keady, 1998; Grant & Whittell, 2000; Hastings & Taunt, 2002; Miller, Pit-ten Cate, & Murphy, 2001; Rimmerman & Muraver, 2001; Scorgie & Sobsey, 2000; Spangenberg & Theron, 2001; Stainton, 1998; Weiss, 2002). Hastings and Taunt (2002) reviewed the literature on positive experiences of raising a child with learning disabilities and have proposed a model for future research. The model suggests that parental positive perceptions function as strategies that help families adapt or cope with the experiences of raising a child with learning disabilities. This process of adaptation is illustrated below in the description of data from two research studies.

When parents were asked directly whether having a child with learning disabilities had made them stronger, parents responded 'yes' in 75% of cases (Wilker et al., 1981). Research on positive aspects of raising a child with learning disabilities has focused on qualitative research. Parents have often been asked to talk about their experiences. Wilker et al. (1981) provide a number of quotes from parents e.g. "Yes, we experience a sorrow that does not disappear with time, but we feel stronger from and even grateful for that experience" pg.314. Other parents suggest that raising a child with learning disabilities has made them much more patient. Some parents have even suggested that God gives these children to special people stating that, "I'm honoured he chose me" pg. 314. Lastly, parents have suggested that "having a child with learning disabilities causes you to ask certain questions that perhaps you would never ask and to develop certain values you would never develop" pg 314.

An in-depth case study of six Mexican mothers (27 to 42 years) who had a child with learning disabilities (five to eleven years, disability included autism and global developmental delay) was conducted by Larson (1998). The focus of the study was on the well-being of mothers parenting children with learning disabilities. These mothers shared hopeful maternal visions and profound personal growth that emerged through the experiences of having a child with learning disabilities. The interviews described opposing forces of loving the child as he or she was and wanting to erase the learning disability. Dealing with the incurable, yet pursuing solutions. Maintaining hopefulness for their child's future while being given negative information and battling with their own fears. The results from Larson's (1998) study suggest that these mothers had turned an unfortunate life circumstance into an opportunity for personal growth. That is, mothers would view their lives positively as long as progression was being made towards desired goals. Positivity was also expressed when mothers sought to manage and control aspects of their lives which they could affect.

The previous discussions indicate that there is considerable variance in outcome for parents of children with learning disabilities and that a plethora of variables may be related to outcomes. I now turn to consider theoretical perspectives that may help to organise these findings and potentially generate predictions for future research study.

1.5. Models of Stress and Coping

In the early 1980's a number of theoretical models were being applied to understand the varying outcomes for families of children with learning disabilities. The first model which was used to understand the experiences of these families was Hill's (1958) ABCX model. A variation on Hill's ABCX model was developed by McCubbin and Patterson (1983). The variation of Hill's model was called the Double ABCX model, adapting the original model to include a feedback loop. The next section describes the above models and includes two other models which have been used within the literature on families who have children with learning disabilities. These models are the Family Adjustment and Adaptation Response (FAAR) model which was developed

by Patterson (1988), and the general Process Model of Stress and Coping which was developed by Lazarus and Folkman (1984).

1.5.1. ABCX Model of Family Adjustment and Coping

Researchers looking for models to explain family adjustment and coping adapted a model by Hill from the late 1950's. Hill had studied families where the stressful event was the separation of soldiers from their wives and children during World War II. The model states that A is a stressful event, B is the resources or support available, C is the perception of the event and X is the outcome (see Figure 1.1.). The basic idea is that each component interacts to cause an outcome. An example provided by Patterson (1982) describes a mother who believes that her child, who has just been diagnosed with a chronic illness and who may soon die, will make no effort to bond with the child (to avoid feeling the loss of the child), or she may blame herself for having caused the illness and invest more attention in the infant as a way to ease the guilt of the pending loss. This model provided an essential base for stress and coping models, but did not supply researchers or practitioners with adequate information. In particular, it did not clearly represent the dynamic nature of the adaptation process.

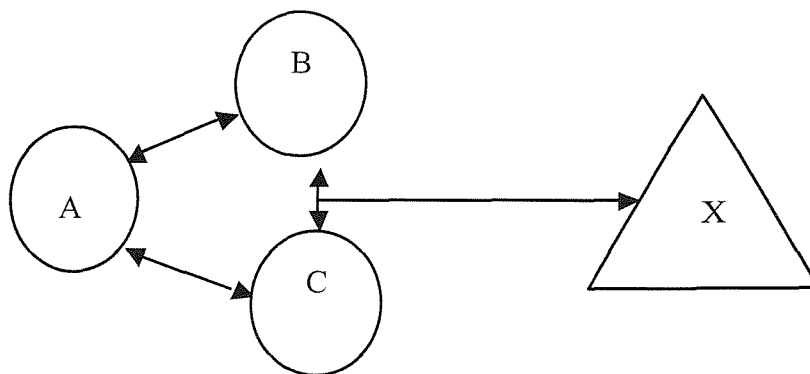


Figure 1.1. The ABCX Model. Hill (1958)

Partly to address this problem, McCubbin and Patterson (1983) extended the original ABCX model by adding a feedback loop (see Figure 1.2). This works as the outcome of one situation feeds back into the next situation. A positive feedback loop is called a “Bonadaption”, a negative feedback loop is called a “Maladaption”. Bonadaption can be described as a spiral of positive reactions (e.g. positive child behaviours, continued promotion of the child’s positive behaviours and maintenance of positive child behaviours). Negative adaptation is referred to as “Maladaption” (e.g. deterioration of the child’s behaviour leading to overall deterioration of the family system). The Double ABCX model addressed the issue that no event occurs in isolation and introduced the concept of "pile-up" of stressors (i.e. the model focuses on the family over time). McCubbin and Patterson describe the factors as: 1) cC the family’s perception of the original stressor; 2) aA describes the pile up of the original stressors, and 3) bB is the perception of resources. Patterson (1982) provides the example of a mother, believing that her child could live, who may search the country for the best medical care possible. In the Double ABCX model, a coping function alters the meaning of the situation to make it manageable to the mother (e.g. believing that they - the family - had a child with disabilities because they would be able to handle it).

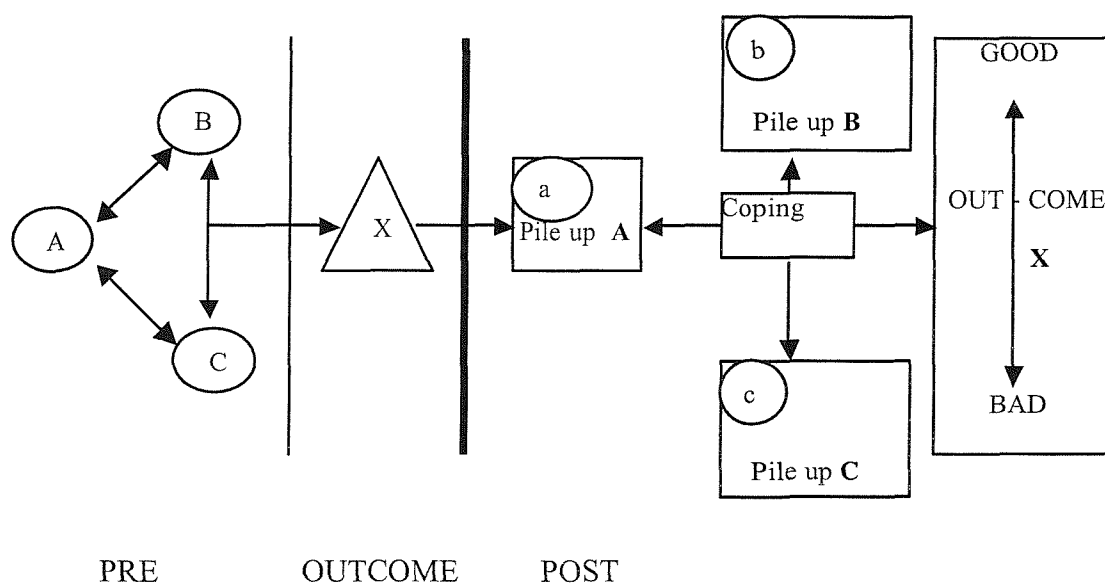


Figure 1.2. The Double ABCX Model (McCubbin & Patterson, 1983)

Research examples of the application of the Double ABCX model include Reddon, McDonald and Kysela (1992) who studied 16 pre-schoolers (aged two to five years old) with learning disabilities and their parents. Parents were generally experiencing significant stress associated with characteristics of their child's functioning. In most cases, excessive demands were depleting parents' resources. However, consistent with the model, a pile up of demands was associated with depletion/lack of family resources, maternal stress, difficulties in family functioning, increased coping efforts, and reports of greater support from external sources. Bristol (1987) also found that the Double ABCX model could be used to predict aspects of successful family adaptation to home care of parents of children with learning disabilities. Furthermore, Bristol (1987) suggests that adding a feedback loop to the model may make it easier to understand the complex reaction between having a child with learning disabilities and successful family adaptation and may ultimately be useful for developing intervention strategies.

Orr, Cameron and Day (1991) conducted a statistical evaluation (using path analysis) of the Double ABCX model in families with children who had learning disabilities. Eighty-six parents of children aged between five and twenty-one years participated in the study. Measures included: behaviour problems (path A); family resources (path B); family coping (path C); and parental stress (path X). The results found that the data fitted best with the path of ACBX. On the basis of these findings, Orr et al. (1991) suggest that firstly we should listen to families, to explore with them their perceptions of their child, the disability, and how it is affecting the family. Once it is understood what families need then the correct resources can be implemented. Orr et al. (1991) conclude that an approach such as the ACBX model may result in more effective use of resources and increase healthy adaptation in families.

1.5.2. The Family Adjustment and Adaptation Response (FAAR) Model

The ABCX model serves as a basis for the Family Adjustment and Adaptation Response model (FAAR; Patterson, 1988) but incorporates a further component by suggesting that parents try to balance problems in order to maintain a typical level of functioning. Family demands and capabilities interact with family meaning to arrive at a level of family adjustment or adaptation. There are two phases of the FAAR model (see Figure 1.3.). During both phases, families attempt to achieve a balance between family demands and family capabilities. The first phase (the adjustment phase) assesses the minor changes which are made in a family's functioning to meet the daily demands of raising a child with learning disabilities. Families make only minor changes to achieve a balance to maintain a typical level of functioning. Families maintain this balance through reducing demands or increasing capabilities. Demands may be a family illness or a change of social conditions. Capabilities refer to how families might meet their demands influenced by the resources the family has (time, money and knowledge of disability) and coping behaviours (social support, respite care and personal beliefs). The second phase (the adaptation phase) has been described as the crisis phase. That is, the demands of having a child with learning disabilities exceed the family's resources. It is at this stage when the family must acquire new resources or change their coping behaviour. Again positive adaptation is referred to as bonadaptation and negative adaptation is referred to as maladaptation.

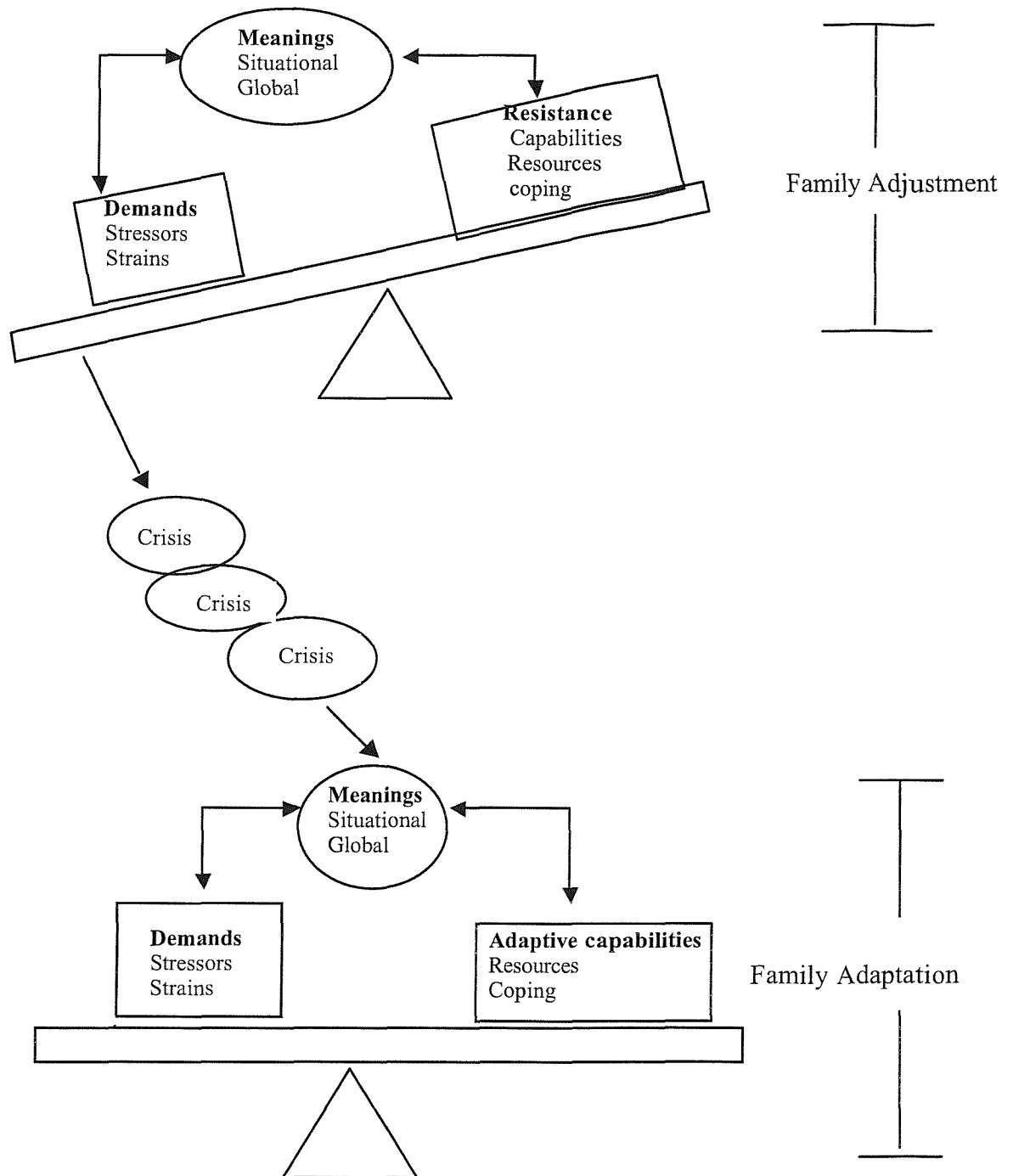


Figure 1.3. Family Adjustment and Adaptation Response model
(FAAR; Patterson, 1988)

The ABCX model, the Double ABCX model and the FAAR model all focus on family dynamics and the differential effects of family types on the experiences of stress.

Because the aforementioned models are family models that have been applied to disability, generalisations to other disabilities can be made. The models however, do not fully represent how individuals within the family adapt and cope to raising a child with learning disabilities. When coping has been considered, it has only been in terms of strategies which seek to maintain family stability. Thus, the outcome of coping is defined in terms of family, as opposed to individual, well-being.

1.6. The Process Model of Stress and Coping

Since the mid 1980's a general model of stress and coping has been used in research on families who have a child with disabilities. This model, the Process Model of Stress and Coping (Lazarus & Folkman, 1984), is more individual and is a general model trying to identify universal processes that may well also be applicable to dealing with disability. This model also provides clear differentiation of different sorts of recourses which is not so clearly defined in the family models describes above. The process model also recognises that some people may not even perceive childhood disability as a stressor in the first place.

The advantages of the process model of stress and coping, according to Beresford (1994) are: that the model was developed as a "stress and coping" model, and coping was not attached as an after-thought. In this process model, the vulnerability to the effects of stress is mediated by coping resources. The model is concerned with how individuals cope with stress generally and not, like the other models described above, deals with family adjustment and coping. The central theme of this process model is that the process of coping mediates the effects of stress on an individual's well-being. Coping is a process or ongoing complex interaction between an individual and the environment.

The Process Model of Stress and Coping has received so much attention that it is considered as the most comprehensive model of stress, coping and adjustment (Coyne & Smith, 1991). This model is presented in Figure 1.4. The model suggests that distress is the result of the interaction of a stressful event (stressor), personal resources, cognitive appraisal of the event, and coping resources. Therefore, this model emphasizes the active role of dealing with a stressor.

In this particular case the child with the learning disability is the potential stressor. The primary and secondary appraisals are understood as the process through which events are evaluated. During the appraisal stage of the model the parent evaluates the meaning of the event. If the parent perceives the situation as a threat then they move onto the secondary appraisal stage. Coping within this model is defined by Lazarus and Folkman (1984) as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" p141. The model supports the idea that not all problems can be mastered (i.e. developing a way to deal with a situation to reduce levels of stress). So, successful coping results from a match between appraisal and coping strategy (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). Coping resources within this model can be either personal coping which are physical or psychological (e.g. personal health, morals, beliefs, previous behaviour, parenting skills, and intelligence). Socio-ecological coping can be thought of as the individuals' environment or their social context (e.g. social support, marital relationship, practical/functional resources, and economic circumstances). Once the individuals have appraised their coping resources either an emotion-focused or a problem-focused strategy is used. Emotion-focused strategies deal with easing painful or distressing emotions resulting from stressors (e.g. taking a long hot bath, tranquillisers, or going for a run). Problem-focused strategies can be external (e.g. taking pain killers, or asking for help) or internal (e.g. cognitive restructuring-redefining the stressor). Finally the process is reappraised - has the stress changed, and am I feeling better?

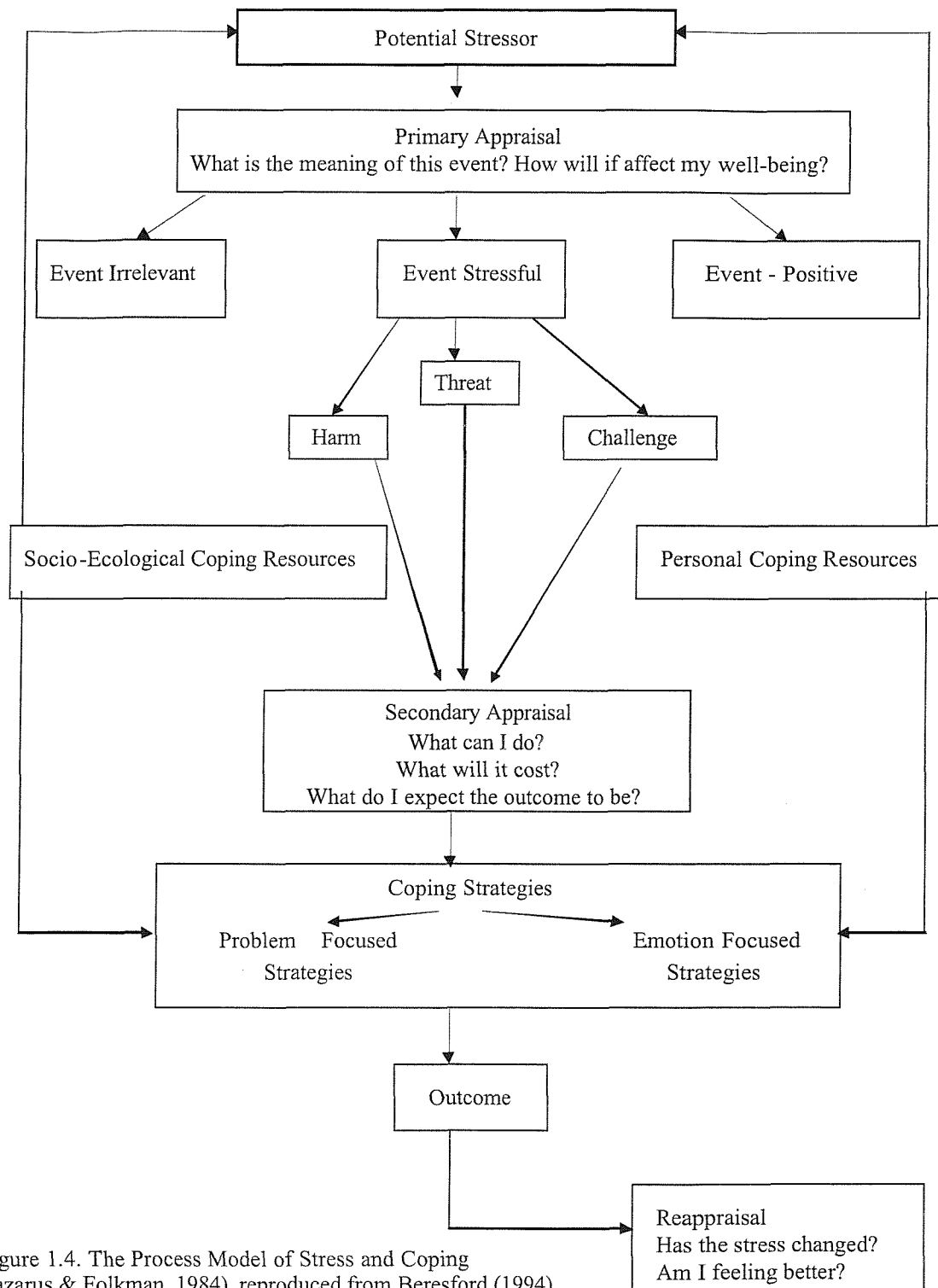


Figure 1.4. The Process Model of Stress and Coping (Lazarus & Folkman, 1984) reproduced from Beresford (1994)

The Process Model of Stress and Coping has been applied to parents who have children with learning disabilities (Barnes, Kroll, Lee, Jones, & Stein, 1998); coping in parents who have children with severe disabilities (Beresford, 1996); psychosocial factors and chronic illness in childhood (Tansella, 1995); and coping with cancer (Somerfield & Curbow, 1992).

To evaluate the quality of the coping, the nature of the stressor, the availability of the coping resource and the outcome need to be considered. Coping is thought to mediate the effect of stress on the individual's well-being. The presence of a chronic illness or disability in a child commits the family to long-term difficulties and problems comprising a variety of different stressors. Effective coping alleviates the problem and reduces emotional distress. If coping is ineffective, distress remains unchanged or becomes aggravated.

1.7. Commonalties in the Theories

There are several commonalties within theories of stress and coping that have been applied to parents of children with learning disabilities. The main perspective is that there is a stressor (or perception of a stressor) which in some way upsets the balance of the family and these families then need some form of resource to enable them to function as they were before the stressor occurred. By applying psychological and other resources a family or parent may balance out the stressor. The main aim is for families to assess the stressors, their resources and their understanding of the situation to maintain a positive outcome i.e. coping. A number of different resources have been studied in the research literature, including: coping styles (see above), social support, occupation, and socio-economic status.

1.8. Parental Resource Variables

Social support (networks of individuals or groups that can offer advice in times of need) has been considered a powerful mediator of personal well-being (Floyd & Phillippe, 1993). Social networks have been found to support people on a day to day basis and in times of crisis (Dunst, Trivette, & Cross, 1986). Although relatively few studies have been undertaken, research suggests that positive effects of social support on personal well-being can moderate the effects of having a child with learning disabilities and can act as a buffer against the psychological assault and social stigma of the stresses arising from raising a child with learning disabilities (Dunst et al., 1986; Romer & Heller, 1983). Dunst's (1986) study showed that, when parents of children with learning disabilities had good supportive networks, parents were less likely to over-protect their child; parents believed their child was more socially acceptable to others, and lastly, parents indicated their child had fewer behavioural problems.

A study by Wanamaker and Glenwick (1998) assessed the relationship between stress, coping and parents' perceptions of child behaviour. Sixty-Four parents of children with Cerebral Palsy participated in this study. The children ranged in age from three to six years. Results suggest that for mothers, high levels of maternal stress and depression were related to low levels of social support satisfaction, support network size, parenting satisfaction and parental efficacy. When mothers felt more stressed they reported lower levels of parenting satisfaction and were less capable of handling their children. Mothers were also more likely to report periods of depression along-side periods of high stress. Taken together these results suggest that mothers who report high levels of stress reported less external coping, (i.e. less social support) and less internal coping, and thus less self-efficacy. Mothers who were depressed also experienced more distress when faced with the demands of parenting. As stress increased mothers, felt more overwhelmed with the parenting experience, and depression increased further.

Occupation: The association between work, parenting and psychological well-being has rarely been studied among mothers of children with learning disabilities. Warfield, (2001) suggest that becoming employed and maintaining employment may place extra burdens on mothers of children with learning disabilities. Yet, other studies suggest that once employed, work provides respite and that the skills mothers develop in parenting their child with learning disabilities are valuable in the work place (Freedman, Litchfield, & Warfield, 1995). Recent findings suggest that there are no differences in child demands, family support or stress by maternal employment status (Warfield, 2001). Warfield's study also found that mothers employed full-time faced the same types of demands and reported the same level of stress as did mothers employed part-time and those not employed. The findings also suggest that mothers find challenges in combining work and child care. This is due to the difficulty in finding child care for children who have lower levels of cognitive functioning, fewer adaptive behaviour skills, and more externalising behaviour problems. Despite these challenges for care-giving, mothers did not believe their work suffered, as they would compensate and work during off hours to complete their work on time. However, this was dependent on their employer's willingness to let them have a flexible work schedule and allow them to work outside the work place.

Socio-Economic Status: There are relatively few articles examining socio-economic status in families of children with learning disabilities even though it may be especially significant in this context. Socio-economic status is generally a robust predictor of satisfaction and well-being for almost all domains of psycho-social functioning (Floyd & Saizyk, 1992). Floyd and Saizyk's study identified that socio-economic status is associated with both parent attitude and parent-child interactions within families raising children with mild to moderate learning disabilities. The findings suggest that parents from high socio-economic status families would emphasise independent initiative, personal growth and closeness in the family. High socio-economic status families would also behave more positively towards their child, use a relatively high rate of praise for appropriate behaviour and engage in more positive reciprocity with

the child than lower socio-economic status families. Furthermore this study also identified that negative exchanges with the child, parental attempts to direct and manage the child's behaviour and a high rate of non-compliance by the child were predictive parent and family problems. These problems were only found for the parents in higher socio-economic status groups. The research suggests that these differences occurred as difficult parents-child relationships violated standards and preferences in the high socio-economic status families but not in the low socio-economic status families. Therefore, this work is consistent with previous research that suggests that raising a child with learning disabilities is more stressful and frustrating for families from higher socio-economic status groups (Mink, Nihira, & Myers, 1983).

1.9. Further Parental Out Comes

In addition to parenting stress, there are a number of other problematic outcomes of the stress process associated with raising a child with learning disabilities. Most researchers have focused on two variables: depression and marital problems.

Depression: Research finds that mothers of children with learning disabilities are at a markedly increased risk of depression when compared with mothers of typically developing children (Beckman, 1991; Dyson, 1996; Gowen, Johnston-Martin, Goldman, & Appelbaum, 1989; Olsson & Hwang, 2001). This effect may be specific to maternal caregivers. For example, Olsson and Hwang (2001) suggest that mothers of children with Autism experience increased stress whereas fathers of children with Autism show typical levels of depression (Bristol, Gallagher, & Schopler, 1988; Veisson, 2000). Olsson and Hwang (2001) suggest that mothers may be more depressed than fathers due to the amount of time spent on additional care demands. Furthermore, Olsson and Hwang (2001) suggest that a mother's self-competence may be more related to the parenting role than a father's. Therefore, mothers may be more vulnerable when stress and difficulties arise in the parenting domain. Lastly, Olsson and Hwang (2001) suggest that fathers may show their distress in ways other than

depression.

Depressive feelings of mothers of children with learning disabilities are likely to vary significantly over time and especially with the age of the child. Gowen et al. (1989) studied 21 mothers of children with learning disabilities and 20 mothers of typically developing children. A variety of non-specific disabilities were included in the study. Children with learning disabilities were first tested at 11 months and then reassessed at 15, 19 and 27 months. The typically developing children were tested at six months with reassessments at 11, 15 and 27 months. The results of the study found that depression scores for mothers were not stable across time. That is, mothers' depression scores were elevated and fell in accordance with individual stressful life events. Even though mothers of children with learning disabilities reported more unusual care demands, their mean level of depression and competence in parenting were not significantly different from those of mothers of typically developing children of this age.

Marital Relationship Quality: Marriage and the parenting alliance concerns the effect of marital functioning on parenting and parent-child relationships. Parenting alliance concerns the ways in which spouses provide support and show respect for each other in the parenting role (Abidin & Brunner, 1995). Previous research findings suggest that a supportive, satisfying marital relationship should foster the development and maintenance of a strong parenting alliance (Cohen & Weissman, 1984). Conversely, marital difficulties may undermine the parenting alliance, and may cause problems with effective parenting (Jouriles et al., 1991). A large body of research indicates that the additional care demands of raising a child with learning disabilities can create exceptional strain on the parenting alliance (Floyd & Zmich, 1991).

Early research into the marital relationship and the effect parents have on their children was conducted by Friedrich, Wiltner and Cohen (1985). This research by Friedrich et al. (1985) questioned whether a well functioning parental relationship may

serve to counteract a child's problem behaviour. One hundred and forty-seven parents of children with learning disabilities participated in this research (7 were fathers). The mean age of the children was ten years. Fifty-seven percent of the children were male and 95% were Caucasian. There was a range of disabilities: 49 had learning disabilities, 41 had Cerebral Palsy, 30 had Down Syndrome and the remainder had unknown aetiologies. A follow up study was also conducted ten months later with 104 mothers. Results from the two studies suggest that marital satisfaction was a significant predictor of change in child behaviour over time. Poor marital relationships can produce long-term behavioural problems in children. These findings are thought to be bi-directional. A positive marital relationship may promote positive child behaviour and positive child behaviour may promote a positive marital relationship. Research by Floyd and Zmich (1991) suggests that there is evidence of both ongoing strain for the parents of school-aged children with learning disabilities, as well as individual differences that are associated with the quality of the marital relationship and the parenting alliance. The results are interesting as more differences emerged for observational data than from self-report questionnaires. The findings suggest that parents of children with learning disabilities are less willing to disclose their marital and parenting problems or they fail to perceive their interactions as negative. The inconsistencies within the results may suggest that stress and other external factors may influence the subjective experience of parents that may mediate the associations between interactional exchanges and feelings of distress. Longitudinal work on the parenting alliance in couples with children with learning disabilities suggests that couples with positive marriages, positive communication skills, and who report relatively greater confidence in their own parenting showed improvements of parenting confidence over 18-24 months (Floyd, Gillion, & Costigan, 1998). These research findings suggest that a positive parenting alliance maintains a good marital quality which positively affects parenting confidence and impacts positively on the parent-child relationship.

1.10. Summary of Research

Research into the effect of having a child with learning disabilities began in the early 1970s. Initial findings were bleak, suggesting that parents felt guilt, disappointment and an overwhelming sense of sorrow when told they had a child with learning disabilities. As a result, developmental research has been predominantly interested in the impact a child with learning disabilities has on the functioning of the family. One of the most commonly researched occurrences is parental stress. Studies into parental stress find that parents of children with learning disabilities are under more stress than parents raising typically developing children. Several models have been developed to understand stress and coping within these families. The principle of these models are the same; parenting stress varies in accordance with resources and coping strategies. Parental stress has been found to fluctuate within and between families of children with learning disabilities. It has been reported that lower socio-economic status parents, parents with more social support and parents who have children with less unusual care-giving demands cope better and are less stressed than parents from higher socio-economic status groups, parents with less social support and parents with children who have more unusual care-giving demands.

1.11. Conclusion

Previous research is helpful in identifying the family unit and individual family members' responses to having a child with learning disabilities. These models do go some way to explain why stress in these families may vary due to the knowledge held by families and individuals, their socio-economic status, and level of social support amongst other factors. However, in most research studies only a relatively small proportion of the variance in parental stress is accounted for. Also, the majority of this research is correlational which does not account for the direction of the effect. That is, research cannot tell us whether it is the child or the parent which is driving the interaction. Therefore, there is still a fair amount of variance to be explained in what predicts stress in parents of children with learning disabilities.

The mechanism that might link child disability variables as stressors and parental stress outcomes (or vice versa) is not wholly due to the psychological and other resource variables identified in stress models. One factor that has received less attention in the learning disability literature is parenting behaviour and especially the relationship between parent and child (although, see chapter two for a review).

Within the broader child psychological literature, research data do suggest a link between parenting stress and parenting behaviour (e.g. Baldwin, Brown, & Milan, 1995; Barnett, Marshall, & Sayer, 1992; Belsky, Woodworth & Crnic, 1996; Dodge, Pettit, & Bates, 1994; McCubbin & Thompson, 1991). Generally the research suggests that parents who show more stress show poorer parenting. Deterioration in the positive aspects of parenting has been found to causally influence children's behaviour, whereby increases in inept parental behaviour (possibly neglectful or abusive, in extreme circumstances) will lead to poorer cognitive and social-emotional development outcomes for children. For example, higher amounts of maladjustment among children and adolescents are positively associated with higher amounts of harsh, negative and inconsistent parenting (Maccoby & Martin, 1983; Rothbaum & Weisz, 1994). Therefore, psychological distress that arises from the demands of parenting has been found to play a particularly important role in the development of dysfunctional parent-child relationships.

The only research that has been conducted to test this relationship suggests that parenting behaviour is a mediator between parenting stress and child adjustment (Deater-Deckard, Pinkerton, & Scarr, 1996). That is, high levels of parental stress correlated with more authoritarian parental discipline, which in turn correlated with more behavioural problems among children. Deater-Deckard, Pinkerton and Scarr (1996) developed a model to summarise these effects (See Figure 1.5). There are three central relationships to the model: 1) between child behaviour and parenting stress, 2) between parenting stress and parenting behaviour and 3) between parenting behaviour

and the presentation of behavioural problems. Deater-Deckard et al. (1996) propose that the inter-relationships in the model are directional as shown by the arrows.

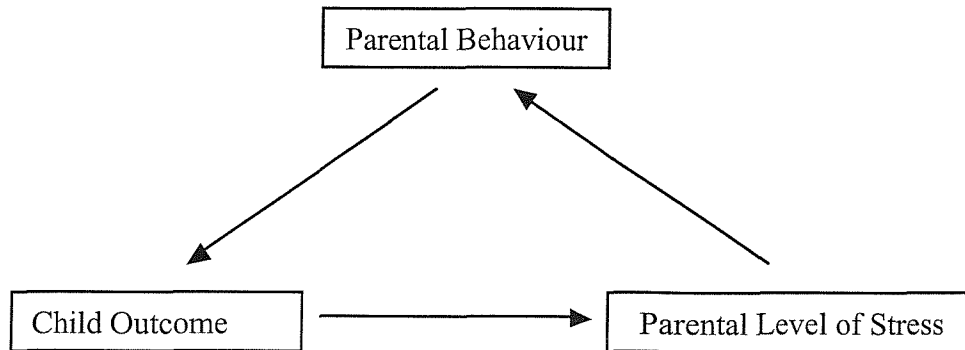


Figure 1.5 Parent-child relationships.

This model expands the focus of research on family functioning in the field of learning disability to a third variable (parenting behaviour) that may explain some variance in child functioning that in turn affects parenting stress. Although this model had not been explicitly applied in the learning disability field to date, there is research literature on parent-child interaction, parenting beliefs and behaviour. Chapter Two returns to this research literature.

CHAPTER TWO

Parent-child Interactional Behaviour

Chapter One was predominantly concerned with the impact a child with learning disabilities has on the functioning of the family. Chapter One described parental stress as the most commonly researched occurrence within these families. Several models have been developed to understand stress and coping, the principle of these models being essentially the same (i.e. parenting stress varies in accordance with resources and coping strategies). However, there is great variation in stress and only a relatively small amount of this variation has been explained. Within child psychology more broadly, it has been suggested that increased levels of parental stress are positively associated with poorer parenting behaviour (Deater-Deckard, 1998). Parents who are more stressed show poorer parenting as they are less responsive and more authoritarian. This chapter focuses on a different area of family research in learning disabilities: parent-child interactions.

2.1. Interactions between Parents and their Child with Learning Disabilities.

Many psychologists have regarded family life as important because it is the environment in which a child is socialised by the parent. The growing complexity of developmental paradigms over the past thirty years (e.g. Bell, 1979) have encouraged a more detailed analysis of the many contributions to the development of children and to parent-child interactions within a family unit. It has also been suggested that the way in which parents interact with their child affects the social competence and responsibility of the child (Damon, 1988). Family dysfunction and disturbed parent-child interactions have repeatedly been shown to be potential risk factors for psychopathology, poor outcome, and treatment resistance in many childhood psychiatric and medical disorders, including Attention Deficit Hyperactivity Disorder (Barkley et al., 2002) and Conduct Disorder (Webster-Stratton & Hammond, 1999).

Research on the relationship between parenting and child outcome has been explored with reference to genetic and environmental contributions over time. One of the clearest and most replicated associations is between conflictual parent-child relationships and adolescent maladjustment. For example, harsh and inconsistent parenting has been associated with later antisocial behaviour (Patterson, DeBaryshe, & Ramsey, 1989). Until recently, such relationships have been considered unidirectional. That is, negative parental behaviour toward a child was thought to lead to negative adolescent adjustment. However, evidence from genetic contributions to the parent-child relationship (Plomin, 1994), alongside evidence that parent-child interactions are bi-directional (Patterson, 1982), suggests that both parent and child characteristics play a part in the parent-child relationship.

The research from Patterson (1982) suggests that the psychological development of children is enhanced through the involvement of progressively more complex patterns of bi-directional interactions with a person to whom the child is securely attached. Patterson's model describes how particular aspects of parenting may bring about an anti-social child behaviour. Under this model, the child's misbehaviour is primarily the result of parental behavioural antecedents and consequences. Patterson (1982) has offered the best description of negative social reinforcement for the interactions of parents and their children. The model suggests that when conflict escalates, parents place a limit on the child's behaviour (e.g. a command is given to put the toy away),

and the child responds with behaviours slightly aversive to the parent (e.g. whining). These behaviours persist until the parent responds further by withdrawing the command to put the toy away. Thus, the child's aversive behaviours are negatively reinforced and the probability of the behaviours future occurrence is enhanced.

Three studies will briefly be described to illustrate the nature of reciprocal relationships between parent and child behaviour. Bugental and Shennum's (1984) research suggests that, abused children would have characteristics which place more demands and stress on the parent i.e. children who have a chronic illness, a learning disability, a physical disability or a communicative handicap. Specifically, the research indicates that children with certain child characteristics, for example unresponsiveness and behavioural inappropriateness, may evoke parental abusive practices. However, as this system is thought to be reciprocal, the parents' beliefs will influence the intensity of their reaction to such child characteristics. Results from Bugental and Shennum (1984) showed that affective behaviour shown by adults in response to their non-compliant child was influenced by parenting. The causes of negative parent interaction problems were shown as increased vocal and facial dysphoria and increased controlling behaviours.

A separate study assessed children who were targeted by parents for higher levels of coercive discipline and who were also negatively evaluated by their family. These children were found to be more unresponsive and more inappropriate/atypical in their behaviour than siblings who were not negatively evaluated by their parents (Frey et al., 1989). Furthermore, this research studied children interacting with parents and with adults who were not their primary care-givers. Research findings suggest that the same pattern of behaviour was found for both parents and non-primary care-givers suggesting that the child may initiate the behaviour which in turn elicits a negative behavioural response from the adult.

On a more positive note, improvement in parenting has been shown by Anderson, Lytton and Romney (1986) to reduce child conduct problems. Anderson et al. (1986) found that if mothers used fewer commands and negative behaviours directed at their child with Conduct Disorder, child behaviour would improve.

In research on families of children with learning disabilities results indicate that the quality and quantity of parent-child interactions may be impaired compared to children without learning disabilities (Hunt & Paraskevopoulos, 1980; Stoneman, Brody, & Abbott, 1983). In the next section I review some typical examples of studies, published over the last twenty years, identifying parent-child interactions when the child has a learning disability. A total of nineteen studies are reviewed, which are thought to be reasonably representative of the literature on parent-child interactions. The review has been split into three sections: single, between, and within-participant designs. Research on parent-child interactions has almost exclusively been conducted using between-family designs (comparison families who have children with and without learning disabilities). This between-family research focus has been at the expense of considering variation within families, which is extremely important if we are to accept that parenting stress, which may influence child maladjustment, also varies within and between families (Deater-Deckard, 1998).

2.2. Single Sample Designs

This first type of study used in research on parenting in families of children with learning disabilities has focused on single samples only. Parenting is measured within a sample of families who share the experience of having a child with learning disabilities. Studies have looked at the amount and level of maternal daily interactions; the influence of child chronological age, and mental age on mother's interaction style; and mother's interactions have been observed over time to assess the change in interactions as the child develops. Single sample designs cannot show us whether parenting is different towards children with learning disabilities. To establish this there is a need to be able to make some kind of comparison. Many researchers have done this using between family design (see section 2.3).

Table 2.1 summarises results from four typical single sample studies. Observations have been used in all cases. However, the duration of these observations varies considerably (i.e. from five minutes to fifty minutes). Using this single sample design researchers have studied a variety of aetiologies, sample sizes and ages. The results from the reviewed studies suggest that mothers of children with Down Syndrome show a wide variation in directiveness (i.e. parents' level of directiveness was related to the child's need for discipline and controlling behaviour), sensitivity, and

elaboration in their interactions. Children with learning disabilities spent much more time in interactions with their mothers than they did with their fathers. Lastly, mothers were found to be sensitive to their child's general behaviour repertoire as inferred from mental age.

Table 2.1 Single Sample Designs

Author	Sample		Method	Results
Crawley and Spiker (1983)	N	18	Observations lasted 20 minutes. Standard set of toys.	Mothers of Down Syndrome children were diverse in their interaction style i.e. they showed wide variation in directivness, sensitivity and elaboration.
	Sex	10 male, 8 female	Coding: 10 maternal and 10 child scales on a Likert 5 point scale.	Sensitive mothers were viewed as elaborate, Pearson's correlated at .89
	Age	24 months average	Overall reliability = 78%	Directive mothers was negatively correlated with elaborativeness, Pearson's correlated at -.48.
	Aetiology	Down Syndrome		
McConachie and Mitchell (1985)	N	21	Parents were observed separately interacting with their child for 5 minutes.	There are a vast range of interactions between mothers and fathers of children with learning disabilities. Overall children spent much more time with their mothers than their fathers. Fathers' interactions were dependent on his level of education and the child's level of speech.
	Sex	unknown	This was repeated 4 weeks later.	
	Age	CA = 32 months, MA = 17 months mean		
	Aetiology	14 DS, rest unknown.		
			Coding: communication, response and feedback.	<u>Spearman Rank correlations between mothers and fathers</u>
			Standard day interview (Douglas et al., 1968)	Response Commands .36
				Questions .65
				Statements .53
				Control .53
				Feedback .50

Table 2.1 Single Sample Designs Continued

Author		Sample	Method	Results
Floyd, Costigan and Phillippe (1997)	N Sex Age Aetiology IQ	98 47 males, 51 females 6 to 18 years mild and moderate 45 -70	Observations were 50 minutes of family interaction. This was performed again 18 to 24 months later.	Parents reduced their demanding behaviour as the child aged. Also parents level of directivness was related to the child's need for discipline and controlling behaviour. Stability over time for <u>Parent</u> Command Negative Positive <u>Child</u> Negative Positive
				Mother Father p<.01 p<.01 p<.05 p<.00 p<.05
Brooks-Gunn and Lewis (1984)	N Sex Age Aetiology Matching	111 65 males, 46 females 3 to 36 months Down Syndrome, Cerebral Palsied and unknown SES and CA.	Mothers were observed free playing with their children for 15 minutes. Coding: vocalise, looking, smile/touch, seek proximity. Mother- directions, read, play toy, show approval, massage infant. child-cry, seek help, gesture, play toy, sit on lap, hold mother, play self, extra movement and bounce. Reliability ranged from 78% to 83 %	Mothers were more sensitive to their child's general behaviour repertoire as inferred from mental age than either chronological age or learning disability. Frequencies of behaviour produced by the infant increased significantly with CA and MA p<.01. Mothers of children with Down Syndrome were more responsive towards their child than mothers of children with physical impairments p<.05. Maternal proximity decreased with child CA p<.00 and MA p<.00. More proximal behaviour was exhibited by mothers of children with physical impairment than mothers of children with Down Syndrome p<.01.

2.3. Between Family Designs

Again, the studies in the following section are representative, but of a between family design. The between family design uses families who have typically developing children as a comparison to families who have children with learning disabilities. Ten studies are included in this section of the review (see Table 2.2 for details).

In research using this design, families have typically been matched on a number of variables. This matching of family characteristics allows the control of variables that may contribute to group differences. In 10 studies reviewed there are a number of different matching criteria used, the most frequent being chronological age and mental age matching; six studies used these matching criteria. Second was gender with five studies; four studies have used socio-economic status and birth order; one of seven studies has used race, parental income, parental age, parental education level, child communication level, the child's behaviour problems, and child play. Within these 10 studies, child ages range from a few months to 18 years. The number of children per group varies from 10 participants in the smallest group to 104 in the largest.

Examples of questions posed in studies with between-family designs include the difference in parental roles; the effect a child with learning disabilities has on the functioning of the family; maternal responsiveness; maternal directives; and the assessment of positive exchanges between parents and children. For all but one of the studies observations were used, typically lasting between 15 and 20 minutes. Mothers, and in a few cases fathers, were asked to play with a specific set of toys, as they normally would during interactions. Only in one instance (Floyd & Phillippe, 1993) was there a more structured task (e.g. parent-child interactions were assessed over a meal-time).

Results of these research studies showed that:

- Mothers of children with learning disabilities dominated interaction sessions and initiated interactions more frequently than mothers of typically developing children.
- Mothers were more directive towards their child with learning disabilities with regard to assistance.
- Mothers played longer with their children when they chose the toy as opposed to

the child choosing the toy for both learning disabled and typically developing child interactions.

- Mothers of children with learning disabilities were more likely to initiate interactions towards their child with learning disabilities than their typically developing child.
- Mothers are more dominant and controlling to encourage their child with learning disabilities to participate in a play situation.
- Mothers of children with Down Syndrome were more likely to use verbal commands towards their child with learning disabilities than mothers of typically developing children even when mental or chronologically aged matched.
- Mothers of children with Down Syndrome exhibited more directive behaviour toward their daughters than towards their sons.
- Parents of children with Down Syndrome were much slower to change their interactions over time. On average mothers of children with Down Syndrome were 6 to 12 months behind on this respect.
- Parents of children with learning disabilities spent more time issuing commands and attempting to gain compliance. Parents of children without learning disabilities engaged in more play activities whereas, parents of children with learning disabilities would play as a form of teaching.
- Mothers of children with Autism spent less time interacting with their children than parents of typically developing children.
- Mothers interacted with their child more than did fathers of Autistic children.
- Parents rated interacting with a typically developing child more fun than a child with learning disabilities.
- Parents of children with Autism and learning disabilities, but not children with Down Syndrome perceived their child as having a more difficult temperament and were altogether more stressed than parents of typically developing children.

Table 2.2 Between Family Designs

Author		Sample	Method	Results	Effect Size		
Eheart (1982)	N	LD = 8, TD = 8	Observation 2 x 20 minutes with particular toys.	Mothers of children with learning disabilities dominated interaction sessions and initiate interactions more frequently than mothers of typically developing children (p<.01). Mothers were more direct towards their child with learning disabilities with regard to assistance (p<.01). Mothers played longer with their children when they chose the toy as opposed to the child choosing the toy for both learning disabled and typically developing child interactions (p<.01).	For the observations the overall effect size is .58		
	Sex	LD = 4 of each sex, TD = 3 males, 5 = females					
	Age	LD = 39 to 49, TD = 24 to 31 months	Coding: Solitary play, number of interactions, mother and child initiations, mother and child responses, maternal feedback, selection of toy by mother or child and maternal positive, negative or directive behaviour		Solitary Play	1.30	
	Aetiology	3 had Cerebral Palsy and the rest had unknown learning disabilities.			Mother/Child Interaction	.65	
					Toy Selection	.43	
	Matching	Children were matched on the basis of their play behaviour over a period of 16 minutes of observation.			Content Maternal	.09	
		Overall reliability of the observation = 85%					
Stoneman, Brody and Abbot (1983)	N	DS = 8, TD = 8	Observation lasted between 20 to 25 minutes.	Mothers were more likely than fathers to play the teacher role during interactions.			
	Sex	4 males and 4 female per group					
	Age	All between 4 to 7 Years old	Coding : Roles, manager, teacher and information seeking. Free play with the same box of toys			Analysis of variance found significant results for all dyadic interactions, responsiveness of child to parent behaviour and difference in behaviour with mother present (p<.05). For Triadic interaction significant results were only found for manager, teacher, positive verbal and all responsiveness of child to parent behaviour (p<.05).	
	Aetiology	Down syndrome Gender, CA, Race and Parent education					Overall reliability of the observation = 80%

Table 2.2 Between Family Designs Continued

Author		Sample	Method	Results	Effect Size	
Tannock (1988)	N	LD = 11, TD = 11	Observations lasted 15 minutes	Mothers of children with learning disabilities are more likely to initiate interactions with their learning disabled child than their typically developing child (p<.05). Mothers were found to be more directive and controlling in interactions with their child with learning disabilities(p<.05). Results suggest that mothers are more dominant and controlling to encourage their child with learning disabilities to participate in a play situation (p<.05).	Turn Take Mother	2.00
	Sex	LD = 7 male, 4 female, TD = 8 male, 3 female	Coding: Turn taking, response control, topic control, responsiveness, topic control, responsiveness, un-involvement, index of interactional activity and dyadic topic maintenance.		Turn Take Child	.60
	Age	LD = 15 to 21, TD = 10 to 22 months			Response Control Mother	1.50
	Aetiology	Down Syndrome			Response Control Child	1.20
	Matching	Matching level of communication, development age, birth order, age of parent, educational level of parent, MA and CA	Topic Control Mother		2.00	
			Topic Control Child		5.80	
			Responsiveness Mother		1.80	
			Responsiveness Child	2.60		
			Reliability ranged from 76 to 98%			
Roach, Barratt, Miller and Leavitt (1998)	N	LD = 84, TD = 30	Observations lasted 15 minutes	Mothers of children with Down Syndrome were more likely to use verbal commands towards their child with learning disabilities than mothers of typically developing children even when MA or CA matched (p<.01). Mothers of children with Down Syndrome exhibit more directive behaviour toward their daughters than towards their sons p<.05).	Overall	.45
	Sex	Unknown	Coding: mother vocal behaviour, non-vocal object behaviour, children's vocal behaviour and child non-vocal object behaviour.		Mental Age	.04
	Age	10-31 months			Chronological Age	.04
	Aetiology	Down syndrome			<u>Mother Interaction</u>	
	Matching	Matching MA, CA and SES			MA	.50
					CA	.58
					<u>Child Interactions</u>	
					MA	.45
					CA	1.40
					Reliability for coding mothers' interactions = 87% . Reliability for coding child interactions = 84%.	

Table 2.2 Between Family Designs Continued

Author		Sample	Method	Results	Effect Size
Lieberman (1995)	N	LD = 9, TD = 11	Observations lasted 20 minutes	Mothers were more likely to play with their child without using toys when the child was 1 year old. Mothers of 1 year old children with learning disabilities were more likely to direct their child's play even when it did not involve toys ($p < .05$) and issued more commands than compared to mothers of typically developing children ($p < .05$). Mothers of children with learning disabilities were more likely to modify their child's behaviour ($p < .05$).	Overall .30
	Sex	LD = 6 males, 3 females, TD = 9 males, 2 females	Coding: modifiers, compliance, passive interactions, mutual and social play.		Modifiers .80
	Age	all between 10 and 15 months			Compliance 1.50
	Aetiology Matching	Unknown CA and SES	Reliability ranged between 68% to 73%		Passive Interactions .50 Play .20
Maurer and Sherrod (1987)	N	DS = 6, TD = 4	Observation = 15 minutes of free play at 12, 18, 24, 30 and 36 months.	Results are only speculation as the sample size is small. Parents of children with Down Syndrome were much slower to change their interactions over time. On average mothers of children with Down Syndrome were 6 to 12 months behind.	Not Applicable
	Sex	DS 4 males, 2 females, TD = 3 males, 1 female			
	Age	Age Months DS = 12 TD = 9	Coding frequencies: communication and suggestion. Context: verbal behaviour, compliance, play, attention and mood.		
	Aetiology Matching	Down Syndrome Matching birth order, gender, parent education, income, MA and CA.	Overall reliability was 80%		

Table 2.2 Between Participant Designs Continued

Author		Sample	Method	Results	Effect Size
Floyd and Phillipe (1993)	N	LD = 53, TD = 51	Observation = 50 minutes	Parents of children with learning disabilities spent more time issuing commands and attempting to gain compliance ($p < .01$). Parents of children without learning disabilities engaged in more play activities where as parents of children with learning disabilities would play as a form of teaching. There were significant differences between parents of children with learning disabilities and parents of typically developing children for Child Compliance ($p < .01$) and Positive Exchanges ($p < .05$).	Not Applicable
	Sex	LD 27 male, 26 female TD 30 male, 21 female.	Structured.		
	Age	6 to 18 years	Coding behavioural management struggles, Coerciveness and positive exchanges.		
	Aetiology	Children had unknown aetiology	Overall reliability = 86%		
Konstantares (1991)	Matching	TD children were chosen by their parents because they were the most challenging	Log of interactions over two days completed by both parents.	Mothers of children with autism spent less time interacting with their children than parents of typically developing children $p < .01$. Mothers interacted with their child more than did fathers of autistic children $p < .01$. Parents rated interacting with a typically developing child more fun than a child with learning disabilities $p < .01$.	Not Applicable
	N	LD = 16, TD = 22	Coding : dressing, feeding, bathing, playing, teaching and bedtime routines.		
	Sex	21 males, 27 females			
	Age	2.5 – 10 years			
	Aetiology	Autistic			
	Matching	Age, gender, birth order,			

Table 2.2 Between Family Designs Continued

Author		Sample	Method	Results	Effect Size
Kasari and Sigman (1997)	N	Autistic = 28, LD = 26, TD = 28	Observation = 3 minutes of free play	Overall there were differences in the way parents perceive the behaviour of the three different child groups. Parents of children with autism and learning disabilities, but not children with Down Syndrome perceived their child as having a more difficult temperament ($p<.01$) and were altogether more stressed than parents of typically developing children ($p<.01$).	<u>Overall</u>
	Sex	68 males, 14 females	Coded Time engaged, and responsiveness		Autistic .30
	Age months	Autistic MA = 23, LD MA = 25, TD MA = 24, Autistic CA = 42, LD CA = 41, TD CA = 20	Reliability range of observation 89-96%		LD .10
					<u>Time engaged</u>
	Aetiology	Autistic, Down Syndrome and unknown			Autistic .10
					LD .30
	Matching	Gender, SES and MA			<u>Responsiveness</u>
					Autistic .30
					LD .00

Effect sizes used to quantify the difference between two groups have been calculated from data provided in studies summarised in Table 2.2 (where possible). Effect sizes can be calculated by finding the difference between the mean values of two groups (one experimental group and one control group), and dividing by the mean of the standard deviations. To convey a meaning to an effect size Cohen (1992) suggests that, as a general rule, an effect size of .3 is small, .5 is medium and .7 is large. Out of the 10 studies that have a typical comparison, effect sizes could only be calculated for five of them (only five studies provided enough data to calculate effect sizes). None of the studies displayed effect sizes within their articles. Eheart's (1982) study demonstrated a moderate effect size; Kasari & Sigman (1997) had a small effect size; Lieberman's (1995) effect sizes were generally low to moderate; Roach, Barratt, Miller and Leavitt (1998) have low to moderate effect sizes and lastly, Tannock (1988) demonstrated large effect sizes. Therefore, there is some variance in effect sizes using this between family design. An effect size demonstrates that a measure can discriminate between two groups. Overall, the present review suggests differences in parenting between families of children with and without learning disabilities in groups of a meaningful size.

There are particular problems with these between family designs as they do not take into consideration the fact that families who have children with learning disabilities may function in a different way to other families. In the first chapter of this thesis I established that members of families who have children with learning disabilities are more stressed, have more marital problems, are likely to be more depressed, have more unusual care giving demands and are more likely to be under financial strain than parents who only have typically developing children. Stoneman (1989) has also criticised comparison groups used in research with families who have children with learning disabilities. Stoneman (1989) argues that the simplest method for reliable comparison is to identify rigorous matching criteria to ensure that groups are similar on important factors (e.g. demographic variables, age of children, and gender). However, this still fails to recognise that the families may be very different from each other due to the broader effects of having a child with learning disabilities. A further possibility for exploring whether parents behave differently towards children with learning disabilities is to look within the family and compare responses to children

with learning disabilities and their siblings. A small number of studies have attempted to use such a design, and they are discussed in the following section.

2.4. Within Family Designs

The final design used in parenting research in learning disabilities is a within family design. This Chapter has identified two published studies using a within family design which (after an exhaustive search) seem to be the only published papers using this design within families of children with learning disabilities. There are still problems of gender matching and chronological age matching within these studies, but a multitude of other family variables are pretty much constant. The studies reviewed below are based on a mother's interactions with her children with and without learning disabilities.

Dallas, Stevenson and McGurk (1992a,b) conducted one study written up as two papers. The papers identified the interactions between mothers and children with Cerebral Palsy and the interactions children with Cerebral Palsy have with their siblings. Their first paper looked at the influence of severity of disability, age and birth order. The second paper looked at interactional structure. Sixty-four children with Cerebral Palsy, of typical intelligence or mild learning disability (IQ in the low 50's) who had no gross sensory deficits, participated. Participants were aged between two and thirteen years old and were observed in a semi-structured play situation with their parents. The sample was divided into four groups of 16 sibling pairs. These pairs were based on birth order and age of the child with Cerebral Palsy. There were eight males and eight females in each group but there was not an equal distribution of same sex pairs and cross sex pairs. The results, with reference to mother-child interactions, suggest that there were no significant differences in interaction when the child with Cerebral Palsy was the youngest of the dyad. This was due to the older typically developing sibling directing the play. When the child with Cerebral Palsy was the eldest of the dyad, the mother showed far higher levels of control towards her child with Cerebral Palsy.

The second study looked for direct influences that a sibling (and secondly parents) may exert on each other's behaviour. Mothers were also more likely to display controlling behaviours towards their child with Cerebral Palsy than their typically

developing child. Mothers were more likely to intervene in sibling interactions when the child with Cerebral Palsy was the younger of the two. Children with Cerebral Palsy were more likely to seek their mother's intervention and were more likely to comply if the mother intervened. At older ages the child with Cerebral Palsy would be more likely to seek sibling interactions than a parental one. This paper suggests that Cerebral Palsy dyad interactions are more hierarchical, with a typically developing sibling being more directive in all situations. Mothers did try to intervene so that the child with Cerebral Palsy played a greater part in the direction of play, but this was generally short lived and certainly not initiated by the child with Cerebral Palsy with any great effect.

The second study by Corter, Pepler, Stanhope and Abramovitch (1992) asked if parents were consistent in their parenting behaviour towards their children with and without learning disabilities. Corter et al. (1992) also investigated whether parenting varied with characteristics such as age and sex of children. Thirty-one children with Down Syndrome and 31 siblings were observed in two, one hour interaction sessions with their mother. Results confirmed that mothers initiated more positive and directive behaviour towards their child with Down Syndrome. Mothers received more positive behaviour from their typically developing child even though the mother initiated less positive behaviour towards this child. There were no differences in negative maternal behaviour towards either child. The mothers' positive and directive behaviours were not affected by birth order, but mothers had higher rates of positive and directive behaviour towards their child with Down Syndrome. The gender of the typically developing child had an effect on the mother's negative behaviour. Mothers were more negative to males, regardless of disability, than they were to females. Typically developing females were more positive to their mothers than typically developing males. In children with Down Syndrome males were more positive to their mothers than females. The older the child with Down Syndrome, the more positive maternal behaviour became, and this child in turn was more positive to their mother.

2.5. Chapter Conclusion

The results in Tables 2.1., 2.2. and section 2.4. identify that parents of children with learning disabilities are more directive and more dominant with their child, as a way of teaching, but also as a way of maintaining compliance. Mothers of children with

learning disabilities are also more likely to experience fewer initiations of rewarding and pleasurable interactions from their child, when compared with a typically developing child. However, the two predominant research designs used (single and between participant designs) do not provide a strong platform from which to compare findings from parents with and without learning disabilities. The studies reviewed in this chapter provide evidence that there are problems within the current literature. The problems highlighted include sample sizes, matching criteria and design methodologies.

A further point worthy of note is that within the child psychology literature more broadly, research on twin and adoption studies are consistent in showing that non-genetic factors account for about half the population variance for most traits and disorders (Cohen, 1992). These findings suggest that the environment affects each member of the family differently through non-shared environmental influences. The concept of a non-shared child-rearing environment recognises that parents may interact with, or structure, a child's physical or social world differently from that of his or her sibling. Such differences may be derived from parental characteristics, or elicited by the child's attributes or predisposition (Feinberg, Neiderhiser, Howe, & Hetherington, 2001). Siblings nevertheless encounter distinct, as well as similar, parenting experiences (Brody, Stoneman, & McCoy, 1992). What this suggests is that parents will modify their interactions depending upon the varying characteristics of the child. Bell (1979) suggested that parents adjust the beliefs they have towards their child over time, through parent-child interactions and in response to their child's development. Therefore, this thesis will consider using a within family design to explore the relationships between children with learning disabilities and their mothers.

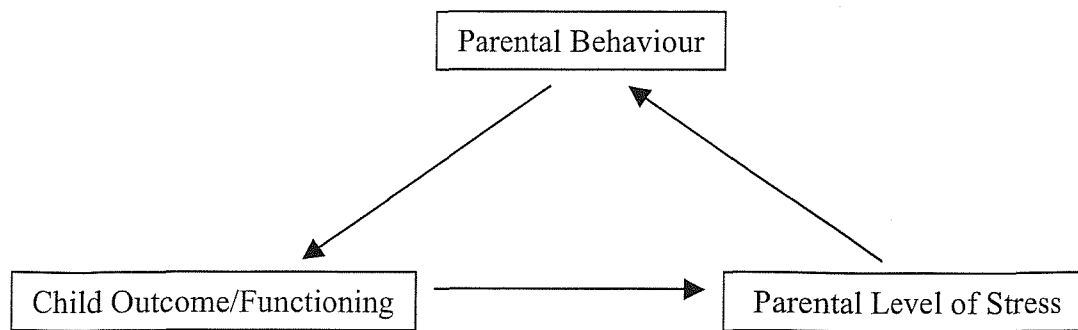


Figure 2.1 Parent-child relationships.

So far, this thesis has identified (from existing published research see Chapter One) that child variables do influence parenting stress (see Figure 2.1), although the proportion of variance explained can be quite small.

The present chapter identifies that there is evidence that parents do parent differently dependent on a key child characteristic: whether the child has a learning disability. This research mainly considers that children's learning disabilities lead parents to behave differently. However, we have also seen that very few researchers have utilised perhaps the strongest methodological feature of a within family design. Thus, the empirical work in this thesis follows this path.

A future issue relates to a practical and conceptual point. The studies reviewed in this chapter have excluded a key dimension of the relationship between parents and children: the emotional dimension. Observational methodology is also very time consuming and often a compromise between the richness of data and reliability is reached. Therefore, the thesis will explore a measurement approach that may be relatively easy to administer, that provided a rich description, and focused on the neglected emotional dimension of the parent-child relationship. That measurement approach is related to the construct of Expressed Emotion.

Expressed Emotion is a measure that has been used in the published literature to examine an individual's negative emotional relationship or intrusive over concern towards an identified individual. Expressed Emotion was developed out of research

on relapse in Schizophrenia by Brown and his colleagues in the late 1950's (Brown, 1958; Brown, Monck, Carstairs & Wing, 1962; Rutter & Brown, 1966). Expressed Emotion has now been used in many published papers on adults and children with psychopathology (See Chapter Three). Early research findings on the possible role of Expressed Emotion in children arose from studies of individual components such as parental warmth and hostility (Vostains, Nicholls, & Harrington, 1994). Research suggests that there is an association between lack of parental warmth and hostility and behavioural problems in children (Quinton & Rutter, 1985). The next chapter introduces the concept of Expressed Emotion and describes how it may be an important construct to explore within the working model displayed in Figure 2.1.

CHAPTER THREE

Expressed Emotion

The intention of the chapter is to introduce the concept of Expressed Emotion (EE). The development of Expressed Emotion is discussed and issues related to measurement and coding are identified. A number of studies are discussed that represent the use of Expressed Emotion in adult and child studies. A review of parental Expressed Emotion towards children with learning disabilities identified two existing published papers. Both of these studies are reviewed in detail.

3.1. Introduction

Expressed Emotion is a construct that is useful in quantifying the attitudes and feelings which people express about their relatives. Expressed Emotion is typically measured using an interview conducted with the relative in the 'patient's' absence. However, more recently, new questionnaire measures have been developed. Expressed Emotion has been used as a research tool to measure levels of negative emotions or intrusive over concern with family members (Stubbe, Zahner, Goldstein, & Leckman, 1993).

A potential advantage of Expressed Emotion is that it may represent unshared variance, a parental attitude directed toward one child only. Due to the unshared aspect of Expressed Emotion, it may differ from measures of psychological adversity such as divorce, socio-economic hardship or marital conflict, which affects all children within the family (Hirshfeld, Biederman, Brody, Faraone, Rosenbaum, & 1997). A distinguishing feature of Expressed Emotion that may account for its success is that as well as accounting for the content of what, for example, parents say about their child, it also accounts for vocal aspects including pitch and emphasis on delivery. This, according to Kuipers (1994), may account for Expressed Emotion's success in transferring between languages and cultures.

Expressed Emotion has proven to be a reliable and robust predictor of the illness outcome of patients with severe psychiatric disorders like Schizophrenia, Mood Disorders, Eating Disorders and Dementia (Wearden, Tarrier, Barrowclough, Zastowny, & Rahill, 2000). One aspect of Expressed Emotion that has not been resolved is whether Expressed Emotion is a trait of parent communication or a product of the interactions between parents and ill relatives (i.e. a state). Findings from Schreiber, Breier and Pickar (1995) suggest that the Expressed Emotion variables of Emotional-over Involvement and Warmth are state related. Mothers showed significantly more Emotional-over Involvement and significantly less warmth towards their adult child with Schizophrenia than towards other children in their family. There

were no significant differences between the number of Critical Comments made by mothers towards their two children, which suggests that Criticism is a trait element. Schreiber et al. (1995) is the only published paper that characterises Expressed Emotion into traits and states. Chapter Nine will return to the issue of Expressed Emotion being a state or trait.

3.2. Development of Expressed Emotion

George Brown and his colleagues developed the concept of Expressed Emotion. Their initial studies focused on the relevance of environmental factors to relapse in Schizophrenia. Brown, Carstairs and Topping (1958) followed a group of Schizophrenic male patients who were discharged into the community from hospital settings. They found that in a significant number of cases, when patients were discharged, improvement was not being made. Further investigation found relapse to be associated with the type of living group to which the individual returned. Brown realised that those returning to live with a very close relative such as a spouse or parent were more likely to relapse than those living with a more distant relative or in a hostel or lodgings. From this, Brown hypothesised that the emotional attitude of relatives, towards patients, may be related to the propensity to relapse. He studied whether the expression of hostility, or of any strong emotion in general by the relative towards the patient, could be isolated as behaviour that contributed to their relapse. Brown found a significant association between intensity of emotion and amount of hostility directed towards the patient by the relative, and the likelihood of deterioration of symptomology and relapse during the following year.

During the 1960's work progressed to develop a measure that could extract the range of feelings and emotions to be found in normal family life. During this time, the scales of Criticism, Hostility, Emotional-over Involvement, Warmth and Positive Comments were finalised. This measure was called the Camberwell Family Interview (Brown, 1958; Brown, Monck, Carstairs, & Wing, 1962; Rutter & Brown, 1966). The original interview took around five to six hours to complete but has been modified by Vaughn

and Leff (1976) and now takes between one and two hours to complete. The studies that subsequently followed adopted a prospective design, usually with families of patients who were hospitalised due to a Schizophrenic episode and then followed up once the patient had been discharged. These studies were usually interested in the occurrence of relapse in Schizophrenia. More recently others have developed interview and questionnaire measures (see sections 3.3.3. to 3.3.11. for a review). Although two of the interview measures have been widely used (the Camberwell Family Interview and the Five Minute Speech Sample), studies using questionnaires require replication for reliability and validity purposes.

One important finding which emerged from early Expressed Emotion research in Schizophrenia is that Expressed Emotion could be related to other clinical groups. Vaughn and Leff (1976) found that Expressed Emotion was not unique to Schizophrenia but that relapse and Expressed Emotion were also related to individuals with Depression. This led researches to use the concept of Expressed Emotion to identify outcome in other clinical groups. Although not derived from theory, Expressed Emotion has been an empirical tool driven by its ability to predict outcome. Research on Expressed Emotion with Schizophrenic patients has proven to be a remarkably consistent predictor of post-hospitalisation relapse within this client group (Kuipers & Moore, 1995; Moore, Kuipers, & Ball, 1992). Research from a meta-analysis identified that 65% of Schizophrenics from high Expressed Emotion homes relapsed 9-12 months after discharge where as only 35% of Schizophrenics returning to low Expressed Emotion homes relapsed (Butzlaff & Hooley, 1998). Within this meta-analysis six studies of unipolar and bipolar depression were also summarised, revealing that approximately 70% of the patients from high Expressed Emotion families relapsed versus 30% of individuals from low Expressed Emotion families.

3.3. Measurement of Expressed Emotion

3.3.1. Camberwell Family Interview

The Camberwell Family Interview (Vaughn & Leff, 1976) was the first instrument to measure Expressed Emotion and is now considered as the gold standard (Van Humbeek, Audenhove, Hert, Pieters, & Storms, 2002). The Camberwell Family Interview is a semi-structured interview conducted with a relative or carer. The interview is designed to collect information and tap attitudes about the identified individual by asking about their relative's behaviour and the quality of the relationship they have had with the patient over the past three months. The Camberwell Family Interview takes an average of one to two hours to complete and is always audio-taped for later coding, which takes on average three to four hours. The aim of the interview is to gain information concerning a) the onset and development of the patient's illness and b) the degree to which the illness has affected family life (e.g. domestic tasks and atmosphere in the home). However, the most crucial aspect of the interview concerns the aspects of the relative or carer behaviour, and in particular the feelings they express about the patient during the course of the interview. The semi-structured interview allows a flexible use of standard questions and probes/encourages an interviewer to listen to information as it emerges and not to interrupt if areas of interest have been spontaneously discussed. The interviewer covers the start of problems, focuses on the previous three months, and asks about other areas of the relationship, such as irritability and tension. Symptoms and coping resources are discussed and, if a relative or carer is vague, recent examples are probed for. A time budget is also requested which allows assessment of the amount of waking time the family or carers spend in the same room together. On the basis of the emotions expressed by the relative or carer during the interview a rating of Expressed Emotion is made. Brown et al. (1962) measured inter-rater reliability for the Camberwell Family Interview between .80 and .90 depending on the dimension of Expressed Emotion. Vaughn and Leff (1976) report reliability for Criticism at .86. These findings suggest the Camberwell Family Interview is a reliable instrument to measure Expressed Emotion.

3.3.1.1. Coding of the Camberwell Family Interview

Criticism – which is the sum of total Critical Comments made about the patient.

These remarks can be judged as critical on the bases of content or voice tone. For a Critical Comment to be scored there has to be a clear and unambiguous statement of resent, disapproval or dislike (e.g. “I really hate it when he shouts and screams at me for no reason at all”). However, if a parent says “I really hate it when he shouts and screams at me but, that is only when I have upset him”, then this would not be coded as a Critical Comment as the parent does not blame the patient directly. Critical Comments that are based on tone are coded even if they do not blame the patient directly. Criticisms are coded as frequencies.

Hostility – is a much more generalised negative feeling and is usually a remark critical of the patient themselves rather than specific actions or behaviours. An example would be “He is stupid. Everything he does is stupid”. Hostility is rated using a four point scale, from zero to four.

Emotional-over Involvement – reflects an exaggerated response to the patient’s illness or markedly over-protective behaviour. An example would be “I haven’t been out for ages. I could go out if I wanted to but I don’t go because I’m looking after Harry”. Emotional-over Involvement is rated on a six point scale, from zero to five.

Warmth – is rated by using the family member’s or carer’s voice tone. In this case, as opposed to Criticism, the voice tone has to be clearly positive rather than negative. Warmth is rated on a six point scale, from zero to five.

Positive Remarks – are defined by content and reflect without ambiguity, praise, approval or appreciation (e.g. “He has a very good sense of humour”). Positive Remarks are rated as frequencies.

Expressed Emotion is split into a dichotomous variable of high and low by most researchers. Relatives are classified as high Expressed Emotion if they make six or more Critical Comments, if they are hostile (i.e. a score of one or more) and if they score one or more on the Emotional-over Involvement domain. Leff and Vaughn (1987) suggest that these criteria are not fixed and can be modified depending on the population.

There are two main components to Expressed Emotion, taken from the Camberwell Family Interview: 1) parents who show high Expressed Emotion due to a degree of criticism, and 2) parents who show high Expressed Emotion due to being Emotionally-over Involved (Dossetor, Nicol, Stretch, & Rajkhowa, 1994). These two identified characteristics reflect two different ways of dealing with emotion. The first suggests that parents who exhibit high Emotional-over Involvement are those who internalise their behaviour and have patients with more severe disabilities. These patients show more behavioural disturbances in public and have more psychological ill health. Relatives or carers of these patients have a poor quality of marriage, have less social support and more professional support than parents who are not Emotionally-over Involved. The second way of dealing with emotion describes relatives or carers who express three or more Critical Comments, externalise their emotional behaviour and the patient is likely to have a milder disability, more general behavioural disturbances and Psychiatric Disorders. These relatives or carers have much less professional support because they do not seek it and have fewer marital problems (Dossetor et al., 1994).

During the 1980's the issue of using the Camberwell Family Interview to measure Expressed Emotion became an area of research interest. The accessibility of the traditional method of assessing Expressed Emotion, using the Camberwell Family Interview, was questioned. Research ideally needed a reliable, shorter assessment measure of Expressed Emotion. Magana, Goldstein, Karno, Miklowitz, Jenkins and Fallon (1986) described the Camberwell Family Interview as "arduous" proclaiming

that it took approximately seventy hours to be fully trained in administration of the one to two hour interview, and another three to four hours coding per interview.

3.3.2. The Five Minute Speech Sample

The first alternative measure to the Camberwell Family Interview was the Five Minute Speech Sample (FMSS, Magana et al., 1986). The Five Minute Speech Sample (see Appendix I for a copy of the instructions) asks a relative or carer to talk about a target person (patient) for a period of five minutes. In contrast to the requirements of the Camberwell Family Interview, the examiners need not be trained in the coding system to administer the interview. Relatives are asked their thoughts and feelings about the patient name over the past six months. They are also asked by the researcher to tell them about what kind of person the patient is and how the two of them get along together.

3.3.2.1. Coding of the Five Minute Speech Sample

The Five Minute Speech Sample examines the relationship between a relative or carer and a target person based on the substance and tone of their comments. The speech sample is analysed under five dimensions. The Five Minute Speech Sample adds several dimensions to the existing Camberwell Family Interview (see Table 3.1) resulting in a measurement of Expressed Emotion (Magana et al., 1986). A new dimension called Initial Statement was added as it was thought to be particularly important as it reflects the initial affective attitudes reported about the patient, and it is therefore coded separately from the remainder of the speech sample. The other new dimensions were developed as part of the Emotionally-over Involved domain. These are, Statement of Attitude, Emotional Outburst, Excessive Detail and Self-Sacrificing Behaviour.

Expressed Emotion towards a target person can be high, borderline or low (see Table 3.2). High Expressed Emotion identifies relatives or carers who are high in Criticism and Emotional-over Involvement; and low Expressed Emotion identifies relatives or carers who are low in Criticism and Emotional-over Involvement. Van Humbeeck et al. (2002) found internal consistency of the Five Minute Speech Sample to be .80 and its test-retest reliability to be $r = .64$. Magana et al. (1986) found a high correspondence between the Camberwell Family Interview and the Five Minute Speech Sample ($\chi^2 = 11.43$, $p < .01$). In a family context, the Five Minute Speech Sample underestimates the score on of the Camberwell Family Interview in 20-30% of the sample (Leeb, Hahlweg, Goldstein, Feinstein, Mueleer et al., 1991; Magana et al., 1986; Malla, Kazarian, Barnes, & Cole, 1991). This finding suggests that a high Expressed Emotion score on the Five Minute Speech Sample implies a high score on the Camberwell Family Interview, but a low Expressed Emotion score on the Five Minute Speech Sample is not necessarily low on the Camberwell Family Interview. A few false positives for high Expressed Emotion may be identified with the Five minute Speech Sample.

Table 3.1. Dimensions of the Five Minute Speech Sample

Dimension	Definition	Coding	Quote
Initial statement	The first statement the mother makes about her child	Positive, Neutral or Negative	A neutral statement - "Billy is six years old".
Relationship	What the mother and the child do together	Positive, Neutral or Negative	A positive statement – "I love going to the park with Sam we have such a good time".
Criticism	Negative comments made by the mother about the child	Frequencies	"Toby is always screaming and shouting and I hate that".
Positive Remarks	Any statement about the child which is positive in nature	Frequencies	"Sam has such a good sense of humour".
Dissatisfaction	Describes a child's unfavourable behaviours, characteristics, or personality traits but are not enough to meet the criticism criteria	Present or Absent	"It irritates me when he does not do as he's told all the time".
Emotional-over Involvement	Self- sacrificing behaviour / Over-protective behaviour	Any Self-sacrificing or Over-protective behaviour.	"I gave up work to look after her, I didn't want to but I felt it was the right thing to do
	Emotional Display	Scored when a mothers cries or is unable to speak.	
	Excessive Detail	Scored when an inordinate amount of information is given about the child's distant past.	
	Statement of Attitude	Scored when the respondent expresses very strong feelings of love for the relative or a willingness to do anything for the child in the future.	"I love her and I really do worry about what will happen to her when I'm no longer around to look after her. I can't discuss this with her siblings yet as they are too young, but I will".

Table 3.2 An outline of Expressed Emotion profiles on the Five Minute Speech Sample.

High EE		Low/Borderline EE
High Critical	High EOI	
Negative Initial Statement	Self-sacrificing Overprotection Lack of Objectivity	Neither High Criticism or EOI
Negative Relationship	Emotional Display	Borderline Critical. One or more Statements of Dissatisfaction
1 or more Criticisms	Combination of 2 or more: - Statement of Attitude - 5 + Positive Remarks - Excessive Detail	Borderline EOI A rating of borderline Self-sacrificing Overprotective Behaviour or 1 or more Statements of Attitude or Excessive Detail about the past or 5 or more Positive Remarks.

EE = Expressed Emotion

EOI = Emotional-over Involved

McCarty and Weisz (2002) suggest that the criteria for assessing high Expressed Emotion were derived from research on adult Schizophrenic patients, and have since been used with a variety of different populations including young children. McCarty and Weisz (2002) suggests that the criteria for scoring Expressed Emotion in relatives of patients with Schizophrenia may not be associated with risk or dysfunction in quite the same way in children without Schizophrenia. Leff and Vaughn (1987) had previously suggested that the criteria for assessing Expressed Emotion was not fixed and could be modified depending on the population. McCarty and Weisz (2002) and Wambolt, O'Connor, Wambol, Gavin and Klinnert (2000) suggest that the Emotional-over Involvement dimension of the Five Minute Speech Sample maybe inappropriate for parents of *adult* children, but may actually be developmentally appropriate for parents of *young* children, who are dependent and need their parents' emotional support. For example, it may be appropriate for parents of young children to recount

details of their child's birth or infancy, and praising the child's qualities may be rather normative and may not signal a pathological parent attitude or significant problem in the parent-child relationship. In contrast, the element of Criticism does seem more likely to indicate a problematic parent-child relationship, regardless of whether the parents were describing an older or a younger child.

Already researchers in developmental psychology have separated the Criticism and Emotional-over Involvement dimensions and findings do suggest the two separate components have different patterns of associations with child psychopathology. For example, high levels of criticism have been correlated with disruptive behaviors and conduct disorders (Baker, Heller, & Henker, 2000; Peris & Baker, 2000; Stubbe et al., 1993; Vostains & Harrington, 1994). Also high maternal Criticism has been related to child depression (Asarnow, Tompson, Woo, Cantwell, 2001). Yet, high Emotional-over Involvement has been associated with children's internalising problems and disorders (Stubbe et al., 1993). The above studies have generally not assessed the specific criteria that comprise the two components, nor have they evaluated the psychometric properties of Criticism or Emotional-over Involvement. So, while the use of Expressed Emotion is on the increase in research with children, there is still a lack of understanding its dimensions.

McCarty & Weisz (2002) recruited 165 boys and 93 girls through a mental health clinic. Children were referred to the clinic due to mood disorders, conduct disorders or substance abuse disorders. The children ranged in age from seven to 17 years. The results showed that the Criticism dimension of Expressed Emotion (using the Five Minute Speech Sample) was associated with child externalising behaviour. This finding has also been shown by Kershner, Cohen and Coyne (1996) and Wamboldt and Wamboldt (2000). However, the number of Positive Remarks a mother made was found to be associated with fewer externalising child behaviours. This result was also found by Chambless, Bryanm Aiken, Steketee and Hooley (1999). That is, the component of Positive Remarks is found to be negatively related to Critical

Comments and that the presence of Positive Remarks was related to the absence of child psychopathology rather than the presence of child psychopathology, which contradicts the traditional Expressed Emotion scoring method. The findings for the Emotional-over Involvement domain suggest that only: 1) emotional display, and 2) overprotective behaviour were associated with child psychopathology. This supports the idea that the scoring criteria for Emotional-over Involvement may not be appropriate for parents of young children. These findings suggest that the Emotional-over Involvement component of Expressed Emotion needs to be reconstructed for use with young child samples. McCarty and Weisz (2002) suggest that novel approaches to the measurement of parental Over Involvement should be considered and that previous studies using global categories of Expressed Emotion with young child samples could be revised attending separately to the Emotional-over Involvement versus Criticism components.

More recently, new measures have been developed or old measures adapted to measure Expressed Emotion. Many of these measures have only been used on a few occasions and most of them have reliability and validity problems. The first set of questionnaires was developed to assess Expressed Emotion from the patients' perspective (see sections 3.3.3 to 3.3.7). The second set of questionnaires was developed to assess Expressed Emotion from the healthy relatives' perspective (see sections 3.3.8 to 3.3.11).

3.3.3. The Level of Expressed Emotion Questionnaire

Using a self-report format the Level of Expressed Emotion Questionnaire (Cole & Kazarian, 1988) examines perceived Expressed Emotion from the patient's perspective. This questionnaire measure can distinguish between high and low Expressed Emotion using a mean cut off on its four scales. These scales are 1) Intrusiveness, 2) Emotional Response, 3) Negative Attitude towards the illness, and 4) Tolerance and Expectations concerning the patient. Internal consistency ranges between .84 and .89, test-retest reliability ranges between .67 and .82. Van Humbeek

et al. (2002) suggest that the Level of Expressed Emotion may be a good alternative to the Camberwell Family Interview but more effort needs to be invested to establish its current validity as the measurement of Expressed Emotion is from the patient's perspective.

3.3.4 .The Influential Relationships Questionnaire

The Influential Relationships Questionnaire (Baker, Helmes, & Kazarian, 1984) asks the patient to rate the behaviour of the two most important persons towards them. There are 37 items and three scales. This questionnaire is a good measure of Criticism, Hostility, and Over Protection. However, as this questionnaire was not developed to measure Expressed Emotion its construct therefore remains unclear and the concurrent validity has not been proven. There is also no way of identifying a cut off for high and low Expressed Emotion. Van Humbeeck et al. (2002) found internal consistency to range between .65 and .93 and test-retest reliability to range between .53 and .85.

3.3.5. The Perceived Criticism Scale

The Perceived Criticism Scale (Hooley & Teasdale, 1989) was originally designed to assess the amount of Perceived Criticism of Depressive patients' spouses. The questionnaire is usually only used in samples of patients with Unipolar Depressive Disorder. There are two items and there are no data on internal consistency. The two questions are: 1) How critical do you think you are of X?, and 2) How critical do you think X is of you? Van Humbeeck et al. (2002) found test-retest reliability to be $r = .75$

3.3.6. The Family Emotional Involvement and Criticism Scale

The aim of the Family Emotional Involvement and Criticism Scale (Shields, Franks, Harp, McDaniel, & Campbell, 1992) is to assess the relative's behaviour towards a patient. The questionnaire contains two core elements of Expressed Emotion: Criticism and Emotional-over Involvement. There are 14 items on this scale with two sub-scales. This scale has no clear cut-off points for high and low Expressed Emotion

but internal consistency is good (it ranges between .76 and .82) (Van Humbeeck et al., 2002). However, there are no data on test-retest reliability. This measure has only been used once. Therefore, it is unclear whether it is a good alternative to the Camberwell Family Interview.

3.3.7. The Patients' Rejection Scale

There are two versions of the Patients' Rejection Scale (Krelsman, Simmens, & Joy, 1979). One shorter measure examines a relative's Criticism and Rejection. The other longer measure also assesses Love, Acceptance, and Disappointment. Neither measure assesses Emotional-over Involvement. This scale has 11 items and only one scale. A cut-off score for high and low Expressed Emotion is not available but internal consistency is .78 and test-retest reliability is .72 (Van Humbeeck et al., 2002). Although both of the questionnaires were based on the Camberwell Family Interview, their concurrent validity have not been measured.

3.3.8. The Questionnaire Assessment of Expressed Emotion

The Questionnaire Assessment of Expressed Emotion (Docherty, Serper & Harvey, 1990) has two scales, Criticism/Hostility (70 items) and Emotional-over Involvement (29 items). In this questionnaire, family members have to indicate how often they conduct a specific behaviour towards a patient. The answers range from never to almost always. The authors provide clear cut-off points for high and low Expressed Emotion. There is good concurrent validity with the Camberwell Family Interview, internal consistency ranges between .90 and .96, and it has been suggested that this measure could be a good alternative to the Camberwell Family Interview although more information is required concerning its psychometric properties (Van Humbeeck et al., 2002).

3.3.9. The Adjective Checklist

The Adjective Checklist (Friedman & Goldstein, 1993) is a self-report measure and is considered a good starting measure to assess the relationship between a parent and a patient (Van Humbeeck et al., 2002). However, there is a lack of data for its predictive validity. This measure has 20 items and two scales (Positive Adjectives and Negative Adjectives). Internal consistency ranges between .88 and .92, there are no test-retest data (Van Humbeeck et al., 2002).

3.3.10. The Family Attitude Scale

The Family Attitude Scale (Kavanagh et al., 1997) was generated on the basis of existing questionnaires and the Expressed Emotion literature. There is no information on cut off scores and no Emotional-over Involvement scale is used. This questionnaire has 30 items but only one scale. Internal consistency is .95 and there is no test-retest reliability (Van Humbeeck et al., 2002).

3.3.11. The Family Environment Scale

The Family Environment Scale (Moos & Moos, 1981) is the only instrument that assesses both the relationship from the perspective of the patient and of the relative. The Family Environment Scale has 90 items and ten scales. There is no fixed internal consistency and no test-retest data. Vostains and Nicholls (1995) tested the construct and predictive validity of the Family Environment Scale by investigating whether its ratings distinguish between broad diagnostic groups of child psychiatric disorders and whether the ratings can predict clinical outcome. The self-rated Family Environment Scale was compared with the Camberwell Family Interview. Although Vostains and Nicholls (1995) found an association between family conflict and high levels of Expressed Emotion, the Camberwell Family Interview was found to be more strongly associated with child behaviour ratings than the parent rated Family Environment Scale. This finding was surprising as results were expected to be strongly associated. Roosa and Beals (1990) suggest that the low level of association between the measures is due to low levels of validity for certain sub-scales of the Family Environment Scale.

3.4. Selecting a measure of Expressed Emotion

Van Humbeek, et al's. (2002) review of the above measures recommends that the information required for an assessment of Expressed Emotion cannot be assessed by questionnaires alone. Vostains and Nicholls (1995) also suggest that these findings require replication and that self-reported measures of family functioning should be used with caution. Taken together these findings suggest that researchers use clinical interviews or observational measures when assessing Expressed Emotion in relatives or carers. Van Humbeek, et al. (2002) suggest that the Camberwell Family Interview still remains the best instrument for assessing Expressed Emotion. However, a quicker alternative to the Camberwell Family Interview is the Five Minute Speech Sample which is considered to be the best alternative as it provides a clearer understanding of the relationship between a relative and a patient than a questionnaire does.

Both the Camberwell Family Interview and the Five Minute Speech Sample have been used extensively within the research literature. Most of the other measures reviewed have been used less frequently. Research conducted on the reliability of the Five Minute Speech Sample and the degree of correspondence between the Camberwell Family Interview and the Five Minute Speech Sample, suggest that there is both good reliability and high correspondence (see section 3.3.2.1.) The predictive validity of the Five Minute Speech Sample has been demonstrated for some childhood disorders. High parental Expressed Emotion has been shown to be strongly associated with persistence of mood disorders in children (Asarnow, Goldstein, Tompson, & Guthrie, 1993). Thus, the Five Minute Speech Sample does have some predictive power when used to assess parental Expressed Emotion towards children.

3.5. Validation of Expressed Emotion

Exploration of the effect of Expressed Emotion on patients has taken three distinct lines, examining the association between Expressed Emotion and i) observational data; ii) psychological arousal, and iii) stressful life events. All of these suggest that families with high Expressed Emotion generate a stressful environment for patients.

In research using observational data results show that relatives who are rated high in Expressed Emotion behave differently from those who are rated low in Expressed Emotion (Valone, Goldstein, & Norton, 1984). Later studies also established that: i) those who scored high on the Criticism dimension of the Five Minute Speech Sample were more Critical during interactions, ii) those who score high on Emotional-over Involvement were more intrusive, and iii) those who are low in Expressed Emotion seem to be able to disengage from Critical interactions much earlier than those who are high in Expressed Emotion (Miklowitz, Goldstein, Fallon, & Doane, 1984; Strachan, Leff, Goldstein, Doane, & Burt, 1986). In a study by Kuipers, Sturgeon, Berkowitz and Leff (1983) behavioural characteristics of high and low Expressed Emotion relatives or carers were investigated along with behaviours of the patient. Kuipers et al. (1983) found that relatives or carers who were rated high in Expressed Emotion spent more time talking to the patient and less time looking at the patient than relatives or carers with low Expressed Emotion. This finding is consistent with Berkowitz, Kuipers, Eberlein-Vries and Leff (1989) who suggest that relatives or carers with low Expressed Emotion are better listeners than relatives or carers who are rated as high Expressed Emotion. Lastly, and more recently, Daley, Sonuga-Barke and Thompson (in press) found similar results with mothers of children with Attention Deficit Hyperactivity Disorder. These studies provide some behavioural validation for the concept of Expressed Emotion.

Psycho-physiological studies of Expressed Emotion were originally carried out to measure the impact of the home environment on the patient (Sturgeon, Kuipers, Beckowitz, Turpin, & Leff, 1981; Tarrier, 1988; Tarrier, Vaughn, Lader, & Leff, 1979). Tarrier et al., (1979) measured three physiological variables associated with the central nervous systems activation in non-acutely ill Schizophrenic patients. Due to the stress of the testing procedure, patients displayed elevated levels of skin conductance and higher blood pressure. The presence of a low Expressed Emotion relative appeared to enhance accommodation to the testing situation, resulting in a drop in blood pressure and a corresponding drop in skin conductance fluctuation. The

presence of high Expressed Emotion relatives did not have the same calming effect on the patient. The frequency of spontaneous fluctuation of skin conductance remained high and blood pressure increased slightly. Yet, later research (Sturgeon, Kuipers, Beckowitz, Turpin, & Leff, 1981) appears to contradict Tarrier et al's (1979) findings. Sturgeon et al. (1984) recruited a further ten participants and added the data to Tarrier et al's (1979). Re-analysis of the data using multivariate analysis of variance results did not replicate the original findings. However, there are several potential reasons why Tarrier et al's findings were not replicated (e.g. different patient diagnosis). Even though findings have not replicated the original work by Tarrier et al. (1979) there is some physiological evidence supporting the validity of Expressed Emotion.

3.6. Expressed Emotion Profiles

Although Brown et al. (1962) concluded that the Expressed Emotion concept is a good predictor of Schizophrenic relapse and a valid measure of the relatives' emotional engagement, there remained one question. What was the connection between the emotional attitude of the relative and the relapse of the patient? Brown et al. (1962) showed that patients from high and low Expressed Emotion families could not be distinguished by Schizophrenic symptoms or socially disturbing behaviour. This led Brown to the conclusion that it is the Critical Comments and the Emotional Attitude of the relative that influences patient outcome. Leff (1976) identified four styles of responding that tended to distinguish low Expressed Emotion relatives from high Expressed Emotion relatives: i) low Expressed Emotion relatives tended to be cool, controlled and concerned but not overly anxious in their response to the patient's illness, ii) low Expressed Emotion relatives tended to respect the patients desire for privacy and social distance; iii) low Expressed Emotion relatives saw the patient as suffering from a recognisable illness, and not as a malingerer or someone who was responsible for their symptoms; and iv) low Expressed Emotion relatives were less impatient, and more tolerant of the patient's behaviour, but also represent recognisable parental or caregiver personality types.

Hubschmid and Zemp (1989) hypothesised that high Expressed Emotion relationships were characterised by patterns of interaction which were particularly stressful for relatives and patients alike. Results from a semi-structured interview were coded using a technique called Structural Analysis of Social Behaviour. Results showed that Expressed Emotion measures correlated strongly with certain features of the parent-carer relationship. Specifically, high Expressed Emotion compared to low Expressed Emotion showed a more negative emotional atmosphere. The structure of this relationship was rigid, conflict prone, and demonstrated an inflexible pattern of interaction.

Research with children and parents has also explored profiles associated with Expressed Emotion. Expressed Emotion was assessed in mothers of pre-school children using a modified version of the Five Minute Speech Sample (Daley, Sonuga-Barke, & Thompson, in press). Validation of Expressed Emotion was assessed using a ten minute observation session and the Family Impact Questionnaire. Initial Statement was significantly correlated with the Negative and Positive dimensions of the Family Impact Questionnaire, Maternal Affection, and Joint Play. Warmth was significantly correlated with both the Negative and Positive dimensions of the Family Impact Questionnaire, Maternal Praise, Affect, and Direction. Relationship was significantly correlated with both the Negative and Positive dimension on the Family Impact Questionnaire, Maternal Expansion, and Affection. Critical Comments were significantly correlated with both Negative and Positive dimensions of the Family Impact Questionnaire, Maternal Affect, Direction, and Joint Play. Positive Remarks were significantly correlated with both the Negative and Positive dimensions of the Family Impact Questionnaire. These data provide further validation support for Expressed Emotion in young children using the Five Minute Speech Sample.

3.7. Expressed Emotion in Research with Adults

It has been demonstrated repeatedly that relapse among schizophrenic patients can be predicted by Expressed Emotion status of the family to which the patient returns. King (2000) examined the direction of influence between the symptom severity in Schizophrenic young adults and the Expressed Emotion of their mothers, using a longitudinal design. Twenty-eight families who had a young adult, between the ages of 19 and 37 years (ten were female), with a diagnosis of Schizophrenia participated in the study. Mothers of these schizophrenic patients were interviewed three times at nine month intervals. The two measures used were the Camberwell Family Interview, to measure maternal Expressed Emotion, and the 24 item Brief Psychiatric Rating Scale to assess severity of patient symptoms. The result of the study failed to find any evidence that Expressed Emotion in mothers was associated with either concurrent or subsequent symptom exacerbation in their young schizophrenic adults. Instead, the study found that there was a temporal stability for both Critical Comments and Emotional-over Involvement in the mothers and symptom severity in the patients. This study found, that for example, 44% of the variance in Critical Comments could be explained by the number of Critical Comments made nine months earlier. When patient negative symptoms were controlled for, 70% of the variance in mothers' Critical Comments could be explained. This identifies that highly critical mothers were critical because they had been critical in the past and because their children had more severe symptoms. These findings suggest that it is the mothers' response to their child's symptoms which leads to high Expressed Emotion.

The relationship between Expressed Emotion and relapse of Depressive symptoms was first assessed by Vaughn and Leff (1976). They found that relatives of depressed patients were just as critical as relatives of schizophrenic patients, but there was a virtual absence of Emotional-over Involvement within these relatives. Ten years later Hooley, Orley and Teasdale (1986) carried out a replication study of Vaughn and Leff's original study. The findings of this replication study were very similar to Vaughn and Leff's with 51% of patients with Depression relapsing and 18% being re-

hospitalised compared to 53% relapse and 23% hospitalisation in Vaughn and Leff's (1976) study. These findings are also replicated in the depressed elderly (Adelstein & Hinrichsen, 2001).

Other studies have determined that psychiatric risk due to Expressed Emotion is not limited to Schizophrenia. For example, Chambless et al. (2001) examined Expressed Emotion with obsessive-compulsive and agoraphobic outpatients. One hundred and one participants with a DSM-III-R diagnosis of either of these anxiety disorders participated in the study. Findings suggest that Expressed Emotion can predict negative treatment outcomes for anxiety disorders. The most consistent predictor of negative treatment outcome was hostility as measured by the Camberwell Family Interview. The findings suggest that if relatives or carers had a hostile rating the odds were approximately six times greater that patients would drop out of treatment than if the relative or carer had no rating of hostility.

Relatives' Expressed Emotion has also been assessed in relation to treatment outcome in adults with Post Traumatic Stress Disorder (Tarrier, Sommerfield, & Pilgrim, 1999). Participants had a diagnosis of Post Traumatic Stress Disorder from the DSM-III-R. Thirty-one participants who had been diagnosed with Post Traumatic Stress Disorder for at least six months but no longer than ten years agreed to participate in the study. Participants completed the Impact of Events Scale; the Penn Inventory (a measure that assesses Post Traumatic Stress Disorder symptoms); the General Health Questionnaire; the Beck Depression Inventory; the Beck Anxiety Inventory and a close relative of the patient completed the Camberwell Family Interview. The results identified that patients living with low Expressed Emotion relatives showed significantly greater improvement in treatment than patients living with high Expressed Emotion relatives. The only significant predictors of Post Traumatic Stress Disorder were Hostility and Criticism. Therefore, the quality of the relationship between the patient and the relative does appear to have a significant effect on the patient's treatment response.

Research on Expressed Emotion in relatives or carers of adult and adolescent diabetics is somewhat contradictory. Results from Stevenson, Sensky and Petty (1991) suggest that there is no association between glucose control and any of the Expressed Emotion scales except Emotional-over Involvement, for which higher levels of Emotional-over Involvement were associated with better glucose control. It is assumed in these studies that a degree of Emotional-over Involvement in relatives of patients with Diabetes may be helpful whereas in studies with Schizophrenic patients Emotional-over Involvement is detrimental to recovery. More recently Koenigsberg, Klausner, Pelino, Rosnick and Campbell (1993) found evidence that relatives' Critical Comments were positively correlated with patients' poor glucose control.

3.8. Expressed Emotion in Research with Children

Although the majority of Expressed Emotion studies have been conducted using adults suffering from psychotic illness, at the beginning of the 1990's the Expressed Emotion construct was applied to children. Weintraub and Wambolt (1996) suggest that due to immaturity, helplessness and dependency on parents, children were more vulnerable to the damaging effects of a relative or carer high Expressed Emotion than adults.

A literature search using PsycINFO and Web of Science from 1992 - 2001 concerning parental Expressed Emotion in children found a combined total of 202 studies. The research identifying parental Expressed Emotion related to a vast number of different childhood issues. A selective review is presented below.

Parental Expressed Emotion has been researched on children with, for example, asthma (Wambolt et al., 2000); depression (Stein et al., 2000); externalising behavioural problems (Peris & Baker, 2000); schizophrenia (Hamilton, Asarnow, & Thompson, 1999); obsessive compulsive disorders (Steketee, Van Noppen, Lam, & Shapiro, 1998); hyperactivity (Roberts, Block, & Block, 1984); eating disorders (Schmidt, Humfress, & Treasure, 1997); conduct disorders (Vostanis, Nicholls, & Harrington, 1994) and general psychopathology (Hirshfield et al., 1997). This large body of

literature suggests that there are positive associations between high parental Expressed Emotion and child psychopathology.

Early findings on the possible role of Expressed Emotion in children arose from studies of individual components of Expressed Emotion such as warmth and hostility (Vostanis et al., 1994). Findings from such studies reported an association between lack of parental warmth and the presence of hostility and child behavioural disturbances (Quinton & Rutter, 1995; Richman, Stevenson, & Graham, 1982). Later studies used a dichotomy of high/low parental Expressed Emotion. These later studies found an association between high maternal criticism and both the presence of maternal depressive illness, and at least one child psychiatric disorder, such as conduct disorder, substance abuse (Schwartz, Dorer, Beardslee, Lavori, & Keller, 1990), disruptive behaviour and obsessive compulsive disorders (Hibbs et al., 1991).

A number of studies have shown an association between parental Expressed Emotion and childhood behavioural problems (e.g. Baker et al., 2000; Hibbs et al., 1991; Hirshfeld et al., 1997; Vostanis et al., 1994). For example, Hirshfeld et al. (1997) in a systematic investigation of the association between behavioural inhibition and Expressed Emotion found that mothers expressed higher rates of Criticism/Dissatisfaction towards behaviourally inhibited children.

Children with behavioural problems show increased social incompetence and academic difficulties, and have lower self-esteem (Jacobs et al., 2002; Rey, Walter, Plapp & Denshire, 2000). These children have a need for increased family guidance. However, as described in Chapter One, parents of these children are more inclined to show elevated levels of stress and dissatisfaction with their parenting. Understanding the home environment becomes important for understanding the bi-directional relationship between parents and children as previous research has shown that these mother-child interactions may be correlated to the development of child psychopathology.

Peris and Baker (2000) looked at child behaviour at pre-school, first grade, and third grade. They investigated whether high Expressed Emotion, Criticism and Emotional-over Involvement were related to child behavioural problems and whether pre-school Expressed Emotion predicted later child behavioural problems. Expressed Emotion scores derived from the Five Minute Speech Sample demonstrated significant stability over a two year period, from pre-school to first grade. Expressed Emotion ratings at pre-school were predictive of Attention Deficit Hyperactivity Disorder symptoms and a diagnosis of Attention Deficit Hyperactivity Disorder at third grade assessment. The stability of Expressed Emotion across child development may reflect a consistent feature of parental attitude. Expressed Emotion was found to be highly related to problem behaviour in children, and may reflect mother's reactions to their child's behaviour.

Studies have also examined Expressed Emotion in children with neurological disorders. A recent prospective cohort study investigated whether Expressed Emotion was associated with levels of compliance in childhood epilepsy (Hodes, Garralda, Rose, & Schwartz, 1999). Twenty-one participants (13 males) with a mean age of 12 years participated in the study. A paediatric case note review was undertaken to identify the proportion of appointments attended and adherence to anti-convulsant regime. Mothers of the patients were interviewed using the Camberwell Family Interview to assess level of Expressed Emotion. Mothers were also asked to complete the General Health Questionnaire and were asked questions about the amount of social support they received. Teachers were asked to complete the Harter Self-Esteem Questionnaire and a depression measure for each patient. The results suggest that maternal hostility at initial assessment and criticism at follow up were significantly higher in the poor compliance group. Child behavioural problems, specifically anti-social behaviour, were also significantly higher in the poor compliance group.

Even when family context is controlled (i.e. using a within family design), differences in Expressed Emotion still exist. The next study utilizes a within family design. Hodes

et al., (1999) compared maternal Expressed Emotion towards siblings with and without epilepsy. They hypothesised that mothers would show increased levels of Expressed Emotion towards children with epilepsy due to higher levels of criticism, severity of epilepsy and level of social support experienced by the mother. Parents of 22 children with epilepsy aged between 6 and 17 years participated with a sibling, close in age to the child with epilepsy, who had no health problems. Children were matched on gender, 13 male and 9 female sibling pairs. Maternal Expressed Emotion was assessed using the Camberwell Family Interview. Results showed that there was significantly more maternal Emotional-over Involvement and a trend towards more Hostility towards children with epilepsy when compared to sibling controls. However, there were no differences in terms of number of Critical Comments. Hodes et al. (1999) conclude that the elevated levels of maternal Emotional-over Involvement towards their child with epilepsy compared to healthy siblings may not be a case for concern, and may be appropriate due to the additional support the child may require.

3.9. Expressed Emotion Research in the Field of Learning Disabilities

3.9.1. Staff-Patient Relationships

Cottle, Kuipers, Murphy and Oakes (1995) addressed the issue of patient violence and levels of Expressed Emotion. Care staff from three different wards in a large psychiatric hospital completed the Camberwell Family Interview and a measure of anxiety. One of these wards dealt with 11 people with mild learning disabilities and behavioural problems. The second ward dealt with seven individuals with chronic mental health needs. The third ward dealt with both mild and severe learning disabilities. Care staff that had been involved with a violent incident were interviewed within one week of the incident and then again one month later. Within a month of the incident 56.6 % of staff had high Expressed Emotion yet, after a month the number of staff with high Expressed Emotion rose to 66.6 %. Both patients with learning disabilities and those with mental illness induced high Expressed Emotion in staff. Staff who expressed high Expressed Emotion due to an incident with one patient did not also show high Expressed Emotion towards other patients with who they had not

had a violent incident. Again this result demonstrates that Expressed Emotion has more of a state like element than a trait like element. In this research no baseline of Expressed Emotion was taken so it was not clear whether the rise in Expressed Emotion was due to incidents of violence or the feeling care staff had towards the patient. Findings from the other published studies replicate these findings and suggest that staff with high Expressed Emotion are critical towards their patients but not Emotionally-over Involved (Cottle et al., 1995; Van Humbeek et al., 2001). Research on staff Expressed Emotion towards patients with learning disabilities has found high Emotional-over Involvement in only one study (Stark & Siol, 1994).

3.9.2. Parent-Child Relationships

The first study of Expressed Emotion focused on children with learning disabilities, was Greedhardy (1987). He believed that mothers who had children with learning disabilities might demonstrate extremes of behaviour towards their children, from over-protection, to complete rejection. Greedhardy suggested that mothers might not actually be aware of their own behaviour towards their child, so explored this hypothesis by examining these mothers' Expressed Emotion. A parent, or the next of kin, to ten adults with learning disabilities ranging in age from 16 to 50 years old, were interviewed for 40 to 60 minutes using the Camberwell Family Interview. This research found that, within families who have a child with learning disabilities, there was no Hostility and only one Critical Comment was made in each of the four families. Warmth was rated between two to three times across all families. Emotional-over Involvement was rated as low in seven of the families, was borderline in two families, and high in the last family.

Research by Dossetor et al. (1994) suggests that high parental Expressed Emotion may be associated with parenting difficulties, which would be reflected in family functioning and the home environment. Fifty children aged between 14 to 19 years who had severe learning disabilities participated in their study. Parents of these children were interviewed using the Camberwell Family Interview among other

measures. The aim of the study was to examine the value of Expressed Emotion as a measure of the relationship between the carer and the adolescent with learning disabilities. The hypothesis was that high Expressed Emotion of the carer towards the adolescent with learning disabilities would be associated with difficulties in the adolescent and carer relationship, and would also be reflected in family functioning and the home environment. Results showed high Expressed Emotion in 35% of parents and nine percent of other carers. Testing of the relationship of Expressed Emotion to other studies shows that high Expressed Emotion was significantly related to carers' psychological ill health, poor practical social support, and insecure style of respite care usage. From the interviews, high Expressed Emotion was significantly related to lower levels and fewer sources of practical help, poorer quality of the marriage, dissatisfaction towards services, and recent difficulty in bringing up their child. Dossetor et al. (1993) found that parents who exhibited high Emotional-over Involvement were those who had a poor quality of marriage and less social support than parents who were not Emotionally-over Involved. The children of high Emotionally-over Involved mothers had more severe learning disabilities and showed greater behavioural disturbances in public. Parents who were highly critical of their children had children with less severe learning disabilities, had less overall behavioural disturbances but were extremely active and got agitated easily.

Greenhardy's (1987) study was only a pilot study with few participants. The second study by Dossetor et al. (1993) found results similar to those in research with schizophrenic patient. The relationship between parents and children with learning disabilities was more negative when parents had a high Expressed Emotion rating. These parents were also more likely to have other problems (e.g. lack of social support and respite care for their child). As with studies on diabetes, mothers may be Emotionally-over Involved with their child but this maybe appropriate. However, Dossetor did not comment on this finding.

Research on parental Expressed Emotion towards children with learning disabilities, although not identifying outcome in these children, does provide important information on the relationship parents have with their children. Research findings thus far suggest that there are deficits in the relationship parents have with their child with learning disabilities. Future research is required to replicate these findings, to identify what may predict negative relationships between parents and children with learning disabilities, and what might be the outcomes of high Expressed Emotion.

3.10. Chapter Conclusions

Expressed Emotion is a measure of negative emotions or intrusive over concern with a family member and has come a long way since its conception in the late 1950's. The concept of Expressed Emotion is developing as more researchers acknowledge its potential. Expressed Emotion has already been used in many areas of research. There is now a large body of literature that measures Expressed Emotion in relatives or carers towards adults with a variety of different psychopathological disorder and more recently health problems (i.e. asthma). Within the adult literature is a small body of literature on Expressed Emotion in staff carers towards people with learning disabilities. Literature is now emerging that considers parental Expressed Emotion towards children. These studies have also identified child psychopathological problems as well as health related issues. However, little research has been conducted specifically relating to children with learning disabilities.

Although it has not been established whether parental Expressed Emotion is primarily the cause or result of child psychopathology there is an association between high parental Expressed Emotion and poor child outcome. These findings have been validated using observation measures which also find that relatives with high Expressed Emotion do interact with patients differently than relatives with low Expressed Emotion. This body of research supports the utility of the Expressed Emotion concept as an assessment of the emotional dimension of parent-child relationships. Expressed Emotion may also have very significant implications for

outcome in children. Therefore, it appears there is value in the concept of exploring the relationship between parents and children in families with children with learning disabilities.

The next Chapter discusses methodological issues related to research on children with learning disabilities and makes a final conclusion on the measure which will be used to assess Expressed Emotion within this thesis.

CHAPTER FOUR

Methodological Issues

The aim of this chapter is to present methodological issues related to the study of parenting children with and without learning disabilities. Firstly, research questions are presented which have been developed out of the literature reviews in the previous two chapters. A design and methodology for this thesis is then discussed, taking into consideration the review of research on parent-child interactions from Chapter Three. Despite the amount of information collected on families which have children with learning disabilities, there is a lack of consensus regarding the experiences of these families (Dyson, 1996). The inconsistency in the literature raises questions that need to be addressed (Minnes, 1998). Two of the main issues surrounding inconsistencies within research on parents who have children with learning disabilities are: i) the complexity of disabilities, and ii) the large number of potentially significant variables and design issues (e.g. chronological age or mental age comparisons, gender matching, and methodological design). Furthermore, research on families who have children with learning disabilities has also seen a limited amount of replication. Measures are seldom used more than once as researchers consider every aspect of the family in their attempt to identify many different domains of family life. Therefore, this chapter discusses research instruments, including the Camberwell Family Interview and the Five Minute Speech Sample to assess Expressed Emotion, (see Chapter Three for a review of Expressed Emotion measures) and parenting questionnaires to measure child and parenting behaviour. Lastly, a plan of research is presented for the empirical work contained within this thesis.

4.1. Research Questions

Chapter One and Chapter Two established that a child with learning disabilities does have a fundamental influence on many domains of family functioning including parental stress. Furthermore, research evidence is consistent with the view that parents behave differently towards children with learning disabilities than they do to other children. Expressed Emotion may be a useful concept in a further explanation of parent-child relationships in families containing a child with learning disabilities. The overall area of research interest is whether parents parent a child with learning disabilities differently from a sibling who is typically developing. Specific questions are:

- What, if any, are the differences in maternal Expressed Emotion towards siblings with and without learning disabilities? That is, what differences are there in the emotional relationship a mother has towards her children with and without learning disabilities?
- Why may there be differences in a mother's relationship towards her children with and without learning disabilities? That is, what parental and other factors may predict, for example, a more negative emotional relationship towards a child with learning disabilities?
- The working model (Deater-Deckard, 1998) suggests that child variables affect parental stress that in turn affects child outcome via an impact on parenting behaviour. Other research also identifies that parent-child effects may be bi-directional (Patterson, 1982). This thesis also aims to identify some tentative relationships between maternal Expressed Emotion and child functioning (specifically, behavioural problems) using a longitudinal research design.

4.2. Research Design

4.2.1. Comparison Groups - Between or Within Family Design?

The studies reviewed in Chapter Two provide evidence that suggests there are methodological problems within the current literature. The problems highlighted include sample sizes, matching criteria, and design methodologies. Past research has used a variety of sample sizes which reduces the ability to generalise findings. Also, within these studies, researchers have used a variety of different matching criteria including gender, socio-economic status, and parental education level. Comparison groups for families who have children with learning disabilities have been reviewed by Stoneman (1989). Stoneman's (1989) review suggests that comparison groups are essential for understanding the functioning of families who have children with learning disabilities. Yet, within the literature, researchers have used inappropriate comparison groups which can be misleading or uninterpretable (Stoneman, 1989). Research articles lack description of participants, inattention to important demographic factors that constitute confounding variables, and lack creativity and innovativeness in conceptualisation and design (Stoneman, 1989). Many of the problems of comparison groups are easily solved (e.g. researchers can elaborate on demographic information about participants). According to Stoneman (1989), the simplest and most straightforward solution is for researchers to employ rigorous matching procedures to ensure that groups are equal on all important demographic variables. Alternatively, research needs innovative ideas to push family research forward methodologically.

The traditional approach to studying family relationships assumes that children in the same family are exposed to similar parenting attitudes and beliefs. However, research data suggest that children are unique in the responses they give to their parents (Belsky, 1984; Shucksmith, Hendry, & Glendinning, 1995). Furthermore, during the 1980's studies in behavioural genetics began to challenge the assumption that children from the same family experience broadly similar environments. Behavioural genetics research found that environmental influences which are relevant to child development are those that make children within the same family different, not similar. That is, the

concept of a non-shared child rearing environment recognises that parents may interact with, or structure, a child's physical or social world differently from that of his or her sibling. For example, Plomin and Daniels (1987) state that siblings raised within the same family are often as different from one another with regard to personality, psychopathology, and behavioural problems as children raised in different families. These sibling differences are more than likely due to non-shared environmental experiences, specifically differential parental treatment (i.e. how children within the family are treated in relation to one another). Research from behavioural geneticists finds that parental affection can be thought of as a source of difference among children in the same family i.e. parents can be more affectionate towards one child than another (Plomin & Daniels, 1987). Furthermore, environmental influences do not result in sibling similarity (Hoffman, 1991). Several researchers have argued that clinicians considering environmental causes of psychopathology should consider non-shared environmental factors that makes siblings different (Plomin, Asbury, & Dunn, 2001). Also highlighted in Plomin et al's (2001) paper is that research has not yet investigated the relative influences of unshared environmental influences in extreme circumstances. The example Plomin et al. give is abusive families. However, in this thesis we are interested in a mother's emotional relationship towards her children with and without learning disabilities.

Most research on parenting and child behaviour has only explored variability between families (Deater-Deckard, 1996). This is problematic because families are usually quite different from one another. The majority of research reviewed in Chapter Two concerns families of typically developing children and comparisons to families who have a child with learning disabilities. Furthermore, there are very few studies using a within-family design which this thesis argues may be the strongest in considering whether parents behave differently towards children with learning disabilities.

Research conducted on differential parenting in families of children with learning disabilities suggests that the typically developing sibling may encounter less parental attention (McKeever, 1983), and have increased care and chore responsibility (McHale & Gamble, 1989). McHale and Pawletko (1992) proposed that differential treatment of siblings may be even more extreme when the younger sibling has a learning disability. McHale and Pawletko (1992) also suggested that there are greater differential parenting differences in families who have children with learning disabilities than in families who have typically developing children. Their results suggest that parents spend the majority of parent-child contact with their child with learning disabilities. However, parents who have children with learning disabilities and also typically developing children spend more time with their typically developing child when compared to families who only have typically developing children (McHale & Pawletko, 1992). The time spent with typically developing children was thought to be intended as “compensation” for the amount of time their child with learning disabilities utilised.

More recently, data from Wolf, Fisman, Ellison and Freeman (1998) confirm the complexity of sibling perceived parental differential treatment in families who have children with learning disabilities. This research identified that siblings of children with pervasive developmental disorders thought that they were preferred over their sibling with learning disabilities. In contrast, siblings of children with Down Syndrome believed they were not favoured over their sibling with Down Syndrome. The implication of this research is that typically developing siblings who believe they are preferred over their sibling with learning disabilities may experience a complex variety of emotional reactions. These emotional reactions included feelings of guilt, anxiety and anger. Where typically developing siblings perceive their sibling with learning disabilities was preferred over them, the typically developing siblings also reported lower self-competence and were described by their parents and teachers as having more internalising symptoms.

In conclusion, the influence a child with learning disabilities has on the family makes generalisation to families without children with learning disabilities impossible.

Therefore, it makes sense to use families where one child has a learning disability but also identify a sibling who is typically developing as a comparison. Using this within family research design alleviates the problems of comparing families who have a child with learning disabilities to families who have no children with learning disabilities.

Using a within family design provides a control for variables such as social economic status, parent education, and parent income. A further complicating factor in family research in this field is that mothers and fathers seem to have a very different parenting experience (e.g. Simmerman, Blacher, & Baker, 2001). In order not to introduce a further design factor at this stage the empirical work focuses on mothers only. Practically, this also maximised the availability of participants.

4.3. Measuring Parenting

Chapter Three argues that Expressed Emotion may constitute a useful measure of the parent-child relationship especially in distinguishing the emotional quality of mothers' relationships with their different children. However, there is a myriad of potential measures but only one is needed for the present research.

Van Humbeek, et al's. (2002) review of Expressed Emotion measures recommends that the information required for an assessment of Expressed Emotion cannot be assessed by questionnaires alone. Vostains and Nicholls (1995) also suggest that findings from questionnaires require replication and that self-reported measures of family functioning should be used with caution. Both the Camberwell Family Interview and the Five Minute Speech Sample have been used extensively within the research literature. Van Humbeek, et al. (2002) suggest that the Camberwell Family Interview still remains the best instrument for assessing Expressed Emotion. However, a quicker alternative to the Camberwell Family Interview is the Five Minute Speech Sample which also provides a clearer understanding of the relationship between family members than a questionnaire does.

This thesis aims to collect data from mothers on a selection of maternal variables and also some child variables. If the Camberwell Family Interview is used to measure maternal Expressed Emotion then this dramatically reduces the time remaining for collecting data on other variables. Therefore, due to the amount of time required to be trained in administering the Camberwell Family Interview (approximately one month) and the additional amount of time taken for coding each interview (around two hours), this thesis will use the Five Minute Speech Sample for assessing Expressed Emotion. However, there is a lack of psychometric data for the use of the Five Minute Speech Sample on mothers of children with learning disabilities. Therefore, the first study of this thesis needs to identify reliability data for the use of the Five Minute Speech Sample on mothers of children with learning disabilities.

There may still be a need to measure further aspects of parenting in the course of any empirical work. In particular, parenting beliefs or attitudes (generally considered trait measures) might partially account for why some parents tend to treat their children more similarly or differently than others. However, there is a large number of potential scales available and some rational selection needs to be made.

4.3.1. Questionnaire Measures on Parenting

Assessments of parenting have been reviewed critically by Holden and Edwards (1989). Out of 84 scales reviewed only six, according to Holden and Edwards (1989), have been used relatively frequently. These questionnaires are: the Parent Child Relations Questionnaire (Roe & Siegelman, 1965); the Parent Behaviour Form (Kelly & Worell, 1976); the Parent Practice Questionnaire (Devereux, Bronfenbrenner, & Rodgers, 1969); the Parent Behavioural Questionnaire (Siegelman, 1965) the Child's Report of Parent Behaviour (Droppleman & Schaefer, 1963) and the Parental Attitude Research Instrument (Droppleman & Schaefer, 1963; Schaefer, 1965).

In general, the measures reviewed in Holden and Edwards' (1989) article are relatively long, often exceeding 100 items. Their psychometric properties are often questionable with regard to the lack of reported reliability and validity of the measures. When reliability is reported, it often demonstrates only marginally acceptable consistency. Most investigators have invented new measures resulting in few instruments seeing repeated use, and as a result few replicated studies. However, questionnaires are easily administered and therefore large sample sizes can be recruited, adding power to questionnaire studies. Limitations of questionnaires include the possible ambiguous nature of questionnaires, and for this particular study, being self-reported behaviour. That is, mothers may be embarrassed to complete the questionnaire honestly or report what they think they should report.

Given concerns over replicability, a check was made on the recent use of parenting questionnaires. A Web of Science search from 1981-2000 was used. These questionnaires included: the Child Rearing Practice Report (Rickel & Biasatitill, 1982), which assesses Parental Restrictive and Nurturant behaviour; the Parent Behaviour Checklist (Fox, 1994), which assesses what children should be able to do at certain ages; the Parent Child Relationship Inventory (Heatherington & Clirigempeel, 1992), which identifies Parenting Skills, Attitudes, Satisfaction and Role Orientation; the Parental Authority Questionnaire (Buri, 1991), which assesses Parenting Practice; the Parent Sense of Competence Questionnaire (Johnston & Mash, 1989), which measures Parenting Efficacy and Satisfaction in the parenting role, and the Parent Styles and Dimensions Questionnaire (Robbinson, Mandleco, Frost, Olson, & Hart, 1995), which breaks down parenting behaviour into Baumrind's Typologies (Authoritative, Authoritarian, and Permissive parenting styles). These questionnaires were identified as being used on more than one occasion. Only one of these questionnaires, the Parenting Sense of Competence Questionnaire, has been used on parents of children with learning disabilities.

The review of questionnaires by Holden and Edwards (1989) identified that many were not reliable or valid. However, two measures that have seen repeated use within research on parenting are the Child Rearing Practice Report (Rickel & Biasatitill, 1992) and The Parenting Sense of Competence Questionnaires (Johnston & Mash, 1989). These two measures work in accordance with each other as one measures beliefs about child rearing and the other measures satisfaction and efficacy. Therefore, using these questionnaires together would help establish a broad assessment of trait variables in mothers of children with learning disabilities. Also, both questionnaires are relatively short which is important as parents may be less willing to complete lengthy questionnaires. Although the Child Rearing Practice Report has not been used with parents of children with learning disabilities it has been used with parents of children with behavioural problems (Hastings, Zahn-Waxler, Robinson, Usher, & Bridges, 2000). However, it will still be important to explore its psychometric properties for mothers of children with learning disabilities.

4.4. Controlling for Salient Child Variables

Chapter Three identifies a large body of literature which suggests that there are positive associations between high parental Expressed Emotion and psychopathology. Specifically, this research suggests that children with more severe problem behaviour and more severe learning disabilities have parents with high Expressed Emotion. Therefore, measures of children's developmental age and problem behaviour need to be included in any within family sibling comparisons. In particular, the importance of childrens' mental age must be considered.

Children with learning disabilities are usually matched on either chronological age or mental age in comparison designs. The major methodological disadvantage in using chronological age matching involves equating research tasks across groups when children differ in competence. Chronological age-matched designs can identify facets about family life that differ in families with a learning disabled child, but do little to help explain or identify the processes that underlie these differences. Mental age

matching is used to equate children with and without learning disabilities on general intellectual ability. This is generally recognised as the preferred approach in family research (Stoneman, 1989), but also from the broader developmental perspective in learning disability research (Hodapp & Zigler, 1995). This perspective asserts that differences between children with non-organic learning disabilities of the same chronological age can be attributed simply to developmental delay. In the context of the present research, chronological age matching is also not practical without access to a sample of twins where one has a learning disability and one does not. Secondly, a measure is needed that can be used to assess functioning in children with or without learning disabilities. Finally, given that most data are to be collected from mothers, it is most economical to select a measure that can rely on parent report rather than the researchers direct contact with the children concerned.

A measure that clearly addresses all of these issues is the Vineland Adaptive Behaviour Scale (Sparrow, Balla, & Cicchetti, 1984). The Vineland Adaptive Behaviour Scale is administered to a parent of the child and asks what the child does, not what the child can do. There are a number of adaptive functionings: Communication, Daily Living Skills, Socialisation, and Motor Skills. The Vineland Adaptive Behaviour Scale has been extensively used within the literature on learning disability. One recent review suggested that it has been used in around 60% of studies measuring Adaptive Behaviour, Curriculum/Education, Intellectual and Language Domains (Luiselli et al., 2001). The measure is described in more detail in section 5.2.3.

A further key issue raised in Chapter One is the elevated level of behavioural problems in children with learning disabilities. Research in this thesis needs to include a measure of behavioural problems because: i) behavioural problems occur more frequently in children with learning disabilities than typically developing children, and ii) child behavioural problems are a major variable affecting parent functioning. Having established that behavioural problems need to be measured, a robust, short, reliable

measure is required. The measure chosen also needs to be appropriate for both children with and children without learning disabilities.

Research conducted on levels and types of behavioural problems in children with learning disabilities has identified few instruments which have been developed specifically for use on children with learning disabilities that have also been subject to rigorous psychometric testing (Aman, 1991). The exceptions to this are the Developmental Behavioural Checklist (Einfeld & Tonge, 1994) and the Nisonger Child Behaviour Rating Scale (Aman, Tasse, Rojahn, & Hammer, 1996). Other general child psychopathology questionnaires have been used with children who have learning disabilities including the Child Behaviour Checklist (Achenbach, 1991); the Strengths and Difficulties Questionnaire (Goodman, 1997), and the Rutter scales (Elander & Rutter, 1996). In order to use the same measure to assess children with learning disabilities and their siblings, a compromise has to be reached as to whether to include a learning disability specific measure or a more general questionnaire. As learning disability specific measures have typically been less rigorously tested than general child measures, the latter seem the best option. An excellent candidate for a short but robust and sensitive measure is the Strengths and Difficulties Questionnaire (Goodman, 1997).

Goodman added items to the Rutter questionnaire (Elander & Rutter, 1996), including consideration, impulsivity-reflectiveness, having friends, being victimised and acting pro-socially in order to develop the Strengths and Difficulties Questionnaire. A factor analysis conducted on the combination of the old and new questions identified five distinct dimensions (Hyperactivity, Emotional Problems, Peer Problems, Pro-social Behaviour and Conduct Disorder). Using these dimensions the Strengths and Difficulties Questionnaire was designed. The Strengths and Difficulties Questionnaire is therefore a brief behavioural screening questionnaire which considers, as its name suggests, both strengths and difficulties of the child. Goodman (1997) provides good concurrent validity of the Strengths and Difficulties Questionnaire against the Rutter

questionnaires (e.g. Total Difficulties of .62). Evidence from Goodman's (1999) paper suggests good correlations between the Child Behaviour Checklist and the Strengths and Difficulties Questionnaire (.87 for Total Difficulties, .84 for Conduct Disorder, .71 for Hyperactivity, .74 for Emotional Problems and .59 for Peer Problems).

Goodman (1999) also demonstrates good test-retest reliability for Total Difficulties score (at .85). Unfortunately, the Strengths and Difficulties Questionnaire psychometric characteristics have not been tested for children with learning disabilities. This is another methodological task that needs to be addressed.

4.5. Procedural Issues

A number of difficulties were experienced in the present research in assessing mothers willing to participate. Therefore, I had to explore a methodology that reduced the need for face to face contact in order to maximise the sample for each study. Most measures could be administered via questionnaires in the mail. However, the Vineland Adaptive Behaviour Scale and the Five Minute Speech Sample are presented in an interview format. It was decided to explore the potential to complete these measures over the telephone. This method of data collection was chosen to maximise the number of possible participants (i.e. a national sample could be used). As the validity of the Five Minute Speech Sample and the Vineland Adaptive Behaviour Scale has not been established for use over the telephone Chapter Five will include a test of this issue.

4.6. Plan of Research

Stage 1 of the research, as mentioned in this chapter, is a reliability check of the measures to be used on mothers of children with learning disabilities. As Holden and Edwards (1989) suggest, most researchers assessing parenting have not used appropriate measures with adequate reliability and validity data. Where research has used reliable and valid measures, findings have often not been replicated. It is therefore essential that the first study of this thesis acknowledges that some of the measure that are to be used within this thesis have not been used on mothers of children with

learning disabilities and therefore need to be piloted within this group. The results of this study are presented in Chapter Five.

Stage 2 is an exploration of maternal Expressed Emotion using a within family design (i.e. is there a difference between maternal Expressed Emotion towards siblings with and without learning disabilities)? More specifically, this study focuses on five basic issues:

- Data from the study sample are compared with normative samples.
- Differences in behavioural problems are explored for children with learning disabilities, typically developing children, and normative samples.
- Comparisons are made between published research on Expressed Emotion in clinical samples, normal controls, and findings from the study sample.
- The correlates of maternal Expressed Emotion towards children with learning disabilities are explained.
- Differences in maternal Expressed Emotion towards siblings with and without learning disabilities are tested. The results of this study are presented in Chapter Six.

Stage 3 builds on the discovery of Expressed Emotion differences between children with learning disabilities and their siblings and explores factors that may account for these differences. This study includes additional measures identified from studies in Chapter One. These additional measures will focus on Maternal Stress, Depression, Anxiety, Family Satisfaction and Marital Satisfaction in conjunction with the measures. This study explores differences between siblings and between siblings and normative data and tackles the potential impact of learning disability aetiological factors. The results of this study are presented in Chapter Seven.

Stage 4 addresses the problem that previous research findings, highlighted within this thesis, are correlational and there is a need to explore maternal-child relationships over time i.e. level of maternal Expressed Emotion and child outcome over time. Therefore, the focus of stage four is on the prospective analysis of maternal Expressed Emotion and behavioural problems. Chapter Eight reports a six month follow up of 21 mothers from the second study (Chapter Five) using a replication of measures. Data from this study are used to explore the relationship depicted in Figure 1.5.

CHAPTER FIVE

Study One: Reliability of Measures

The purpose of this chapter is to describe the research methods to be used and to ensure that all measures employed have adequate reliability when being used with mothers of children with learning disabilities. Fourteen mothers and fourteen sibling pairs (one sibling with a learning disability the other typically developing) participated in this reliability study. This chapter tested the test-retest and internal consistency of the Child Rearing Practice Report and the Parenting Sense of Competence Questionnaire. Test-retest and code-recode analysis was conducted for the Five Minute Speech Sample. For the Five Minute Speech Sample and the Vineland Adaptive Behaviour Scale, code-recode reliability was conducted for face-to-face and for telephone data collection separately. Moderate to good internal consistency was found for the Child Rearing Practice Report Restrictive scale, Parenting Sense of Competence Questionnaire Satisfaction scale and the Strengths and Difficulties Questionnaire. Results also suggest that Expressed Emotion is an acceptable measure for use with mothers of children with learning disabilities when the dimension of Relationship is removed. The results from the Five Minute Speech Sample and the Vineland Adaptive Behaviour Scale when checked for agreement for use over the telephone support the adaption of this method for interviewing mothers.

5.1. Participants

Fourteen mothers and 14 sibling pairs (one sibling with a learning disability the other typically developing) participated in this reliability study. Mothers were recruited through two schools for children with mild learning disabilities. Siblings were selected, by the mother, to be the closest in chronological age to the child with learning disabilities. Siblings were not attending a special school and did not have a statement for special educational needs. Mothers were also identified by the school as not having learning disabilities themselves. Both children were aged between four and 14 years due to age limits for some of the questionnaires.

Children were identified by their mother as having Autism (12 children) and mild learning disabilities (two children). Mothers ranged in age between 32 and 46 years with a mean age of 36 ($SD = 3.25$). Children with learning disabilities were between the ages of four and eleven years with a mean age of 6.43 ($SD = 2.21$). Siblings were also aged between four and eleven years with a mean age of 7.71 ($SD = 2.13$). There were ten male and four female children with learning disabilities. There were seven typically developing sibling males and seven females. Seven sibling pairs were of the same sex (two female pairs and five male pairs).

5.2. Measures to be Used in the Thesis

5.2.1. The Child Rearing Practice Report

The Child Rearing Practice Report (Block; Rickel & Biasatitill, 1982) was used to assess parenting beliefs (see Appendix B and discussion in Chapter Four). This measure has been used extensively in the parenting literature (e.g. Hastings et al., 2000; Lemanek, Jones, & Lieberman, 2000). However, the Child Rearing Practice Report has not previously been used in published research with parents who have children with learning disabilities.

The Child Rearing Practice Report is a 35 item self-report questionnaire with two subscales: Nurturant, and Restrictive parenting. The items are rated using a 5 point Likert scale anchored at “strongly agree” and “strongly disagree”. Items from the Nurturant scale include: “I am easy going and relaxed with my child”, and “I encourage my children to talk about their troubles”. Items from the Restrictive scale include: “I do

not allow my child to question my decisions” and, “I believe that children should be seen and not heard”. Cronbach’s Alpha has been reported as .85 for the Restrictivness scale, and .84 for the Nurturance scale (Rickel & Biasatitill, 1982). More recently, Olsen, Martin and Halverson (1999) found an alpha of .83 for the Restrictivness scale and .83 for the Nurturant scale.

All 14 mothers were asked to comment on the items of the Child Rearing Practice Report questionnaire. From the questionnaire, there were four questions which mothers considered intrusive. One question from the Nurturant scale: “I believe in toilet training a child as soon as possible”, and three questions from the Restrictive scale: “I don’t think that children of different sexes should be allowed to see each other naked”, “I dread answering my child’s questions about sex”, and “My child and I have warm intimate moments together”. Therefore, I explored properties of this questionnaire with these items removed, as well as the main issue of its properties with parents of children with learning disabilities.

5.2.2. Parenting Sense of Competence Questionnaire

The Parenting Sense of Competence Questionnaire (PSOC; Johnston & Mash, 1989) is a 17 item self-completion questionnaire (see Appendix C for a copy of the questionnaire and discussion in Chapter Four). Items are rated using a 5 point Likert scale ranging from “strongly agree” to “strongly disagree”, and can be scored as two sub-scales: Parenting Satisfaction (an affective dimension reflecting parenting satisfaction, anxiety, and motivation), and Parenting Efficacy (an instrumental dimension reflecting competence, problem solving ability, and capability in the parenting role). Items from the Satisfaction scale include: “My talents and interests are in other areas – not being a parent”, and “I honestly believe I have all the skills necessary to be a good mother to my child”. Items from the Efficacy scale include: “I go to bed the same way I wake up in the morning: feeling like I have not achieved very much”, and “If anyone can find the answer to what is troubling my child, I am the one”.

The Parenting Sense of Competence Questionnaire has already been used with mothers’ of children with learning disabilities (Walker, Vanslyke, & Newbrough, 1992). Walker et al., (1992) administered the Parenting Sense of Competence



Questionnaire to 23 mothers' of children with moderate learning disabilities. Walker et al., (1992) found Cronbach Alphas for the Satisfaction sub-scale to be .70 and for Efficacy to be .68. Given that only one study has reported reliability for the Parenting Sense of Competence Questionnaire for mothers of children with learning disabilities, it was tested again in this pilot study.

5.2.3. Adaptive Behaviour Scales

The Vineland Adaptive Behaviour Scales (VABS; Sparrow et al., 1984) (see Appendix K for a copy of the measure and discussion in Chapter Four) contain 297 items, which provide an assessment of adaptive behaviour across four domains: Socialisation, Communication, Daily Living Skills, and Motor Skills. The interviewer administers the survey form to a parent or caregiver of an individual from birth to 18.11 years or a low functioning adult. The format of the interview is semi-structured typically lasting between 20 to 60 minutes. The Vineland Adaptive Behaviour Scale identifies what the child does in everyday life. Parents are asked general questions about each of the domains in turn. The questions asked of the parent are broad. For example, on the Communication domain, a parent could be asked "tell me what Charlie's reading and writing is like". From the parent's response, the researchers can code the child's ability. Specific questions can be asked if the parent has not mentioned information sufficient for a rating during the interview. However, specific questions are avoided, as asking all questions on each domain would be very time consuming. The information obtained from the Vineland Adaptive Behaviour Scale includes normative referenced information based on the performance of representative national standardisation samples of about 4800 typically developing individuals and individuals with learning disabilities. Internal consistency (Cronbach's Alpha) for the Communication domain has been shown to be .89, for Daily Living Skills domain .90, and for the Socialisation domain .86. Test-retest reliability (a two to three week interval) for the Communication domain was at .86, for the Daily Living Skills domain .85, and for the Socialisation domain .81. Construct, content and criterion-related validity are all found to be acceptable (Sparrow et al., 1984). Given the large amount of research using the Vineland Adaptive Behaviour Scales for children with learning disabilities psychometric data, other than those relating to its use as a telephone interview, were not explored. Where the thesis has used age equivalent scores they have been generated from the Vineland Adaptive Behaviour Scales Table

B 10 which are generated from overall mean scores. Overall mean scores are generated by multiplying the overall domain scores together and dividing by Four.

5.2.4. Behaviour Problems Questionnaire

The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1999), was used as a measure of child behaviour problems (see Appendix D for a copy of the questionnaire). The Strengths and Difficulties Questionnaire is a brief behavioural screening questionnaire that can be completed in about five minutes by the parents of children aged four to 16. The Strengths and Difficulties Questionnaire has five scales of five items each including: Pro-social Behaviour (e.g. “is your child kind to younger children?”), Conduct Disorder (e.g. “often has temper tantrums”), Emotional Symptoms (e.g. “many worries often seems worried”), Hyperactivity (“easily distracted”), and Peer Relationships “has at least one good friend”.

The Strengths and Difficulties Questionnaire is extended with an Impact Supplement that asks whether the parent thinks their child or teenager has a problem. If the child is thought to have a problem, the Impact supplement enquires further about distress, social impairment, burden, and chronicity (Goodman, 1999). The first question of the Impact supplement asks if the child has difficulties in any of the following areas: emotion, concentration, behaviour, or being able to get on with other people. These problems are scored on a four point scale (no problems to severe problems). If the respondent answers “no problems” then no more questions are asked. If the respondent answers “yes” then they complete the remaining items. These items are included: “Do the difficulties upset or distress your child?”, and “Do the difficulties put a burden on you or the family as a whole?” Test-retest reliability over a three to four week period was found to be .54 (intraclass correlation, Goodman, 2001). The Strengths and Difficulties Questionnaire is a well validated instrument and has been proven to be as effective as both the Child Behaviour Checklist (Achenbach, 1991) and the Rutter Scales (Elander & Rutter, 1996) in identifying clinically significant levels of behavioural disturbance in children (Goodman, 1997; Goodman & Scott, 1999). Internal consistency (Cronbach’s Alpha) was found to be above .80 for the Total Difficulties score, and retest reliability was .62 after four to six months (Goodman, 2001). The Strengths and Difficulties Questionnaire was administered to 98 children, between the ages of 11 and 15, with learning as a part of a major study of

the mental health of children and adolescents in Great Britain (Meltzer, Gatward, Goodman, & Ford, 2000). Emerson (in press) reported internal consistency data for this disability sample of .71 for Total Difficulties, and .87 for Impact. This is the only study to report the psychometric properties of the Strengths and Difficulties Questionnaire for children with learning disabilities. Therefore, further exploration was carried out within this pilot sample.

5.2.5. Five Minute Speech Sample

For a detailed description of Expressed Emotion see Chapter Three. For a copy of the instructions of the Five Minute Speech Sample see Appendix I. Psychometric data on the Five Minute Speech Sample are reported within the present study. Given the specialised nature of the Five Minute Speech Sample, considerable training was required before data collection could be initiated (See Appendix I for details).

5.3. Procedure

Two schools for children with mild learning disabilities were approached and asked to facilitate contact with families that met the recruitment criteria for the pilot study (see 5.1). The schools were reassured that none of the families could be identified until they contacted the researcher personally. The schools' only role was to facilitate the distribution of the questionnaire booklet. Mothers were asked to fill in the questionnaires and asked to return the booklet to the University in pre-paid envelopes. The questionnaire booklet comprised two Strengths and Difficulties Questionnaires (one for their child with learning disabilities and one for their typically developing child), the Child Rearing Practice Report and the Parenting Sense of Competence Questionnaire. Figure 4.1 demonstrates the participant sample and sub-samples for Study One.

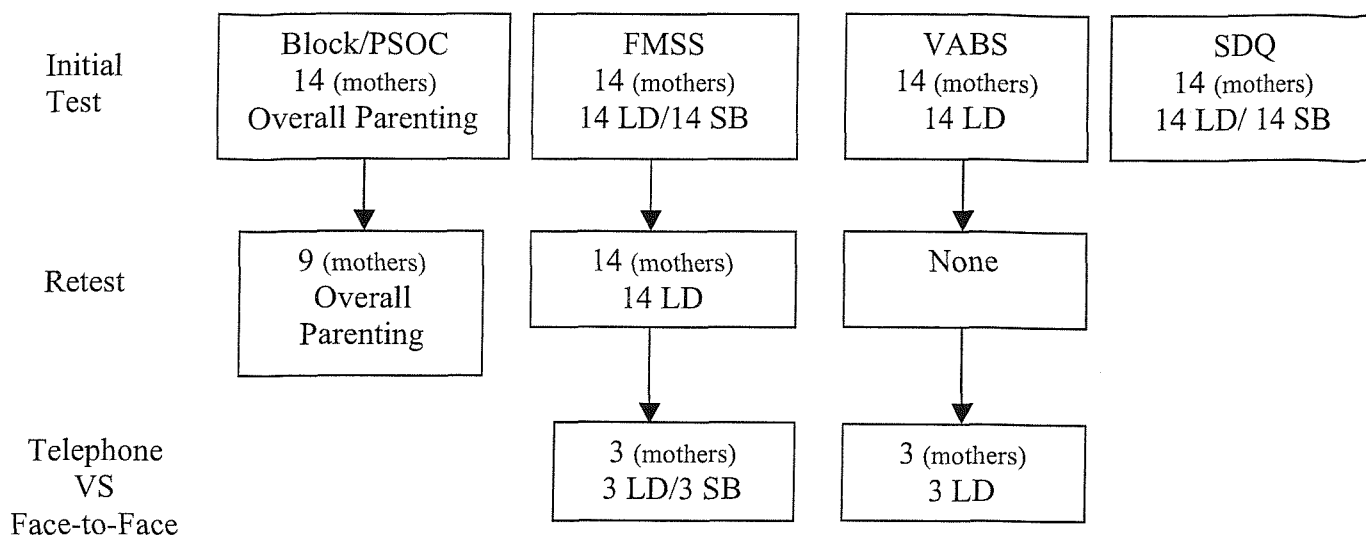


Figure 5.1 A flow chart to demonstrate participant recruitment.

LD = Learning Disability, SB = Sibling

Once the questionnaire data were returned, mothers were contacted by telephone. A date was made for a home visit. During this home visit mothers were asked to provide a Five Minute Speech Sample for each child and a Vineland Adaptive Behaviour Scale for their child with learning disabilities. One month later all mothers were contacted and asked to complete the Child Rearing Practice Report and the Parenting Sense of Competence Questionnaire for test-retest reliability purposes (nine were returned, 64% response rate). Again, questionnaires were posted to each mother and returned to the University in a pre-paid envelope. All the mothers agreed to be re-tested on the Five Minute Speech Sample. Again, home visits were made. A small sub-sample of six mothers were re-tested to check agreement of the Five Minute Speech Sample and the Vineland Adaptive Behaviour Scale over the telephone. Three mothers provided a face-to-face and a telephone Five Minute Speech Sample for their child with learning disabilities and their typically developing child (i.e. six speech samples were collected in total). Three different mothers provided a face-to-face and a telephone Vineland Adaptive Behaviour Scale for their child with learning disabilities.

5.4. Results

5.4.1. Data Analysis Strategy

The results of reliability testing are presented for each measure in turn. Table 5.1. identifies the range of reliability tests conducted for each measure.

Table 5.1 The Reliability Test used for each Measure.

Measure	Code recode	Test retest	Reliability				
			Inter-rater	ICC	Kappa	% Agreement	Internal Consistency
Block	×	✓	×	×	×	×	✓
PSOC	×	✓	×	×	×	×	✓
SDQ	×	×	×	×	×	×	✓
FMSS	✓	✓	✓	✓	✓	✓	×
VABS	×	✓	✓	✓	×	×	×

5.4.1.1. Comparison Samples

A Southampton sample (Cornah, Stevenson, Thompson, Sonuga-Barke, & Raynor, in press) was used as a comparison for data from the Child Rearing Practice Report and the Parenting Sense of Competence Questionnaire. Cornah et al's. (in press) sample consisted of 125 mothers. The mean age of the mothers was 33.4 years ($SD = 4.56$), children were aged nine to 11 years ($SD = .80$), and there were 71 males and 54 females. This study was concerned with parenting strategies towards typically developing children who had behavioural problems.

In 1999, the Office of National Statistics conducted a survey of the Mental Health of Children and Adolescents in Great Britain (Meltzer et al., 2000). Ninety-eight adolescents with learning disabilities completed a self-report Strengths and Difficulties Questionnaire. Emerson (in press) reported Cronbach's Alpha for each sub-domain of the Strengths and Difficulties Questionnaire for this sample. Emerson (in press) is used as comparison data for the Strengths and Difficulties Questionnaire.

5.4.1.2. Reliability Analysed

Cronbach's Alpha is a coefficient of reliability that measures how well a set of items (or variables) measures a single uni-dimensional latent construct (i.e. is a test for internal consistency). Internal consistency is thought to be extremely high if alpha is .90, moderately high if alpha is between .70 and .90, and acceptable if alpha is .60. For the social sciences the general rule of acceptance for Cronbach's alpha is .80. (Cohen, 1992). Alpha co-efficients were calculated to examine the internal consistency for the Child Rearing Practice Report (with the questions highlighted in section 4.1 removed), the Parenting Sense of Competence Questionnaire and the Strengths and Difficulties Questionnaire.

Three types of reliability were examined for Expressed Emotion. These were: code re-code reliability (the examiner coding the same test twice), test-retest reliability (repeated administration of the same measure) and, inter-rater reliability (two raters coding the same test). Depending on the variables, three different measures of reliability were used: Cohen's Kappa, percentage agreement and intraclass correlations (ICC). Kappa measures the agreement between two sets of nominal data. A value of 1.0 indicates perfect agreement, a value of zero indicates that agreement is no better than chance. Percentage agreements have been used when there is no variance in the data (the calculation of Kappa requires some variance in the data). Reliability was also examined using intraclass correlations, which produce a measure of agreement between ratings on scaled items. Intraclass correlations are used for data that are recorded in frequencies. Bi-variate correlations were not used because they measure how variables or rank orders are related.

5.4.2. Reliability of the Block Child Rearing Practice Report

Table 5.2 Internal consistency for the Child Rearing Practice Report.

Measure	α (N = 14 Study 1)	α (N = 125 Cornah et al., in press)	ICC (9 Mothers, re-test)
Restrictive Parenting	.78	.46	.89
Nurturant Parenting	.42	.57	.33

Table 5.2 finds test-retest reliability (ICC) for the Block Child Rearing Practice Report to be excellent for Restrictive parenting .89. Test-retest data for Restrictive parenting also identify that it is reliable over time. However, the test-retest reliability for the sub-scale of Nurturant parenting was low at .33, and internal consistency was poor. Internal consistency data for these scales in Cornah et al's sample (in press) are poor. This may be due to the focus of the sample on children with behavioural problems. However, despite encouraging data on the reliability of the Restrictive parenting sample with mothers of children with learning disabilities, caution is needed given its apparent unreliability in other UK families.

5.4.3. Reliability of the Parenting Sense of Competence Questionnaire

Table 5.3 Internal consistency and test-retest reliability for the Parenting Sense of Competence Questionnaire.

Measure	α (N = 14 Study 1)	α (N = 125 Cornah et al., in press)	ICC (9 Mothers, re-test)
PSOC Satisfaction	.75	.75	.85
PSOC Efficacy	.45	.76	.40

Table 5.3 shows test-retest reliability and internal consistency (ICC) for the Parenting Sense of Competence Questionnaire (nine mothers) to be excellent for Satisfaction .85. However, test-retest and internal consistency data for the sub-scale of Efficacy are poor. Within a typically developing sample (Cornah et al., in press) the Efficacy scale did demonstrate good internal consistency. It is unclear why the Efficacy sub-scale is unreliable for the pilot sample of mothers with children with learning disabilities, but it was excluded from further analysis in the following studies.

5.4.4. Reliability of the Strengths and Difficulties Questionnaire

For the Strengths and Difficulties Questionnaire, data collected for this thesis were compared to results from Emerson (in press). Data from both studies together suggest reasonable reliability for the Total Difficulties score, Pro-social Behaviour and the Impact score. However, the data on the consistency of the domains of problem behaviour are variable.

Table 5.4 Internal Consistency for the Strengths and Difficulties Questionnaire.

Dimension of the SDQ	α	α
	(N = 14 Study 1)	(N = 98, Emerson, in press)
SDQ Total Difficulties	.63 (.73)	.71
SDQ Emotional Problems	.66 (.56)	.56
SDQ Conduct Disorder	.56 (.77)	.60
SDQ Hyperactivity	.55 (.77)	.61
SDQ Peer Problems	.59 (.60)	.30
SDQ Pro-social Behaviour	.67 (.78)	.60
SDQ Impact	.59 (.67)	.87

NB Results for internal consistency with siblings sample are in parentheses.

Table 5.4 demonstrates that the internal consistency for the Strengths and Difficulties Questionnaire is still good. The data from Emerson (in press) finds higher internal consistency for the overall Strengths and Difficulties Questionnaire, Conduct Disorder, Hyperactivity and Impact than the internal consistency from this first study.

5.4.5. Reliability of the Five Minute Speech Sample

The speech samples were collected on two separate occasions, one month apart. Code re-code reliability was examined for 14 children with learning disabilities and 14 typically developing siblings. Test-retest reliability was conducted for 14 speech samples for the child with learning disabilities. For code-recode data, cases were rated twice by the same coder one week apart. Inter-rater reliability was also tested by a trained research assistant at the University coding the same speech samples two weeks after I had coded them.

Table 5.5 Reliability of the Five Minute Speech Sample using code-recode, test-retest and inter-rater reliability.

FMSS Dimensions	Code-recode (N=14 mothers LD child only)	Test-retest (14 mothers LD child only)	Inter-rater (N= 8 LD)
Kappa / % Agreement			
Initial Statement	.81**	85%	93%
Relationship	.60*	.26	.62*
Dissatisfaction	.68**	.58*	.54*
EOI	.85**	.88**	100%
Overall Expressed Emotion	.83**	.78**	.79**
ICC			
Critical Comments	.69**	.78**	.60*
Positive Remarks	.85**	.94**	.78**

ICC = Intraclass Correlations

LD = Learning Disability, SB = Sibling, EOI = Emotional-over Involvement

* Significant at $p < .05$

** Significant at $p < .01$

Kappas on code-recode data for the Five Minute Speech Sample indicate that there is good agreement between both ratings, indicating good reliability. Test-retest data on the mothers shows adequate agreement for all dimensions of the Five Minute Speech Sample except Relationship. The dimension of Relationship was also found to be unstable across time. Inter-rater reliability provided moderate to good agreement between both raters on all dimensions.

As the Five Minute Speech Sample has not been used over the telephone before, a small sample from this study was re-tested to check agreement between the mothers' responses over the telephone and face-to-face (see Table 5.6).

Table 5.6 Agreement between the Five Minute Speech Sample collected face-to-face and over the telephone.

FMSS	Face/Telephone (six mothers 3 LD/3 SB)
Kappa	
Initial Statement	.50*
Relationship	.27
Dissatisfaction	.56*
% Agreement	
Self-sacrificing Behaviour	83%
Emotional-over Involvement	87%
Overall Expressed Emotion	100%
ICC	
Criticism	.56*
Positive remarks	.56*

* Significant at $p < .05$

LD = Learning Disability, SB = Sibling

ICC = Intraclass Correlation

Results from Table 5.6 show that there is a reasonable to good level of agreement between the Five Minute Speech Sample data coded face-to-face and over the telephone except for the dimension of Relationship. These results are encouraging given the small sample and the inherent degree of unreliability in coding the Five Minute Speech Sample. Individual scores for each sub-domain of the Five Minute Speech Sample can be used to calculate a binary score of high or low Expressed Emotion (see Chapter Three). It is this binary score which is usually reported in the literature. This score is heavily dependant on Criticism and Emotional-over

Involvement, but less dependent on Relationship. Therefore, the poorer reliability of the Relationship domain is less important

5.4.6. Vineland Adaptive Behaviour Scale-Telephone Administration

Table 5.7 Reliability of the Vineland Adaptive Behaviour Scale using intraclass correlations collected face to face and over the telephone.

VABS	Face/Telephone (six mothers, LD only)
Overall Composite	.78
Communication	.79
Socialisation	.73
Daily Living	.83
Motor Skills	.75

LD = Learning Disability

Results from Table 5.7 are supportive of the use of the Vineland Adaptive Behaviour Scale over the telephone.

5.5. Discussion

This study aimed to identify whether the measures to be used in this thesis were reliable for use with mothers who have children with learning disabilities. Moderate to good internal consistency and test-retest reliability was found for the Child Rearing Practice Report Restrictive scale, Parenting Sense of Competence Questionnaire Satisfaction scale and some dimensions of the Strengths and Difficulties Questionnaire. The sub-scales of parenting Efficacy and Nurturant parenting did not demonstrate good reliability. As a result of the poor test-retest reliability and lack of internal consistency for these subscales, Efficacy and Nurturant will not be used further in this thesis. With regard to the Strengths and Difficulties Questionnaire, the following analysis will focus on the Total Difficulties, Pro-social Behaviour, and Impact Scales.

This study also demonstrated good code-recode, test-retest and inter-rater reliability for the Five Minute Speech Sample with mothers of children with learning disabilities. The results from the Five Minute Speech Sample and the Vineland Adaptive Behaviour Scale when checked for agreement for use over the telephone. Further studies can therefore use telephone interviews for both the Five Minute Speech Sample and the Vineland Adaptive Behaviour Scale with reasonable confidence. However, the Vineland Adaptive Behaviour Scale manual does not provide normative age equivalents above 5.11 years for the Motor Skills domain making this scale inappropriate for use with children with learning disabilities. Omitting the Motor Skills domain does not interfere with attaining an overall adaptive behaviour score. Furthermore, as there is limited time available to conduct the telephone interview for both the Five Minute Speech Sample and the Vineland Adaptive Behaviour Scale, the Motor Skills domain will not be used within this thesis.

CHAPTER SIX

Study Two: A Preliminary Investigation of Expressed Emotion in Mothers of Children with Learning Disabilities.

The aim of the research study described in this chapter was to explore factors associated with maternal Expressed Emotion towards their child with learning disabilities. Thirty-three mothers who had a child with learning disabilities and at least one child without disabilities between the ages of 4 and 14 years participated in the study. Mothers completed self-assessment questionnaires which addressed their sense of parenting competence, beliefs about child-rearing practices, and their experience of behavioural and emotional problems of their child with learning disabilities. Telephone interviews were conducted to assess maternal Expressed Emotion towards the child with learning disabilities and towards a sibling using the Five Minute Speech Sample (Magana et al., 1986), and also to assess the adaptive behaviour of the child with learning disabilities using the Vineland Adaptive Behaviour Scale (Sparrow, Balla, & Cicchetti, 1984). Mothers with high Expressed Emotion towards their child with learning disabilities were more satisfied with their parenting ability, but their children had more behaviour problems. Analysis of differential maternal parenting, through comparisons of Expressed Emotion towards their two children, showed that mothers were more negative towards their child with learning disabilities for all domains of the Five Minute Speech Sample except Dissatisfaction.

A small number of factors associated with maternal Expressed Emotion towards children with learning disabilities were identified. Differences in maternal Expressed Emotion towards their child with learning disabilities and their other child suggest that Expressed Emotion is child-driven rather than a general maternal characteristic.

6.1. Introduction

Recent interest on Expressed Emotion has explored its utility as a measure of the emotional relationship between parent and child (see Chapter Three). The research literature on Expressed Emotion in parents of children with learning disabilities is sparse, with only two published studies to date. The results from Dossetor et al's (1994) study identify specific associations between aspects of maternal Expressed Emotion, childhood disability, and maternal psychosocial variables (i.e., quality of marriage, social support, and child behavioural problems). However, the scant literature surrounding Expressed Emotion in parents of children with learning disabilities has not helped to identify specific mechanisms through which the association between Expressed Emotion and variables associated with disabilities such as behaviour problems might be explained. One potential mechanism is that Expressed Emotion affects parenting behaviour which in turn affects child outcomes (see Chapter Three). However, little attention has been given to the emotional dimension of the parenting relationship in families of children with learning disabilities.

It is predicted that high ratings on Expressed Emotion will be associated with lower child adaptive behaviour scores and more behaviour problems. It is also thought that higher rates of parenting satisfaction and restrictive parenting will be associated with lower Expressed Emotion ratings. Although correlates of maternal Expressed Emotion might be identified, focusing on one child only fails to establish the overall impact of learning disability variables on the emotional relationship between parent and child. The second focus of this study was to explore Expressed Emotion towards two children (one with learning disabilities, one without) in the same family. If child factors primarily affect Expressed Emotion (see model in Chapter One), we might expect mothers to report different emotional relationships with their two children. It is predicted that mothers will be more negative towards their child with learning disabilities. In contrast, if Expressed Emotion is more of a general maternal characteristic we might expect maternal

Expressed Emotion towards their two children to be similar. Thus, this second focus of the present study is a preliminary test of within-family differences that might be explained in more detail in a subsequent study.

6.2 Method

6.2.1. Participants

Thirty-three mothers who had a child with learning disabilities and at least one other child between the ages of 4 and 14 years participated in the research. The mothers' mean age was 41.93 years ($SD = 6.14$, range 30-56 years), with 16 mothers in full-time employment, and the remainder working as full-time carers for their children. The children with learning disabilities had a mean age of 9.02 years ($SD = 3.54$, range 4-14 years), and a gender ratio of 15 males to 18 females. Typically developing children had a mean age of 8.91 years ($SD = 3.71$, range 4 – 14 years), and a gender ratio of 17 males to 16 females. Twenty sibling pairs were of the same gender. Diagnostic descriptions for the children with learning disabilities included: Autism (7 children); Down Syndrome (18 children); Cerebral Palsy (1 child); and unknown aetiologies (7 children). The children with learning disabilities had an average developmental delay of 3.76 years ($SD = 4.38$), calculated using the composite score of the Vineland Adaptive Behavioural Scale (VABS, Sparrow et al., 1984). The Vineland Adaptive Behavioural composite score mean for the sample of children with learning disabilities was 51.61 ($SD = 15.77$, range 29-89).

6.2.2. Measures

Maternal measures focused on parenting beliefs, parenting self-esteem and Expressed Emotion. The Block Child Rearing Practice Report (Rickel & Biasatitill, 1982) was used to assess parenting beliefs and the Parenting Sense of Competence Scale (Johnston & Mash, 1987) was used to assess parenting self-esteem. Expressed Emotion is used to describe the attitudes and feelings a relative or caregiver expresses about an individual. In this study, Expressed Emotion is used as a measure of the emotional climate between the mother and each of her two children, assessed using the

Five Minute Speech Sample (Magana et al., 1986). Two measures were taken for the child with learning disabilities in the present research. First, the Strengths and Difficulties Questionnaire (Goodman, 1997), was used as a measure of the child's behaviour problems. Second, the Vineland Adaptive Behaviour Scale (Sparrow et al., 1984) was used as a measure of adaptive behaviour. Detailed descriptions of each of these measures and their properties can be found in Chapters Four and Five.

6.2.3. Procedure

Questionnaires were mailed to special schools for children with mild to moderate learning disabilities in Southern Hampshire, UK who had agreed to facilitate contact with parents. Mothers then returned the questionnaire packs in prepaid envelopes if they were willing to participate in the research. General, rather than personally addressed, reminder letters were sent out via these schools one month later. Replies were received from 62 mothers but only 33 mothers indicated that they would be willing to also take part in the telephone interview. Once mothers had returned the initial questionnaires they were contacted again by telephone. Mothers provided a Five Minute Speech Sample for their child with learning disabilities and another for their child identified as being closest in age to the child with learning disabilities (the order of speech samples was counterbalanced) and a Vineland Adaptive Behaviour Scale for their child with learning disabilities was administered. The present analysis focuses on the data gathered from the 33 mothers who agreed to a telephone interview and therefore for whom there was a measure of Expressed Emotion.

6.3. Results

Analysis of maternal Expressed Emotion data addressed three issues. First, data from mothers of children with learning disabilities were compared with data from mothers of children with other childhood problems in published research reports. These descriptive analyses may give some indication of the relative levels of high and low Expressed Emotion in mothers of children with learning disabilities. Second, correlates of maternal Expressed Emotion towards their child with learning disabilities were

explored. Finally, maternal Expressed Emotion expressed towards their children with and without learning disabilities was compared.

6.3.1 Maternal Expressed Emotion Compared with Published Reports

Three published reports on maternal Expressed Emotion and child psychopathology were identified as reporting the proportions of mothers classified as high versus low Expressed Emotion (Hibbs et al., 1991; Peris & Baker, 2000; Stubbe, Zahner, Goldstein, & Leckman, 1993). The data from these published reports were compared to data from the present study. These published studies reported considerable levels of high Expressed Emotion in mothers of children with disruptive behavioural disorders (Hibbs et al., 1991; high Expressed Emotion = 81%), mothers of pre-school children with externalising behavioural problems (Peris et al., 2000; high Expressed Emotion = 79%), and mothers of children with obsessive compulsive disorders (Hibbs et al., 1991; high Expressed Emotion = 73%). In the present sample, 19 (60%) mothers were classified as having high Expressed Emotion. This proportion was significantly lower than that in the clinical groups from Hibbs et al. (1991) and Peris and Baker (2000), but significantly higher than the normal controls in Hibbs et al's study (high Expressed Emotion = 13%), and in Stubbe et al's study (high Expressed Emotion = 23%) (using Binominal tests, all differences significant at $p < .05$).

6.3.2. Maternal Expressed Emotion Towards Their Child with Learning Disabilities

In order to explore factors associated with high versus low maternal Expressed Emotion, a series of between group comparisons were made. Before these tests were conducted, one sample Kolmogorov-Smirnov tests were used to compare maternal and child variables to a normal distribution. All of the tests were significant, indicating that the data were not normally distributed and hence non-parametric tests were required. High versus low Expressed Emotion mothers were thus compared using Mann - Whitney tests. The results of these analyses are displayed in Table 1. Mean values for the high and low Expressed Emotion groups are presented for ease of comparison.

Table 6.1. Comparisons Between Mothers with High versus Low Expressed Emotion Towards Their child with Learning Disabilities.

	High Expressed Emotion N=20 Mean (SD)	Low Expressed Emotion N=13 Mean (SD)	p
<u>Maternal Variables</u>			
Age	38.93 (4.38)	41.95 (6.52)	.16
Restrictive Parenting	46.92 (4.35)	47.22 (7.53)	.50
Parenting Satisfaction	23.08 (2.60)	20.85 (3.10)	.05
<u>Child Variables</u>			
Chronological Age	7.92 (2.69)	9.05 (3.97)	.50
VABS Overall Composite	52.25 (16.11)	72.55 (36.7)	.21
VABS Communication	2.61 (1.23)	4.21 (3.64)	.80
VABS Socialisation	3.15 (2.06)	4.93 (3.27)	.18
VABS Daily Living Skills	3.58 (2.11)	4.94 (3.20)	.39
SDQ Total Difficulties	16.54 (4.46)	11.90 (4.29)	.00
SDQ Emotional Problems	2.69 (2.78)	1.35 (1.90)	.17
SDQ Conduct Disorder	3.15 (1.77)	1.90 (1.45)	.04
SDQ Hyperactivity	7.62 (1.98)	6.00 (2.03)	.06
SDQ Peer Problems	4.08 (2.06)	2.95 (1.67)	.07
SDQ Pro-social Behaviour	4.85 (3.08)	6.10 (2.53)	.28
SDQ Impact	7.31 (3.28)	1.65 (1.95)	.00

NB Overall VABS calculated using Composite score (equivalent to a Developmental Quotient), Vineland Adaptive Behaviour Scale domains calculated using age equivalent scores.

These analyses show that there are significant differences between mothers with high Expressed Emotion and mothers with low Expressed Emotion. Mothers with high Expressed Emotion were: more satisfied with their parenting ability, their children had

more behavioural problems overall, more conduct problems, marginally more hyperactive behaviours, and their children had a greater negative impact on the family.

To explore if Expressed Emotion was associated with the working status of the mother's or the child's gender (dichotomous variables), chi-square analyses were carried out. These analyses identified no differences between mothers who were working or caring ($\chi^2 (1, n = 33) = 0.35, p = ns$) and no effect of child gender ($\chi^2 (1, n = 33) = 0.21, p = ns$).

6.3.3. Differences in Maternal Expressed Emotion Towards Their Two Children

In order to explore if maternal Expressed Emotion towards their two children was different or similar, a series of Wilcoxon Signed Rank tests were conducted on the domains of Expressed Emotion coded from the Five Minute Speech Sample.

Differences were found for Criticism ($z (32) = -1.67, p < .05$), Initial Statement ($z (32) = -3.21, p < .01$), Positive Comments ($z (32) = -3.50, p < .01$), Self-Sacrificing Behaviour ($z (32) = -2.89, p < .01$), and Emotional-over-Involvement ($z (32) = -3.94, p < .01$). As overall Expressed Emotion and Dissatisfaction were dichotomous variables, they were tested using Binomial tests. A significant difference existed for overall Expressed Emotion ($p < .001$), but there was no significant difference for Dissatisfaction. Cross-tabulations were conducted to identify the direction of these significant effects. These data are summarised in Tables 6.2 and 6.3. In all cases, mothers expressed more negative (i.e., "higher" levels of) Expressed Emotion towards the child with learning disabilities.

One variable that may have a strong effect on parental responses to children is the gender of the child. It was possible that these differences of Expressed Emotion could be explained by the fact that some mothers were reporting on children of different genders. Therefore, these comparisons were conducted again for the sub-set of 20 same sex dyads. An identical pattern of results was obtained and so these analyses are not repeated here.

Table 6.2. Cross Tabulations for Dictomous Expressed Emotion Variables

		Sibling	
Overall Expressed Emotion		High	Low
LD child	High	0	13
	Low	0	20
Self-Sacrificing		Present	Absent
LD child	Present	0	13
	Absent	1	21
Dissatisfaction		Present	Absent
LD child	Present	7	12
	Absent	4	10

LD = Learning Disabilities

Table 6.3. Cross Tabulation for Global Expressed Emotion Categories

		Sibling		
		High	Borderline	Low
EOI				
LD Child	High	0	6	9
	Borderline	0	10	4
	Low	0	0	4
IS		Positive	Neutral	Negative
LD child	Positive	6	1	0
	Neutral	13	13	0
	Negative	0	0	0

NB. EOI = Emotional-Over-Involvement, IS = Initial Statement, LD = Learning Disabilities

6.4. Discussion

The results of the present study show: 1. That mothers of children with learning disabilities in the present sample had lower rates of high Expressed Emotion than in other reports of clinical child samples using similar methodology, 2. That these mothers had higher rates of high Expressed Emotion than mothers of normal controls from studies with comparable methodologies, 3. That both maternal feelings about parenting (specifically, satisfaction), and more severe child behavioural problems, were associated with high Expressed Emotion, and 4. That maternal Expressed Emotion towards their child with learning disabilities is more negative than Expressed Emotion towards their children without learning disabilities. This fourth finding was supported by comparisons with control samples from previous research, but also more directly through the use of a within-family design in the present study. This effect was also independent of gender differences in sibling pairs.

The fact that the present sample of mothers had high Expressed Emotion in a proportion between that typically found in clinical and control samples may be due to a bias in the present sample which contained 18 children with Down Syndrome. Research on parenting stress in mothers of children with learning disabilities typically shows that mothers of children with Down Syndrome are more stressed than mothers of children from the general population, but less stressed than mothers of children with other disabilities (e.g. Stores et al., 1998). In future research, it will be important to recognise the potential impact of particular aetiologies on parental adaptation and functioning (Dykens & Hodapp, 2001) and also to make direct comparisons with other clinical samples.

The analysis of correlates of maternal Expressed Emotion towards children with learning disabilities identified that both maternal and child factors may be relevant in determining levels of maternal Expressed Emotion. Previous research highlights several child factors that influence maternal Expressed Emotion. For example, elevated levels of child behavioural problems, conduct problems, hyperactivity and impact the child

has on the family all increase levels of maternal Expressed Emotion (e.g., Baker, Heller, & Henker, 2000; Daley, Sonuga-Barke, & Thompson, in press). Previous research in the field of learning disabilities has also emphasised the associations between behavioural problems and Expressed Emotion (Dossetor et al., 1994). The associations between maternal parenting satisfaction and Expressed Emotion found in this study are less easy to explain. While it might appear that high Expressed Emotion mothers derive greater satisfaction from their parenting role, this is an unlikely explanation. The Parenting Sense of Competence satisfaction scale was completed by the mother as a measure of overall parenting satisfaction across all children in the family. Given the high levels of behavioural problems and impact among the children with learning disabilities and the fact that all mothers in this study had more than one child, this finding may more likely represent higher levels of relative satisfaction with their typically developing child. However, these issues need to be resolved with further research.

Little attention has been given to other maternal and family factors associated with Expressed Emotion, and only a limited range of variables was explored in the present study. However, the research that has been conducted on families of children with learning disabilities has demonstrated relationships between physical impairment, parenting stress, marital satisfaction, depression, social support, and coping (e.g. Boyce, Marshall, & Peters, 1999; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Grant & Whittell, 2000). These factors have yet to be studied in relation to levels of maternal Expressed Emotion towards children with learning disabilities. Therefore, more research on parental and familial correlates of Expressed Emotion is required in order to understand what other factors may contribute to apparently elevated levels of Expressed Emotion in families with children who have learning disabilities.

Research studies with other clinical samples have generally found strong associations between Expressed Emotion and parental stress (Baker, Heller, & Henker, 2000). However, it is not clear whether stress drives parental Expressed Emotion or whether

Expressed Emotion is a determinant of stress (although see proposed model in Chapter One). If the latter is true, it may help to explain elevated stress in parents of children with learning disabilities (i.e. Expressed Emotion may mediate the effects of childhood disability on parental stress). If the former is true Expressed Emotion may help to explain the impact of parental stress on children via parenting behaviour. These issues are explained in the analyses presented in Chapter Eight.

In terms of child variables, the clearest finding was the association between behaviour problems and maternal Expressed Emotion. Given that behaviour problems are found to occur at higher rates in children with learning disabilities when compared to those without disabilities (Dykens, 2000), this effect may explain the differences in maternal Expressed Emotion towards children with learning disabilities and their sibling. The present data are also consistent with the view that behaviour problems may be one of the key factors driving parental stress (see Hastings, 2002). The present data are merely correlational, but the intriguing possibility that parental Expressed Emotion may help to explain some of the processes responsible for either the development or maintenance of behaviour problems should be explored in further prospective research. This is especially significant given interest in analysing carer behaviour in order to further the remediation of behaviour problems in people with learning disabilities (Hastings & Brown, 2000). Of course, we cannot rule out the possibility that child behaviour problems may elevate maternal Expressed Emotion. These questions again require study using prospective designs.

CHAPTER SEVEN

Study Three: Further Exploration of Maternal Expressed Emotion Towards Children with and without learning Disabilities.

The purpose of this chapter is to explore a number of issues which arose from the analyses presented in Chapter Six, and also from the working model in Chapter One. Seventy-five mothers and 75 sibling pairs (one siblings with a learning disability the other typically developing) participated in this exploration study. This study repeated the basic methodology of Study One with the addition of several measures. Data from this larger sample of mothers of children with learning disabilities confirmed that Expressed Emotion was more negative towards a child with learning disabilities than towards a typically developing sibling in the same family. The clearest findings from the analyses is a consistent association between mothers' reports of stress and Expressed Emotion towards their child with a learning disability. This suggests that parenting may well be associated with child factors suggested in my working model. That is, mothers with higher levels of stress and mental health problems will be associated with mothers who have higher Expressed Emotion Levels. Also, mothers with more family satisfaction and marital satisfaction will be associated with lower Expressed Emotion Levels.

A continuous measure of Expressed Emotion was required for this prospective analysis presented in Chapter Eight. Preliminary data on a new method for scoring Expressed Emotion were encouraging. Simple, replicable, methods for scoring dimensions of both positive and negative Expressed Emotion were developed. The main finding, of sibling differences and association between maternal stress and Expressed Emotion towards the child with learning disabilities, were replicated using the negative Expressed Emotion scale. All of these findings appear to have been unaffected by aetiological factors relating to learning disability which was identified as a potential controlling variable in Study One

7.1. Introduction

The results from the preliminary study described in the previous chapter suggest that there are differences in maternal Expressed Emotion towards siblings with and without learning disabilities. This effect requires further replication and focus, and represents the primary aim of the study described in the present chapter. A number of issues arising from the analyses presented in Chapter Six, and also from the working model in Chapter One, require further attention in the present study. First, a broader range of factors, specifically maternal variables that may be associated with Expressed Emotion, need exploration. The main candidate variable is maternal stress or mental health. An association between Expressed Emotion and stress is a key part of my working model. Further maternal (marital relationship) and family (family satisfaction) measures associated with Expressed Emotion in previous research (see Chapter Three) are also included.

The second issue to be addressed is that of aetiology of learning disability and its potential impact on Expressed Emotion. Thus, a larger sample with broader representation of major aetiology groups (specifically, Down Syndrome and Autism) was recruited. Finally, the thesis wanted to explore whether correlates of Expressed Emotion towards children with and without learning disabilities were similar given that there was little Expressed Emotion towards siblings in Study One (e.g. mothers were coded as high Expressed Emotion towards their typically developing child), a continuous measure of Expressed Emotion was required for the prospective analysis presented in Chapter Eight. Thus, analyses are presented exploring the development of a continuous Expressed Emotion measure.

This study repeated the basic methodology of Study One with some additional measures. Measures of maternal well-being were the Parenting Stress Index short form (PSI/SF; Abidin, 1990), and the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). Both of these measures were chosen as they have been used previously with parents of children with learning disabilities (e.g. Hastings & Brown, 2002; Kasari &

Sigman, 1997, Rydebrandt, 1991, Wolf et al., 1998). Both the Parenting Stress Index short form and the Hospital Anxiety and Depression Scale are short measures, so will not be laborious to complete. The Golombok Rust Inventory of Marital State (GRIMS; Rust, Bennun, Crowe, & Golombok, 1988) was chosen as it has been widely used before and is a robust, short measure of marital satisfaction. Finally, the Family Satisfaction Scale (FSS; Olson, & Wilson, 1982) was added as this provides a measure of family Adaptability and Cohesion - family variables which may be related to maternal Expressed Emotion.

7.2. Participants

The children with learning disabilities were within the age range 4 - 14 years due to the age restrictions on the Strengths and Difficulties Questionnaire. Again, families were not excluded if they contained more than one typically developing sibling. However, mothers were asked to nominate the sibling closest in age to their child with learning disabilities for data collection purposes. The children with learning disabilities had a mean age of 9.75 years (SD = 4.04), and there were 48 males and 26 females. Children with learning disabilities had a mean composite score, as measured on the Vineland Adaptive Behaviour Scale of 52.67 (SD = 21.39), the minimum composite score was 20.00, the maximum composite score was 98.00. The typically developing child had a mean age of 10.34 years (SD = 4.35), there were 35 males and 39 females. Overall there were 24 male pairs and 16 females pairs of siblings. The marital status of the mothers included 58 who were married, 12 who were divorced, and five who were living with their partner. Twenty-six were employed full-time and 15 were employed part-time. Of the fathers in the family, 54 were employed full-time, four were full-time carers and two were retired. The average number of children per family was 2.88 (range 2 - 10 children). There were no significant differences in chronological age between the sibling groups overall ($t(74) = .10, p = ns$) or in gender balance ($\chi^2(1, N = 74) = .53, ns$).

7.3. Measures

7.3.1. Maternal and Family Measures

7.3.1.1. Family Satisfaction

The Family Satisfaction Scale (FSS; Olson & Wilson, 1982) (see Appendix E for a copy of the questionnaire) assesses Family Cohesion and Family Adaptability. The Family Cohesion scale includes eight items, and assesses the emotional bonding between family members. Questions from the Cohesion scale include: "How satisfied are you with how close you feel to the rest of your family?", and "How satisfied are you with your freedom to be alone when you want to be?". The Adaptability scale includes six items, and refers to the ability of the family system to change its power structure, role relationships and relationship rules in response to situational and developmental stresses. Questions include: "How satisfied are you with your ability to say what you want in your family?", and "How satisfied are you with how clear is it what the family expect from you?". The questionnaire is scored from dissatisfied (scored 1) to extremely satisfied (scored 5) with your family. Scores are summed, and the higher the score the more satisfied the respondent is with their family. Olson and Wilson (1982) demonstrate excellent construct validity and reliability scores (Cronbach's Alpha was .92 overall, and .85 and .84 for Cohesion and Adaptability, respectively). Test-retest reliability over a five week time period was .75. For the present sample, Cronbach's Alpha for total Family Satisfaction was .73, for the sub-scale of Cohesion .84 and for the sub-scale of Adaptability .83.

7.3.1.2. Marital Satisfaction

The Golombok Rust Inventory of Marital State (GRIMS; Rust et al., 1988) (see Appendix F for a copy of the questionnaire) is a short questionnaire that assesses the state of a marriage or the overall quality of the relationship between two people who live together. There are 28 items, each rated on a four point scale, from "strongly disagree" to "strongly agree". Scores are summed, and the higher the score the more severe the relationship problem. Questions include "I really appreciate my partner's sense of humour", and "I never have second thoughts about our relationship". Reliability of the GRIMS was reported by Rust et al., (1990) to be good (Cronbach's Alpha in a standardised sample was .89 for females, and .85 for males). For the present sample of

mothers of children with learning disabilities, Cronbach's Alpha was .87.

7.3.1.3. Parenting Stress

The Parenting Stress Index short form (PSI/SF; Abidin, 1990) (see Appendix H for a copy of the questionnaire) was used as a measure of maternal stress. There are 36 items split into three sub-scales: Parental Distress (e.g. "Since having this child, I feel that I am almost never able to do things that I liked to do"), Dysfunctional Parent-child Interactions (e.g. "My child smiles at me much less than I expected"), and Difficulties with the Child (e.g. "My child turned out to be more of a problem than I had expected"). Abidin (1990) reports that reliability and validity data are excellent: for the Total Stress score test-retest reliability was .84, and Cronbach's Alpha was .91. The Cronbach's Alpha for the present sample for Total Stress was .93. For the sub-scales, Cronbach's Alpha was .85 for Parental Distress, .78 for Dysfunctional Parent-child Interaction, and .88 for Difficult Child.

7.3.1.4. Maternal Anxiety and Depression

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) (see Appendix G for a copy of the questionnaire) is a 14 item scale developed to provide a measure of both Anxiety (seven items) and Depression (seven items). Examples of items from the Anxiety scale include: "I feel tense and wound up", and "Worrying thoughts go though my mind". Examples of items from the Depression scale include: "I still enjoy the things I used to enjoy", and "I can laugh and see the funny side of things". Items, for both Anxiety and Depression, are scored on a four point scale and a total score for each scale is achieved by summing the scores on the sub-scales. Higher scores represent high levels of Anxiety or Depression. Although developed initially for use with clinical samples, the Hospital Anxiety and Depression Scale has also been used extensively in community samples. For example, in a recent study of mothers of children with Autism (Hastings & Brown, 2002) Cronbach's Alpha values for Depression (.86) and Anxiety (.89) were high. In the present sample internal consistency was also high (.80 for Anxiety, and .84 for Depression).

7.3.1.5. Expressed Emotion

The Five minute Speech Sample (see Chapter Three for a summary of Expressed Emotion; see Appendix I for the instructions) was used as a measure of maternal Expressed Emotion.

7.3.2. Child Measure

The Strengths and Difficulties Questionnaire, and the Vineland Adaptive Behaviour Scales were used to assess characteristics of the child with learning disabilities. The Strengths and Difficulties Questionnaire was also completed for the typically developing sibling.

7.4. Procedure

Participants were recruited using two methods. First, participants from Study One were contacted again and asked if they were prepared to participate in a further study. Twenty-one of the 33 mothers said that they were prepared to complete questionnaires and a telephone interview again. Second, 305 letters were sent via 15 Hampshire and Dorset special schools and one local parenting group. The letter explaining the research was accompanied by a consent form and a pre-paid self-addressed envelope to the University. Mothers were asked to complete the consent form and return it to the University. Once the consent form had arrived back at the University, questionnaires were distributed to the mothers. As in the previous study, mothers were asked to nominate a sibling close in age to the child with learning disabilities for the purposes of data collection. Out of the 305 letters sent out via schools, 94 consent forms were received. Initial questionnaires and a personally addressed reminder letter were sent out, one month apart, to mothers who agreed to participate. A total of 75 questionnaires were completed and returned (80%). When mothers returned the completed questionnaires, they were telephoned within three weeks and asked to provide a Five Minute Speech Sample, a Vineland Adaptive Behaviour Scale for their child with learning disabilities, and a Five Minute Speech Sample for their typically developing child.

7.5. Results

7.5.1. Descriptive Analysis

Descriptive data from the two parenting measures (the Child Rearing Practice Report and the Parenting Sense of Competence Questionnaire) partially replicate the findings from Chapter Five. Mothers are significantly less Restrictive in their parenting behaviour (Mean = 45.17, SD = 7.28) than in comparison to Cornah et al. (in press) (Mean = 54.64, SD = 6.30) ($t(74) = -8.36, p < 0.01$). This result replicated findings from Chapter Five. However, mothers' level of Satisfaction (Mean = 25.32, SD = 4.38) in the parenting role was not significantly different when compared to the sample in Cornah et al. (in press) (Mean = 26.40, SD = 4.38) ($t(74) = -1.60, p = ns$). Mothers in the previous study (Chapter Six) reported less satisfaction with their parenting ability but this significant difference was not replicated within the present study.

Mothers' overall level of Family Satisfaction (Mean = 39.23, SD = 7.91) was no different to data from a normative sample (Mean = 40.28 : Olson & Wilson, 1982, no SD given) ($t(74) = 2.68, p = ns$). In contrast, marital Satisfaction scores for mothers in this sample can be considered "above average" (Mean = 26.13, SD = 9.53). This result supports findings from Floyd and Zmich (1991) who found that both mothers and fathers of children with learning disabilities were more satisfied with their marriage than mothers and fathers of typically developing children.

Results for both measures of maternal well-being are consistent, showing increased problems in mothers of children with learning disabilities. Maternal Anxiety and Depression scores (Mean = 7.33 and 4.29, representatively) indicated that, overall, mothers were borderline abnormal for Anxiety, but were in the normal range for Depression. For Anxiety, 45 mothers were in the normal range, 18 were borderline and 12 were abnormal. Therefore, 40% of the mothers were borderline or above, indicating an elevated level of anxiety in the sample. Sixty-three percent of mothers were within the normal range for depressive symptoms, six were borderline and two were abnormal, therefore 10% of these mothers could be considered depressed. A recent study by Hastings and Brown (2002) found that in mothers of children with Autism 54% of

mothers were in the borderline or clinical range for Anxiety and 38% were borderline or in the clinical range for Depression.

In terms of parenting stress, mothers in the present study (PSI Total Score Mean = 98.92, SD = 20.43) were more stressed than parents in the normative sample (Mean = 71.00, SD = 15.40) ($t(74) = 11.84, p < .01$). Furthermore, 64% of the mothers in the present study were in the clinical range for parental stress. These findings on the Hospital Anxiety and Depression scale and the Parenting Stress Index are a general replication of studies which show increased stress in mothers of children with learning disabilities. The above analysis of maternal variables suggest that the present sample of mothers is typical in displaying higher levels of stress and mental health problems and increased levels of marital satisfaction. However, a lack of appropriate published data using other measures makes it difficult to conclude whether or not they are reasonably representative in terms of parenting and family satisfaction. Data on the Strengths and Difficulties Questionnaire for the children with learning disabilities and their siblings can also be used to explore the representativeness of the sample. The analyses summarised in Table 7.1 and 7.2 shows that the sample of children with learning disabilities is typical in that they have elevated levels of behavioural problems compared with their siblings. However, the children with learning disabilities had fewer problems than a normative sample (see Table 7.3). This suggests that the present sample may not be entirely representative. Mothers may have under-reported problems in the siblings.

A final comparison can be made between children with learning disabilities for a nationally representative sample reported by Emerson (in press) (see Table 7.4). These data suggest that the present sample generally has fewer problems than a population sample of children with learning disabilities. Thus, it seems unlikely that the children with learning disabilities in the present sample are representative of the population of children with learning disabilities generally.

Table 7.1. Differences Between Children with Learning Disabilities and Their Sibling for the Strengths and Difficulties Questionnaire.

Sub Scale	LD	Sibling	t	Effect Size
Total Difficulties	16.81 (6.23)	7.04 (5.06)	11.72*	-1.73
Emotional Problems	2.35 (1.98)	1.84 (1.87)	1.68	-.26
Conduct Behaviour	2.99 (2.05)	1.37 (1.35)	6.68*	-.95
Hyperactivity	7.07 (2.19)	2.17 (1.96)	16.55*	-1.04
Peer Problems	4.52 (2.34)	1.68 (1.74)	8.46*	-1.39
Pro-social Behaviour	5.07 (3.93)	8.47 (1.60)	-6.46*	1.23
Impact	5.07 (3.48)	.76 (1.45)	-9.75*	-1.74

* $p < .001$

Means are displayed. Figures in parentheses are standard deviations.

Table 7.2 Differences Between Children with Learning Disabilities and a Normative Sample for the Strengths and Difficulties Questionnaire.

Sub Scale	LD	Normative	t	Effect Size
Total Difficulties	16.81 (6.23)	8.40 (5.8)	11.70**	-1.40
Emotional Problems	2.35 (1.98)	1.90 (2.0)	1.96*	-.23
Conduct Behaviour	2.99 (2.05)	1.60 (1.7)	5.86**	-.74
Hyperactivity	7.07 (2.19)	3.50 (2.5)	14.11**	-1.52
Peer Problems	4.52 (2.34)	1.50 (1.7)	11.16**	-1.50
Pro-social Behaviour	5.07 (3.93)	8.60 (1.6)	-7.79**	1.27
Impact	5.07 (3.48)	0.40 (1.1)	11.00**	-2.04

* $p < .05$

** $p < .01$

Means are displayed. Figures in parentheses are standard deviations.

NB normative data for British sample age range 5-15 years (Meltzer et al., 2000)

LD = Learning Disability

Table 7.3. Differences Between Siblings of Children with Learning Disabilities and a Normative Comparisons for the Strengths and Difficulties Questionnaire.

Sub Scale	Sibling	Normative	t	Effect Size
Total Difficulties	7.04 (5.06)	8.40 (5.8)	-2.33*	- .27
Emotional Problems	1.84 (1.87)	1.90 (2.0)	-.28	.03
Conduct Behaviour	1.37 (1.35)	1.60 (1.7)	-1.45	.15
Hyperactivity	2.17 (1.96)	3.50 (2.5)	-5.86**	.60
Peer Problems	1.68 (1.74)	1.50 (1.7)	.90	-.10
Pro-social Behaviour	8.47 (1.60)	8.60 (1.6)	-.72	.08
Impact	.76 (1.45)	.40 (1.1)	2.15*	-.28

* $p < .05$

** $p < .01$

Means are displayed. Figures in parentheses are standard deviations.

NB normative data for British sample age range 5-15 years (Meltzer et al., 2000).

Table 7.4. Differences Between data from Emerson (in press) and Children With Learning Disabilities From This Study. Comparisons for the Strengths and Difficulties Questionnaire.

Sub Scale	LD	Emerson	t
Total Difficulties	16.81 (6.23)	16.49 (6.73)	.38
Emotional Problems	2.35 (1.98)	3.41 (2.50)	-4.29**
Conduct Behaviour	2.99 (2.05)	3.15 (2.49)	-.70
Hyperactivity	7.07 (2.19)	6.50 (2.67)	2.20*
Peer Problems	4.52 (2.34)	3.52 (2.26)	3.58*
Pro-social Behaviour	5.07 (3.93)	7.75 (2.17)	-5.76**
Impact	5.07 (3.48)	7.01 (5.00)	-4.54**

* $p < .05$

** $p < .01$

Means are displayed. Figures in parentheses are standard deviations.

NB normative data for British sample age range 5-15 years (Meltzer et al., 2000).

7.5.2 Aetiology Effects

In order to explore whether aetiological differences were evident for maternal Expressed Emotion the sample was divided into three groups: children with Autism (23), children with Down Syndrome (26), and children with mixed or unknown aetiologies (24).

Kruskal-Wallis Tests were used, as data from the Five Minute Speech Sample were non-parametric (see Appendix J for statistical results). This analysis revealed no significant effects of learning disability aetiology on any dimension of the Five Minute Speech Sample. A similar analysis was conducted to explore potential effects of learning disability aetiology of the target children on maternal Expressed Emotion towards their sibling. Again, there were no significant effects (see Appendix J for statistical results). As maternal Expressed Emotion towards either child appeared unaffected by the aetiology of their child's learning disability, this variable was not used further in the following analyses.

7.5.3. Expressed Emotion Towards Siblings with and without Learning Disabilities.

A primary aim of the present study was to attempt to replicate findings of differences in maternal Expressed Emotion towards siblings with and without learning disabilities in a larger sample. In order to explore if maternal Expressed Emotion towards their two children was different or similar, a series of Wilcoxon Signed Rank tests were conducted on the domains of Expressed Emotion coded from the Five Minute Speech Sample. Differences were found for Criticism ($z(74) = -4.08, p < .05$), Initial Statement ($z(74) = -1.601, p = ns$), and Positive Comments ($z(74) = -3.34, p < .01$). As overall Expressed Emotion and Dissatisfaction were dichotomous variables, they were tested using Binomial tests. A significant difference existed for overall Expressed Emotion ($p < .001$), and ($p < .001$) for Dissatisfaction. Cross-tabulations were conducted to identify the direction of these significant effects. These data are summarised in Tables 7.5 and 7.6. In all cases, mothers expressed more negative (i.e., “higher” levels of) Expressed Emotion towards the child with a learning disability.

Table 7.5. Cross Tabulations for Dichotomous Expressed Emotion Variables

		Sibling	
Overall Expressed Emotion		High	Low
LD child	High	0	27
	Low	0	48
self-sacrificing		Present	Absent
LD child	Present	0	33
	Absent	0	42
Dissatisfaction		Present	Absent
LD child	Present	5	37
	Absent	5	28

LD = Learning Disability

Table 7.6. Cross Tabulation for Global Expressed Emotion Categories

		Sibling		
		High	Borderline	Low
<u>EOI</u>				
LD Child	High	0	0	21
	Borderline	0	0	0
	Low	0	0	54
<u>IS</u>		Positive	Neutral	Negative
LD child	Positive	0	3	0
	Neutral	1	45	0
	Negative	3	23	0

NB. EOI = Emotional-Over-Involvement

IS = Initial Statement

LD = Learning Disability

The results displayed in Tables 7.5 and 7.6 show that mothers' Expressed Emotion towards their two children differed. These differences occurred for: Criticism Dissatisfaction, Positive Remarks, Emotional-over Involvement, and overall Expressed Emotion. In all instances mothers had higher Expressed Emotion levels towards their child with learning disabilities, thus replicating the results in Chapter Six.

7.5.4. Correlates of Maternal Expressed Emotion

As in the previous study maternal Expressed Emotion was split into two categories of high or low derived from previous published literature on Expressed Emotion (see Chapter Three). This section replicates the analysis in Chapter Six but with a larger sample size and a broader range of measures. Results are summarised in Tables 7.7 and 7.8.

Table 7.7 Maternal Factors Associated with High Expressed Emotion Towards Children with Learning Disabilities.

	High EE N = 27	Low EE N = 48	u	p
Maternal Variables				
HADS Anxiety	8.44 (4.45)	6.71 (3.18)	522.50	.16
HADS Depression	4.63 (2.54)	4.10 (2.99)	532.50	.25
Marital Satisfaction	26.85 (8.62)	25.66 (7.55)	285.00	.69
Overall FSS	38.22 (7.59)	39.79 (8.10)	556.00	.47
FSS Cohesion	22.37 (4.68)	23.23 (5.19)	589.00	.51
FSS Family Adaptability	15.85 (3.37)	16.38 (3.36)	571.00	.57
Restrictive Parenting	45.70 (7.69)	44.87 (7.10)	563.00	.584
Parenting Satisfaction	26.22 (4.47)	24.81 (3.48)	498.00	.367
Total PSI	107.74 (20.73)	93.96 (18.70)	292.00	.01
PSI Parental Distress	33.37 (8.45)	29.47 (7.53)	410.00	.05
PSI Dysfunctional Interaction	31.78 (6.61)	28.04 (6.93)	397.50	.01
PSI Difficult Child	42.33 (10.57)	37.13 (7.92)	401.00	.03
PSI Defensive Responding	20.56 (5.46)	18.38 (4.92)	471.00	.13

Means are displayed. Figures in parentheses are standard deviations

Bold type highlights significant association.

HADS = Hospital Anxiety and Depression Scale

FSS = Family Satisfaction Scale

PSI = Parenting Stress Index

In order to explore if maternal Expressed Emotion was associated with occupation or marital status (dichotomous variables), chi-square analyses were carried out. These analysis identified no differences between mothers who were working or caring (χ^2 (2, N=75) = .29, ns), fathers who were working or caring (χ^2 (2, N=75) = .65, ns), and whether parents were married or not (χ^2 (2, N=75) = .85, ns).

Table 7.8 Results from an Mann Whitney test to identify what child factors are associated with high maternal Expressed Emotion towards children with learning disabilities.

Child Variables	High EE N = 27	Low EE N = 48	u	p
Overall VABS	48.56 (21.27)	55.31 (20.90)	476.00	.06
VABS Communication	2.89 (2.18)	4.41 (2.94)	407.50	.02
VABS Socialisation	3.56 (2.40)	4.76 (2.92)	439.00	.06
VABS Daily Living Skills	3.21 (2.00)	4.45 (2.88)	440.00	.06
SDQ Total Difficulties	17.63 (6.16)	16.28 (6.29)	445.50	.24
SDQ Hyperactivity	7.52 (2.33)	6.81 (2.09)	434.00	.12
SDQ Conduct	2.85 (2.01)	3.06 (2.01)	442.00	.08
SDQ Emotional	2.70 (1.71)	2.15 (2.10)	581.00	.84
SDQ Peer-Problems	4.52 (2.24)	4.52 (2.42)	623.00	.90
SDQ Pro-social Behaviour	4.85 (5.43)	5.218 (2.82)	486.00	.12
SDQ Impact	5.70 (3.37)	4.71 (3.82)	527.00	.23
Child Chronological Age	8.7 (4.12)	10.35 (3.91)	482.50	.09

Means are displayed. Figures in parentheses are standard deviations

NB VABS Overall score calculated using the Composite score (i.e. equivalent to a developmental quotation). Each domain score was calculated using an age equivalent score.

Bold type highlights significant Association

VABS = Vineland Adaptive Behaviour Scales

SDQ = Strengths and Difficulties Questionnaire

Overall 36% of mothers were coded as high Expressed Emotion towards their child with learning disabilities. This is a similar proportion to that identified in Study One.

However, the pattern of correlates of maternal Expressed Emotion was not replicated for study one suggesting that these associations are unstable or sample-dependent. The clearest findings from the analyses outlined in this section is a consistent association between mothers' reports of stress and Expressed Emotion towards their child with a learning disability. Thus, there is evidence for this association as predicted from my working model.

Only two of the mothers were coded as high Expressed Emotion toward the other child in the family. Therefore, an analysis of correlates of high versus low Expressed Emotion could not be conducted for the siblings. In the next section the development of a continuous measure of Expressed Emotion is described that enables the use of a prospective analysis (See Chapter Eight).

7.6. Alternative Coding of Expressed Emotion

McCarty and Weisz (2002) suggest that Expressed Emotion can be conceptualised as a positive dimension (Positive Remarks) and a negative dimension (other codes). Thus, for the present analysis, a positive Expressed Emotion score was derived from the total number of positive comments. In order to explore how to develop a negative Expressed Emotion dimension a factor analysis was conducted on maternal Expressed Emotion towards their child with a learning disability (similar results were obtained for analyses of sibling Expressed Emotion and therefore this analysis is not reported here). The results of a principle component analysis using varimax rotation and extraction of one factor only (based on a scree plot) are displayed in Table 7.11. The analysis suggests that a single negative Expressed Emotion dimension would be appropriate to use.

Table 7.9 Results of the Principle Components Analysis.

Dimension of EE	Factor Loading
EOI	.80
Dissatisfaction	.63
Criticism	.58
Initial Statement	-.54

1 High score = High Expressed Emotion

2 High score = Positive Initial Statement

To obtain a Negative Expressed Emotion score, the four appropriate dimensions of the Five Minute Speech Sample were scored as binary categories. Table 7.10 identifies how each dimension of Expressed Emotion was scored as either high or low. These classifications were based on a logical application of scoring (e.g. positive and neutral scored as low Expressed Emotion for Initial Statement), or distributions in the present data set (e.g. mothers tended to divide into those making no critical comments and those making one or more). A five point negative Expressed Emotion scale was thus derived (ranging from zero to four). This method of scoring could be replicated for siblings and also over time and in any future research. Tables 7.11 and 7.12 show the distributions of scores on positive and negative Expressed Emotion scales in the present sample.

Table 7.10 New Scoring System Negative Expressed Emotion.

Dimension of EE	Score	
	0	1
Initial Statement	Positive and Neutral Scores	Negative Scores
Criticism	No Critical Comments	One or more Critical Comments
Dissatisfaction	No Dissatisfied Comment	One or more Dissatisfied Comments
Emotional-over Involvement	Low and Borderline Scores	A High Score

Table 7.11 Distribution for Negative Expressed Emotion Scale

Negative EE Score	Score LD Child	Score Typically Developing SB
0	9	23
1	26	44
2	20	8
3	17	0
4	3	0

EE = Expressed Emotion

LD = Learning Disability

SB = Sibling

Table 7.12 Distribution for Positive Expressed Emotion.

Positive EE Score	LD	SB
0	15	5
1	20	6
2	21	24
3	11	26
4	3	5
5	2	9
6	1	0
7	2	0

EE = Expressed Emotion

LD = Learning Disability

SB = Sibling

Before conducting further analyses with the new negative Expressed Emotion scale, two exploratory tests were conducted. First, the scores of mothers originally coded as overall high or low Expressed Emotion on the Five Minute Speech Sample were compared using a Mann-Whitney test. This revealed a higher negative Expressed Emotion scale score for mothers coded overall as high Expressed Emotion ($u = 410, p < .05$). This suggested that the new scale assessed a similar construct to the overall Expressed Emotion coding, as would be expected. Second, the two new scales were explored for any effects of learning disability aetiology. Again, Kruskal Wallis tests showed no effect of aetiology on mothers' positive or negative Expressed Emotion to their child with a learning disability or sibling.

Correlates of both positive and negative Expressed Emotion were explored for children with learning disabilities and their siblings using Spearman's correlations. Maternal variables and sibling variables were found to be unrelated to dimensions of positive and negative Expressed Emotion towards siblings. However, there were associations between

some maternal and child variables and negative Expressed Emotion but not positive Expressed Emotion towards the child with learning disabilities. The significant associations were with Total PSI Stress ($r(75) = .46, p < .05$), Impact ($r(75) = .24, p < .05$), Total Difficulties on the Strengths and Difficulties Questionnaire ($r(75) = .32, p < .05$), Parenting Satisfaction measured on the Parenting Sense of Competence Questionnaire ($r(75) = .31, p < .05$), and Chronological Age of the child with learning disabilities ($r(75) = -.23, p < .05$).

The issue of within-family differences in maternal Expressed Emotion was also explored using the two new Expressed Emotion scales. Using Wilcoxon tests, there was no difference between siblings on maternal positive Expressed Emotion ($z(75) = .69, ns$), but mothers were coded with higher levels of negative Expressed Emotion towards their child with learning disabilities ($z(75) = -4.81, p < .00$). Thus, the main finding of differential Expressed Emotion towards children in the same family when one child has a learning disability was replicated.

Data from this larger sample of mothers of children with learning disabilities confirmed that Expressed Emotion was more negative towards a child with learning disabilities than towards a typically developing sibling in the same family. This emotional dimension of the parenting relationship appears to be affected by child differences especially the presence of learning disability. This suggests that parenting may well be associated with child factors proposed in my working model. The present data cannot inform us about the direction of affect as hypothesised in the model.

The difference in Expressed Emotion towards children in the same family may be explained partly by child factors such as adaptive behaviour and behaviour problems. However, results relating to Expressed Emotion correlates in this study and in Study One are unstable and may be affected by sample and/or measurement variables. In the present sample, however, a strong association was noted between parenting stress associated with the care of the child with a learning disability and maternal Expressed Emotion towards that same child. Thus, the finding is supportive of the association predicted by my

working model but again no data on causality are available to test the direction of effect.

Preliminary data on a new method for scoring Expressed Emotion were also encouraging. Simple, replicable, methods for scoring dimensions of both positive and negative Expressed Emotion were developed. The main finding, of sibling differences and association between maternal stress and Expressed Emotion towards the child with learning disabilities, was replicated using the negative Expressed Emotion scale. However, no differences were found for the positive Expressed Emotion dimension. This finding is worthy of explanation in future research as the implication may be that mothers are equally positive about their relationship with their child with learning disabilities and are being more negative at the same time. The development of these new Expressed Emotion scores also facilitates the longitudinal analysis in Chapter Eight.

All of these findings appear to have been unaffected by aetiological factors relating to learning disability which was identified as a potential controlling variable in Study One. However, given the likely biases in the present sample (see below) differences in Expressed Emotion towards children with various learning disabilities syndromes may still be worthy of future research attention.

A number of additional methodological problems are also apparent in this study. First, response rates were again low and recruitment of mothers was difficult. Second, data on maternal variables suggested that the sample may not be extraordinary. However, data on behavioural problems of the children with learning disabilities and their sibling suggested that the sample was not representative of the UK population. Finally, the lack of associations between variables identified in previous research (especially behavioural problems) and maternal Expressed Emotion raises questions about sample specific effects. Thus, all of the present findings should be treated with caution until replicated and extended.

With these caveats in mind, it is now possible to conduct a preliminary test of the directional relationship identified in the working model. Because some mothers from Study One were recruited into Study Two, there is a small sample for whom key variables were measures at two time points. Thus, a simple prospective analysis is possible and is described in the following chapter.

CHAPTER EIGHT

Study Four: Longitudinal Analysis of Expressed Emotion

Research findings from previous chapters have demonstrated associations between key variables. However, there is still a need to explore maternal-child relationships over time. In this chapter I aim to explore relationships of maternal Expressed Emotion, child behavioural problems, and maternal stress over a six month period. The research in this chapter is a follow-up of 21 mothers from Study Two (Chapter Five). All the 21 mothers had a child with learning disabilities between the ages of 4 and 14 years. The key questionnaire measures available at both measurement points were: child behaviour problems, impact of the child on the family, child adaptive behaviour and maternal Expressed Emotion.

The results were consistent with the model suggesting that maternal stress mediates the effect of parenting on child outcome (behaviour problems). This was a different relationship to that predicted in my working model. Methodological limitations including the small and selective sample and less than ideal available measures are discussed.

The models reviewed in Chapter One identify the family unit and individual family members' responses to having a child with learning disabilities. These models do go some way to explain why stress in these families may vary due to the knowledge held by families and individuals, their socio-economic status, and level of social support amongst other factors. However, in most studies only a relatively small proportion of the variance in parental stress is accounted for. Also, the majority of this research is correlational which does not account for the direction of the effect. That is, research cannot tell us whether it is the child or the parent which is driving the interaction. Therefore, there is still a fair amount of variance to be explained in what predicts stress in parents of children with learning disabilities.

The mechanism that might link child disability variables as stressors and parental stress outcomes (or vice versa) is not wholly due to the psychological and other resource variables identified in stress models. One factor that has received less attention in the learning disability literature is parenting behaviour and especially the relationship between parent and child (although, see Chapter Two for a review).

Within the broader child psychological literature, research data do suggest a link between parenting stress and parenting behaviour (see Chapter One). Generally the research suggests that parents who show more stress show poorer parenting. Deterioration in the positive aspects of parenting has been found to causally influence children's behaviour, whereby increases in inept parental behaviour (possibly neglectful or abusive, in extreme circumstances) will lead to poorer cognitive and social-emotional development outcomes for children. Therefore, psychological distress that arises from the demands of parenting has been found to play a particularly important role in the development of dysfunctional parent-child relationships.

The only research that has been conducted to test this relationship suggests that parenting behaviour is a mediator between parenting stress and child adjustment

(Deater-Deckard, Pinkerton, & Scarr, 1996). That is, high levels of parental stress correlated with more authoritarian parental discipline, which in turn correlated with more behavioural problems among children.

This model expands the focus of research on family functioning in the field of learning disability to a third variable (parenting behaviour) that may explain some variance in child functioning that in turn affects parenting stress.

My working model (see Chapter One) suggests that child behavioural problems will predict maternal stress, which in turn will predict parenting behaviour, which predicts child behavioural problems (See Figure 8.1).

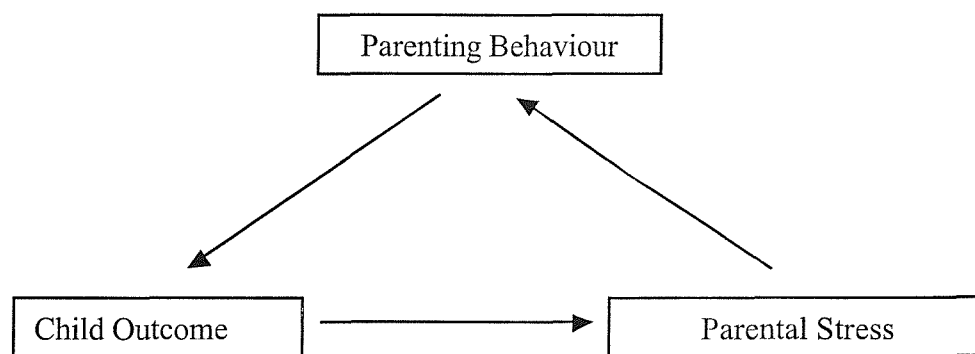


Figure 8.1 Predicted Relationships Between Parent and Child Variables

Previous studies in this thesis have explored Expressed Emotion as a potential parenting measure in mothers of children with learning disabilities. Results from these studies have suggested associations between Expressed Emotion and child variables (including behaviour problems and, to a lesser extent, adaptive behaviour), and Expressed Emotion and maternal stress. A great deal of published research also

demonstrates clear associations between child variables, especially behavioural problems, and parental stress (Hastings, 2002). However, within the field of learning disabilities, the direction of these associations between child and parent (especially, Expressed Emotion) have very rarely been established. The present analysis built on an opportunity within my research to explore these relationships longitudinally.

8.2. Method

8.2.1. Participants

Twenty-one mothers who had a child with learning disabilities between the ages of 4 and 14 years participated in the research. The mothers' mean age was 40.95 years ($SD = 5.00$), with 10% of mothers in full-time employment, 35% work part-time, and the remainder work as full-time carers for their children. The children with learning disabilities had a mean age of 8.24 years ($SD = 3.46$), and a gender ratio of 11 males to 10 females. Diagnostic descriptions for the children with learning disabilities included: Autism (4 children), Down Syndrome (12 children) and Unknown Aetiologies (5 children). The children with learning disabilities were developmentally delayed on average by 3.76 years ($SD = 4.38$) calculated using an aggregate of the Vineland Adaptive Behavioural Scale (Sparrow et al., 1984). Their mean composite score was 66.16 ($SD = 13.36$, range = 34 - 86).

8.2.3. Materials

Measures available at both time points for all 21 mothers and their child with a learning disability were:

- Child Variables – Strength and Difficulties Questionnaire (Total Behaviour Problem score), and the Vineland Adaptive Behaviour Scales (Composite score).
- Maternal Expressed Emotion – data from the Five Minute Speech Sample using the procedure for scoring positive Expressed Emotion and negative Expressed Emotion (see Chapter Seven).

- Maternal “Stress” – one question from the Strengths and Difficulties

Questionnaire on the Impact supplement was used. This was: “Do the difficulties put a burden on you or the family as a whole?” No other measure of impact on the family and or mother was available at both time points.

8.2.4. Procedure

The 33 mothers who provided questionnaire and interview data for Study Two (Chapter Five) were contacted again, six months later, and asked to participate in a follow up study. Replies were received from 21 of these mothers (64%) who agreed to participate and their data were included in the analyses in Chapter Seven.

8.3. Results

Two analyses were conducted on the present data set. First, data on the stability of maternal Expressed Emotion towards children with learning disabilities was explored over a six month interval. This analysis adds to the exploration of the properties of Expressed Emotion in the context of learning disability (see Chapter Five). The second analysis focused on cross-lagged correlations between the key variables.

8.4. Stability of Expressed Emotion

Stability of Expressed Emotion towards the child with a learning disability was calculated using the original Five Minute Speech Sample coding of high versus low Expressed Emotion and for the scores of positive and negative Expressed Emotion (See Chapter Seven). The results of these analyses are presented in Table 8.1.

Table 8.1 Stability of Expressed Emotion for Children with Learning Disabilities.

Dimension of EE	Stability Coefficient
Negative Expressed Emotion ¹	.45*
Positive Expressed Emotion ¹	.29
Overall EE (High/Low) ²	.70

¹ Stability assessed using Speaman Correlation

² Stability assessed using Kappa

* Significant correlation $p < .05$

These analyses suggest stability over six months, especially for negative Expressed Emotion, but enough variability to explore changes in Expressed Emotion over time and how this relates to changes in maternal stress and child variables.

8.5. Crossed Lagged Correlations

Associations across time between pairs of variables were explained using cross-lagged correlations. The association between variable A and Time 1 and variable B at Time 2 was calculated whilst controlling for variable B as measured at Time 1. Note that only the factor scores and not the high/low Expressed Emotion scores are being used in the crossed-lagged correlations.

8.6. Crossed-Lagged Correlations for Negative Expressed Emotion

Cross-lagged correlations between negative Expressed Emotion and other variables are displayed in Table 8.2. below.

Table 8.2. Crossed-Lagged Correlations for Negative Expressed Emotion

Time One	Crossed-Lagged Correlation	Time Two
Total Difficulties	(.04) .47	Negative EE
Negative EE	(.99) .00	Total Difficulties
Overall VABS	(.99) -.00	Negative EE
Negative EE	(.25) .27	Overall VABS
Pro-social Behaviour	(.36) .22	Negative EE
Negative EE	(.27) -.25	Pro-social Behaviour
Impact	(.71) .09	Negative EE
Negative EE	(.01) .59	Impact
Impact	(.00) .62	Behaviour problems
Behavioural Problems	(.85) .05	Impact
VABS	(.30) .24	Impact
Impact	(.36) .22	VABS
Pro-social Behaviour	(.40) .20	Impact
Impact	(.42) .19	Pro-social Behaviour

p values are in parentheses

The results of these analyses suggest longitudinal relationships between behaviour problems and negative Expressed Emotion, but not Pro-social or adaptive behaviour. Furthermore, negative impact was associated over time with behaviour problems, but not pro-social and adaptive behaviour. Finally, negative Expressed Emotion predicted negative impact over time and not vice versa.

8.7. Crossed-Lagged Correlation for Positive Expressed Emotion

Cross-lagged correlations between positive Expressed Emotion and other variables are displayed in Table 8.3 below.

Table 8.3. Crossed-Lagged Correlation Positive Expressed Emotion

Time One	Crossed-lagged Correlations	Time Two
Total Difficulties	(.85) -.04	Positive EE
Positive EE	(.14) -.34	Total Difficulties
Overall VABS	(.40) .20	Positive EE
Positive EE	(.35) -.22	Overall VABS
Pro-Social Behaviour	(.96) -.01	Positive EE
Positive EE	(.42) .19	Pro-social Behaviour
Impact	(.39) -.20	Positive EE
Positive EE	(.32) -.23	Impact

p values are in parentheses

No significant associations over time were found between positive Expressed Emotion and negative impact or child variables.

8.8. Discussion

The first results to note from the present analysis relate to the stability of Expressed Emotion in mothers towards children with learning disabilities. Negative Expressed Emotion was found to be relatively stable over a six month period. This finding is consistent with the result of previous research with other clinical populations. For example Scazufea and Kuipers (1998) assessed stability of Expressed Emotion in relatives of patients with schizophrenia over a nine month period. Sixty-four percent of relatives had the same level of Expressed Emotion at the two measurement points, 25% had changed from high to low Expressed Emotion and 11% had changed from low to high Expressed Emotion.

Within other research with children, Expressed Emotion has been found to be stable over one month in a sample of parents of disadvantaged and ethnic minority children (Mcguire & Felton, 1994). However, Vostanis and Nicholls (1995) found that mothers of children with Conduct Problems expressed significantly less Criticism and higher levels of Warmth at a nine month follow-up interview. Combined with data from the previous analysis, Expressed Emotion towards children may well change gradually over time or perhaps more specifically with changes in the child e.g. behaviour problems (Peris & Baker, 2000).

The results of the crossed-lagged correlation analysis, taken at face value, indicate the following:

- A negative, rather than a positive, dimension of Expressed Emotion is related longitudinally to maternal stress and child characteristics.
- Children's behaviour problems, and not pro-social or adaptive behaviour, are longitudinally related to maternal stress and Expressed Emotion.
- The causal direction implicated is not as predicted by my working model. Rather, an emotional dimension of parenting (Expressed Emotion) affects maternal stress that in turn affects the presentation of children's behavioural problems.

However, due to a number of conceptual and methodological issues, these results must be treated with caution and considered a preliminary explanation of these relationships. Problematic issues include: the conceptual relationship between parenting and Expressed Emotion, the small and rather selective sample, the measurement of maternal stress using a single “impact” item, source variance due to the fact that mothers provided all the data gathered, and the status of Expressed Emotion as a mediating variable (as implied by my working model). These issues, among others, are discussed in more detail in the following Discussion Chapter.

CHAPTER NINE

General Discussion

The purpose of this final chapter is to summarise the findings of the empirical work conducted within this thesis, to consider the implications of the findings for mothers of children with learning disabilities, and discuss theoretical and conceptual issues. The starting point of this thesis was the need to explore relationships between child functioning, parental stress and the relationships between parents and children.

Three main aims were addressed in this thesis.

- What, if any, are the differences in maternal Expressed Emotion towards siblings with and without learning disabilities? That is, what differences are there in the emotional relationship a mother has with her children with and without learning disabilities?
- Why might there be differences in a mother's relationship with her children with and without learning disabilities? That is, what maternal and other factors predict aspects of this relationship?
- The working model (c.f. Deater-Deckard, 1998) suggests that child variables affect parental stress that, in turn, affects child outcome via an impact on parenting behaviour. Other research also identifies that parent-child effects may be bi-directional (e.g. Patterson, 1982). This thesis aimed to identify some tentative relationships between maternal Expressed Emotion and child functioning (specifically, behavioural problems) using a prospective research design.

In order to address these aims, it was also important to assess the psychometric properties of the Five Minute Speech Sample for mothers of children with learning disabilities. Therefore, there were four stages to this thesis. The first stage of the research focused on the reliability of the measures to be used on mothers who have children with learning disabilities. The second stage was an exploration of maternal Expressed Emotion using a within family design (i.e. was there a difference in maternal Expressed Emotion towards siblings with and without learning disabilities?). The third stage of the research built on the discovery of Expressed Emotion differences between children with learning disabilities and their siblings, and explored further factors that may be associated with maternal Expressed Emotion. This study included additional measures identified from the literature review in Chapter One. The final stage of the research focused on the prospective analysis of maternal Expressed Emotion and behavioural problems.

9.1 Results

A brief overview of the results suggests that the present sample of mothers is typical in displaying higher levels of stress and mental health problems and increased levels of marital satisfaction. However, a lack of appropriate published data using other measures makes it difficult to conclude whether or not they are reasonably representative in terms of parenting and family satisfaction. This suggests that more research needs to be conducted within this area if we are going to be able compare and generalise research findings.

With regard to Expressed Emotion, in all cases mothers expressed more negative (i.e. “higher” levels of) Expressed Emotion towards the child with learning disabilities. This finding was also apparent regardless of the aetiology of the child’s disability. The data from this thesis were compared with published results from clinical samples. Mothers of children with learning disabilities had lower rates of high Expressed Emotion than other clinical samples and higher rates of high Expressed Emotion than mothers of normal controls. Both of these comparisons were made with studies with comparable methodologies. The finding that mothers may have lower levels of Expressed Emotion than other clinical samples may be due to the sample selection. In particular, the sample contained a large number of children with Down Syndrome. This issue will be discussed in the methodology section. Also worthy of note was that

the pattern of correlates of high maternal Expressed Emotion was not replicated between studies one and two suggesting that these associations are unstable or sample-dependent. The only consistent finding from the analyses is an association between mothers' reports of stress and Expressed Emotion towards their child with learning disabilities. This relationship is supportive of predictors from the working model.

Throughout this thesis the working model has been referred to (c.f. Deater-Deckard, 1998) which suggests that child variables affect parental stress that, in turn, affects child outcome via an impact on parenting behaviour. The final aim of this thesis was to identify some tentative relationships between maternal Expressed Emotion and child functioning (specifically, behavioural problems) using a longitudinal research design. However, the results from Chapter Eight were not supportive of the working model. The results of the crossed-lagged correlation analyses suggest negative, rather than positive, characteristics of the children are related longitudinally to maternal stress and maternal Expressed Emotion. Specifically, children's behaviour problems, and not pro-social or adaptive behaviour, are longitudinally related to maternal stress and Expressed Emotion. However, the causal direction implicated is not as predicted by the working model. Rather, an emotional dimension of parenting (Expressed Emotion) was found to affect maternal stress that, in turn, affected the presentation of children's behavioural problems. However, there are a number of methodological reasons why this result may not be as expected (see Methodology section).

Only two of the mothers in Chapter Seven were coded as high Expressed Emotion towards a typically developing child in the family. Therefore, an analysis of correlates of high versus low Expressed Emotion could not be performed for the siblings. Therefore a new continuous coding system was developed which has potential as a simple, replicable method for scoring dimensions of both positive and negative Expressed Emotion. The continuous nature of the new coding system also enables a prospective correlational analysis. The literature on Expressed Emotion has focused on a positive dimension (Positive Remarks) and a negative dimension (other codes) (e.g. McCarty & Weisz, 2002). This thesis also used a positive Expressed Emotion score derived from the total number of positive comments. In order to explore a negative Expressed Emotion dimension, a factor analysis was conducted on maternal

Expressed Emotion towards their child with learning disabilities. The results of a principal component analysis suggested that a single negative Expressed Emotion dimension would be appropriate to use. This method of scoring could be replicated for siblings, and also over time and in any future research. The new scale assessed a similar construct to the current coding of Expressed Emotion. That is, those coded as high in Expressed Emotion using the original Five Minute Speech Sample methods scored higher on the new negative Expressed Emotion scale.

Overall, Expressed Emotion does seem to be related to child factors (i.e. those associated with learning disability). This supports the notion that Expressed Emotion may be associated with child factors as predicted in the working model. Using the new coding system data from Study Two confirmed that Expressed Emotion was more negative towards a child with learning disabilities than towards a typically developing sibling in the same family. Analysis was conducted to explore potential effects of learning disability aetiology of the target children on maternal Expressed Emotion. Again, there were no significant effects. The overall findings from Chapter Seven suggest that parenting may well be associated with child factors as suggested in the working model. Furthermore, simple, replicable, methods for scoring dimensions of both positive and negative Expressed Emotion were developed. Although these findings require replication, the initial results are promising for the use of a continuous coding system for Expressed Emotion. However, there are two points to note about this new way of coding Expressed Emotion. Firstly, data from other samples may not fall as well into one negative factor. Secondly, having a continuous measure of Expressed Emotion emphasises the dimensional nature of Expressed Emotion as there is no cut-off point for high Expressed Emotion. Theory in the field would need to be developed to encompass such a change in emphasis.

9.2 Methodological Issues

There are a number of methodological issues which have been highlighted throughout this thesis. Predominantly these have been associated with small sample sizes, and resulting non-representative samples. Other important issues when working with families who have children with learning disabilities are the reliability of measures, and replication of findings. These issues will be discussed below.

Throughout this research there have been many problems with recruitment. Although numerous questionnaires were distributed through schools and parenting associations the response rates were still very poor. Often, mothers who have children with learning disabilities were just too busy caring for their child to participate in this research. Thus, the recruitment problem may be a factor of the time commitment needed from mothers. Chapter One presented research which suggests that families who have children with learning disabilities have a greater number of unusual caregiving demands associated with less socially responsive children who have more difficult temperaments, display more repetitive behavioural patterns, and have more severe disabilities (Beckman, 1983; Chavira et al., 2000). Parents may also need to maintain physiotherapy sessions at home (especially with children who have motor skills problems) and help the child to achieve certain developmental milestones (e.g. walking, talking, and self-care) that ordinarily would occur without much parental effort.

Another methodological issue related to the sample was the number of children recruited with Down Syndrome. This may be an important factor in explaining why the data on behavioural problems in these children are dissimilar to Emerson's (in press) data. The data are typical in that the children have elevated levels of behavioural problems compared with siblings and a normative sample. However, the siblings had fewer reported behavioural problems than the normative sample. That is, mothers may have under-reported problems in the siblings. One explanation for this is that mothers may hold an idealised view of typically developing children within this sample. Alternatively, mothers with less problematic children may have been more likely to participate in the research. Also, the children with learning disabilities had fewer behavioural problems than Emerson's (in press) data. Thus, it seems unlikely that the children with learning disabilities in the present sample are representative of the population of children with learning disabilities generally.

Published research also suggests that there are within-condition effects. Research on behavioural problems in children with learning disabilities typically shows that children with Down Syndrome have fewer behavioural problems than children with other learning disabilities (Stores et al., 1998). Research also suggests that parents of children with autism and behaviour disorders experience clinically higher levels of

parenting stress than parents of children with Down Syndrome, that the behavioural problems of children with autism and behaviour disorders were more intense than children with Down Syndrome, and lastly that parents of children with autism and behaviour disorders experiences higher levels of dysphoria than mothers of children with Down Syndrome (Dumas, Wolf, Fisman, & Culligan, 1991). All of these effects could have biased the results. In future research, it will therefore be important to recognise the potential impact of particular aetiologies on parental adaptation and functioning (Dykens & Hodapp, 2001).

Research on parent-child interactions has almost exclusively been conducted using between-family designs. This between-family research focus has been at the expense of considering variation within families, which is extremely important if it is to accept that parenting stress, which may influence child maladjustment, also varies within and between families (Deater-Deckard, 1998). The literature reviewed in Chapter Two provides evidence that parents do parent differently dependent on a key child characteristic: whether the child has a learning disability. Therefore, using a within-family design had several advantages over using a single sample design or between-family design. The use of a within-family design methodology worked well within the setting of this thesis and future research should consider using within-family designs to eliminate complicated matching criteria. However, this thesis did not control for the number of children within the family or for birth order. Both of these may contribute, although this is controversial, to research findings (Bagenholm & Gillberg, 1991; Dallas et al., 1993; Mactavish, Schleien, & Tabourne, 1997). However, there are also disadvantages to using a within-family design. Particularly reflecting the results, mothers may have had idealised views of their typically developing children which makes comparisons to children with learning disabilities difficult. That is, if the typically developing sibling's behaviour is not representative of behavioural problems in typically developing children generally then using a within-family design may be problematic.

Chapter Five aimed to identify whether the measures to be used in this thesis were reliable and valid for use with mothers who have children with learning disabilities. The Chapter found moderate to good internal consistency and test-retest reliability for the Child Rearing Practice Report Restrictive scale, Parenting Sense of Competence

Questionnaire Satisfaction scale, and some dimensions of the Strengths and Difficulties Questionnaire. The sub-scales of parenting Efficacy and Nurturant parenting did not demonstrate good reliability. As a result of the poor test-retest reliability and lack of internal consistency for these subscales, parenting Efficacy and parenting Nurturant were not used further in this thesis. Chapter Five also demonstrated good code-recode, test-retest and inter-rater reliability for the Five Minute Speech Sample with mothers of children with learning disabilities. The results from the Five Minute Speech Sample and the Vineland Adaptive Behaviour Scales when checked for agreement for use over the telephone were satisfactory. This finding may prove to be invaluable to researchers as collecting data over the telephone may improve response rates in families.

One issue that has not been discussed is the measurement of maternal stress using a single “impact” item from the Strengths and Difficulties Questionnaire (Chapter Eight). Due to limitations in measures applied at both time points, the only measure which could use to highlight maternal stress was “Do the difficulties put a burden on you or the family as a whole?”. This item was not robust enough to establish maternal stress. Stronger conclusions could have been drawn if the Parenting Stress Index short form had been used at both time points. Therefore, these results must be treated with caution and considered as a preliminary exploration of parent-child relationships. Future research should examine this model with specific measures identifying parental stress, child outcome, and parenting behaviour if we are to establish causal relationships. A further difficulty with the data from Chapter Eight was the factor of time. Measurement of Expressed Emotion has been seen to fluctuate over time and research in Chapter One identifies how parental stress may fluctuate over the course of the family’s life cycle. Thus, when collecting data on Expressed Emotion, life events should be taking into consideration and longitudinal research should take several measures of Expressed Emotion over the duration of the research project.

9.3 Measurement and Future Issues

A potential limitation of this thesis is the nature of the measures. All the measures used within this thesis can be considered as maternal self-report or maternal reports on child behaviour. Having said that, the Five Minute Speech Sample is a self-report measure but mothers are not familiar with the coding manual and so are blind to the purpose of the measure. The Five Minute Speech sample worked well as a measure of the emotional relationship a mother had towards her two children, with and without learning disabilities. Although the Five Minute Speech Sample has been well validated with observations (Daley et al., in press) there are few validated alternative approaches (see Chapter Three). Due to Expressed Emotion being specific to, for example, the relationship one person has with another it is not feasible to collect data from a proxy source (e.g. teacher or other parent). With regard to child behavioural problems, it may have been interesting to collect teacher data on both the behavioural problems of the child with learning disabilities and the typically developing sibling. This may have alleviated the problem of mothers' potential under-representing of problems with their typically developing child.

An interesting point to make about research on parents of children with learning disabilities is that research on the impact a child with learning disabilities has on parents has mainly focused on mothers, who have traditionally assumed the role of primary carer. The impact of a child with learning disabilities on fathers has been given relatively little attention in research. What little research that has been conducted on fathers explains the lack of father involvement in several ways (Lille, 1993): the father's inability to cope with a child who has learning disabilities, and a father's discomfort in showing physical affection. Perhaps one reason why research has concentrated on mothers is due to Heller et al's. (1997) findings, that indicated that even in the late 1990s care-giving for a child with learning disabilities has a greater impact, both objectively and subjectively, on the lives of mothers than on fathers. Although fathers may still not assume the role of the primary carer it does not mean that research should exclude them. Future research on parental Expressed Emotion should therefore consider collecting data on fathers as well as mothers.

A further variable not measured within this thesis, but highlighted in Chapter One, was family socio-economic status. Chapter One highlights that there are relatively few articles examining socio-economic status in families of children with learning disabilities, even though it may be especially significant. Research suggests that socio-economic status is generally a robust predictor of satisfaction and well-being for almost all domains of psycho-social functioning (Floyd & Saizyk, 1992). Floyd and Saizyk's study identified that socio-economic status is associated with both parent attitude and parent-child interactions within families raising children with mild to moderate learning disabilities. Floyd et al's., (1992) findings suggests that families who have a higher socio-economic status may have more problems adjusting to a child with learning disabilities but also that high socio-economic status families are more likely to have more severely affected children. Future research should take socio-economic status into consideration when researching the impact that a child with learning disabilities has on the family. Ethnicity may also be an important area for research. For example, a recent article by Lam and Mackenzie (2002) discussed the problems faced by mothers of children with Down Syndrome in Hong Kong. This article was written in view of the sociocultural background of the region, and the highly competitive nature of Hong Kong society. There are also data to suggest that ethnicity may be an important predictor of stress in families who have children with learning disabilities (Ong, Chandran, & Peng, 1999).

Blacher and Hatton (2001) recently reviewed current perspectives on family research in learning disabilities. Their paper captures one of the main aims of this thesis, suggesting that researchers are beginning to make some methodological advances in family research. Although this thesis has focused on mothers of children with learning disabilities, there is now a growing body of research that highlights the experiences not only of fathers but also grandparents and adoptive parents (although Expressed Emotion data have not yet been collected). Even though the negative impact of a child with disabilities is still being examined, researchers are slowly beginning to investigate the positive aspects of caring for a child with learning disabilities. What research needs to do now is establish predictors of positive aspects of having a child with learning disabilities. Within this thesis there were no predictors of positive Expressed Emotion identified. However, recent descriptive research has supported anecdotal reports that parents experience positive feelings towards their child with

learning disabilities, perceive a number of positive effects on themselves and their family, and even report significant transformations in their views on life and how it should be lived (e.g., Grant et al., 1998; Scorgie & Sobsey, 2000; Stainton & Besser, 1998; Taunt & Hastings, 2002). Given that parents report positive experiences and perceptions, future research needs to account for these phenomena theoretically and explore their potential implications for family functioning and professional practice.

9.4 Expressed Emotion

Expressed Emotion has been a construct used within this thesis because it is useful in quantifying the attitudes and feelings which people express about their relatives. Expressed Emotion has been used successfully as a research tool to measure levels of negative emotions or intrusive over concern with family members (Stubbe, Zahner, Goldstein, & Leckman, 1993). A potential advantage of Expressed Emotion, and one reason why it was useful in this thesis, is that it represents unshared variance, a parental attitude directed toward one child only. A distinguishing feature of Expressed Emotion that may account for its success is that as well as accounting for the content of what, for example, parents say about their child, it also accounts for vocal aspects including pitch and emphasis on delivery. This, according to Kuipers (1994), may account for Expressed Emotion's success in transferring between languages and cultures. Future cross-cultured research on Expressed Emotion in parents of children with disabilities is needed in order to confirm this expectation.

Although it has not been established whether parental Expressed Emotion is primarily the cause or result of child psychopathology, there is an association between high parental Expressed Emotion and poor child outcome (see Chapter Three). These findings have been validated using observation measures which also find that mothers with high Expressed Emotion do interact with children differently than mothers with low Expressed Emotion (Daley et al., in press). This body of research supports the utility of the Expressed Emotion concept as an assessment of the emotional dimension of parent-child relationships. Expressed Emotion may also have very significant implications for outcome in children. Therefore, it appears to be a concept of value in exploring the relationship between parents and children in families of children with learning disabilities.

One aspect of Expressed Emotion that has not been resolved is whether Expressed Emotion is a trait of parent communication or a product of the interactions between parents and ill relatives (i.e. a state). Findings from Schreiber, Breier and Pickar (1995) suggest that the Expressed Emotion variables of Emotional-over Involvement and warmth are state-related. Mothers showed significantly more Emotional-over Involvement and significantly less warmth towards their child with Schizophrenia than a typically developing child. There were no significant differences between the number of Critical Comments made by mothers towards their two children, which suggests a trait element to some dimensions of Expressed Emotion. The results from this thesis suggest that high/low Expressed Emotion, Emotional-over Involvement, Initial Statement, Critical Comments, Positive Remarks are state-related. That is, there were significant differences between siblings suggesting that mothers have different attitudes towards each child. However, there was no difference between the number of dissatisfied comments made by mothers suggesting that dissatisfaction towards children may be trait-related. Future analysis could examine these differences controlling for other variables which influence Expressed Emotion such as behaviour problems in the children and the siblings. Replication of the results from the present thesis is also crucial in order to establish the limits of external validity.

The relationship between behavioural problems and parenting stress has been the subject of a large number of recent studies (Baker, Henker, & Heller, 2000; Abidin, 1995; Deater-Deckard, Pinkerton, & Scarr; Deater-Deckard, 1998). These studies suggest that parents of children with behavioural problems experienced greater levels of stress than parents of children in comparison groups. Previous research also highlights several child factors that influence maternal Expressed Emotion. For example, elevated levels of child behavioural problems, conduct problems, hyperactivity and impact the child has on the family all increase levels of maternal Expressed Emotion (e.g., Baker, Heller, & Henker, 2000; Daley et al., in press; Dossetor et al., 1994). Utilising the Expressed Emotion components of warmth and hostility researchers such as Quinton and Rutter (1985) reported an association between lack of parental warmth and hostility, and child behavioural disturbances. More recently, Peris and Baker (2000) demonstrated a strong relationship between mothers' high Expressed Emotion status and the extent of their child's behavioural problems. Despite the implication of Expressed Emotion in the development of

childhood behavioural problems in general, few studies have examined child and familial factors associated with high and low Expressed Emotion. The only research published to date suggests that high Expressed Emotion at pre-school predicted child behavioural problems both in preschool and first grade (Baker et al., 2000). Baker et al. (2000) also suggest that child behaviour problems were predicted by maternal stress. When Expressed Emotion and maternal stress were entered together in the analyses the effect of Expressed Emotion was overshadowed by maternal stress. This study supports the notion that Expressed Emotion maybe a stress response to the demands involved in parenting children with behavioural problems.

The analysis of correlates, within this thesis, of maternal Expressed Emotion towards children with a learning disability identified that both maternal and child factors may be relevant in determining levels of maternal Expressed Emotion. The main finding, of sibling differences and association between maternal stress and Expressed Emotion towards the child with learning disabilities, were replicated using the negative Expressed Emotion scale. However, no differences were found for the positive Expressed Emotion dimension. This finding is worthy of exploration in future research as the implication may be that mothers are equally positive about their relationship with their child with learning disabilities but at the same time are more negative.

9.5. The Working Model

It has been seen within this thesis that children with learning disabilities have elevated levels of behaviour problems and that these behaviour problems may be significant predictors of elevated levels of stress in parents of children with learning disabilities. However, very little research has been conducted to determine the direction of these effects. Thus, understanding parent behaviour and the influences upon it may be crucial in understanding the development and maintenance of behaviour problems in children with learning disabilities. This model therefore expands the focus of research on family functioning in the field of learning disabilities to a third variable (parenting behaviour) that may explain some variance in child functioning that in turn affects parenting stress. The longitudinal element of the research provided me with the opportunity to tentatively test some of the assumptions set out in the model. However, perhaps due to methodological problems, the data from Chapter Eight did not support

the working model. Rather, an emotional dimension of parenting (Expressed Emotion) was found to affect maternal stress that, in turn, affected the presentation of children's behavioural problems. The lack of clarity in these findings may result from some of the advantages and disadvantages of the working model.

Firstly, there were several advantages of this working model:

- The use of parenting "behaviour" which should have explained some variance in child functioning, in turn affecting parenting stress.
- This working model extends the models in Chapter One as it assumes causality.
- As previously mentioned, with a more specific measure of parental stress associations may have been identified. Identifying directions of association between the parent-child relationship may help research establish early intervention strategies to reduce parental stress levels.
- Practical implications. Although not directly linked with the thesis, behavioural intervention programmes focus on changing the way in which adults provide consequences for children's behaviour problems. Specifically, clinicians interested in changing parent behaviour with the view to remediating children's behaviour problems could include parental stress reduction as an element in their treatment plans. Reducing parental stress may have an indirect beneficial effect on the child's behaviour by improving the quality of parenting behaviour.

However, there are several limitations to the working model.

- It is a very simple model identifying only a few factors. Taking behaviour problems, influential factors could include biology, the environment, and developmental variables in addition to the effects of parenting behaviour.

- There is no mention of coping. The models in Chapter One emphasise the role of appraisal processes and the resources that parents may have to cope with their child's behavioural problems. At the family level, the double ABCX model (McCubbin & Patterson, 1983) suggests that family members will become stressed if they do not have the resources to cope with the child's behavioural problems.
- Future research should consider identifying positive aspects of raising a child with learning disabilities. Recent descriptive research has supported anecdotal reports that parents experience positive feelings towards their child with learning disabilities, perceive a number of positive effects on themselves and their family, and even report significant transformations in their views on life and how it should be lived.

All of the above issues have important implications for the research findings. Most importantly, the lack of representative samples suggests that all results need to be viewed with caution and replication is required. The small sample sizes make generalisations difficult, if not impossible, and only having mother self-report data limits the value of findings.

9.6. Concluding Remarks

This thesis has been unique in several ways. Firstly, it has established that Expressed Emotion can be used as a telephone interview. This is an important finding for all researchers using this measure. Secondly, it has established that mothers do have quite different relationships towards children with and without learning disabilities. In all cases, the relationship a mother had with her child with learning disabilities is more negative. Therefore, it is important for future research to identify why mothers have a more negative relationship towards their child with learning disabilities, which may in turn lead to positive interventions with these families. Through using intervention strategies, or by finding ways to reduce the predictors of negative Expressed Emotion, these families may find some help when raising a child with learning disabilities. Thirdly, this thesis created a new coding system for Expressed Emotion, which may be more sensitive and appropriate for use with large-scale

within-family designs. Although the findings require replication, the results may provide researchers using Expressed Emotion on children with a more appropriate coding system than the existing measure. Finally, this thesis also aimed to identify some tentative relationships between maternal Expressed Emotion and child functioning (specifically, behavioural problems) using a prospective research design. Some relationships were found that require further replication.

Appendices

Appendix A

Prevalence and Definitions of Learning Disabilities.

There is at present a general consensus on the assessment procedure and criteria for diagnosis of learning disabilities. The most recent classification system for learning disabilities has shifted the basis for assessment and classification from a description of deficits to a description of the amount of support an individual requires (Luckasson, Coulter, Polloway, Reiss, et al., 1992).

Definitions of a learning disability have been numerous and can usually be linked to the predominant conceptualisation of intelligence at the time. Past definitions that have relied on terminology, aetiology and prognosis have given way to definitions that describe current behaviour or behavioural deficits related to other children in the population with the same chronological age.

The APA (1985) standards do not classify individuals with learning disabilities on the severity of their deficits rather classification is based on individual support requirements. For example, the need for intermittent, limited, extensive or pervasive support in each of the following areas: intellectual functioning and adaptive skills, psychological/emotional functioning, physical/health and environment (Coulter, 1996).

Learning disabilities, according to the DSM IV, refer to substantial limitations in present functioning. The DSM IV characterises a learning disabled person as someone who has significant sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following areas: communication, self-care, home living, social skills, community use, self direction, health and safety, functional academics, leisure and work.

According to both the American Psychological Association (1985) and the DSM IV a learning disability denotes a level of behavioural performance without reference to aetiology. Thus, it does not distinguish between a learning disability associated with psychosocial influences and a learning disability associated with biological deficits. A learning disability is descriptive of current behaviour and does not necessarily imply prognosis. Prognosis is related more to such factors as associated conditions, motivation, treatment and training opportunities than to a learning disability its-self.

The DSM IV definition describes a learning disability on the basis of scores on standardised intelligence tests, evaluation of adaptive behaviour, and the age at which the problem manifested. In order to receive a diagnosis of learning disabled, an individual must score approximately two standard deviations below the population mean for IQ (a score of 70 or less). The DSM IV maintains four levels of classification that have been accepted for many years. Table A1 shows levels of learning disability and their corresponding IQ score ranges.

Table A: classification of learning disabilities

Classification	IQ
Mild learning disability	50-55 to approximately 70
Moderate learning disability	35-40 to 50-55
Severe learning disability	20-25 to 35-40
Profound learning disability	below 20 or 25

Appendix B

Block Child Rearing Practice Report

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
I am easygoing and relaxed with my children	5	4	3	2	1
I believe children should be aware of how much I sacrifice for them	5	4	3	2	1
I believe children should not have secrets from their parents	5	4	3	2	1
I believe that children should be seen and not heard	5	4	3	2	1
I believe that scolding and criticism makes children improve	5	4	3	2	1
I control my children by warning them about the bad things that can happen to them	5	4	3	2	1
I do not allow my children to get angry with me	5	4	3	2	1
I do not allow my children to question my decisions	5	4	3	2	1
I do not allow my children to say bad things about their teacher	5	4	3	2	1
I don't think children should be given sexual information	5	4	3	2	1
I don't want my children to be looked upon as different from others	5	4	3	2	1
I encourage my children to be curious, to explore and question things	5	4	3	2	1
I encourage my children to talk about their troubles	5	4	3	2	1
I encourage my children to wonder and think about life	5	4	3	2	1
I expect my children to be grateful and appreciate all advantages they have	5	4	3	2	1
I express my affection by hugging, kissing and holding my children	5	4	3	2	1
I feel that children should be given comfort and understanding when they are scared or upset.	5	4	3	2	1

Appendices

I feel that children should have time to daydream, think and even loaf sometimes	5	4	3	2	1
I find it interesting and educational to be with my children for long periods	5	4	3	2	1
I find some of my greatest satisfactions in my children	5	4	3	2	1
I instruct my children not to get dirty when they are playing	5	4	3	2	1
I joke and play with my children	5	4	3	2	1
I let my children know how ashamed and disappointed I am when they misbehave	5	4	3	2	1
I make sure my children know that I appreciate what they try to accomplish	5	4	3	2	1
I prefer my children not to try things if there is a chance they might fail	5	4	3	2	1
I respect my children's opinions and encourage them to express them	5	4	3	2	1
I talk it over and reason with my children when they misbehave	5	4	3	2	1
I teach my children that in one way or another, Punishment will find them when they are bad	5	4	3	2	1
I teach my children to keep control of their feelings at all times	5	4	3	2	1
I think my children should be encouraged to do things better than other people's children	5	4	3	2	1
I trust my children to behave as I would expect them to, even when I am not with them	5	4	3	2	1
I try to keep my children away from other children or families whose ideas or values are different from our own	5	4	3	2	1
I want my children to make a good impression on others	5	4	3	2	1
When I am angry with my children, I let them know about it	5	4	3	2	1
I believe in praising children when they are good and think it gets better results than punishing them when they are bad	5	4	3	2	1

Appendix C

Parenting Sense of Competence Questionnaire

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
The problems of taking care of a child are easy to solve once you know how your actions affect your child - an understanding I have acquired.	5	4	3	2	1
Even though being a parent can be rewarding, I am frustrated now while my child is at his/her present age.	5	4	3	2	1
I do not know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated.	5	4	3	2	1
Being a parent is manageable, and any problems are easily solved.	5	4	3	2	1
Being a parent makes me tense and anxious.	5	4	3	2	1
I would make a fine model for a new mother/father to follow in order to learn what s/he would need to know in order to be a good parent.	5	4	3	2	1
I go to bed the same way that I wake up in the morning: feeling like I have not achieved very much.	5	4	3	2	1
My mother/father was better prepared to be a good mother/father than I am.	5	4	3	2	1
A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one.	5	4	3	2	1
I meet my own personal expectations for expertise in caring for my child.	5	4	3	2	1
If anyone can find the answer to what is troubling my child, I am the one.	5	4	3	2	1
Sometimes I feel like I'm not getting anything done.	5	4	3	2	1
Considering how long I've been a mother/father, I feel thoroughly familiar with this role.	5	4	3	2	1
My talents and interests are in other areas - not being a parent.	5	4	3	2	1
If being a mother/father of a child were only more interesting, I would be better motivated to do a better job as a parent.	5	4	3	2	1
I honestly believe I have all the skills necessary to be a good mother/father to my child.	5	4	3	2	1
Being a good mother/father is a reward in itself.	5	4	3	2	1

Appendix D

Strengths and Difficulties Questionnaire

Is your child.....	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children (treats, toys, pencils etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often has temper tantrums or hot temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, tends to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally obedient, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries, often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies or cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often volunteers to help others (parents/teachers/other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks things out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets on better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sees tasks through to the end, good attention span	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall, do you think that your child has difficulties in one or more of the following areas: emotion, concentration, behaviour or being able to get on with other people?

If you have answered 'yes', please answer the following questions about these difficulties:

- Do the difficulties upset or distress your child?

Not at	Only a	Quite	A great
all	little	a lot	deal

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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- Do the difficulties interfere with your child's everyday life in the following areas?

Not at	Only a	Quite	A great
all	little	a lot	deal

HOME LIFE

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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FRIENDSHIPS

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

CLASSROOM LEARNING

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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LEISURE ACTIVITIES

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------

- Do the difficulties put a burden on you or the family as a whole?

Not at	Only a	Quite	A great
all	little	a lot	deal

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Appendix E

Family Satisfaction Scale

How satisfied are you:

	D	SS	GS	VS	ES
with how close you feel to the rest of your family?	1	2	3	4	5
with your ability to say what you want in your family?	1	2	3	4	5
with your family's ability to try new things?	1	2	3	4	5
with how fair the criticism is in your family?	1	2	3	4	5
with the amount to time you spend with your family?	1	2	3	4	5
with the way you talk together to solve family problems?	1	2	3	4	5
with your freedom to be alone when you want to?	1	2	3	4	5
with how strictly you stay with who does what chores in your family?	1	2	3	4	5
with your family's acceptance of your friends?	1	2	3	4	5
with how clear is it what your family expects of you?	1	2	3	4	5
with how often you make decisions as a family, rather than individually?	1	2	3	4	5
with the number of fun things your family does together?	1	2	3	4	5

(D=Dissatisfied, SS=Somewhat Satisfied, GS=Generally Satisfied, VS=Very Satisfied, ES=Extreemly Satisfied).

Appendix F

The Golombok Rust Inventory of Marital State

My partner is usually sensitive to and aware of my needs

SD D A SA

I really appreciate my partner's sense of humour

SD D A SA

My partner doesn't seem to listen to me any more

SD D A SA

My partner has never been disloyal to me

SD D A SA

I would be willing to give up my friends if it meant saving our relationship

SD D A SA

I am dissatisfied with our relationship

SD D A SA

I wish my partner was not so lazy and didn't keep putting things off

SD D A SA

I sometimes feel lonely even when

SD D A SA

I am with my partner if my partner left me life would not be worth living

SD D A SA

We can “agree to disagree” with each other

SD D A SA

It is useless carrying on with a marriage beyond a certain point

SD D A SA

We both seem to like the same things

SD D A SA

I find it difficult to show my partner that I am feeling affectionate

SD D A SA

I never have second thoughts about our relationship

SD D A SA

I enjoy just sitting and talking with my partner

SD D A SA

I find the idea of spending the rest of my life with my partner rather boring

SD D A SA

There is always plenty of “give and take” in our relationship

SD D A SA

We become competitive when we have to make decisions

SD D A SA

I no longer feel I can really trust my partner

SD D A SA

Our relationship is still full of joy and excitement

SD D A SA

One of us is continually talking and the other is usually silent

SD D A SA

Our relationship is continuously evolving

SD D A SA

Marriage is really more about security and money than about love

SD D A SA

I wish there was more warmth and affection between us

SD D A SA

I am totally committed to my relationship with my partner

SD D A SA

Our relationship is sometimes strained because my partner is always correcting me

SD D A SA

I suspect we may be on the brink of separation

SD D A SA

We can always make up quickly after an argument

SD D A SA

Appendix G

Hospital Anxiety and Depression Scale

I feel tense or “wound up”

Most of the time A lot of the time From time to time, occasionally Not at all

I still enjoy the things I used to enjoy

Definitely as much Not quite so much Only a little Hardly at all

I get a sort of frightened feeling as if something awful is about to happen

Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all

I can laugh and see the funny side of things

As much as I always could Not quite so much now Definitely not so much now Not at all

Worrying thoughts go through my mind

A great deal of the time A lot of the time From time to time but not too often Only occasionally

I feel cheerful

Not at all Not often Sometimes Most of the time

I can sit at ease and feel relaxed

Definitely Usually Not often Not at all

I feel as if I am slowed down

Nearly all the time Very often Sometimes Not at all

I get a sort of frightened feeling like “butterflies” in the stomach

Not at all Occasionally Quite often Very often

I have lost interest in my appearance

Definitely I don't take as much care as I should I may not take quite as much care

I take just as much care as ever

I feel restless as if I have to be on the move

Very much indeed Quite a lot Not very much Not at all

I look forward with enjoyment to things

As much as I ever did Rather less than I used to Definitely less than I used to

Hardly at all

I get sudden feelings of panic

Very often indeed Quite often Not very often Not at all

I can enjoy a good book or radio or TV programme

Often Sometimes Not often Very seldom

Appendix H

Parenting Stress Index Short Form

	<i>Strongly Agree</i> 1	<i>Agree</i> 2	<i>Not Sure</i> 3	<i>Disagree</i> 4	<i>Strong Disag</i> 5
I often have the feeling that I can not handle things very well		2	3	4	5
I find myself giving up more of my life to meet my child's needs than I ever expected	1	2	3	4	5
I feel trapped by my responsibilities as a parent	1	2	3	4	5
Since having this child, I have been unable to do new and different things	1	2	3	4	5
Since having this child, I feel that I am almost never able to do things that I like to do	1	2	3	4	5
I am unhappy with the last purchase of clothing I made for myself	1	2	3	4	5
There are quite a few things that bother me about my life	1	2	3	4	5
Having this child has caused more difficulties than I expected in my relationship with my spouse (male/female friend/partner)	1	2	3	4	5
I feel alone and without friends	1	2	3	4	5
When I go to a party I usually expect not to enjoy myself	1	2	3	4	5
I am not as interested in people as I used to be	1	2	3	4	5
I don't enjoy things as I used to	1	2	3	4	5
My child rarely does things for me that make me feel good	1	2	3	4	5
Most times I feel that my child does not like me and does not want to be close to me	1	2	3	4	5
My child smiles at me much less than I expected	1	2	3	4	5
When I do things for my child I get the feeling that my efforts are not appreciated very much	1	2	3	4	5
When playing, my child does not often giggle or laugh	1	2	3	4	5
My child does not seem to learn as quickly as most children	1	2	3	4	5
My child does not seem to smile as much as most children	1	2	3	4	5
My child is not able to do as much as I expected	1	2	3	4	5
It takes a long time and it is very hard for my child to get used to new things	1	2	3	4	5

I feel that I am:

- | | | | | | |
|---|---|---|---|---|---|
| 1 not very good at being a parent | | | | | |
| 2 a person who has trouble being a parent | 1 | 2 | 3 | 4 | 5 |
| 3 an average parent | | | | | |
| 4 a better than average parent | | | | | |
| 5 a very good parent | | | | | |

(please select which applies to you and circle number)

I expected to have closer and warmer feelings for my child than I do and this bothers me	1	2	3	4	5
--	---	---	---	---	---

Sometimes my child does things that bother me just to be mean	1	2	3	4	5
---	---	---	---	---	---

My child seems to cry or fuss more often than most children	1	2	3	4	5
---	---	---	---	---	---

My child generally wakes up in a bad mood	1	2	3	4	5
---	---	---	---	---	---

I feel that my child is very moody and easily upset	1	2	3	4	5
---	---	---	---	---	---

My child does a few things which bother me a great deal	1	2	3	4	5
---	---	---	---	---	---

My child reacts very strongly when something happens that my child does not like	1	2	3	4	5
--	---	---	---	---	---

My child gets upset easily over the smallest thing	1	2	3	4	5
--	---	---	---	---	---

My child's sleeping or eating schedule was much harder to establish than I expected	1	2	3	4	5
---	---	---	---	---	---

I have found that getting my child to do something or to stop doing something is:

- | | | | | | |
|---------------------------------------|---|---|---|---|---|
| 1 much harder than I expected | 1 | 2 | 3 | 4 | 5 |
| 2 somewhat harder than I expected | | | | | |
| 3 about as hard as I had expected | | | | | |
| 4 somewhat easier than I had expected | | | | | |
| 5 much easier than I had expected | | | | | |

(please select which applies to you and circle number)

Think carefully and count the number of things which your child does that bother you. For example dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. Please circle the number which includes the number of things you counted 1: 10+

- | | | | | | |
|--------|---|---|---|---|---|
| 1: 10+ | 1 | 2 | 3 | 4 | 5 |
| 2: 8-9 | | | | | |
| 3: 6-7 | | | | | |
| 4: 4-5 | | | | | |
| 5: 1-3 | | | | | |

(please select which applies to you and circle number)

There are some things my child does that really bother me a lot	1	2	3	4	5
---	---	---	---	---	---

My child turned out to be more of a difficulty than I had expected	1	2	3	4	5
--	---	---	---	---	---

My child makes more demands on me than most children	1	2	3	4	5
--	---	---	---	---	---

Appendix I

Instructions for the Five Minute Speech Sample

I would like to hear your thoughts and feelings about (child's name) over the past six months, in your own words and without me interrupting with any questions or comments. When I ask you to begin I would like you to speak for 5 minutes, telling me about what kind of person (child's name) is and how the two of you get along together. After you begin to speak I would prefer not to answer any questions until after the five minutes are over. Do you have any questions before we begin.

Appendix J

**Kruskal-Wallis Test between Learning Disabilities for the
Five minute Speech Sample.**

For the dimension of Initial Statement (χ^2 (2, N = 75) 2.10 = ns); for the dimension of Criticism (χ^2 (2, N = 75) 1.06 = ns); for the dimension of Dissatisfaction (χ^2 (2, N = 75) = 2.44 ns); For the dimension of Self-Sacrificing Behaviour (χ^2 (2, N = 75) .64 = ns); For the dimension of Emotional Out Burst (χ^2 (2, N = 75) 1.09 = ns); For the dimension of Excessive Detail (χ^2 (2, N = 75) 1.89 = ns); For the dimension of Positive Statement (χ^2 (2, N = 75) 1.13 = ns); For the dimension of Attitude (χ^2 (2, N = 75) .13 = ns); For the dimension of Emotional Over Involvement (χ^2 (2, N = 75) 1.92 = ns); For the dimension of Overall Expressed Emotion (χ^2 (2, N = 75) .44 = ns).

**Kruskal-Wallis Tests between Siblings of Different Aetiological Groups
for the Five Minute Speech Sample.**

For the dimension of Initial Statement (χ^2 (2, N = 75) 3.46 = ns; for the dimension of Criticism (χ^2 (2, N = 75) .90 = ns; for the dimension of Dissatisfaction (χ^2 (2, N = 75) 1.23 = ns; For the dimension of Self-Sacrificing Behaviour (χ^2 (2, N = 75) = ns; For the dimension of Emotional Out Burst (χ^2 (2, N = 75) = ns; For the dimension of Excessive Detail (χ^2 (2, N = 75) = ns; For the dimension of Positive Statement (χ^2 (2, N = 75) 3.55 = ns; For the dimension of Attitude (χ^2 (2, N = 75) = ns; For the dimension of Emotional Over Involvement (χ^2 (2, N = 75) = ns; For the dimension of Overall Expressed Emotion (χ^2 (2, N = 75) .90 = ns).

Appendix K

Vineland Adaptive Behavioural Scale

VINELAND

ADAPTIVE BEHAVIOR SCALES

Sara S. Sparrow, David A. Balla, and Domenic V. Cicchetti
A revision of the *Vineland Social Maturity Scale* by Edgar A. Doll

INTERVIEW EDITION Survey Form Record Booklet

ABOUT THE INDIVIDUAL:

Name _____ Sex _____

Home address _____

Telephone (____) _____ Grade _____

School or other facility _____

Present classification or diagnosis _____

Race (if pertinent) _____

Socioeconomic background (if pertinent) _____

Other pertinent information _____

AGE: YEAR MONTH DAY

Interview date _____

Birth date _____

Chronological age _____

Age used for starting points _____

Type (circle one): chronological mental social

REASON FOR THE INTERVIEW: _____

ABOUT THE RESPONDENT:

Name _____ Sex _____

Relationship to individual _____

ABOUT THE INTERVIEWER:

Name _____ Sex _____

Position _____

DATA FROM OTHER TESTS:

Intelligence _____

Achievement _____

Adaptive behavior _____

Other _____

BEFORE BEGINNING ADMINISTRATION, READ THE INSTRUCTIONS IN THE MANUAL CAREFULLY.

General Directions: In each adaptive behavior domain, begin scoring with the item designated for the individual's age. Score each item 2, 1, 0, N, or DK, according to the scoring criteria in the manual (Appendix C). Record each score in this booklet in the designated box. Establish a *basal* of seven consecutive items scored 2 and a *ceiling* of seven consecutive items scored 0 for each domain. (For reference when totaling scores, the highest possible sums are printed in the upper right corner of the sum boxes.)

ITEM
SCORES

- 2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

RECEPTIVE

EXPRESSIVE

WRITTEN

1. Turns eyes and head toward sound.
2. Listens at least momentarily when spoken to by caregiver.
3. Smiles in response to presence of caregiver.
4. Smiles in response to presence of familiar person other than caregiver.
5. Raises arms when caregiver says, "Come here" or "Up."
6. Demonstrates understanding of the meaning of "no."
7. Imitates sounds of adults immediately after hearing them.
8. Demonstrates understanding of the meaning of at least 10 words.
9. Gestures appropriately to indicate "yes," "no," and "I want."
10. Listens attentively to instructions.
11. Demonstrates understanding of the meaning of "yes" or "okay."
12. Follows instructions requiring an action and an object.
13. Points accurately to at least one major body part when asked.
14. Uses first names or nicknames of siblings, friends, or peers, or states their names when asked.
15. Uses phrases containing a noun and a verb, or two nouns.
16. Names at least 20 familiar objects without being asked.
DO NOT SCORE 1.
17. Listens to a story for at least five minutes.
18. Indicates preference when offered a choice.
19. Says at least 50 recognizable words. DO NOT SCORE 1.
20. Spontaneously relates experiences in simple terms.
21. Delivers a simple message.
22. Uses sentences of four or more words.
23. Points accurately to all body parts when asked. DO NOT SCORE 1.
24. Says at least 100 recognizable words. DO NOT SCORE 1.
25. Speaks in full sentences.
26. Uses "a" and "the" in phrases or sentences.
27. Follows instructions in "if-then" form.
28. States own first and last name when asked.
29. Asks questions beginning with "what," "where," "who," "why," and "when." DO NOT SCORE 1.
30. States which of two objects not present is bigger.
31. Relates experiences in detail when asked.
32. Uses either "behind" or "between" as a preposition in a phrase.
33. Uses "around" as a preposition in a phrase.

24

42

0

Count items before basal as 2, items after ceiling as 0.

Sum of 2s, 1s, 0s page 2

RECEPTIVE

EXPRESSIVE

WRITTEN

ITEM
SCORES

2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

4. Uses phrases or sentences containing "but" and "or."
5. Articulates clearly, without sound substitutions.
3. Tells popular story, fairy tale, lengthy joke, or television show plot.
7. Recites all letters of the alphabet from memory.
3. Reads at least three common signs.
9. States month and day of birthday when asked.
0. Uses irregular plurals.
1. Prints or writes own first and last name.
2. States telephone number when asked. N MAY BE SCORED.
3. States complete home address, including city and state, when asked.
4. Reads at least 10 words silently or aloud.
5. Prints or writes at least 10 words from memory.
3. Expresses ideas in more than one way, without assistance.
7. Reads simple stories aloud.
3. Prints or writes simple sentences of three or four words.
9. Attends to school or public lecture more than 15 minutes.
0. Reads on own initiative.
1. Reads books of at least second-grade level.
2. Arranges items or words alphabetically by first letter.
3. Prints or writes short notes or messages.
4. Gives complex directions to others.
5. Writes beginning letters. DO NOT SCORE 1.
6. Reads books of at least fourth-grade level.
7. Writes in cursive most of the time. DO NOT SCORE 1.
8. Uses a dictionary.
9. Uses the table of contents in reading materials.
0. Writes reports or compositions. DO NOT SCORE 1.
1. Addresses envelopes completely.
2. Uses the index in reading materials.
3. Reads adult newspaper stories. N MAY BE SCORED.
4. Has realistic long-range goals and describes in detail plans to achieve them.
5. Writes advanced letters.
6. Reads adult newspaper or magazine stories each week. N MAY BE SCORED.
7. Writes business letters. DO NOT SCORE 1.

Count items before basal as 2, items after ceiling as 0.

1. _____
2. _____
3. _____
4. _____

2 20 46
26 62 46

Sum of 2s, 1s, 0s page 3
Sum of 2s, 1s, 0s page 2
Number of Ns pages 2 and 3
Number of DKs pages 2 and 3

SUBDOMAIN RAW SCORE
(Add rows 1–4 above)

RECEPTIVE

EXPRESSIVE

WRITTEN

ITEM
SCORES

2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

1 1. Indicates anticipation of feeding on seeing bottle, breast, or food.

2. Opens mouth when spoon with food is presented.

3. Removes food from spoon with mouth.

4. Sucks or chews on crackers.

5. Eats solid food.

6. Drinks from cup or glass unassisted.

7. Feeds self with spoon.

8. Demonstrates understanding that hot things are dangerous.

9. Indicates wet or soiled pants or diaper by pointing, vocalizing, or pulling at diaper.

10. Sucks from straw.

11. Willingly allows caregiver to wipe nose.

12. Feeds self with fork.

13. Removes front-opening coat, sweater, or shirt without assistance.

14. Feeds self with spoon without spilling.

15. Demonstrates interest in changing clothes when very wet or muddy.

16. Urinates in toilet or potty-chair.

17. Bathes self with assistance.

18. Defecates in toilet or potty-chair.

19. Asks to use toilet.

20. Puts on "pull-up" garments with elastic waistbands.

21. Demonstrates understanding of the function of money.

22. Puts possessions away when asked.

23. Is toilet-trained during the night.

24. Gets drink of water from tap unassisted.

25. Brushes teeth without assistance.

DO NOT SCORE 1.

26. Demonstrates understanding of the function of a clock, either standard or digital.

27. Helps with extra chores when asked.

28. Washes and dries face without assistance.

29. Puts shoes on correct feet without assistance.

30. Answers the telephone appropriately.

N MAY BE SCORED.

31. Dresses self completely, except for tying shoelaces.

32. Summons to the telephone the person receiving a call, or indicates that the person is not available. N MAY BE SCORED.

33. Sets table with assistance.

50

6

10

Count items before basal as 2, items after ceiling as 0.

Sum of 2s, 1s, 0s page 4

PERSONAL

DOMESTIC

COMMUNITY

ITEM
SCORES

2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

34. Cares for all toileting needs, without being reminded and without assistance. DO NOT SCORE 1.
35. Looks both ways before crossing street or road.
36. Puts clean clothes away without assistance when asked.
37. Cares for nose without assistance. DO NOT SCORE 1.
38. Clears table of breakable items.
39. Dries self with towel without assistance.
40. Fastens all fasteners. DO NOT SCORE 1.
41. Assists in food preparation requiring mixing and cooking.
42. Demonstrates understanding that it is unsafe to accept rides, food, or money from strangers.
43. Ties shoelaces into a bow without assistance.
44. Bathes or showers without assistance. DO NOT SCORE 1.
45. Looks both ways and crosses street or road alone.
46. Covers mouth and nose when coughing and sneezing.
47. Uses spoon, fork, and knife competently. DO NOT SCORE 1.
48. Initiates telephone calls to others. N MAY BE SCORED.
49. Obeys traffic lights and Walk and Don't Walk signs. N MAY BE SCORED.
50. Dresses self completely, including tying shoelaces and fastening all fasteners. DO NOT SCORE 1.
51. Makes own bed when asked.
52. States current day of the week when asked.
53. Fastens seat belt in automobile independently. N MAY BE SCORED.
54. States value of penny, nickel, dime, and quarter.
55. Uses basic tools.
56. Identifies left and right on others.
57. Sets table without assistance when asked.
58. Sweeps, mops, or vacuums floor carefully, without assistance, when asked.
59. Uses emergency telephone number in emergency. N MAY BE SCORED.
60. Orders own complete meal in restaurant. N MAY BE SCORED.
61. States current date when asked.
62. Dresses in anticipation of changes in weather without being reminded.
63. Avoids persons with contagious illnesses, without being reminded.

Count items before basal as 2, items after ceiling as 0.

22

14

24

Sum of 2s, 1s, 0s page 5

PERSONAL

DOMESTIC

COMMUNITY

- | Category | Sub-category | Value |
|----------|--------------|-------|
| A | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| B | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| C | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| D | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| E | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| F | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| G | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| H | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| I | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| J | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| K | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| L | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| M | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| N | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| O | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| P | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| Q | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 40 |
| | 5 | 50 |
| | 6 | 60 |
| | 7 | 70 |
| | 8 | 80 |
| | 9 | 90 |
| | 10 | 100 |
| R | 1 | 10 |
| | 2 | 20 |
| | 3 | 30 |
| | 4 | 4 |

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

PERSONAL

DOMESTIC

COMMERCIAL

2	Yes, usually
1	Sometimes or partially
0	No, never
N	No opportunity
DK	Don't know

[illegible]

40 24 10

Sum of 2s, 1s, 0s page 7

COPIES ONLY

ITEM
SCORES

- 2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

		INTERPERSONAL RELATIONSHIPS	PLAY & LEISURE TIME	GOING OUT/AS
38.	Responds appropriately when introduced to strangers.			
39.	Makes or buys small gifts for caregiver or family member on major holidays, on own initiative.			
40.	Keeps secrets or confidences for more than one day.			
41.	Returns borrowed toys, possessions, or money to peers, or returns borrowed books to library.			
42.	Ends conversations appropriately.			
43.	Follows time limits set by caregiver.			
44.	Refrains from asking questions or making statements that might embarrass or hurt others.			
45.	Controls anger or hurt feelings when denied own way.			
46.	Keeps secrets or confidences for as long as appropriate.			
47.	Uses appropriate table manners without being told. DO NOT SCORE 1.			
48.	Watches television or listens to radio for information about a particular area of interest. N MAY BE SCORED.			
49.	Goes to evening school or facility events with friends, when accompanied by an adult. N MAY BE SCORED.			
50.	Independently weighs consequences of actions before making decisions.			
51.	Apologizes for mistakes or errors in judgment.			
52.	Remembers birthdays or anniversaries of immediate family members and special friends.			
53.	Initiates conversations on topics of particular interest to others.			
54.	Has a hobby.			
55.	Repays money borrowed from caregiver.			
56.	Responds to hints or indirect cues in conversation.			
57.	Participates in nonschool sports. N MAY BE SCORED.			
58.	Watches television or listens to radio for practical, day-to-day information. N MAY BE SCORED.			
59.	Makes and keeps appointments.			
60.	Watches television or listens to radio for news independently. N MAY BE SCORED.			
61.	Goes to evening school or facility events with friends, without adult supervision. N MAY BE SCORED.			
62.	Goes to evening nonschool or nonfacility events with friends, without adult supervision.			
63.	Belongs to older adolescent organized club, interest group, or social or service organization.			
64.	Goes with one person of opposite sex to party or public event where many people are present.			
65.	Goes on double or triple dates.			
66.	Goes on single dates.			

Count items before basal as 2, items after ceiling as 0.

1. 16 16 26

2.

3.

4.

56 40 36

Sum of 2s, 1s, 0s page 8

Sum of 2s, 1s, 0s page 7

Number of Ns pages 7 and 8

Number of DKs pages 7 and 8

SUBDOMAIN RAW SCORE

(Add rows 1-4 above)

**ITEM
SCORES**

- 2 Yes, usually
1 Sometimes or partially
0 No, never
N No opportunity
DK Don't know

Note: The Motor Skills domain is for individuals 5-11-30 or under, and optional for older individuals for whom a motor deficit is suspected. See Chapters 4 and 5 in the manual for procedures for administering and scoring the Motor Skills domain for individuals 6-0-0 or older.

COMMENTS

Holds head erect for at least 15 seconds without assistance when held vertically in caregiver's arms.

Sits supported for at least one minute.

Picks up small object with hands, in any way.

Transfers object from one hand to the other.

Picks up small object with thumb and fingers.

Raises self to sitting position and maintains position unsupported for at least one minute.

Crawls across floor on hands and knees, without stomach touching floor.

Opens doors that require only pushing or pulling.

Rolls ball while sitting.

Walks as primary means of getting around.

Climbs both in and out of bed or steady adult chair.

Climbs on low play equipment.

Marks with pencil, crayon, or chalk on appropriate writing surface.

Walks up stairs, putting both feet on each step.

Walks down stairs, forward, putting both feet on each step.

Runs smoothly, with changes in speed and direction.

Opens doors by turning and pulling doorknobs.

Jumps over small object.

Screws and unscrews lid of jar.

Pedals tricycle or other three-wheeled vehicle for at least six feet.

N MAY BE SCORED.

Hops on one foot at least once, while holding on to another person or stable object, without falling.

Builds three-dimensional structures, with at least five blocks.

Opens and closes scissors with one hand.

Walks down stairs with alternating feet, without assistance.

Climbs on high play equipment.

Cuts across a piece of paper with scissors.

Hops forward on one foot at least three times without losing balance.

DO NOT SCORE 1.

Completes non-inset puzzle of at least six pieces. DO NOT SCORE 1.

Draws more than one recognizable form with pencils or crayons.

Cuts paper along a line with scissors.

Uses eraser without tearing paper.

Hops forward on one foot with ease. DO NOT SCORE 1.

Unlocks key locks.

Cuts out complex items with scissors.

Catches small ball thrown from a distance of 10 feet, even if moving is necessary to catch it.

Rides bicycle without training wheels, without falling. N MAY BE SCORED.

Count items before basal as 2, items after ceiling as 0.

1.

2.

3.

40

32

Sum of 2s, 1s, 0s page 9

Number of Ns page 9

Number of DKs page 9

SUBDOMAIN RAW SCORE

(Add rows 1-3 above)

GROSS

NET

Note: The Maladaptive Behavior domain is for individuals 5-0-0 or older. Administration is optional.

ITEM SCORES
 2 Yes, usually
 1 Sometimes or partially
 0 No, never
 DO NOT SCORE N OR DK.

PART 1

1. Sucks thumb or fingers.
2. Is overly dependent.
3. Withdraws.
4. Wets bed.
5. Exhibits an eating disturbance.
6. Exhibits a sleep disturbance.
7. Bites fingernails.
8. Avoids school or work.
9. Exhibits extreme anxiety.
10. Exhibits tics.
11. Cries or laughs too easily.
12. Has poor eye contact.
13. Exhibits excessive unhappiness.
14. Grinds teeth during day or night.
15. Is too impulsive.
16. Has poor concentration and attention.
17. Is overly active.
18. Has temper tantrums.
19. Is negativistic or defiant.
20. Teases or bullies.
21. Shows lack of consideration.
22. Lies, cheats, or steals.
23. Is too physically aggressive.
24. Swears in inappropriate situations.
25. Runs away.
26. Is stubborn or sullen.
27. Is truant from school or work.

A. PART 1 RAW SCORE
 (Sum of 2s, 1s, 0s Part 1)

PART 2 Note: Part 2 is for individuals who will be compared only with supplementary norm groups.

28. Engages in inappropriate sexual behavior.
29. Has excessive or peculiar preoccupations with objects or activities.
30. Expresses thoughts that are not sensible.
31. Exhibits extremely peculiar mannerisms or habits.
32. Displays behaviors that are self-injurious.
33. Intentionally destroys own or another's property.
34. Uses bizarre speech.
35. Is unaware of what is happening in immediate surroundings.
36. Rocks back and forth when sitting or standing.

Intensity
 Circle one
 Severe Moderate

Severe	Moderate
S	M
S	M
S	M
S	M
S	M
S	M
S	M
S	M
S	M

B. Sum of 2s, 1s, 0s Part 2

COMMENTS

PARTS 1 AND 2 RAW SCORE
 (Add A and B)

COMMENTS

ABOUT THE INTERVIEW:

Respondent's estimate of the individual's functioning

Language used in the interview

Special characteristics of the individual

Estimate of rapport established with the respondent

Estimate of the respondent's accuracy

General observations

eland Adaptive Behavior Scales: INTERVIEW EDITION Survey Form

al's name

Chronological age

interview

Supplementary norm group (if applicable)

beginning the score summary, read
r 5 in the manual.

SCORE SUMMARY

SUBDOMAIN	Raw Score	Standard Score $\bar{X}=100$, $SD=15$ Tables B.1 and B.2	Band of Error _____% Confidence Table B.3	National %ile Rank Table B.4	Stanine Table B.4	Supplementary Norm Group %ile Rank Table B.5	Adaptive Level Tables B.6 and B.8	Supplementary Norm Group Adaptive Level Tables B.7 and B.9	Age Equivalent Tables B.10 and B.11
Receptive									
Expressive									
Written									
Personal									
Domestic									
Community									
LIVING SKILLS DOMAIN SUM									
Interpersonal Relationships									
Play and Leisure Time									
Coping Skills									
Gross									
Fine									
MOTOR SKILLS DOMAIN SUM									
SUM OF DOMAIN STANDARD SCORES									
ADAPTIVE BEHAVIOR COMPOSITE									

after 5 in the manual to graph scores.)

SCORE PROFILE

Standard Score ± Band of Error	20	30	40	50	60	70	80	90	100	110	120	130	140	150	160
COMMUNICATION DOMAIN															
LIVING SKILLS DOMAIN															
SOCIALIZATION DOMAIN															
MOTOR SKILLS DOMAIN															
ADAPTIVE BEHAVIOR COMPOSITE															

percentile rank: 1 2 5 9 16 25 37 50 63 75 84 91 95 98 99

-5SD -4SD -3SD -2SD -1SD MEAN +1SD +2SD +3SD +4SD

(ONAL

ADAPTIVE BEHAVIOR DOMAIN

minister for ages 5-0-0 and older)

Part 1

Parts 1 and 2

Raw Score

Maladaptive Level: Table B.12

Supplementary Norm Group
Maladaptive Level: Table B.13

al interpretive information (see Chapters 5 and 6 in the manual)

recommendations



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B 0 9 8 7 6

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