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## **DOCTOR OF PHILOSOPHY**

**The stress of parenting a child with an intellectual disability: a longitudinal study of the impact of child factors and parental resources on positive and negative parental well-being**

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The Stress of Parenting a Child with an Intellectual Disability: A Longitudinal Study of  
the Impact of Child Factors and Parental Resources on Positive and Negative Parental  
Well-Being

By Christopher Hill

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SCHOOL OF PSYCHOLOGY

ABSTRACT

The Stress of Parenting a Child with an Intellectual Disability: A Longitudinal Study of  
the Impact of Child Factors and Parental Resources on Positive and Negative Parental  
Well-Being

By Christopher Hill

There is a significant body of evidence reporting that parents of children with intellectual disabilities are more stressed than parents of typically developing children. However, previous research has also highlighted large variations in the levels of stress and other problems reported by parents. There is increasingly a move towards exploring the existence and nature of bi-directional relationships that occur between parental stress and variables such as child behaviour. This thesis aimed to further assess this longitudinal relationship but with the inclusion of a number of unique features. First, a model was proposed to guide the research and the analysis. This incorporated aspects of a number of influential models in the stress and coping literature. Second, a variety of child measures were included that examine multiple aspects of a child's development. Third, it featured both positive and negative outcomes. Fourth, potential mediating and moderating processes were investigated. Analyses were conducted at two time points and an observational study was completed after the main data collection. 138 mothers and 60 fathers took part at Time 1 whilst 113 mothers and 50 fathers took part at Time 2. The participating families completed a series of questionnaires at both time points and were interviewed over the phone. T-tests and bivariate correlations were used to investigate basic relationships amongst the variables and the both the cross-sectional (Time 1) and longitudinal (Time 1 and Time 2) data were analysed using regression analyses. In the observational study, 20 mothers participated, and were visited at their home. They completed a standard play task with their child and this was recorded by the research team. The data were analysed using t-tests and bivariate correlations. Child psychopathology was found to significantly predict parental stress over time, but no

longitudinal relationship was found. Stress, coping and support were found to significantly predict both positive and negative parental outcomes with a number of bi-directional effects observed. A number of mediating and moderating relationships were also found, with wishful thinking coping strategies featuring strongly. The implications of the results are discussed, with reference to future research and clinical implications.

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This thesis is in memory of Colin, a participant in this research.



## Chapter 1

## Theoretical Perspectives on Adjustment in Parents of Children with Intellectual Disabilities

1.1 Chapter Summary

This chapter serves as a broad introduction to the thesis and begins to address the relevant literature. An introductory section presents research that suggest parents of children with intellectual disabilities report more stress than parents of typically developing children. The variability in the experience of stress is then discussed, before the chapter reviews key theoretical models of stress. The history and development of these models is discussed, complete with examples of its application within the research literature. A critical analysis of each position follows, with an eventual proposal of a working model, based on successful components of the theoretical models, to guide the research presented in this thesis.

1.2 Introduction

An enormous amount of research has been devoted to understanding the impact that a child with intellectual disabilities has upon their family. More specifically, the well-being of the parents has been of particular interest. Studies generally find that parents of children with intellectual disabilities report more stress than parents of typically developing children. For example, Baker, Blacher, Crnic and Edelbrock (2002) studied 225 children with and without developmental delays. The research was concerned with the relative impacts of behaviour problems and cognitive delays on parents. Both mothers ( $F_{(1,220)} = 13.76, p < .001$ ) and fathers ( $F_{(1,188)} = 4.76, p < .05$ ) of the children with developmental delays reported greater negative impact of the child on the family, than the parents of the typically developing children. This trend has been further identified in a host of other studies, by researchers investigating various domains of the parental well-being (e.g. Beckman, 1991; Beresford, 1996; Cahill & Glidden, 1996; Chavira, Lopes, Blacher, & Shapiro, 2000; Chetwynd, 1985; Crnic, Friedrich, & Greenberg, 1983; Deater-Deckard, 1998; Dumas, Wolf, Fisman, & Culligan, 1991; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Dyson, 1991; Floyd & Gallagher, 1997; Hodapp, Fidler & Smith, 1998; Krauss, 1993; Ong, Chandran, & Peng, 1999; Stores, Stores, Fellows, & Buckley, 1998; Wanamaker & Glenwick, 1998; Weiss, 2002).

There is also evidence that parental experience of stress is stable over time. Dyson (1993) carried out a follow-up study on a sample of families studied two years earlier (Dyson, 1991). Of the 110 families in the original study, 74 were located and agreed to participate for a second time. Thirty-eight of the families had children with intellectual disabilities, the other 36 were typically developing. The measures included the Questionnaire on Resources and Stress (QRS, Friedrich, Greenberg & Crnic, 1983) a rating of the impact of the child where the total score is a global index of parental stress. Comparisons were made between the data collected in the initial study and the later one, and with the parents of children who did not have disabilities. Parents of both typically developing children and children with intellectual disabilities showed a high degree of stability (.85,  $p < .001$ ) in parental stress and a modest degree of consistency over time in family functioning. The parents of children with intellectual disabilities also showed far higher levels of stress at both time points than did the parents of the typically developing children.

This degree of stability in parental stress has been indicated in other research. For example, Lecavalier, Leone and Wiltz (2006) utilised a longitudinal design in their research with families of children with autism spectrum disorders. A sub-sample of 81 parents from an original cohort of 293 rated their stress twice, with a one-year interval. The ratings at both time points by the parents indicated that their stress was stable over the one-year test period (.79,  $p < .001$ ). Thus, existing research appears to support the observation that stress is relatively stable over time, suggesting that there is a chronic element to parental stress.

### 1.3 Variability of Stress Outcomes in Families

The nature of the stress experience is unique to every parent. Despite considerable evidence for increased stress experienced by parents of children with intellectual disabilities (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), many families do adapt successfully to the challenges of raising a child with disabilities (Carr, 2005; Flaherty & Glidden, 2000; Glidden & Johnson, 1999; Glidden & Pursley, 1989). Indeed, recent meta-analytic work (Risdal & Singer, 2004; Rossiter & Sharpe, 2001) has

raised questions regarding the veracity of data showing increased problems for families of children with intellectual disabilities in marital distress and sibling adjustment. There is also evidence that the majority of parents can see a positive contribution to their lives brought about by having a child with an intellectual disability (Hastings, Allen, McDermott & Still, 2002; Hastings & Taunt, 2002).

In the light of these findings on adaptation and positive perceptions, there is considerable evidence of variation in familial response to raising a child with intellectual disabilities. This evidence supports the need to develop an understanding of why families vary so greatly in their experiences of nurturing a child with an intellectual disability. Before reviewing existing empirical literature in more detail, it is important to describe theoretical models of stress that have been applied to families of children with intellectual disabilities.

#### 1.4 Theoretical Models of Stress – A Historical Perspective

Stress, and the process of coping, adaptation, and adjustment can be, and have been, conceptualised in numerous ways. In the following section, influential models in the field of stress research will be reviewed. In the past, two broad frameworks were used to define stress: the life-events model, and the response-oriented model (Lazarus, 1999). In the first, the life-events model, the focus is on the stress-provoking event (stressor), whilst the second, the response-oriented model, focused on the reaction. In the life-events model, stress was seen as the result of the presence or absence of specific events or situations. The level of stress could then be assessed in terms of the number of experienced life-events in a certain period of time. The use of the Social Readjustment Rating Scale (Holmes & Rahe, 1967) is an example of the application of this model in research. The response-oriented model defined stress based on the nature of a person's response to a situation. Through certain physiological (e.g., galvanic skin response) or psychological reactions (e.g., anxiety), a person may be deemed to be under stress. The work of Selye (1976) epitomised this response approach.

There were clear limitations in both models. With research into the life-events model, it naturally proved difficult to design a list that incorporated all possible life events. A limitation of the response-oriented model was that it was difficult to determine the relationship between stressors and responses (i.e., what was causing the person to

experience stress?). In addition, neither model accounted for the issue of individual differences, namely, what one person may perceive as stressful, another may not consider stressful at all. Furthermore, the models did not consider that the relationship between stressors and responses could be affected by other variables such as cognitive appraisal. Cognitive appraisal relates to the importance of the individual's perception of events, thus rendering an event stressful only if it is appraised as such. Finally, both models focused on the negative outcomes of stress only. They did not take into account that some people see stressors as challenges, which may ultimately result in positive outcomes, such as personal growth.

#### 1.4.1 Transactional Models of Stress and Coping

In response to the shortcomings of earlier approaches to the understanding of stress, Lazarus and Folkman (1984) proposed a transactional model (see Figure 1.1). In this model, stress is defined as the result of a transaction between a person and his/her environment. The level of stress is determined by the interaction between a stressor, a person's appraisal of this situation, and his/her coping response. This transactional model takes into account the relative balance between environmental demands/challenges and a person's resources to face them, therefore allowing for individual differences. Furthermore, this approach allows for different outcomes of an event without assuming that there will be fixed functional and dysfunctional ways of dealing with stress. Also known as the process model of stress and coping (Beresford, 1994), this approach suggests that distress is the result of the interaction of a stressful event (stressor), personal resources, cognitive appraisal of the event, and coping responses, thereby emphasising the active role of an individual in dealing with a stressor.

To contextualise this model, we may consider an event associated with the care of the child with the intellectual disability to be a potential stressor, for example, an episode of behavioural problems. Cognitive appraisal by the parent of the child with intellectual disabilities is understood as the process through which the behaviour is evaluated. During the appraisal stage of the model, the parent evaluates the meaning of the current episode of challenging behaviour. If the parent perceives the situation as a threat (e.g., 'this behaviour is going to stop me getting my child to school on time') then they move onto the secondary appraisal stage. This appraisal stage is mediated by the coping resources of the parent (e.g., 'what resources can I bring to bear on this problem?'). Beresford (1994)

identifies two types of coping resources, socio-ecological coping resources and personal coping resources. Socio-ecological coping resources are found in the parent's environment or social context (e.g., social support, marital relationship, practical/functional resources, and economic circumstances). Personal coping resources are both physical and psychological variables (e.g., physical health, beliefs, previous coping experiences, parenting skills, and intelligence).

Once the parent has appraised their coping resources, they will employ one of two types of coping strategies, emotion-focused or problem-focused. Emotion focused coping serves to regulate stressful emotions either directed at the somatic level of the emotion and/ or the level of feelings. Emotion focused coping strategies aimed at the somatic level may include the parent taking a long hot bath, using tranquillisers, or going for a run. These function to reduce adverse physical sensations associated with the stressful incident. Emotion focused coping aimed at feelings function to change the emotional state. Examples of these include watching comedy, or having fun with friends. The second coping approach, problem focused coping, serves to manage or alter the source of stress. Problem-focused strategies can be external (e.g., taking pain killers, or asking for help) or internal (e.g., cognitive restructuring).

The transactional model then identifies a period of reappraisal where the parents will ask themselves whether the stress has changed and evaluate whether they are feeling better. Coping is defined 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" (Lazarus & Folkman, 1984, 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 is a result of a match between appraisal and coping strategies rather than of the relative efficacy of one strategy over another (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986).

Quine and Pahl (1991) tested the Process Model of Stress and Coping in a sample of mothers of children with severe intellectual disabilities, Down's syndrome, cerebral palsy, and spina bifida. They investigated the relationships between child characteristics, coping resources, and maternal distress. Results of regression analyses showed that 56% of the variance in mothers' distress could be explained by child variables and coping resources. Results provided support for the transactional stress and coping model because coping

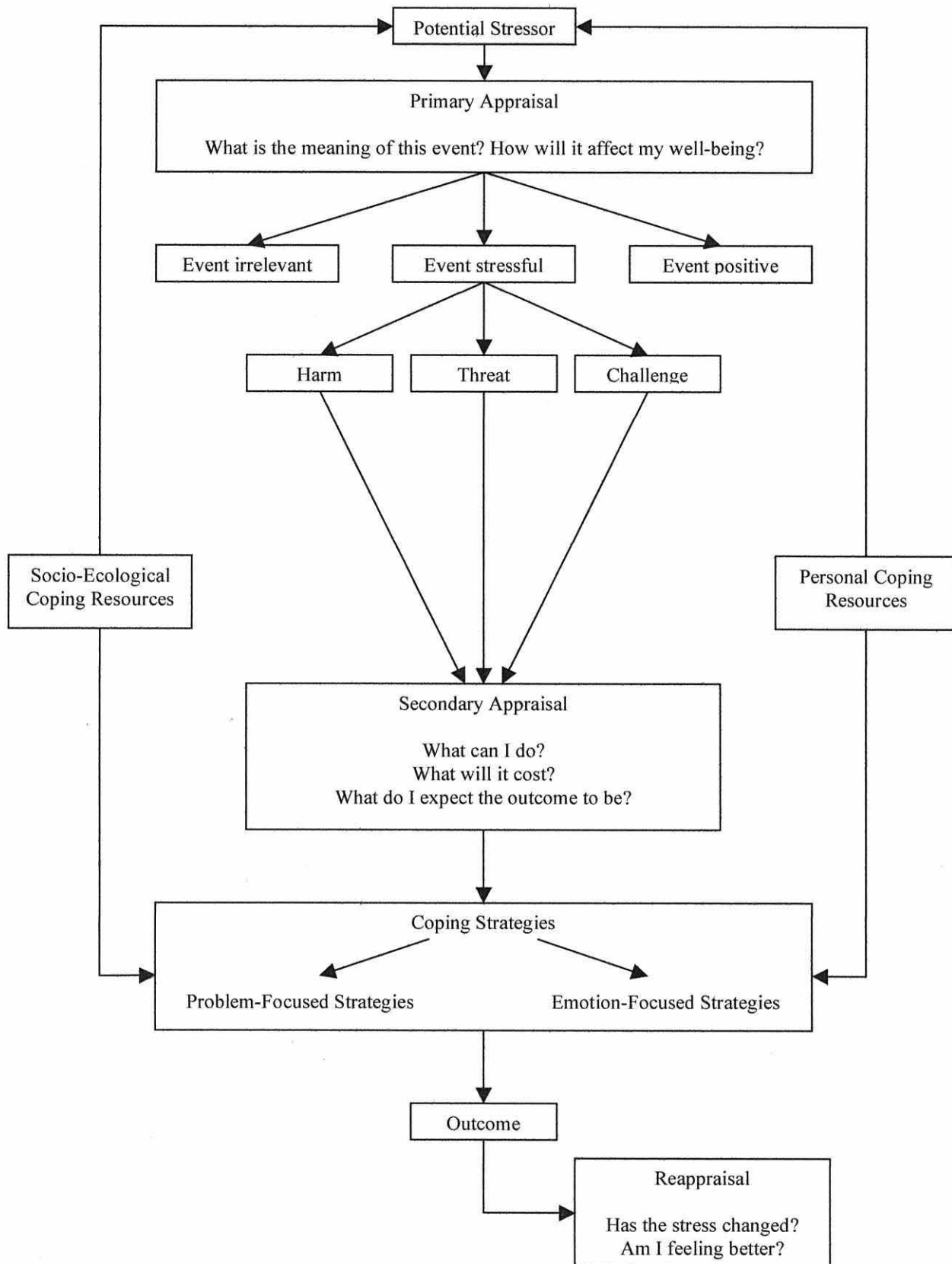


Figure 1.1 The Process Model of Stress and Coping (Lazarus & Folkman, 1984)  
reproduced from Beresford (1994)



resources mediated the effect of child characteristics on maternal distress. More specifically, mothers of higher social class, with greater financial resources, and who were more accepting of their child, reported less stress. Quine and Pahl (1991) also used path analyses to plot the effects of child characteristics and coping resources on maternal stress. This analysis found that all the variables in the model, bar life events had a direct effect on maternal stress. Child age and social class were distal causes, with no incoming links. Child academic skills, child behaviour problems, maternal acceptance and adjustment to the child, maternal assessment of ability to cope, financial worries, life event stress and recent illness were mediating causes. The nine variables explained 56% of the variance in stress scores.

McDougall, Kerr, and Espie (2004) utilised a qualitative methodology to explore the parental experience of sleep disturbance in children with Rett syndrome. Their findings were consistent with a transactional model of stress and coping, which suggests that the experience of stress is influenced by individual appraisal and perceived availability of resources. The researchers suggested that a parent's experience of stress regarding sleep disturbance might be mediated by beliefs about the causes, consequences, and perceptions of support and ability to cope. The findings suggested that parents might engage in both emotion-focused and problem-focused strategies in coping with sleep problems. The use of problem-focused strategies may be more prevalent given that parents tend to check their children in bed, listen out for noise, and sleep with their child. These behaviours were not accompanied by increased reports of distress, suggesting that cognitive appraisal of the situation may be important.

#### 1.4.2 Double ABCX Model

The Process Model of Stress and Coping (Folkman & Lazarus, 1984) is essentially an individual stress model. Other models that have influenced the direction of research have been more family-based. The Double ABCX Model (McCubbin & Patterson, 1981) is based on the ABCX Model (Hill, 1958) but is designed to accommodate the role of family coping within a theoretical framework. So, taking the model from left to right, (See Figure 1.3.2) the characteristics of a stressor event (a), the family's internal resources (b) and the family's definition of a stressor (c) all contribute towards the prevention or precipitation of a crisis (x). Given the Double ABCX model's focus over time, it recognises that, post-crisis, there may be a pile-up of family stressors that serve to increase the difficulty of adaptation (aA). Coping utilises the family's resources they have

built up and employed (bB) and the perception made by the family of events during their period of readjustment (cC). The outcome of the family (xX) is defined in terms of bonadaptation and maladaptation and work as the outcome of one situation feeds back into the next situation. A positive feedback loop is called a “Bonadaptation” and 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). A negative feedback loop is called a “Maladaptation”, an example being the deterioration of the child’s behaviour leading to overall deterioration of the family system. Furthermore, Bristol (1987) suggests the addition of the feedback loop may make it easier to understand the complex reaction between having a child with intellectual disabilities and successful family adaptation, and may ultimately be useful for developing intervention strategies.

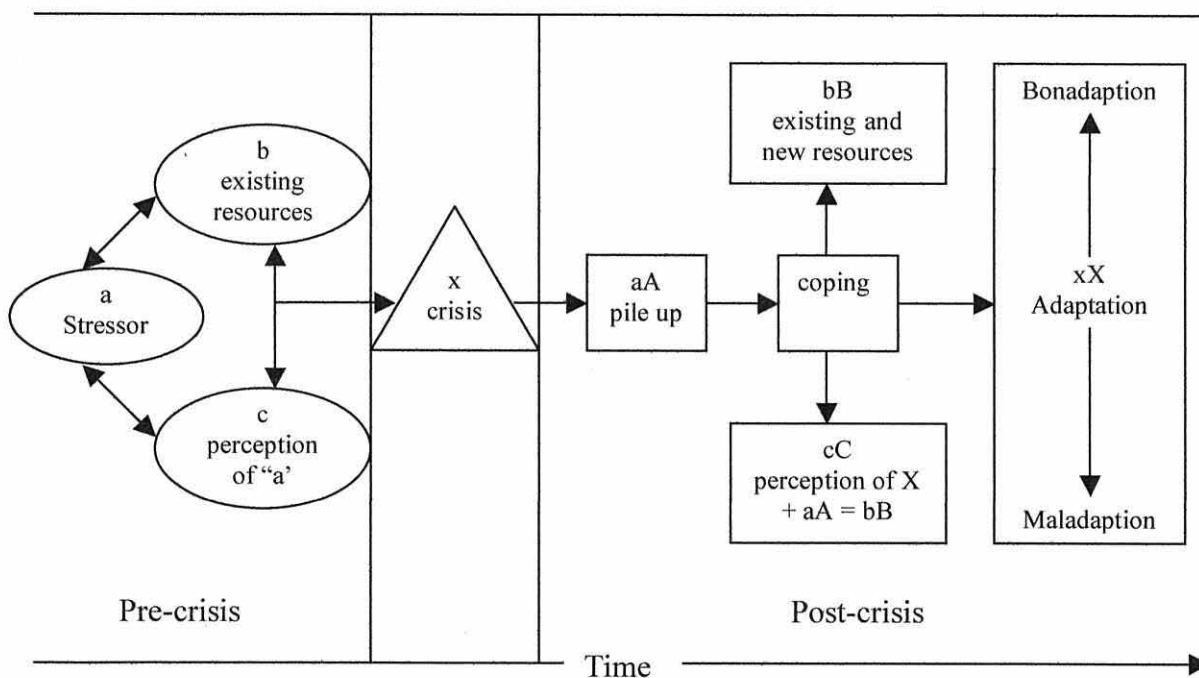


Figure 1.2 The Double ABCX Model (McCubbin & Patterson, 1983)

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 intellectual disabilities and their parents. The pile-up of stressors/demands was assessed through various measures of the parents and children, including the Parenting Stress Index (PSI; Abidin, 1986), the Life Experiences Survey (Sarason, Johnson, & Siegel, 1978), Family Inventory of Resources for Management (McCubbin, Comeau, &



Harkins, 1987) and the Social Support Inventory (McCubbin, Patterson, Rossmand, & Cooke, 1983). 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 stressors/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) assessed the applicability of the Double ABCX model in predicting healthy functioning in families of children with autism or severe communication disorders. Bristol highlighted that the measures chosen for investigation in the research were not an exhaustive list of dimensions, more a representation of variables that previous research had shown to be relevant to stress and coping in such families. Results obtained supported the effectiveness of the Double ABCX model in conceptualising the processes of adaptation in families with children with disabilities. Stressors, family resources, and perception of the stressor were all significant predictors of family adaptation. Orr, Cameron, and Day (1991) conducted a statistical evaluation (using path analysis) of the Double ABCX model in families with children who had intellectual disabilities. Eighty-six parents of children aged between five and 21 years participated in the study. Measures used in the research included the frequency of behaviour problems (path A), the Family Inventory of Resources and Management (McCubbin et al., 1987) (path B), the Family Crisis Oriented Personal Evaluation Scales (McCubbin, Olson, & Larsen, 1987) (path C) and the Parenting Stress Index (Abidin, 1986) to assess parental stress (path X). The causal ordering of the model suggested an ACBX relation rather than the much vaunted ABCX relation. It is suggested that this makes sense from an intervention perspective, as the effectiveness of resources in reducing stress in families of children with intellectual disabilities depends on how the family/ parent defines the child's needs, level of functioning, problem behaviours, and other characteristics. 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 provided. Orr et al. (1991) conclude that an approach using the modified Double ACBX model may result in more effective use of resources and increase healthy adaptation in families.

### 1.4.3 A Two-Factor Model

Lawton, Moss, Kleban, Glicksman, and Rovine (1991) proposed and tested a two-factor model of psychological well-being (see Figure 1.3) separately for spouse and adult-child care-givers of persons with Alzheimer's disease. The model is based conceptually on Lazarus's theory of coping with stressful events (Lazarus & Folkman, 1984) and Bradburn's (1969) two-factor view of psychological well-being. The model includes stressors, resources, appraisals, and outcomes. Stressors are seen as external to the individual, and objective in nature. In the case of a parent of a child with intellectual disabilities, stressors may be the severity of behaviour problems exhibited by the child and the amount of help that has to be provided by the parent. The resources the parent has are independent of the stressors. These are characteristics possessed by the parent that enable or impede their ability to cope with stressors. In terms of parents of children with intellectual disability, these resources may be their physical health, the quality of the relationship between the parent and the child, and social support the parent may receive. Appraisals include perceptions, attitudes and concerns and have been identified as the cognitive and affective responses to the care-giving stressors (Lawton et al., 1992).

The model includes both the positive (satisfaction) and negative (burden) appraisals associated with providing care, in our case, to a child with an intellectual disability. Appraisals of satisfaction may include an increased sense of self-worth (Zarit, Reever & Bach-Peterson, 1980) for the parent. Appraisals of burden include the parent's perceptions of their anxiety and demoralisation associated with caring for a child with an intellectual disability. The outcome in the model is the psychological well-being of the parent. As in the stress and coping model, a person's appraisals determine the use of coping strategies, which are believed to mediate the relationship between the stressor and the outcome of psychological well-being.

In line with the two-factor view of psychological well-being, the model distinguishes between positive and negative affect. Positive and negative affect (emotional states) are affected by all stages of the model, the stressor, the resources of the parent, and the appraisals they make. These states of positive and negative affect are at least partially independent and may have different antecedents. For example, negative affect has been associated with health and other internal attributes whilst the quality of social behaviour and other external events seem to predict positive emotional states.

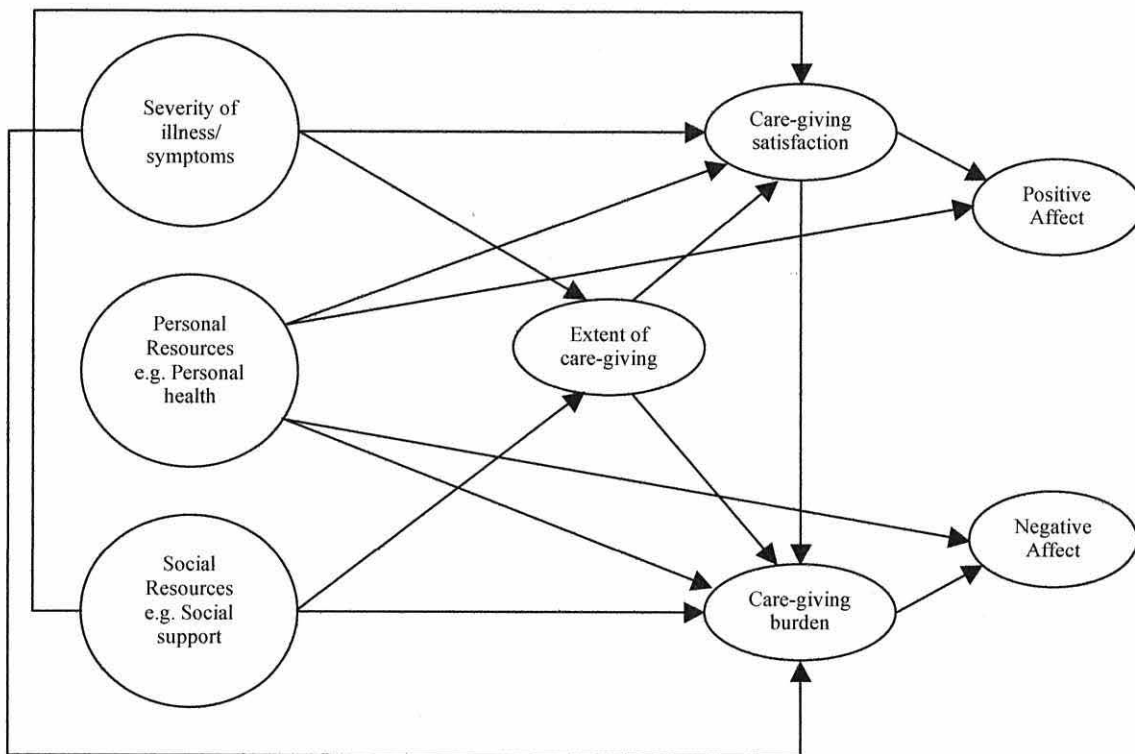


Figure 1.3 The Two-Factor Model of Care-Giving Appraisal and Psychological Well-Being (from Lawton et al., 1991, p. 183)

This distinction is reflected in the two-factor model, with proposed links between positive appraisals (e.g., care-giving satisfaction) and positive affect and negative appraisal (e.g., care-giving burden) and negative affect.

Within the field of intellectual disabilities, two studies have attempted to operationalise this two-factor care-giving model (Pruchno, Patrick, & Burant, 1996; Smith, 1996). Pruchno et al., (1996) used a conceptual framework for predicting the psychological well-being of women developed from the model tested by Lawton et al, (1991). Pruchno et al., (1996) conducted interviews with 838 mothers over the age of 50, whose child had either a developmental disability or schizophrenia. Despite considerable differences in the types of stressors experienced by the two groups, the underlying relationships among the model constructs were similar for both groups. This support for a model developed for a very different population (people with caring responsibilities to elderly spouses and parents) gives an indication of the robust nature of the two-factor approach. The merit of conceptualising well-being as having both positive and negative components that are related to one another, yet also independent of one another was supported by this

research. The data show that positive and negative appraisals are predicted by different variables. Mother-child relationship predicted positive appraisals, whilst child maladaptive behaviour, mother's health, and the help needed from the mother predicted negative appraisals. The results indicated the pivotal role that negative appraisals of care-giving have for determining both the positive and the negative well-being of mothers of children with developmental disabilities. Positive appraisals, the authors suggest, play a distinctly different role to negative appraisals. They have a direct relationship to positive well-being and are also a significant determinant of negative appraisals. The results of this work suggest that when mothers make positive evaluations of their care-giver role, these positive appraisals have the ability to reduce the extent to which the care-giving role is perceived as burdensome, thus reducing the overall sense of negative well-being. Pruchno et al., (1996) suggest a potential modification of the model to move focus to positive appraisals and their predictors.

In another study utilising a two-factor model, Smith (1996) investigated 225 mothers of offspring with an intellectual disability who lived at home. The effects of objective care-giving stressors, care-giving resources, and subjective positive and negative appraisals on the positive and negative dimensions of psychological well-being were examined. Smith (1996) used structural equation modelling to test the model. It was found that pathways present in the Lawton et al., (1991) work were not found to be significant. These were 'care receiver impairment' to 'subjective burden', 'help provided' to 'subjective burden', 'health of care-giver' to 'subjective burden' and from 'support' to 'help provided'. Furthermore, a pathway not found in the previous research of Lawton et al., (1991) emerged. This was 'positive well-being' to 'subjective burden'. This is of potential theoretical importance as it may further inform the debate of whether care-giving appraisals and measures of global well-being are simply at opposing ends of the same spectrum. Again, consistent with the dual valence prediction of the two-factor theory (Lawton et al., 1991), greater subjective burden among their sample of mothers increased the negative dimension of well-being while greater care-giving satisfaction increased the positive dimension. The application of the two-factor model in these studies generally provides support for a model comprising of two-relatively independent, but interlinked processes. However, the fact that different measures were used in the studies and the fact that the model went through numerous modifications and the lack of support for certain

pathways highlights the caution that is best exercised when using existing models to guide research.

There are also a number of studies providing indirect data supportive of a two-factor model (Hastings & Taunt, 2002). In particular, positive outcomes such as satisfaction with care-giving and cohesion in families of children with intellectual disabilities have typically been found to have different predictors than negative outcomes such as stress and depression (e.g., Margalit & Ankonina, 1991; Sloper et al., 1991; Stoneman & Crapps, 1988; Walden et al., 2000). A two-factor model of care-giving incorporates the increasingly research valued notion of parental positive perceptions, whilst still providing a theoretical framework in which to continue pursuing research into stress in the family.

### 1.5 Critical Analysis and Commonalities

The models reviewed in Section 1.4 have had a marked influence over the direction of research in the area of stress and coping in parents of children with intellectual disabilities. Naturally, there is common ground between the theories, and also some issues that deserve further discussion. In this section, the intention is to discuss some concerns regarding the models, previous criticisms that have been levelled at them, and the key issues to draw out of them, which may inform the development of the research in this thesis. The way in which coping has been defined in the Process Model of Stress and Coping (Lazarus & Folkman, 1984) may lead to some confusion over the effect it has on the relationship between the stressful encounter and adjustment outcome. It is unclear whether coping is a mediator or a moderator variable. That is, does the stressful encounter have an indirect effect on the adjustment outcome, with the stressful encounter impacting upon coping which in turn influences the adjustment outcome? Or does the nature of the relationship between the stressful encounter and the adjustment outcome vary according to the level of coping? Lazarus defines coping in the model as a mediator variable ‘because the coping process arises *de novo* from the transaction between the person and the environment’ (Lazarus, 1999, p121-122). However, it could be argued that their description actually depicts coping as a moderator. In Lazarus’ description, coping affects the relationship between stressor and outcome such that the impact of the stressor on outcome varies according to the extent and type of coping mechanisms used. It is clear that certain coping mechanisms can serve to lower the risk of poor adjustment outcome in the face of a stressful encounter. According to Baron and Kenny’s (1986) analysis, this is an example of moderation because coping



changes the direction of the effect of a stressor on adjustment outcome rather than determining how the effect occurs, (i.e., coping moderates rather than mediates the relationship). More specifically, a mediator variable specifies how a given effect occurs, whilst a moderator variable specifies the conditions under which the effect occurs and the conditions under which the size and direction of the effect vary (Baron & Kenny, 1986). This distinction between moderation and mediation is discussed in detail in Chapter Three.

The inclusion of the transactional perspective (i.e., the notion that stress results from the transaction between a person and the environment), has addressed some of the shortcomings of the early stress models. However the Process Model of Stress and Coping has received some criticism as well. For example, Aldwin, (2000) criticised the emphasis the model puts on the role of subjective appraisals. Furthermore, testing the model has proved difficult, especially in cross-sectional studies, as the model incorporates cognitive processes. For the evaluation of adjustment outcomes, it is important to know where in the process a person is. For example, if a person is still dealing with an actual event it is hard to estimate what the outcome will be. Results of a study involving married women whose partner recently suffered a myocardial infarct or had died, showed progressive decay in the aversive effects of this stressful life event over time (Surtees & Wainwright, 1999). In contrast, results of a study involving newly referred patients from a child psychiatry service in London showed that although recent negative life events were more common in these patients than in controls, there was only limited support of the *causal* relationship between these events and the onset of psychiatric disorder in children aged 8-16 years (Sandberg, Rutter, Pickles, McGuinness, & Angold, 2001). Despite this critique, the model has extensively guided stress, coping and adjustment research. In summary, the Process Model of Stress and Coping is perhaps too complicated to test specifically, given the inclusion of cognitive processes, and subjective appraisals. However, key principles are identified including the emphasis placed upon a transactional perspective and the importance of coping.

The Double ABCX model (McCubbin & Patterson, 1983), focuses on family dynamics and the differential effects of family types on the experiences of stress. The model, however, does not fully represent how individuals within the family adapt and cope with a child with intellectual disabilities. Beresford (1994) highlights three limitations within such models. First, there is a relatively small amount of attention given to the impact of factors external to the family and intrapersonal factors within the stress equation. Second, the

family-based models have been slow to account for coping within their structure, the focus having been on family dynamics and the effect of family type on stress and its impact. Third, when coping has been considered, it has been from the point of view of strategies to enable the family to maintain its stability. Thus, the outcome of coping is defined in terms of family, as opposed to individual, well-being. However, one might consider the limitation of the model in its functioning at the level of the family to be the reason that it has been applied with success by researchers. Increasingly, perhaps driven by family systems work, researchers have wished to examine the family as a whole and not break it down into its constituent parts. In this sense, the Double ABCX model continues to guide avenues of family research. Of most direct relevance to the present discussion is the Double ABCX model's consideration that healthy adaptation may characterise the family's response to stress, and the consideration of active coping in addition to passive support.

Whilst the models based on individual well-being and those developed to understand the impact on the family group have dealt with positive outcomes that are reported by some families and the impact that these perceptions may have on stress, coping and the family, research into these positive outcomes has gone somewhat neglected. As Hastings and Taunt (2002) posit, one might assume that positive appraisals or perceptions will be present in the *absence* of negative outcomes such as stress. However, previous research using positively framed measures in the disability literature (e.g., Clark & Watson, 1988) suggests that the absence of stress model is not a helpful one. Parents could, and do, have both positive and negative experiences related to the parenting of their child with intellectual disabilities. If positive perceptions are viewed as outcomes, then one needs to measure both positive and negative outcomes as reported by the parent.

A two-factor model acknowledges that positive and negative outcomes can occur simultaneously for the parent. Thus, the two-factor model offers advantages to the researcher within intellectual disabilities to deal with the potential that a parent may experience both outcomes together. Again, slightly different mechanisms are posited for the Process Model of Stress and Coping and Double ABCX Model in comparison to the two-factor model. In the first two models, negative experiences may lead to positive outcomes, through the parent recognising the challenge and striving to meet it, thus

enhancing their self-esteem. As we have mentioned, the two-factor approach see this differently, with separate mechanisms working for positive and negative outcomes.

There are several commonalities within theories of stress and coping that might help us to develop a model of well-being for parents of children with intellectual disabilities. All three of the models reviewed see the child as a central stressor. A distinction can be identified in the two-factor model, which, as we have seen, identifies that positive and negative appraisals may occur together and that they derive from slightly different processes. For example, data have shown that positive appraisals predicted positive well-being and negative appraisals predicted negative well-being (Pruchno et al., 1996). All the models also mention the potential for negative outcomes, with stress and burden being the most obvious. These may have longer-term implications for mental health.

Two possible criticisms of the two-factor approach are apparent. Firstly, the two-factor model as hypothesised in the work of Lawton et al., (1992) does not define a clear causal pathway to suggest that characteristics of the cared-for person, the child with intellectual disabilities, are the primary stressors or even that there are other caring-related stressors that start off the causal process. From the work of Lazarus and Folkman (1984), one would expect this, for there must be a stressor for the parent to appraise. The symptoms of the cared-for person and care-giver health are present in the Lawton model, but they are not shown as causally preceding the help received, for example. Secondly, criticism might be directed towards the treatment of coping within the two-factor conceptual framework. The model explicitly mentions one type of support, the help received by the care-giver, and one type of personal resource, in the form of the health of the care-giver, but other forms of coping that may be utilised by the parent are not clearly represented within the model.

To summarise, the main theme to be drawn from existing theoretical models is that there is a stressor (or perception of a stressor) which in some way affects the parent, and these parents 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 parent may balance out the stressor. The main process is for parents to assess the stressors, their resources and their understanding of the situation to maintain a positive outcome (i.e., coping).



### 1.6 A Proposed Integration

This chapter has reviewed models of stress and coping that have had an influence on researchers working with parents of children with intellectual disabilities. To inform the research in this thesis, a proposed integration is presented in Figure 1.4. This draws on common themes evident in the reviewed models, summarising the important concepts for this thesis.

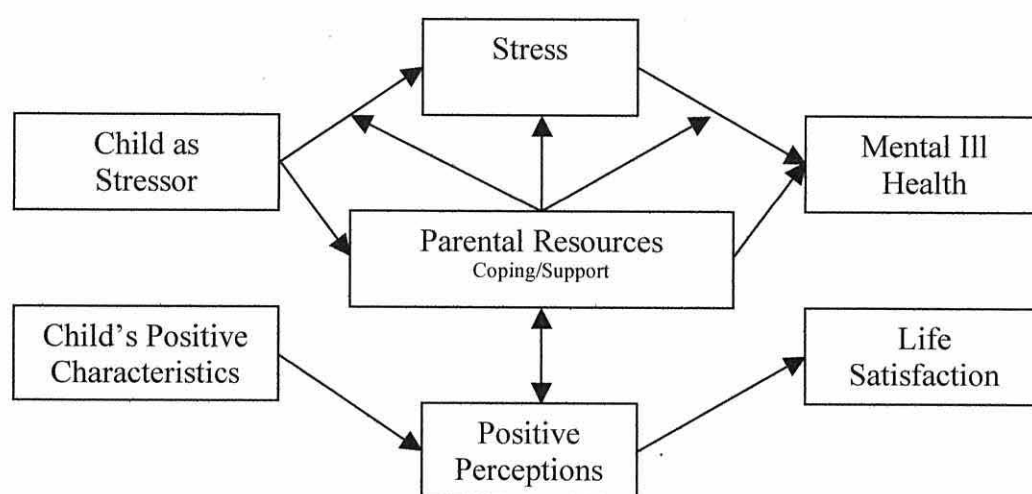


Figure 1.4 The Proposed Integrated Model

The main feature of this model is that ultimate outcomes for parents may be negative (mental ill-health) or positive (e.g., life satisfaction), and that these have distinct and independent pathways. Thus, stressful aspects of the child lead to stress, which in turn may lead to mental ill health. Similarly, positive aspects of the child are associated with various positive perceptions that in turn feed life satisfaction or general positive affect.

Key parental resources are also represented in the integrated framework (coping and available support). They have also been analysed as outcome variables with the child data and predictor variables in relation to the parental outcome data. However, all the variables in the 'middle layer' of the model are also investigated as to whether they function as moderator or mediator variables (See further discussion in Chapter Three). Finally, empirical studies discussed in Section 1.4 above suggest that there may be some link between positive perceptions and parental stress. Hastings and Taunt (2002) hypothesise that this link may be due to positive perceptions being a type of coping mechanism. In the following chapter, I review empirical studies addressing the well-being of parents of

children with intellectual disabilities. The framework presented in Figure 1.4 is used to organise the large amount of research literature in the field. By doing this, I also explore empirical support for this potential framework.

## Chapter 2

### A Review of Empirical Studies of Adjustment in Parents of Children with Intellectual Disabilities

#### 2.1 Introduction

At the end of Chapter 1, a model was proposed that includes concepts from the review of influential models in the field of stress and coping research, as applied to the study of parents of children with intellectual disabilities. This model identifies the child as a stressor for the parents, but also acknowledges that parents may experience positive perceptions as a result of recognition of positive characteristics within the child. These positive and negative outcomes are conceptualised separately, reflecting the influence of the two-factor approach on this thesis. Also included are the key components of stress and parental resources such as coping and support. A number of variables may act as mediators or moderators. For example, the effect of parental resources on the relationship between the child as stressor and the parent's experience of stress may be a mediating or moderating effect. Mental ill health is identified as an outcome resulting from stress, or the combined impact of stress and parental resources. This model is not presented as a replacement or improvement on any previous models, more as a mechanism for the organisation and exploration of themes that are important in this thesis. In the remainder of Chapter 2, each aspect of the model above is explicitly reviewed, with reference to existing empirical literature.

#### 2.2 The Child as a Stressor

This section is concerned with the identification of aspects of the child that could account for the stress that parents may experience. These include: child gender, child age, child disability, communicative and adaptive skills, and child behaviour problems. Each of these is reviewed in turn below. In particular, evidence is reviewed that behaviour problems are causally related to parental stress.

##### 2.2.1 Gender

A number of studies have identified that the gender of the child is a significant predictor of domains related to familial stress, such as family functioning and adaptation, with parents of female children reporting better overall adjustment than those of male children

(Frey, Fewell et al., 1989; Henggeler et al., 1990; Krauss, 1993). Frey, Greenberg et al., (1989) posit that as fathers tend to bond with their male children through the mutual participation in activities, something not always possible in some children with disabilities, their stress levels may be elevated. Although child gender is often reported and controlled in family research data, a rationale for gender effects is often not explained. A key factor is likely to be that boys with intellectual disability typically have more behaviour problems than girls (e.g., Henggeler et al., 1990, Emerson, 1995).

### 2.2.2 Age

Age can typically be understood to two ways. First, chronological age is simply the child's age in years. Second, mental age is a construct that may be assessed through measures such as the Bayley Scales of Infant Development (1969), and is the infants' performance, in absolute terms, converted into a mental age equivalent, that would be scored by most typically developing infants of a given chronological age. In studies within the field of intellectual disabilities, evidence suggests mental age is confounded with self-sufficiency, academic abilities, and IQ scores (Sloper et al., 1991). It is also understandable that chronological age may not have the same bearing it may in a normally developing population, and that other closely related variables might be of more utility. Ansty and Spence (1986) found no significant relationship between maternal stress and child chronological age in a sample of 94 mothers of children with intellectual disability. As with all the variables discussed, chronological age may impact upon other relationships, for example, between child behaviour and parental stress, Gowen, Johnson-Martin, Goldman and Appelbaum (1989) reported that parents of infants with developmental disabilities appeared to be affected by the child's lack of ability rather than behavioural problems. Furthermore, Orr et al., (1993) found parents of children in mid childhood to be potentially more stressed by their behavioural problems than the parents of adolescents with developmental disability.

There is a clear distinction between chronological age and mental age. Chronological age may be a variable of considerable relevance in developmental psychology research studies of normal development as chronological age and mental age are strongly related. However, children with intellectual disabilities don't necessarily develop in 'typical' ways. Following a 'two-group approach' (Zigler & Hodapp, 1986) to intellectual disability, children may be delayed, yet still follow a similar pattern of development to

typically developing children. In contrast, they may have an intellectual disability with organic origins, which means that functioning in various areas may develop very differently to typically developing children. Therefore, chronological age is likely to be less informative, when compared to mental age and other developmental measures. These are explained in greater detail in Section 2.2.3.

### 2.2.3 Disability, Communication and Cognitive/Adaptive Skills

There is evidence that stress may differ across different aetiological groups. Hodapp, Dykens and Masino (1997) sampled parents of children with Prader-Willi Syndrome, a genetic disorder typically resulting in individuals with short stature, mild levels of intellectual disability and preoccupations with food, resulting in obesity. In comparison to parents of children with mixed aetiologies of intellectual disability, parents of the children with Prader-Willi Syndrome showed higher levels of parent and family problems, on a subscale of the Questionnaire on Resources and Stress (Holroyd, 1974), a commonly used measure of familial stress. Holroyd and McArthur (1976) compared mothers of children with autism, Down Syndrome and children who were seeing an outpatient psychiatric clinic. Mothers of children with autism were reported to be more upset and disappointed about their child, concerned over dependency, worried about the impact on the family and future vocations for the child. Naturally, certain conditions have specific behaviours that may serve as stressors to parents. Disaggregating the stress of the aetiological condition from the stress of behaviours within the condition may not be straightforward. The elements of the condition such as specific behaviour problems, parental social isolation, and associated medical complications may be impacting factors. Existing studies have typically not addressed the specificity of identified aetiological group differences.

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 this study, participants were 48 couples and 48 children. Sixty percent of the children had Down syndrome, 16% had cerebral palsy and the remaining children had a variety of mild and moderate intellectual disabilities. 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 that is over emphasised when a child has intellectual disabilities whereas fathers take on more of a recreational role (i.e. playing with their children). Fathers may find raising a child with intellectual disabilities (who cannot participate in what would be considered typical recreational activities) harder to interact with than typically developing sons. This dimension has clear common ground with the information presented in preceding sections regarding the gender of the child.

Boyce, Behl, Mortensen and Akers (1991) used a sample of 479 families, with the children having a developmental quotient of 65. They found that the adaptive behaviour of the child, that is the ability to take care of themselves and cognitive and motor skills, were significantly correlated to maternal stress, over and above other child-related stressors. This research was supported by Weiss, Sullivan and Diamond (2003) finding that lower levels of adaptive functioning predicted higher levels of parental stress in a sample of 97 individuals with intellectual disability. However, Hastings (2002) observed that adaptive behaviour is less important as a predictor of parental stress than child behaviour problems, when controlled for in regression analyses.

More recently, Smith et al. (2001) initiated a study of 880 parents of children with moderate to severe intellectual disabilities. Fifty-nine percent of the children were male, and 78% were Caucasian. Children had a mean age of 2 years and 11 months. The measures included the Parenting Stress Index short form (PSI/SF; Abidin, 1990) and the Battelle Development Inventory to 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.

Smith et al. (2001) found the child's social skills were found to be a stronger predictor of parent stress than motor skills, communication, adaptive behaviour, or cognitive ability. Kopp et al., (1992) showed through behavioural observations that there is a strong difference in social behaviour between children with developmental disorders and their typically developing classmates, a finding supported by Baker et al., (2002). Baker and colleagues found that young children with developmental delays were significantly different from their typically developing peers on subscales concerning with Social

Withdrawal and Attention Problems. They discussed the issue, highlighting that as children grow older, the domain of social skills increases in importance as a potential moderator for other problems.

#### 2.2.4 Behaviour Problems

For many years, it has been recognised that children and adolescents with intellectual disabilities are at an increased risk for the development of behavioural and emotional problems (Bregman, 1991; Dykens, 2000; Rutter, Graham & Yule, 1970). Hastings (2002) developed the idea that parents and children affect one another, with child behaviour problems leading to stress in parents and parents under stress using parenting behaviours that reinforce the very behaviour in the child that they perceive as stressful. The evidence base suggests that child behaviour problems may be a key causal factor in parental stress. Before considering the empirical literature in detail, I will review what one might mean when one variable is said to be causally implicated with another.

##### 2.2.4.1 Criteria for Implying Causality

It is commonly held that causality can only be demonstrated when the presence of at least three specific criteria is met (Mitchell & Jolley, 2004). Three such criteria are:

- 1) Co-variation: changes in the independent variable result in changes in the dependent variable. Co-variation can be established by estimating the level of correspondence between variations in the dependent and independent variable. For example, a parent whose child has fewer behavioural problems suffers from less stress. This could be evidenced in a group design (children with and without behaviour problems) or a correlational design.
- 2) Spuriousness: the change in the dependent variable can only be a result of a change in the independent variable, and not accounted for by other variables. An example of this would be parental stress being a result of their child's behaviour problems not due to other factors, such as the age of the child with intellectual disabilities or the presence of a sibling in the family. Spuriousness is established by ensuring other factors remain constant whilst studying the effect of the independent variable on the dependent variable. Although this may appear a daunting task, careful design of the study as well as the application of certain statistical techniques may help account for irrelevant variables. For example,



randomisation ensures the irrelevant factors vary randomly. Furthermore, other factors can be measured and controlled for in statistical analyses. In the data analysis the effect of the irrelevant factors can then be estimated.

- 3) Temporal precedence: the change in the independent variable occurs before the change in the dependent variable. Temporal precedence can be established in a longitudinal design or a true experimental design. Temporal precedence is supported when in a longitudinal design the measure of the dependent variable at Time 2 can be predicted by measures of the independent variable at Time 1. Thus, following from previous examples, prospective data would need to show that the independent variable, child behaviour problems, at Time 1 predicts the dependent variable, parental stress at Time 2. Similarly, by manipulating the independent variable in a randomized experiment one can establish that the cause (independent variable) comes before the changes in the dependent variable occur.

The following review of child behaviour problems as stressors for parents is structured following these three causality criteria.

#### 2.2.4.2 Evidence of Association (Co-Variation)

The first criterion, that of an association between child behaviour problems and parental stress has been the subject of sustained interest in the intellectual disability field for some time. A significant amount of research has demonstrated that when children with intellectual disabilities display behaviour problems, the parents are more likely to report increased stress and the presence of minor psychiatric conditions such as anxiety and depression.

Blacher, Shapiro, Lopez, Diaz and Fusco (1997) used a sample of 148 Latina mothers of children with intellectual disabilities. They found maladaptive behaviour to be significantly related to depression scores. The authors posited various explanations of these findings including the potential for depression to be a factor contributing to the reporting of maladaptive behaviour. That is, mothers with depression may perceive their child's behaviour as more maladaptive as a consequence of their depression. They also suggested that factors associated with depression including inattentiveness and inappropriate discipline may lead to changes in parent-child interactions, precipitating



maladaptive behaviour. These points illustrate the importance of further causality criteria, especially temporal precedence.

Orr, Cameron, Hobson and Day (1993) investigated age-related changes in stress in mothers of children with developmental delays. Of the participants, 39 of the children were at the preschool level, 40 were aged between 6 and 12, and 33 in the adolescent group, aged between 13 and 18. The research found that behaviour problems were highly correlated with maternal stress in both the middle childhood and adolescent groups. Data were not available for the preschool group. They also found that the middle childhood years were consistently more difficult for mothers to cope with.

Sloper, Knussen, Turner and Cunningham (1991) looked at families of children with Down Syndrome. One hundred and twenty three families participated in this research with measures used including the Malaise Inventory (Rutter, Tizard and Whitmore, 1970), a measure of stress, a behaviour checklist (Richman et al., 1982) and a coping questionnaire (Folkman & Lazarus, 1985). This research extended previous work by including measures of father responses and factors such as coping strategies and the inclusion of positive measures. For mothers, the child's level of behaviour problems was strongly related to outcome in the stress measure. Other factors were also related including coping strategies used, family relationships and socio-economic factors. Data were not presented on what degree of the variance was explained by behaviour problems alone although the contribution of behaviour problems was independent of other factors (i.e., non-spuriousness).

A study by Quine and Pahl (1985) also supports an association between child behaviour problems and parental stress. In this study, the Malaise Inventory was used with 200 families of children with intellectual disabilities in the South of England. The highest levels of stress in the sample were associated with the presentation of behaviour problems by the child, and the presence of multiple impairments. Stores, Stores, Fellows and Buckley (1998) again used a sample of families of children with Down Syndrome. The particular focus of interest concerned the daytime behaviour problems of these children and the impact on maternal stress. They used comparison groups of children with other intellectual disabilities, non-intellectually disabled siblings and a group of non-intellectually disabled children sampled from the general population. As in the Sloper et

al., (1991) study, the measure of stress used was the Malaise Inventory (Rutter, Tizard & Whitmore, 1970). Maternal stress was found to be higher in the sample of children with other intellectual disabilities and maternal stress was found to be significantly associated with behaviour problems in all four samples used.

It is evident that support for the existence of an association between child behaviour problems and parental stress has been consistently presented in a diverse range of studies. The second question to ask is whether this association is independent of other variables and that the association is non-spurious.

#### 2.2.4.3 Evidence of Non-Spuriousness

The second criterion is to demonstrate that the associations made are non-spurious. That is, that the change in the dependent variable is a result of a change in the independent variable, and not accounted for by other variables. Thus we need to offer research that suggests that behaviour problems are accounting for the parental stress over and above the myriad of other factors that could be having an effect. In this section, a number of studies are presented that claim to have done this, to some extent. First, data from group designs have noted that stress in parents of children with intellectual disability who have co-morbid behaviour problems is similar in its intensity to stress suffered by parents of children who are typically developing but also have behaviour problems.

Dumas, Wolf, Fisman and Culligan (1991) assessed parental reports of parenting stress, child behaviour problems and dysphoria in 150 families of children with autism, Down syndrome, behaviour disorders and normal development. Parents of children with autism and parents of children with behavioural disorders experienced significantly higher levels of stress than parents of children who had Down syndrome or who were typically developing. In addition, parents of children who had behaviour disorders were the only ones to report that their children presented difficulties that were statistically and clinically more numerous and more intense than those of children in all the three other groups. So, even when adaptive and intellectual ability varies between the groups, parental stress can be seen as raised in the presence of child behaviour problems.

Baker, Blacher, Crnic and Edelbrock (2002) looked at 225 children with and without developmental delays. The research was concerned with the relative impacts of behaviour

problems and cognitive delays on parents. Both mothers and fathers of the children with developmental delays reported greater negative impact of the child on the family, the variable utilised by this particular study as stress. Regression analyses found that when the influence of behaviour problems on parental stress was accounted for, mental development explained no additional variance. Thus, child-related stress was significantly more related to behaviour problems than to cognitive delays the child may have.

A study by Hodapp, Dykens and Masino (1997) investigated families of children with Prader-Willi Syndrome, a genetic disorder typified by mild levels of intellectual disability, obsessions with food, and obesity. The researchers looked at 42 children with the syndrome, who lived at home with their parents. They noted that whilst IQ, a cognitive measure, was not significantly correlated with family stress, various measures of the child's maladaptive behaviours were. Furthermore, investigation confirmed that these behaviours were not generally related to family support levels or other characteristics. This particular research highlights the consistency of the findings that behaviour problems have significantly related to parental stress, over and above the child's cognitive delays and furthers the understanding by identifying the trend in a specific aetiology, Prader-Willi Syndrome.

Konstantareas and Homatidis (1989) sampled the parents of 44 children with autism, gathering data on both the parents' ratings of the severity of the child's symptoms and their stress. Child and family characteristics were also recorded to enable variables to be controlled for that may have an influence on symptom perception and stress. The characteristic most predictive of stress in both parents was the child's self-abusive behaviour. Self-injurious behaviour is generally recognised to be a component of behavioural problems (Emerson, 2001). Hyperirritable behaviour was second most predictive of parental stress, another variable that may well be considered problem behaviour.

As previously mentioned (Section 2.2.4.2), Quine and Pahl (1985) conducted a study using the Malaise Inventory (Rutter, 1970) with 200 families of children with intellectual disabilities in the South of England. The highest levels of stress in the sample were associated with the presentation of behaviour problems by the child and the presence of multiple impairments. Of interest to the demonstration of non-spuriousness, further

regression analyses found that behaviour problems were the single biggest factor of importance in predicting stress in carers. Another study by the same team (Quine & Pahl, 1991) reports on a study of 166 mothers, again with children with severe intellectual disabilities. The aim was to establish both factors that were associated with maternal stress, and those which may serve the function of mediating the impact and effects of the stress. Stress was measured with the Malaise Inventory (Rutter, 1970) and the study used the conceptual structure of the Transactional Model of Stress and Coping (Folkman & Lazarus, 1984). Of the child variables, multiple regression analyses showed that behaviour problems were the significant source of stress for the mother, once again supporting the suggestion that behaviour problems predict parental stress when other variables are controlled.

So, data reviewed support the following assertions: 1) Stress in parents who have children with intellectual disabilities and concomitant behavioural problems is similar to that experienced by parents with typically developing children with behaviour problems (e.g., Dumas et al., 1991); 2) Child adaptive behaviour is not associated with parental stress when behaviour problems are, or that child behaviour problems emerge as a predictor of parental stress when adaptive behaviour is controlled (Blacher et al., 1997; Hodapp et al., 1997; Konstantereeas et al., 1989); 3) Behaviour problems in children also predict parental stress when other factors such as social support, age and socio-economic status have been controlled (Orr et al., 1991; Quine & Pahl, 1991; Sloper et al., 1991).

#### 2.2.4.4 Evidence of Temporal Precedence

The previous sections have amply demonstrated that there is a reliable evidence base for the first two criteria required to establish causality in the relationship between parental stress and behaviour problems. Attention must now turn to the issue of temporal precedence as the final criterion required. A well-established method of investigating temporal precedence is to utilise a longitudinal research design, showing that changes in the causal variable precede time changes in an outcome. A number of research studies have investigated behaviour problems of children with intellectual disability and their parents' stress over time.

Nihira, Mink and Meyers (1985) used a longitudinal design to examine 148 adolescents with developmental delays over a 3-year period. They found a bi-directional relationship

between Harmony and Quality of Parenting (potentially a measure of stress/ well-being in the parents) and maladaptive behaviour. The authors emphasise that the primary direction of effect was from the child to the environment over the three years of the study. They further caution that the work shows only suggestive evidence for causal inference. No control was made for the possible impact of other variables on the analyses.

A more robust design was employed by Lecavalier, Leone and Wiltz (2006), who took a sample of 293 young people, aged between 3 and 18, with autistic spectrum disorders. Their research aim was twofold. First, to further understand the relative impacts of behaviour problems and level of functioning on the stress of the care-giver and second, provide a measure of the stability of behaviour problems and care-giver stress. They found that parent and teacher ratings of behaviour problems were more associated with stress than any other child or care-giver characteristic. Data were collected across a one-year period, thus the design was longitudinal in nature, enabling temporal precedence to be addressed. Parent reports were found to be stable over a 12-month period and the data suggested that there was reciprocal exacerbation of behaviour problems and parental stress. This supports a bi-directional model of influence between child and parent.

As previously discussed, Baker et al. (2002) found that when the influence of behaviour problems on parenting stress was accounted for, mental development explained no additional variance. A year later, Baker et al. (2003) investigated whether that same relationship was stable over time. Two hundred and five families with three-year-old children took part in a study over two years. Of the sample, 82 were classed as developmentally delayed. The remainder were typically developing. Behaviour problems were found to be stable over the research period for both the children with and without the developmental disabilities. As expected, problems of children with the developmental delays continued to be greater than those who were typically developing. Again as expected, stress scores were considerably higher for the parents of children with the disabilities. The child's behaviour problems at 36 months and changes in child behaviour problems over the one-year period were associated with increases in the stress reported by the parent. In addition, parent stress at the initial 36-month stage and parent stress changes over the year were related to child behaviour problem increases. Again, these data support a bi-directional relationship between the variables.

Orsmond, Mailick-Seltzer, Krauss and Hong (2003) examined the occurrence and stability of problem behaviours over a six-year period, the lengthiest period of time over which these types of longitudinal studies have been performed. In contrast to the previous studies, the sample consisted of 193 adults with intellectual disabilities who lived with their mothers. The data found a bi-directional effect between maternal well-being (stress on the family, care-giver burden, depressive symptomatology and perception of the relationship with the child) and behaviour problems. The research again provides support for not only a child-driven relationship between the variables, but also the reverse, that parental factors influence the behaviour of their children. This particular work has extended these findings to adults with intellectual disabilities living at home with their mothers.

Hastings, Daley, Burns and Beck, (2006) assessed mothers of children with intellectual disabilities at two time points, two years apart. Seventy-five families took part at the initial time point whilst 56 consented to take part a second time. Data were gathered on the maternal stress, mental health and the child's internalising and externalising behaviour problems. Once again, as with other research, a bi-directional relationship was supported, although in this research it was only found for the child's externalising behaviour problems. These results were independent of maternal mental health and demographic factors.

The final study in support of the criteria of temporal precedence is research carried out by Keogh, Garnier, Bernheimer and Gallimore (2000), who used a sample of 80 children with intellectual disabilities. They tested models of child-environment interaction, assessing the children at the ages of three, seven and 11 years of age, thus introducing a longitudinal element to the research design. Rather than directly measure parental stress, the researchers made an assessment of the accommodations made by the family for the child. Such accommodations may include actions taken, avoided or delayed in order to sustain a normal family routine. These may be high intensity, such as the mother giving up a job in order to look after the child, or low intensity, such as the mother continuing to work and utilising a live-in grandparent to help with care-giving. Their findings identified that hassle associated with the child's behaviour problems predicted family accommodations over time. Family accommodations at the earlier time points did not however, predict later child behaviour problems. Therefore, in contrast to the research



presented above where a consistent bi-directional relationship has been observed between maternal stress and child behaviour problems, Keogh et al., (2000) found evidence supporting a unidirectional link, of a child-driven model where behaviour problems in the child temporally precede the impact upon their family.

#### 2.2.5 Positive Characteristics of the Child

Whilst the extant literature appears clear regarding the importance of behaviour problems in predicting parental stress, the proposed model also identifies the potential of positive characteristics exhibited by the child to affect parental well-being. These 'pro-social behaviours' include "behaviours that show a concern for the well-being of others and includes displays of empathy, helping behaviour and altruism" (Stevenson, 1997, p. 46). Beck, Hastings and Daley (2004) suggest that although there may be small correlations between pro-social and problems behaviours (such as aggression) (e.g., Eron & Huesmann, 1984), evidence from behaviour genetics research suggest that the genetic and environmental mechanisms responsible for pro-social behaviour are different to those of problem behaviour (Stevenson, 1997). Therefore, it stands to reason that behaviour problems and pro-social behaviour should be measured and explored separately in research on children's behaviour.

Very few data are available on the extent of pro-social behaviour in populations of children with intellectual disabilities. Data from the normative sample for the Nisonger Child Behavior Rating Form (Aman, Tassé, Rojahn, & Hammer, 1996; Tassé, Aman, Hammer, & Rojahn, 1996) that includes social competence items, show the presence of pro-social behaviours in children with all levels of intellectual disability and suggest that there are no age or sex effects for these characteristics. This recognition of the presence of positive behaviours in children with intellectual disabilities is rarely noted in research literature, although parents have often reported that their child has positive characteristics and behaviours that they value (Hastings & Taunt, 2002).

In the Beck et al., (2004) study of whether pro-social behaviour and behaviour problems independently predict maternal stress, 74 mothers of children with intellectual disabilities completed measures of stress and mental health and reported on their child's adaptive behaviour, problem behaviour, and pro-social behaviour. In addition to providing support for previous research that behaviour problems were an independent significant predictor

of maternal stress, Beck et al. also found that the lack of a child's pro-social behaviour independently predicted higher levels of maternal stress. Thus, mothers of children with intellectual disabilities at the greatest risk of stress may be those whose children show high levels of behaviour problems and also a lack of pro-social behaviour.

To return to the proposed model at the beginning of the chapter, the hypothesised pathways suggest that parents are likely to experience stress outcomes raising a child with intellectual disabilities but that they may also experience a number of positive perceptions (Hastings & Taunt, 2002). In light of the research on pro-social behaviour, one might predict in general that pro-social behaviour is a strong predictor of positive parental perceptions and behaviour problems are the primary source of parental stress. However, as Beck et al., (2004) mention, it is unlikely that the relationship is this clear cut, showing that pro-social behaviour may also be a negative predictor of maternal stress.

#### 2.2.6 Child as Stressor - Conclusions

The review of aspects of the child that may impact upon the stress of the parent has raised a number of important points. However, it is evident from the references in other work and the volume of research into it, that child behaviour problems are identified as a key factor in the stress experienced by parents of children with intellectual disabilities. This is the only variable explored in research that has been shown to have a causal relationship with parental well-being.

#### 2.3 Parental Coping

Coping has been investigated as a quality, as a process leading from a crisis to a state of adaptation and as an outcome variable, taken to indicate an absence of stress. Coping is understood to be an important factor affecting the relationship between the occurrence of a stressful event and the outcome (Beresford, 1994). Outcomes have been almost exclusively measured in terms of the parent, rather than the child (Beresford, 1994). To comprehensively analyse the domain of coping, coping resources used by parents will be reviewed, with evidence of any relation to well-being outcomes. Following this, coping strategies will be identified and research into the mechanism of effects on outcomes discussed.



### 2.3.1 Coping Resources

It is understood that the resources available to a parent or individual affects the appraisals made of events and situations (Fong, 1991), and may impact upon the coping strategies employed by the individual. Beresford (1994) also highlights the link between coping resources and vulnerability, and how the former affects the resources used by the individual. If resources are not available at the time, then the individual is deemed more vulnerable. Beresford elucidates upon this by pointing out that a parent may have an increased vulnerability as a consequence of the effect of stress, but that the impact of stresses associated with caring for a child with intellectual disabilities is affected by other factors. If the relationship between stress and coping is understood to be transactional, as advocated in the Process Model of Stress and Coping (Folkman & Lazarus, 1984), variables may be conceived as either resources or outcomes. For example, the parents' satisfaction in their relationship may be used as both a resource in one instance, or an outcome variable in another. In the following pages, coping resources that may be available to parents will be reviewed, bearing in mind these distinctions.

### 2.3.2 Perceptions of Competence and Self-Efficacy

Self-efficacy is the perception of one's skills in a given domain. This has implications for parental well-being and there has been a substantial body of research directed towards this domain, identifying self-efficacy as a crucial variable in predicting behaviour and the understanding of psychological well-being. Within the literature of families with children who have intellectual disabilities, the self-efficacy of parents has been explored in two ways. In the first, as a predictor of parental outcomes, self-efficacy has been found to be a predictor of parental stress (e.g. Krauss, 1993). In the second, as an outcome variable, self-efficacy has found to be predicted by child variables including child behavioural problems (e.g. Heller, 1993). In most research in this area, self-efficacy has been operationalised in terms of parental competence. Hastings and Brown (2002) looked at 26 mothers and 20 fathers of children with intellectual disabilities and their reports of self-efficacy, anxiety and depression. Self-efficacy was identified as a mediator in the relationship between problem behaviour exhibited by the children and mothers' reports of their anxiety and depression levels. However, in fathers self-efficacy acted as a moderator between child behavioural problems and father anxiety. This research both supports previous research identifying self-efficacy as an important variable in the link between certain child variables and the parents' mental health outcomes and highlights the complexity that exists between

the child and their parents' stress/ well-being. The role of mediators and moderators will be dealt with in greater detail in Chapter 3. An area that is closely linked with parental self-efficacy is parenting skills. Skills that parents may find of benefit to them in coping with the difficulties posed by a child with disabilities include discipline, communicative skills, and supervision (Webster-Stratton, 1991). An increase in the competency with which a parent deals with behavioural problems has been found to both reduce the behavioural problems (Moran and Whitman, 1991) but also serves to improve the parents' own sense of their competence, which we have seen can have effects on the stress of a parent.

Quine and Pahl, (1991) reported on a study of 166 mothers of children with severe intellectual disabilities. The aim was to establish both factors that were associated with maternal stress and those which may serve the function of mediating the impact and effects of the stress. Stress was measured with the Malaise Inventory (Rutter, 1970) and was the study used the conceptual structure of the Transactional Model of Stress and Coping (Folkman & Lazarus, 1984). The researchers used hierarchical regressions to further assess causal priority. Whilst behaviour problems again contributed the most variance of the child variables, the researchers found the impact of child behaviour problems may be mediated by the mother's feelings of competence to cope.

### 2.3.3 Cultural Background and Religious Beliefs

The vast majority of the research within the field has focused on white, Christian samples. Research with other cultural and religious groups, for example, Latino mothers, does suggest that these mothers are similar to their Anglo counterparts in that they experience an increased burden of care (Shapiro & Tittle, 1990). Blacher, Shapiro, Lopez, Diaz and Fusco (1997) investigated whether Latino mothers of children with intellectual disabilities experienced increased stress and risk of depression. They found depression scores to be considerably elevated, but were unable to explain whether this as a result of the intellectual disability. However in the sample, maladaptive behaviour was significantly related to depression scores. Overall the researchers concluded that all were highly vulnerable to psychological challenges and did not have the resources to alleviate depression. The depressed mothers however, did not differ significantly from non-depressed mothers on coping styles, the strength of their religious belief, age, income, education, or employment.

Investigating the role of religion as a coping resource of families of children with autism, Tarakeshwar and Pargament (2001) interviewed forty-five parents, identifying stressors associated with autism. They completed measures of depression and anxiety, stress-related growth and religious outcome. Greater use of positive religious coping methods was associated with greater stress-related growth and religious outcome. More negative coping methods were associated with increases in depressive affect and greater anxiety.

Whilst the results of some of this research are encouraging, caution must be exercised when looking at variables such as culture, ethnicity and religious beliefs because they are related to so many other variables. Thus, their role in predicting parent-related stress is difficult to delineate (Boyce, Behl, Mortensen & Akers, 1991).

#### 2.3.4 Coping Strategies

Coping strategies are actions, behaviours and thoughts that a parent may employ to deal with a stressor. Folkman et al., (1986) describes two functions, or ways of coping. These are emotion-focused coping and problem-focused coping. Emotion-focuses coping strategies function to ease the emotions that arise from the stressor, such as fear or guilt. They are specifically directed at the somatic level and/or the emotional level of the feelings. An emotion-focused coping strategy targeted at the somatic level of the feeling would be, for example, having a bath, its aim to be a reduction in the adverse physical reaction of stress. An emotion-focused coping strategy directed towards the person's emotional state might be going to a comedy club with friends, a strategy aimed directly at a change in the emotional state. Problem-focused coping is concerned with the attempt to change the "troubled person-environment relation causing the distress" (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986, p. 993). This type of coping strategy may be directed internally or externally. An example of a problem-focused coping strategy directed towards an external source of stress may be the request of help an outside agency. In contrast, a problem-focused coping strategy directed at an internal source of stress would include techniques such as cognitive restructuring. One key observation is that a coping strategy may serve emotion-focused and problem-focused roles for an individual. A fine example is the use of social support, which may serve both functions simultaneously.

Brown and Hepple (1989) identified the coping strategies that parents viewed as most successful for them in the care of their child, with intellectual disabilities or multiple disabilities. Talking to a spouse was the most frequently mentioned strategy employed by the parents. They suggested, as above, that this served a dual role of both relieving the emotional distress and enabling the parents to discuss of how best to manage difficulties. A second study, by Bristol (1984) identified 45 coping responses, which included a wide variety of coping strategies. All these strategies were identified by at least one mother to be 'extremely helpful', but conversely, 33 were also rated by at least one mother to be "of no help at all". This study successfully highlights the issue at hand, that despite the fact that all the participants in the research were under similar stressors, there was a large degree of variation in the strategies used and the perception of their efficacy. The use of different coping strategies has been linked with differential outcomes in well-being studies. Sloper et al., (1991) used an adapted version of Folkman and Lazarus' Ways of Coping Checklist (1980). In it, two coping strategies are identified, wishful thinking and practical coping. Practical coping was found to significantly predict mothers' perceived satisfaction with life. The use of a wishful thinking coping strategy was found to significantly predict poor mental and physical health. This leads to the conclusion that the use of different coping strategies has varying effects on maternal well-being, supporting the need for multiple outcome measures. No coping strategies were found to be significant predictors of fathers' mental and physical health.

In a study of paternal stress in fathers of adolescents with and without intellectual disabilities (Houser & Seligman, 1991), overall levels of stress did not differ. Significant differences were reported in the use of coping strategies. All fathers in the sample used problem-solving coping strategies most frequently. However, the fathers of the adolescents with intellectual disabilities used distancing, positive reappraisal and escape-avoidance more often than their counterparts. It was suggested that the use of these coping strategies by the fathers might actually have a negative effect upon the mother. For example the use of an escape-avoidance coping strategy may increase the onus on the mother to provide care, placing her at greater risk of stress. The authors go on to suggest that an effective intervention may be the coaching of fathers in other coping strategies, to alleviate some problems experienced by the mother.

An issue in the work done on coping strategies has focused on the way they have been categorised in the research. Beresford (1994) reports that work done on emotion-focused coping strategies has been affected by the methodological approach taken in the study. Thompson et al., (1992) collapsed emotion-focused coping strategies into a single category and subsequently found this strategy to be positively associated with poor adjustment. In more qualitative work, for example, Bregman (1991) found that parents used certain emotion-focused coping strategies effectively and perceived them as helpful. This habit in the quantitative literature of collapsing a number of different emotion-focused coping strategies under a single heading may be limiting the researchers' ability to explain the impact of the different strategies.

Consistent findings emerging from the literature on the subject of coping strategies appear to be the usefulness of active coping strategies and cognitive coping strategies in the well-being of parents. Examples of active coping are planning and the seeking of information. This has been reported in both qualitative and quantitative work (Bregman, 1980; Sloper et al., 1991; Thompson et al., 1992). Examples of cognitive coping strategies include self-praise (Bregman, 1980).

### 2.3.5 Social Support

The notion of support and the differential effect it may have on parental outcomes is well documented in the literature. Three levels of social support may be identified (Schilling, Gilchrist & Schinke, 1984). The first is the support from close family and friends. The second is neighbours and more distant friends. The third and final level is infrequent support, and may include formal support from various authorities. Parents of disabled children have reported themselves as feeling lonely and socially isolated (Phillip & Duckworth, 1982). The lack of social support can be one of the most stressful factors in coping with a child with a disability (Bristol, 1979; Quine & Pahl, 1985). This social isolation may be real, perceived, or self-imposed. Behavioural problems in their children (Meltzer et al., 1989) and feelings of inadequacy as a parent may cause parents to isolate themselves from the community. Exhaustion through the increased parenting demands may limit community interaction and the maintenance of friendships (Gough et al., 1993). Bristol (1979), in a sample of mothers of children with autism, found an association between available social support and parental and familial stress. Dunst's (1986) study showed that, when parents of children with intellectual 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. The issue of social support is complex in its relationships with factors such as ability of the parent in social situations and their ability to utilise such support (Trute & Hauch, 1988).

A study by Wanamaker and Glenwick (1998) assessed the relationship between stress, social support 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.

Gowen, Johnson-Martin, Goldman and Appelbaum (1989) assessed 41 infants and their mothers, investigating, amongst other variables, relations of maternal depression, child characteristics and the mother's social support system, across time. They found that mother's rating of the helpfulness of her social support was significantly negatively related with her feelings of depression.

The support a parent may receive from their spouse may also be implicated in the success with which they cope with the parenting demands of having a child with a disability. In a review of six studies of families of children with disabilities, Sloper and Turner (1991) found spouse support was related to positive outcomes in both mothers and fathers. Other studies (e.g. Byrne, Cunningham & Sloper, 1988), suggest that spouse support is the most important form of support for the parents. Spouse support is often viewed as a single construct, when in fact a more useful position may be to look at the various facets of it (Beresford, 1994). For example, a husband may be 'supportive' by actively assisting in

the care of a child, a practical support, or alternatively as an emotional support. Little research has focused on this differentiation thus far.

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 questioned whether a well functioning parental relationship might serve to counteract a child's problem behaviour. One hundred and forty-seven parents of children with intellectual disabilities participated in this research (seven 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 intellectual 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 exacerbate long-term behavioural problems in children. These findings were posited 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 intellectual 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 intellectual 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

exchanges and feelings of distress. Longitudinal work on the parenting alliance in couples with children with intellectual 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 that positively affects parenting confidence and impacts positively on the parent-child relationship.

### 2.3.6 Parental Occupation

The association between work, parenting and psychological well-being has rarely been studied among mothers of children with intellectual disabilities. Contrasting evidence has been offered, supporting both an increase and a decrease in burden. Warfield (2001) suggests that seeking and maintaining employment may place extra burden on mothers of children with intellectual disabilities. In contrast, Freedman, Litchfield and Warfield, (1995) have suggested that once employed, work provides respite and that the skills mothers develop in parenting their child with intellectual disabilities are transferred and valued in their place of work. Recent findings suggest that there are no differences in child demands, family support or stress by maternal employment status (Warfield, 2001). Mothers in full-time employment reported facing the same types of demands and reported the same level of stress as did mothers employed part-time and those not employed.

Sloper et al., (1991) interviewed 123 families. Hierarchical multiple regression once again found that the effects of the child's behaviour problems on maternal stress, as measured by the Malaise Inventory (Rutter et al., 1970), might be influenced by mothers' employment. Life events and social class were also found to be significant predictors of behaviour problems on stress. The finding that mothers' employment may impact upon maternal stress suggests that it may function as an important resource factor and support to mothers, enabling them to go to work, which may have a beneficial effect.

### 2.3.7 Coping and Support: Mediated and Moderated Relationships

The impact of coping and support, two important parental resources has been discussed. The literature reviewed suggests coping and support have main effect predictive relationships with outcomes of stress and mental health. However, the model proposed



suggests that coping and support may mediate or moderate the relationship between negative child characteristics and parental stress and mental health.

Initially, some evidence offered supports the presence of mediators and moderators. Quine and Pahl (1991) suggested that mother's assessment of their own coping skills mediated the impact of behaviour problems on stress. However, a number of conditions must be satisfied to confidently conclude that a mediation process has taken place. Quine and Pahl (1991) did not explicitly state whether the mediation model had been statistically tested, thus one must be wary of using the terms 'mediator' or 'moderator', when only a simple effect might have been observed.

Research by Sloper et al. (1991) highlights a significant issue regarding moderators. Using hierarchical multiple regression, they concluded that the relationship between child behaviour problems and maternal stress was moderated by mothers' employment. Sloper and colleagues (1991) also concluded that life events and social class were significant moderators of behaviour problems on stress. Following recommendations by statisticians (Aiken & West, 1991; Baron & Kenny, 1986) an interaction term should be calculated in order to test a moderation effect. This is calculated from the product of the predictor variable and the hypothesised moderator and should be entered into the final step of the regression analysis. While Sloper et al. (1991) appear to have used hierarchical regression analyses, the analyses do not contain the product terms necessary to investigate interactions between the predictor variable of child behaviour problems and the moderators of mothers' employment, life events and social class in predicting maternal stress. With this in mind, prudence is advisable when reviewing conclusions drawn from existing literature regarding the role of mediators and moderators in intellectual disabilities.

Hastings and Brown (2002) found that self-efficacy was a mediator in the relationship between behaviour problems and anxiety and depression in mothers. However, for fathers, the evidence suggested that self-efficacy moderated the relationship between child behaviour problems and anxiety. This study utilised frameworks suggested by Baron and Kenny (1984) to support the role of mediating and moderating factors. No other studies reviewed explicitly mention mediating or moderating factors in the relationship between child behaviour and parental stress. Due to the relevance of this

topic and the hypothesised presence of mediating and moderating variables in the proposed model, this topic will be discussed in further detail in Chapter Three.

#### 2.4 Parental Stress and Mental Health

Glidden and Floyd (1997) observed that researchers in the field of familial stress and developmental disabilities have found inadequacies in the way that stress has been conceptualised and measured. Early investigators used global aggregated measures of stress simply to demonstrate that families experience negative reactions. More recent work, with more complex theoretical underpinnings, prompted researchers to disaggregate global measures in order to target specific components linked to theoretically derived models of stress and the process of coping over time. This observation highlights a consistent issue within the field of stress in families of children with intellectual disabilities, concerning the nature of how people define, measure and differentiate between stress, psychological well-being and mental health. There has been a focus on parental stress as a key factor within well-being, and this is reflected in the proportion of the available literature that has investigated the well-being of parents of children with intellectual disabilities. In a recent paper, investigating maternal stress and behaviour problems, Hastings et al., (2006) highlight that researchers have tended to view parental mental health outcomes and stress outcomes in families of children with intellectual disabilities in two main ways.

First, they have understood these terms to be relatively interchangeable measures of parental well-being. For example, Orr, Cameron, Dobson and Day (1993) in their study into age related changes in stress of families with a child with intellectual disabilities described depression to be a typical parent stress reaction in their introduction to the research. This naturally leads to confusion as to whether stress is an outcome in its own right or whether it is linked to mental health problems. In a second example, Dunn, Burbine, Bowers and Tantleff-Dunn, (2001) investigated moderators of stress in parents of children with autism. Whilst the title of their paper clearly identifies stress as the outcome of interest, they tested three outcome measures: social isolation, spousal relationship difficulties, and depression. So it appears the suggestion is that stress and depression are either the same concept or that the pathway between stress and depression is so well grounded that a measure of depression is effectively a proxy measure of stress.

Second, Hastings et al., (in press) note that previous researchers may have assumed that parenting stress plays a causal role in the development and maintenance of enduring mental health problems. Olsson and Hwang's (2001) research measured depression in mothers and fathers of children with intellectual disabilities. They concluded in their introduction that the extra stress associated with caring for a child with intellectual disabilities places parents at an increased risk of depression, but did not include a measure of parental stress in their investigations.

There is a dearth of studies where stress and mental health have been separately measured and both included within the same research. A notable exception is Hastings et al, (In press), who utilised a longitudinal regression analyses, finding maternal depression to be causally related to maternal stress over and above the effect of the child's behaviour problems. Exploratory analyses also found evidence of a bi-directional relationship, with maternal stress independently predictive of maternal depression over time. Therefore, these findings suggest a different relationship between stress and parental mental health than previous work has posited, where each function as risk factors for the other.

The broader term of well-being may be understood as an umbrella term encompassing measures of stress, depression and other mental health problems. In one study into stress, anxiety and depression (Sharpley, Bitsika & Efremidis, 1997), the researchers used the Zung Self-Rating Anxiety Scale (SAS; Zung, 1971) and the Zung Self-Rating Depression Scale (SDS; Zung, 1965). To address a perceived weakness in the instruments, they added three questions to assess parents' stress in more specific ways. Thus, they concluded, with the established measures, the questions about stress formed an overall measure of well-being, supporting the assertion that well-being is used as an overarching term. In a Chinese study, Shu, Lung and Haung (2002) used the Chinese Health Questionnaire, a modified version of Goldberg's General Health Questionnaire (GHQ; Goldberg, 1981). Its stated usage is to "assess psychological well-being", by screening people for mild psychiatric disorders. No mention is given to any stress items thus leading to the conclusion the developers of Chinese Health Questionnaire at least implicitly understand the concept of well-being to be linked to mental health.

Another potential limitation of stress research is evident when looking through the existing literature. There is a broad range of stress measures that have been used within

research. For example, Blacher, Shapiro, Lopez, Diaz and Fusco (1997) used eight different subscales from three different measures to assess stress in Latina mothers of children with intellectual disability. These included four scales from the Family Impact Questionnaire (Donenberg & Baker, 1993), the Family Problems subscale from the Questionnaire on Resources and Stress (Friedrich, Greenberg & Crnic, 1983) and three subscales from the Family Environment Scale (Moos & Moos, 1986). In contrast, Konstantareas and Homatidis (1989) assessed child symptom severity and stress in parents of autistic children using the Childhood Autism Rating Scale (CARS; Schopler, Reichler, DeVillis & Daly, 1980) and asked parents to rate their child's symptoms and then indicate on a four-point scale how much they were stressed by each symptom. These two examples highlight the difference in how stress is measured in previous research. This observation of the diverse measures that have been employed as an indicator of stress lead one to conclude that the validity of the concept of stress is suspect, as no 'industry standard' exists. Thus, the interpretation of the concept of stress lies with individual researchers, who will choose different measures for a plethora of reasons including cost, ease of application, aims of the study and target participant population.

There are however, a number of standardised instruments that have found favour with researchers and are in widespread use. Examples of such instruments are the Malaise Inventory (Rutter et al., 1970), the Questionnaire on Resources and Stress- Short Form (QRS-F; Friedrich et al., 1983) and the Parenting Stress Index (PSI; Abidin, 1983).

Whilst not all parents of children with intellectual disabilities suffer with depression, perhaps due in part to variables such as genetic propensity, child characteristics, family characteristics, socio-economic status, and marital relationship, a significant amount of research has found that parents of children with intellectual disability report higher levels of child-related stress than parents of typically developing children (e.g. Beckman, 1991; Dumas et al., 1991; Warfield et al. 1999). Other research investigating the mental health of parents of children with disabilities have found higher scores for maternal depression compared to controls (e.g. Blacher et al., 1997; Hoare et al., 1998).

To understand the relationship between stress and mental health, and in particular depression, it may be pertinent to leave the intellectual disability literature. Turning briefly to more mainstream stress and depression literature, it is possible to identify

stressors such as life events, including divorce, the death of a loved one, the loss of a job, that may act in a similar way to the stress of a child with intellectual disabilities exhibiting behaviour problems, although one must bear in mind that an intellectually disabled child is an ongoing stressor. Kessler (1997) found evidence of a link between life event stressors and the onset of depressive episodes. In a sample, of non-clinical university students, Lu (1994) identified that different types of stressors have been linked with either anxiety or depression. In the research, they found that recent stressful life events predicted anxiety while daily hassles predicted depression. Jones (1993) found that within women of an inner-city sample, events with loss were associated with depressive disorders and events with elements of danger were associated with anxiety disorder. This does suggest that in other areas of research, that a link between stressful situations and minor psychiatric problems such as anxiety or depression, are reasonably well supported.

### 2.5 Parental Positive Perceptions/Outcomes

Researchers have begun to understand that many families of children with intellectual disabilities have positive thoughts and perceptions about raising their child. Despite the domain of parental positive perceptions being as yet under-developed in the literature, it may prove to be another significant factor in the understanding of why some parents and families suffer greater stress than others. Hastings and Taunt (2002) provided a review of the existing literature in the domain of positive perceptions the experiences of family members. Using their work as a start point, this section maps out basic research within the area of positive perceptions.

Hastings and Taunt's (2002) review drew out four key conclusions. First, families of children with disabilities report both negative and positive perceptions. In qualitative research Scorgie (Scorgie & Sobsey, 2000; Scorgie, Wilgosh & MacDonald, 1999) interviewed 15 parents identified by external agencies as 'good copers'. Analysis of these interviews by the research team led to the development of 16 items that pertained to measure positive impact of the child. A further 80 parents rated the items on agreement, with the items receiving a median rating of 'agree-strongly agree'. The researchers thus reported positive effects from the parents.

A study by Behr, Murphy and Summers (1992) represents one of the only studies in this research domain to have utilised a quantitative methodology to understand the

experiences of the parents and identify the dimensions these experiences may fit into. Behr et al. (1992) identified positive items relating to positive contributions made by the child with the disability. They developed a positive contributions scale with 50 items and used factor analysis to identify 9 dimensions on which the subscales of the measure were based.

The second key point was that descriptive studies of positive perceptions show good degree of agreement in the identification of key issues. Hastings and Taunt, (2002) were able to identify the following themes that appeared in the research. All the issues were identified in at least two of the studies mentioned previously or work also done by Turnbull, Behr and Tollefson, (1986), Stainton and Besser, (1998) and Grant, Ramcharan, McGrath, Nolan and Keady, (1998):

- 1) Pleasure/ satisfaction in providing care for the child
- 2) Child is a source of happiness
- 3) Sense of accomplishment in having done one's best for the child
- 4) Sharing love with the child
- 5) Child provides a challenge or opportunity to learn and develop
- 6) Strengthened family and/ or marriage
- 7) Gives a new or increased sense of purpose in life
- 8) Has led to the development of new skills, abilities or new career opportunities
- 9) Become a better person
- 10) Increased personal strength or confidence
- 11) Expanded social or community networks
- 12) Increased spirituality
- 13) Changed one's perspective on life
- 14) Making the most of each day, living life at a slower pace

Further data provided by Scorgie and Sobsey (2000) posits that the vast majority of families do encounter some form of positivity in the experience of parenting a child with disabilities. In a study of adults with intellectual disabilities who continued to live at home, parents endorsed positive items such as "Having a disabled child has made my family closer" (80% of the sample) far more than the items concerned with negative impact.



Thirdly, previous research has suggested that positive and negative perceptions are associated with differing variables. Judge (1998) studied 69 parents of children with disabilities in early intervention programmes. She used the concept of family hardiness as a measure of positive perceptions. The research found that self-blame, self-controlling efforts and a wishful thinking coping strategy were negative predictors of the measure of family hardiness, whilst distancing/ detachment and support seeking behaviour were positive predictors. All these results were obtained whilst controlling for the group demographics.

Finally, Hastings and Taunt's review highlighted that whilst families of children with disabilities do generally report increased stress (Donenberg & Baker, 1993; Margalit & Ankonina, 1991), no definitive data have been evidenced to suggest that these same families report fewer positive feelings towards their child. For example, Margalit and Ankonina, (1991) found no difference between families with and without children with disabilities on a measure of general positive affect. Indeed, Haldy and Hanzlik (1990) found that mothers of children with Down Syndrome rated their competence within the domain of child-rearing at infancy (a positive measure) as higher than that reported by mothers of children without such developmental problems. Further support is lent by research carried out by Lehman and Roberto (1996), who found mothers of teenagers with disabilities to be more positive than mothers of teenagers without such disabilities.

This body of evidence justifies the inclusion of positive perceptions within the proposed model. The focus must now turn from the general review to identifying specific relationships and the evidence that supports them. Firstly, what evidence is there that child variables relate to positive perceptions? Very little research has focused on this domain. In one recent study (Hastings et al., in press) took the parents of 48 children (41 mother – father pairs) with autism who reported on child characteristics and their own stress and mental health. Child variables measured included behaviour problems, adaptive behaviour and autistic symptoms exhibited by the child. A measure of the positive perceptions of the parents was also taken. Results of systemic analysis suggested that the child variables measured were not predictive of maternal or paternal positive perceptions, although they were related to maternal stress.

A second relationship is identified between positive perceptions and life satisfaction. Work by Sloper, Turner, Knussen and Cunningham (1991) found that positive perceptions (operationalised as family cohesion and the self-sufficiency of the child) best predicted maternal satisfaction with life. Conversely, father scores were best predicted by quality of the marital relationship (a positive perception), stressful life events and financial difficulties (both of which are negative perceptions). This research also highlights the potential moderating effect of family variables, in this case parental gender. Wright, Matlock and Wright (1985) found that in a comparison between families of children with disabilities and families of children without disabilities, there was no significant difference in life satisfaction.

Another hypothesised pathway in the proposed model lies between positive perceptions and parental resources such as coping and support. Whilst again this area has not attracted copious research, there are data supportive of a relationship. Hastings, Allen, McDermott and Still (2002) took 41 mothers of children with intellectual disabilities, who completed a questionnaire on demographic factors, child demographic variables (including care-giving demand), social support, coping strategies and dimensions of positive perceptions. Results identified that mothers' perceptions of the child as a source of happiness/fulfilment and as a source of strength and family closeness drawn were positively associated with the coping strategy of reframing. Positive perceptions may function as a mechanism for coping with the stresses and strains of caring for a child with intellectual disabilities. The effects were found after controlling other key factors including social support and the care difficulties associated with the child with intellectual disabilities. Furthermore, existing family-focused and individual focused theories suggest that positive perceptions have a role in the coping process, with researchers having proposed that positive perceptions may assist in the coping with of traumatic and stressful events (Folkman & Moskowitz, 2000; Taylor, 1983). The extant literature appears to support the proposed inclusion of the positive perceptions and the pathways existing between it, parental resources and life satisfaction.

## 2.6 Other Variables Related to Parental Stress

Whilst the key aspects of the proposed model have been reviewed, it is pertinent to now review other factors not yet identified which may be of importance in this research. In particular, other variables associated with parental well-being may need to be controlled



in future family research.

### 2.6.1 Age

Flynt and Wood (1989) studied 90 mothers with a child with moderate intellectual disabilities. The children were each in one of three normative transition periods. Whilst no significant differences in family stress were recorded across the age groups, the age of the mother was found to be significantly related to perceived stress. Older mothers reported lower perceived family stress levels than younger mothers. However, maternal age at birth was not recorded and this could be a significant factor in the time a mother has had to develop skills, experiences and other coping strategies prior to the birth of their child. Furthermore, other research by Beckman (1983), did not find any significant effects of maternal age.

### 2.6.2 Socio-Economic Status, Deprivation and Poverty

Scorgie, Wilgosh and MacDonald (1998) reviewed recent literature regarding stress and coping in families of children with disabilities. Results regarding the socio-economic status of the family were inconclusive. Some studies (e.g. Flynt & Wood, 1989; Trute & Hauch, 1988) suggested that socio-economic status had little or no relationship to family stress and adjustment. These studies did however, have a sample of families that were middle-class, with both parents present, and possibly not representative of the general pattern found. Flynt and Wood, (1989) did however note that poorer families might utilise fewer coping strategies. Other research found however, that families with higher incomes had greater choice in assisting them to cope (Willoughby & Glidden, 1995) and enjoyed more varied support systems (Barakat & Linney, 1992).

Floyd and Saizyk, (1992) reported that socio-economic status was generally a robust predictor of satisfaction and well-being for almost all domains of psychosocial functioning. Their 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 of 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 intellectual disabilities is more stressful and frustrating for families from higher socio-economic status groups (Mink, Nihira, & Myers, 1983).

Poverty has also been posited to have a powerful impact on the well-being and functioning of children and families (e.g., Lichter, 1997; Magnuson & Duncan, 2002). The association between poverty and health has been identified as particularly important for families of children with intellectual disabilities as they are more likely to be living in poverty (e.g., Fujiyura, 1998; Emerson, 2003). Emerson, Robertson and Wood (2005) identify that deprivation is a major determinant of health. They highlight that lower income levels tend to lead to poor levels of nutrition, poor housing conditions and more complex access to healthcare services. In their research, they sampled 615 children from the inner city of a major conurbation in England. Data was obtained, wherever possible, from both parents or home carers and teachers. They used the Department of Environment, Transport and Regions' Index of Multiple Deprivation (IMD 2000). The IMD consists of a total deprivation score, made up of six dimensions of deprivation, income, employment, health, education, housing and access to services. The deprivation scores are available by postcode, which was obtained from the respondents. They found disruptive behaviour as measured by the Developmental Behaviour Checklist (DBC; Enfield & Tonge, 2002) was found to be associated with social deprivation. Given that a clear association has been identified between child behaviour problems and parental stress, the finding that social deprivation has an impact on behaviour is of interest to the current review.

Emerson (2003) investigated mothers of children with intellectual disability, the mothers' mental health and correlates with their social and economic situation. It was found that families supporting a child with intellectual disabilities were significantly economically

disadvantaged when compared to families supporting a child without intellectual disabilities. Maternal mental health problems were also significantly related to poverty, amongst other variables such as child gender and the child experiencing more than one potentially stressful life event. In additional exploratory analyses, Emerson (2003) suggested that poverty appeared to act as a moderator between maternal distress and emotional and behavioural difficulties in children with intellectual disabilities. However, with reference to previous discussions (Section 2.3.7) regarding the caution with which mediating and moderating relationships are suggested, Emerson (2003) did not test a moderating model. The conclusions drawn would therefore benefit from further investigation before the presence of a moderating influence was accepted.

Despite the relative paucity of work focusing on the role of deprivation as a factor affecting the model put forward at the end of Chapter One, it would appear that it merits inclusion, particularly with the relative simplicity of obtaining poverty figures via the IMD. It is naturally closely related to socio-economic status.

## 2.7 Conclusions and Model Revision

The relationship between a child's disability and parental stress, once thought to be a simple linear relationship (Michaelis, 1977; Mitsos, 1976), is now understood to consist of far more complex multivariate processes. Whilst sources of parental stress have, for a considerable time, been linked with variables such as behaviour problems, more and more research has indicated the complexity of the interactions between characteristics of the child and a diverse range of influences. A running theme through much of this review has been regularity with which behavioural problems has been present in relationships with other factors. It is this facet of the child that will be of key interest in the forthcoming research. The review has consistently demonstrated the importance of the impact, perception, severity and frequency of child behaviour problems on the parental experience of stress.

The model proposed at the beginning of this chapter now needs some revision. In the adjusted model below, a number of pathways have been identified as being bi-directional in nature, based on data from previous research. These are links between child stressors, namely behaviour problems, and parental stress. The link between parental resources and stress may be bi-directional. Stress and mental health have been found to share a bi-

directional causal relationship, as has the relationship between child stressors, such as behaviour problems and parental resources.

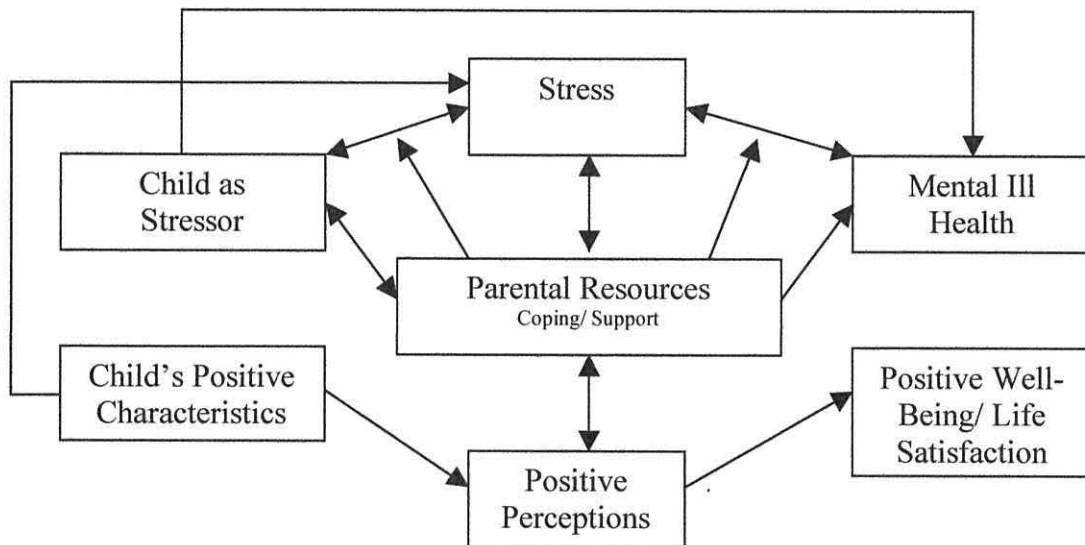


Figure 2.1 An Integrated Model of Stress and Coping in Parents of Children with Intellectual Disability

The research within the domain of stress and coping amongst parents of children with intellectual disabilities, taking into account all the areas identified on the conceptual model is somewhat limited. Furthermore, the research that is available is at times, not closely enough tied to current theory. To conclude, there appear to be a number of methodological and conceptual issues that remain relatively untested within the existing literature. The next chapter will discuss these issues in more detail, thus validating the need for the present research.

## Chapter 3

## Further Methodological and Conceptual Issues and Thesis Outline

3.1 Introduction

The preceding chapters have highlighted a number of areas that may benefit from further analysis. The following chapter aims to discuss these issues in some detail and begin to explain how the research presented in this thesis intends to address them. The first of these issues is that of the nature of longitudinal research and the relative benefits of this approach in comparison to other designs that may be utilised. Discussion of the wider issue of causality will also be presented. The issue of bi-directional relationships will then be addressed, discussing the notion of child effects and the relative paucity of research within the field of intellectual disabilities. Then, mediation and moderation as distinct and testable features of research will be addressed. The relative freedom with which these terms are used in previous research will be identified along with discussion of the importance of testing for these variables and the subsequent need to establish their significance with specific statistical techniques such as Sobel testing and bootstrapping. Next, the chapter will focus on the importance of a breadth of measurement with regard to child characteristics. Finally, the chapter reviews how systemic issues may influence the research presented in this thesis.

3.2 Longitudinal Research – Causality

The widely accepted statement “correlation does not imply causation” expresses the difficulty with which a researcher may confidently proclaim to have established cause and effect in a relationship of interest. In Chapter Two, it was identified that causation can only be demonstrated in the presence of at least three specific criteria: evidence of co-variation; evidence of non-spuriousness; evidence of temporal precedence. The issue of causality is such an important one, with significance to this research, that I now return to this concept.

In research methodology, the ‘gold standard’ for establishing causation is the ‘true’ experimental design, taking a large number of representatively sampled people, randomly dividing them into groups and manipulating the presentation of a key causal variable between the groups. This design may be further enhanced by the experiment being

double-blind, where neither the participants nor the researcher knows who belongs to the control group. However in clinical psychology, experimental research of this nature is often not considered ethical, for a variety of reasons, for example, people being denied access to a potentially helpful treatment, such as a control group not receiving a treatment. Whilst waiting list controls have been touted as a potential method of easing this ethical issue, within the field of intellectual disability, immediate intervention is often an effective method of reducing behaviour such as self-injury. In such a situation, a waiting list control would not be appropriate, as the participant's self-injury and damage would mean non-intervention is unacceptable. Therefore, researchers utilising non-experimental methodology must investigate other options to evaluate causality. It is commonly held that causality can be investigated if information over time is available. This relates to the causal criterion of temporal precedence. That is, causal variables are assumed to precede in time those outcomes they affect. This, along with evidence of association and non-spuriousness is provided through the application of a longitudinal design methodology. This is a research design where participants are assessed at more than one time point. Longitudinal studies can vary in design: repeated cross-sectional studies; prospective studies; and retrospective studies. Cross-sectional studies are commonly used in the social sciences for the collection of data for assessing the determinants of behaviour. Repeated cross-sectional studies collect data over two or more time points with a new sample on each occasion. An example of this type of research might be an investigation into the attitudes to intellectual disability. Data might have been collected at various time-points from the 1950's to the present day, naturally accessing a different sample of participants on each occasion. With a different sample interviewed at each time point, it is more difficult to ensure that they come from similar backgrounds, thus increasing the potential influence of confounding variables. In prospective studies, the same individuals are interviewed repeatedly across time. Variations of this design include representative panels, made up of a random sample of respondents and repeated data collections at fixed intervals and cohort panels, made up of a specific population who experience the same event within a given period of time. Retrospective studies such as Glidden and Schoolcraft (2003) employed a retrospective measurement to help them look longitudinally at depression in both birth mothers and adoptive mothers of children with intellectual disabilities. The mothers completed a semi-structured interview which included questions both about the present time and also a retrospective look at the time of either the diagnosis (birth mothers) or adoption (adoptive mothers). These were referred



to as Time 2 and Time 1 respectively. There are clearly some problems with this design that could potentially cause difficulties when assessing causality. The Time 1 data may not be accurate, either through recent events influencing the reports of the mothers, or memory recalling the time in a less accurate manner. Thus, it is difficult to determine whether the Time 1 data are an accurate representation of the events and emotions of that time. The classical prospective longitudinal design helps us with the criterion of temporal precedence. Taking multiple measurements of the same construct over time allows us to control for earlier measurements to see if the change in the independent variable occurs before the change in the dependent variable. This has benefits over other longitudinal designs. With repeated cross-sectional designs, you have the problem of sampling an equivalent population, whilst in retrospective designs, the concerns remain over the accuracy of the retrospectively collected data.

Despite the relatively large amount of research in the area of stress and intellectual disabilities, few studies have utilised a longitudinal methodology. In the previous chapter, seven were identified from the current literature (Baker et al, 2002; Baker et al., 2003; Lecavalier et al., (2006); Nihira et al., 1985; Orsmond et al., 2003; Hastings et al, 2006). Previous research has indicated that longitudinal designs naturally vary in the frequency of the data collection, depending upon other criteria in the design of the study. Within the field of stress in parents of children with intellectual disabilities, repeated measures have been performed over 12 months (e.g. Baker et al., 2003; Lecavalier et al., 2006), three years (Nihira et al., 1985) and six years (Orsmond et al., 2003). This shows a considerable variation. All approaches have their advantages and disadvantages, for example, a longitudinal study conducted over a period of 6 years allows data at multiple time points to be collected, potentially increasing the reliability of the measurement and offering greater choice in the nature of the longitudinal analysis to be carried out. A disadvantage of this approach is the length of time it takes to collect the data, both in terms of personnel but also finance. Furthermore, high rates of participant attrition might be recorded due to the involvement it requires and the likelihood of life events precipitating a withdrawal from the study. In contrast, a data collection period of 12 months enables that vital element of measurement at two distinct time points to be included, yet it is possible to complete within an acceptable amount of time for the constraints of many research projects. A disadvantage of such an approach might be that the length of time is not sufficient for significant change to be observed.



All these longitudinal studies have investigated the relationship between child behaviour problems and parental stress. However, the model proposed and refined in Chapter 2 is suggestive of a causal relationship between other variables apart from behaviour problems and parental stress. There is a significant lack of longitudinal research that supports a causal relationship between other variables in the working model. An exception to this is the Hastings et al., (2005) study (See Chapter 2 for a review of the research). This study found maternal depression to be temporally related to maternal stress over and above the effect of the child's behaviour problems. Exploratory analyses also found evidence of a bi-directional relationship, with maternal stress independently predictive of maternal depression over time. Unfortunately, few other studies have explored these relationships. Gowen, Johnson-Martin, Goldman and Appelbaum (1989) used a longitudinal methodology in a group of children with disabilities (including children with Down syndrome and cerebral palsy) and typically developing children and their mothers. They found that maternal depression was significantly predicted by child variables including level of functioning and care-giving difficulty at 27 months of age. No support was found for a prediction of maternal depression from measures of the mother's support system at any of the child age assessment points. There was also no support found for predicting feelings of parenting competence from child variables at any of the child age assessment points.

Thus, it appears there is a paucity of research applying longitudinal methods to investigate other relationships between variables posited in the proposed model. As has already been established, the longitudinal design is a robust method of examining temporal relationships between variables and therefore this is a valid avenue of research. The current research intends to use this methodology to explore the hypothesised relationships between such variables as child characteristics and the use of parental resources, child characteristics and stress, and stress and mental ill health.

### 3.3 Bi-Directional Relationships

The existing research that has influenced the models reviewed in Chapter 1 has generally assumed one causal direction. Hence the model proposed at the end of Chapter 1 assumed a single direction. However, data reviewed in Chapter 2 led to a refinement of the proposed model and the addition of some bi-directional relationships amongst the variables.

Research into typical social development has often assumed a parent-child direction of influence but research (Bell, 1968) has shown that child characteristics also affect parenting behaviour, including such variables as child gender and child temperament. Research in the field of intellectual disabilities perhaps seem a little naïve in this respect, and this discussion now turns to the research that has found a bi-directional relationship between variables of interest to this research.

The most well-established bi-directional relationship within the proposed model lies between child behaviour problems and parental stress. In the previous chapter, research was presented that supported this (Baker et al., 2002; Baker et al., 2003; Lecavalier et al., In press; Nihera et al., 1985; Orsmond et al., 2003; Hastings et al., 2005). Whilst the results of longitudinal research support the hypothesis that child behaviour problems instigate changes in parental well-being, the suggestion is that parental well-being affects child behaviour problems. Given the consistent finding, over many years of research, that children with intellectual disabilities are at an increased risk of behavioural and psychological problems (e.g. Baker et al. 2002; Dekker & Koot, 2003; Rutter, Graham & Yule, 1970) and the fact that parents of children with disabilities report more stress and mental health problems, there emerges the possibility that the increased risk of behavioural and psychological difficulties in children may be in part driven by family variables.

So, there is evidence that child behaviour problems and stress share a bi-directional relationship, explored with longitudinal methods of evaluating causality. Given that there has been a lack of systematic application of longitudinal methods to other relationships posited in the proposed model, it is feasible that other bi-directional relationships may exist. Therefore, relationships from the proposed model can now be considered and the likelihood of their existence within a bi-directional relationship discussed. Within the model, a bi-directional relationship is posited between the variables of stress and mental ill health. As previously discussed in Chapter 2, stress and mental ill health have long been used interchangeably in research, with few studies looking at these domains individually. A study was identified by Hasting et al. (2005) that found a bi-directional relationship between stress and depression, whilst controlling for the effects of child behaviour problems. Given that a similar longitudinal design is employed in the current research, it is likely that a similar result will be observed. Another bi-directional

relationship has been hypothesised between the variables of parental resources and stress. Previous research (See Chapter 2 for a full discussion) has found parents perception of their social support (e.g. Bristol, 1979; Quine & Pahl, 1985) can have an impact on their stress ratings. However, it is feasible that stress may indirectly influence the type and levels of social support received. For example, increased stress may cause the parent to act differently around potential support, for example, a parent may resent a friend who has a typically developing child, thus reducing her potential support. There may also be a bi-directional relationship between social support and mental ill health. Similarly to the relationship between stress and social support, mental ill health constructs of anxiety and depression may impact social support. For example, anxiety might mean that the parent lacked the confidence to access socially supportive situations and depression might serve to reduce the motivation and energy that maintaining a relationship with social support might entail. These examples are all logical possibilities for relationships within this design using these variables.

### 3.4 The Moderator-Mediator Distinction

Throughout the review of the literature in Chapter 2, it became increasingly clear that many variables are posited at some point or another to moderate or mediate relationships within the proposed model. The following discussion examines the issue of mediating and moderating variables and their role in the current research.

Although the terms mediator and moderator are often used interchangeably in the literature, the two terms are distinct from one another, both in concept and statistically (Baron & Kenny, 1986). A moderator variable may be qualitative (e.g., gender) or quantitative (e.g., level of reward) and affects the direction and/or strength of the relation between independent and dependent variables. A moderator effect is also said to have occurred within a correlational framework if the direction of the correlation changes. In contrast, a mediator variable is tested using a path-analytic model and it will account (fully or partially) for the relation between a dependent and an independent variable. As Baron and Kenny (1986, p. 1176) note “Mediators explain how external physical events take on internal psychological significance”. Thus, stated simply, moderating variables specify when effects will occur and mediators explain how or why effects occur.

An example of mediation may be the effect of the child's behaviour problems on the stress levels of the parent being mediated by social support. High levels of behaviour problems may reduce social support, which then increase the stress of the parent. Thus, the mechanism by which child behaviour problems impacts on stress levels is explained. However, this relationship may also be moderated rather than mediated. For example, low parental stress may be expected when behaviour problems are low regardless of the level of social support, whereas high levels of behaviour problems may have an effect of parental stress when coupled with low versus high levels of social support. So, are these concepts investigated in research? Baron and Kenny (1986) identify that a moderator variable may be understood through the use of a path diagram.

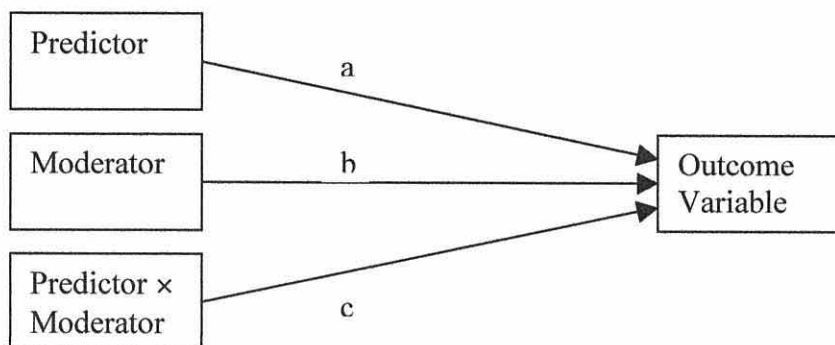


Figure 3.1 Moderator Model (Based on Baron & Kenny, 1986)

The model illustrated has three causal paths that feed into an outcome variable. Hastings and Johnson (2001) provide an example of testing a model of moderation in their research into stress in families on home-based intervention programmes for children with autism. They hypothesised that coping resources and social support would moderate the effects of autism on parental stress. So, parents with poor coping resources would be most likely to be negatively affected by their child's behaviour and other symptoms. In order to examine the presence of moderator effects, regression analyses were used to explore the unique variance accounted for by the product terms representing the interactions between independent variables and potential moderator variables. To obtain the product terms z-scores are calculated. Hastings and Johnson used simple regression analysis and entered both the main effects and interaction effects simultaneously. A moderated relationship was found where positive beliefs in the efficacy of a Lovaas intervention tended to reduce reports of pessimism, especially when autism symptomatology was high. So, to look at these variables in terms of their fit in the moderator model outlined above, Path A refers to the predictor variable, in this example, autism symptomatology. Path B refers to the

perceived efficacy of the Lovaas intervention and Path C relates to the interaction calculated between the two. This interaction is the product of the predictor variable and the moderating variable. Main effects may well be observed for the predictor and moderator, however these are not relevant to the testing of the moderator model, except by way of statistical control. Furthermore, the moderator will ideally be uncorrelated with predictor and the dependent variable to provide a clear interaction. Figure 3.2 shows these variables in a moderator model diagram.

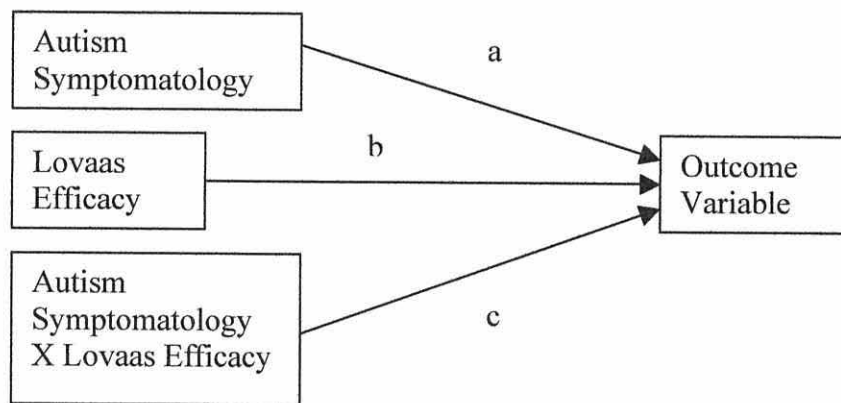


Figure 3.2 Moderator Model of Data from Hastings and Johnson (2001)

The path diagram approach may also be used to understand mediating variables, as part of a causal chain.

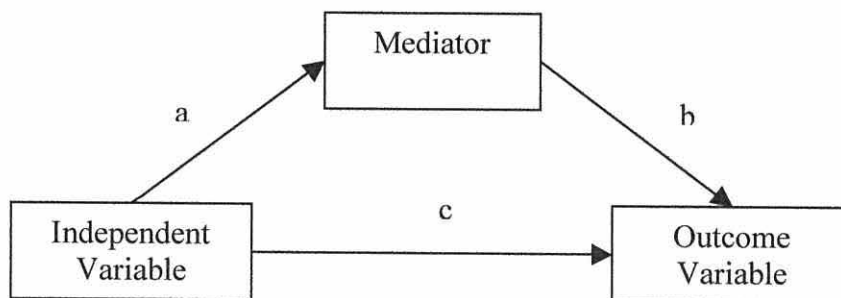


Figure 3.3 Mediator Model (Based on Baron and Kenny, 1986)

The mediator model includes three variables composed of two causal paths leading into the outcome variable. The independent variable may have a direct impact on the outcome variable, depicted by Path c. The impact of the mediator may also directly impact through Path b. The independent variable is linked to the mediator through Path a. A variable may act as a mediator when three conditions are met. First, variations in the levels of the

independent variable can significantly account for the variations in the mediator. Second, variations in the mediator significantly account for variations in the dependent variable. Third, when these are controlled (i.e. both Paths a and b), a previously significant relation between the independent and dependent variables is no longer significant. If the correlation of Path c is reduced to zero, one can assume strong evidence for a mediator variable. If the correlation of Path c is not at zero but is reduced, then the suggestion may be that partial mediation is in action. To test a mediation model, one may use an ANOVA as an indicator of mediational influences. However, the most thorough test of mediation utilises regression models. Three equations need to be provided. First, the regression of the mediator onto the independent variable. Second, regress the dependent variable onto the independent variable and third, regress the dependent variable and the independent variable onto the mediator. From these equations three conditions must hold: 1; the independent variable must significantly predict the mediator in the first equation; 2. In the second equation the independent variable must significantly predict the dependent variable; 3, in the third and final equation, the mediator must significantly predict the dependent variable. If there is full mediation, the independent variable will have no effect when the mediator is controlled. In partial mediation, there will be a decrease in the beta weight of the independent variable. If these steps are met, then the data are consistent with the hypothesis that either full or partial mediation is present within the model. However, before the mediation can be reported, the significance of the indirect effect of the independent variable on the dependent variable via the mediator variable needs to be calculated. The most commonly used test of this is the Sobel Test (Sobel, 1982). The test of the indirect effect is given by dividing ab by the following equation:

$$\sqrt{b^2 s_a^2 + a^2 s_b^2 + s_a^2 s_b^2}$$

Where a and b represent the unstandardised regression coefficients (B) for Paths a and b respectively and  $s_a$  and  $s_b$  represent the standard errors of these regression coefficient. MacKinnon, Lockwood, Hoffman, West and Sheets (2002) compared 14 methods of assessing mediation effects, recommending the Sobel test as superior in terms of power and intuitive appeal. Bootstrapping is another method of assessing the indirect effect. Bootstrapping is a non-parametric approach and may be used with smaller samples with



confidence. Providing the data are normally distributed, the Sobel statistic will be used in the present research.

Hastings and Brown (2002) looked at 26 mothers and 20 fathers of children with intellectual disabilities and their reports of self-efficacy, anxiety and depression. In order to explore evidence for self-efficacy as a mediator of child behaviour problems and anxiety and depression in parents, a hierarchical regression analysis was used. In the first step, a measure of the child's behaviour problems was entered as the independent (predictor) variable. In the second step, parental self-efficacy scores were entered as the mediator variable. Self-efficacy was identified as a mediator in the relationship between problem behaviour exhibited by the children and mothers' reports of their anxiety levels. Thus, mothers are more anxious because child behaviour problems reduce their self-efficacy. This research both supports previous research identifying self-efficacy as an important variable in the link between certain child variables and the parents' mental health outcomes. However, it is important to urge caution here, the temptation being to assume that path models show causality. This study still used cross-sectional data and thus cannot be interpreted to imply causality. Therefore, it is important to extend the use of appropriate use of mediation and moderation to longitudinal designs. To my knowledge, this has yet to be done within the field of intellectual disability and the family.

Whilst this review has identified examples of research with both mediation and moderation models appropriately explored, this type of research does appear to be in a minority. As can be seen from the review of literature in Chapter 2, existing research has typically been explored in terms of main effect relationships. However, given the mounting support that suggests a complex interaction of numerous variables, a research design that will attempt to account for any potential mediating or moderating relationships is necessary. A third possibility is that factors such as social support may act as protective factors (c.f., Rutter, 1985), which function as a type of moderating variable. In this situation, in conditions of increased risk, such as more severe or frequent behaviour problems exhibited by the child, the parent with higher levels of social support will have fewer adjustment problems than parents with lower levels of social support. In conditions of lower risk, when the child's behaviour problems are less frequent and severe, social support has no effect on parental adjustment. Researchers have also



suggested that compensatory factors may have an effect, but not in situations where the risk becomes too high (Garmezy, Masten, Tellegen, 1984).

### 3.5 Measurement of Child Variables

Chapter 2 saw the establishment of child characteristics and particularly child behaviour problems as key elements in the proposed model. However, it is important that the current research includes a broad measurement of child characteristics. The areas that require measurement would be an assessment of behaviour problems, adaptive behaviour, pro-social behaviour and any co-morbid mental health problems the child may suffer from. Typically, these multiple dimensions of child characteristics have not been addressed together (a notable exception being Hastings et al., 2005). Including measures of all these constructs in the research enables a comprehensive model to be assessed using more 'classical' measures of the child, such as behaviour problems and adaptive behaviour measure and more recent domains of research interest such as child psychopathology and pro-social behaviour.

In terms of adaptive behaviour the evidence has been mixed regarding the impact on parental stress (See Chapter 2 for a discussion). A child's relative ability in one area, for example communication, may serve to aid the parent in coping. Conversely, further disabilities, for example being confined to a wheelchair, may serve to increase the care demand made on a parent, thus leading to further stress. Dual-diagnosis is the term used to describe the co-morbid existence of intellectual disabilities and mental health problems or psychopathology. Many children who have a dual diagnosis go untreated due to the increased complexity of offering a diagnosis of psychopathology when the child has a severe intellectual disability. With the development of measures specifically designed to assess dual diagnosis in children and adults (e.g. Reiss & Valenti-Hein, 1994), a valid and reliable instrument now exists to understand to impact of mental health problems on children with intellectual disability more easily. Psychopathology (e.g. depression, paranoia, thought disorder) may be one of several potential causes of behaviour problems in children with intellectual disabilities. Therefore, the ability to delineate the causes of behaviour problems through the application of a dual diagnosis tool is important to any research which purports to further understand relationships associated with child behaviour. Maes, Broekman, Dosen and Nauts (2003) used the Reiss Screen and the Reiss Scales with 66 children and adults with intellectual disability. They found that dual

diagnosis has a more negative impact on the family situation than intellectual disability alone. Finally, measurement of pro-social behaviour is a construct of increasing interest in current research. Beck, Hastings, Daley and Stevenson (2004) took a sample of 74 mothers of children with intellectual disability. They used the pro-social measure from the Nisonger Child Behaviour Rating Form. They found that pro-social behaviour was a negative predictor of maternal stress.

Many previous studies have examined just one child dimension in their work. Baker et al. (2003) used the Child Behavior Checklist as a measure of child variables in their study of 205 pre-school children. Hodapp, Dykend and Masino (1997) again used the Child Behavior Checklist in their study of 42 families of children with Prader-Willi syndrome. Boyce et al. (1991) used the Battelle Developmental Inventory to assess adaptive, social and communicative behaviour in their study of stress in families of children with disabilities. More recently dimensions of child psychopathology and pro-social behaviour have begun to attract increasing interest from the intellectual disability research community. As discussed, Reiss and Valenti-Hein (1994) have developed an instrument for dual diagnosis of children with intellectual disabilities. This was used by Maes et al (2003) but again, this was not used in conjunction with other measures of the child. In terms of pro-social behaviour Lecavalier et al. (2006) used measures of adaptive behaviour, behaviour problems and pro-social behaviour. This study appears to be somewhat exceptional in the fact that it measures three different dimensions of the child. However, a literature search confirms that such studies are few and far between. Furthermore, it appears that no study has measured adaptive behaviour, behaviour problems, child psychopathology and pro-social behaviour. This exploration of the full range of psychological functioning will be used in the current research to more explicitly examine child-parent stress relationships, using a longitudinal design in order to evaluate causality.

### 3.6 A Focus on the Mother-Child Dyad

The majority of the research in the area of stress in parents of children with intellectual disabilities has focused on the mother-child dyad. Far less work has investigated fathers, siblings and grandparents, and little if any work has looked at these variables together. As previously mentioned, it has been asserted that mothers and fathers are differentially

affected by the experience of raising a child with a disability (e.g. Goldberg et al., 1986; Sloper et al., 1991)(For a more comprehensive review of this issue, see Chapter 2).

Given that mothers and fathers appear to be affected differently by the experience of caring for their child with an intellectual disability, the present work intends to examine, wherever possible, both mother and father variables and the parent's individual perception of the child variables, such as the child's behaviour problems. Taking the example of child behaviour, researchers generally rely on the participants' opinions, typically through the medium of questionnaire measures and checklists. This opinion has generally been sought from the mother, presumably for reasons including ease of collection (mothers typically spend more time at home with the children than fathers) and higher levels of stress and depression expressed by mothers than fathers (e.g. Goldberg et al., 1986). Criticisms of this approach have been forthcoming, as it is understood that fathers form different relationships with their children and have different opportunities in which to observe them, thus possibly altering the way they may interpret some behaviours (Phares, 1996). Goldberg, Marcovitch, MacGregor and Lojkasek (1986) reported fewer distress symptoms in fathers than mothers in research into stress in families with a child with disabilities. Sloper et al., (1991) specifically included a sample of fathers as well as mothers in an attempt to further understand the differential effects on gender on response. For mothers, child behaviour problems, excitability and self-sufficiency were strongly related to outcome. Their coping strategies, family relationships and socio-economic status were also significantly related. Conversely, for fathers, no child characteristics were related to outcomes, but marital factors and extra-familial factors were. Other studies (Beckman, 1991; Krauss, 1993; Smith, Innocenti, Boyce & Smith, 1993) found that mothers of children with disabilities found challenges associated with daily childcare were related to health problems, feelings of restriction in their role, depression and lack of support from their spouse. The fact that it is mothers who generally carry the brunt of the child-caring responsibility in both families with typically developing and developmentally disabled children (e.g. Heller et al., 1997; Young & Roopnarine, 1994) may be linked with the reduction in fathers' perceptions of parenting difficulties (Gavidia-Payne & Stoneman, 1997). Hastings (2003), in a study with 18 married couples with children with autism, found mothers reported more anxiety than fathers and that maternal stress was associated with child behaviour problems and paternal mental health symptoms. No such results were found with the father sample. It is

feasible that mothers and fathers have some views in common with one another and some that are formed independently, that may differ. Thus, it is appropriate to aim to sample both of these views, in order to obtain the most accurate assessment of the situation.

### 3.7 Ethical Considerations

Both the proposed longitudinal study and the observation research have a number of potential ethical concerns that seems appropriate to discuss. The main longitudinal data collection went through two forms of ethical approval. First, as the overall research project was funded by The Health Foundation, the proposed longitudinal research had to be approved by their ethics committee prior to funding being granted. Secondly, both longitudinal research and the observation study had separate ethics applications tended. This were assessed by the School of Psychology Ethics Board and found to be ethically appropriate.

Of the aspects of the design that merit discussion, a number stand out. Informed consent is a consistently important aspect of research with all participants but perhaps particularly when people with intellectual disabilities are involved. In the proposed research, it is the parents of children with intellectual disabilities that are completing questionnaires and providing responses. However, it is still important for these parents to understand why the research is being done, what is being asked of them, their rights as participants and the extent of the involvement. All prospective participating families will be sent an information sheet that describes the nature of the research and the reasons they have been asked to participate. This sheet also provides contact details of the researchers for the potential participants to use, should they require further information or clarification of any point. The information makes a point of informing the potential participants that whether they choose to become involved in the research will in no way affect the care they receive from either health authorities or Social Services. Furthermore, potential participants are informed that they are free to end their participation in the research at any time and for any reason. A website has also been designed, in order to supply parents with another medium through which they can learn about the project, the researchers involved in the work and further opportunities to ask any unanswered questions. It is hoped that these measures ensure that informed consent is a priority in the research design. Linked to the participation of families, is the issue of payment. The decision was taken to offer payment to families who agreed to participate. This is done to maximise the

response rate of the research, given that postal participation is a difficult method of recruitment for research. A sum of money is offered to mothers and fathers who participate. If they participate in the follow-up, approximately one year later, they are offered a second payment. Again, the information sheet explains that this payment is offered as recompense for the inconvenience of completing the postal questionnaires and telephone interview. The information sheet also clearly explains that families are under no obligation to accept this money and that should they withdraw at any time, this sum would still be available to them to collect. Thus, it is hoped that participants understand the reasons that the fee is offered, they can withdraw from the study at any point and they will still be offered the payment and that finally they do not have to accept the money should they not want to and that their decision of whether or not to accept the money does not impact their access to services.

A central aspect to the design is the battery of postal questionnaires the participant has to complete and return to the researchers. Whilst it is thought unlikely that any of the measures will cause upset, people experience distress in many otherwise neutral situations. The act of reflecting on their life and how it has been affected due to having a child with an intellectual disability may serve to upset some participants. The information sheet clearly indicates that participants are free to withdraw from the research at any time, and this obviously includes occasions where they feel that the questions have caused offence or feelings of distress. Furthermore, participants are free to contact the research team or the head of school in any situation in which they feel they have been caused unnecessary harm. Due to the design of the research, all participants are contacted by telephone approximately 2 weeks after the completion and return of their questionnaire packs. This is to administer the final part of the data collection, the adaptive child behaviour measure. This telephone call is made at a time selected by the participant and serves a secondary function of the researchers being able to check with the participant about how they found the completion of the questionnaires and to provide an opportunity for the parents to talk through any part of the questionnaires that they did not understand or had found difficult to complete.

The second part of the research utilises an observation design to collect on mother/child dyads in their home environment. After the second data collection for the main study, which occurs approximately one year the data collection discussed above, participating



families whose child had an adaptive behaviour quotient over four are telephoned to ask whether they would be interested in taking part in an observational study. The researcher explains that the main data collection is now finished and thanks them for their help. The researcher will then explain that they are looking for families who would be happy to be visited in person and to be videoed playing some games with their child. Once again, it is made clear that if they are not happy about this they can simply say no and that this decision will have no impact on anything else. If they are happy, then a full information pack will be sent to the participant to read through. Again, participants are told that they are free to stop at any time, including when the researchers are at the house, if they are not happy. Two researchers will visit, one male and one female, both of whom have enhanced disclosure from the Criminal Records Board. With regard to confidentiality, this is explained to participants. Data will be kept in a locked filing cabinet without the participants' names attached. Participants are also told that all the results gathered will describe overall findings and not information about individual families and that no video material will be shown to anyone outside of the project team, and will only be used for the purposes of our research.

To ensure that participants are kept up to date with what is being done with the information they provide, newsletters will be sent to all participating families describing the progress of the work and the outcomes once they are found. Again, the contact details for the researchers are provided so if any participant has a question about wither the research or how their data is being used, they can ask. On a similar note, should any participant decide that they do not want their data to be used, even after its collection, they can request its removal from the database. This has no implications for the fee or their access to services.

### 3.8 Conclusions, Objectives and Outline of Thesis

Chapter 3 has provided further discussion of methodological and conceptual issues arising from the introduction and literature review. The main areas for a more detailed inquiry were those of longitudinal research and its place within research methodologies. The issue of bi-directionality, associated with longitudinal designs was then presented. This was followed by a conceptual analysis of mediation and moderation with examples from the intellectual disability literature presented. The chapter was concluded by an exploration of the issues of measurement of child characteristics and the significance of

including both parents in intellectual disability family research. The remainder of this section will focus on presenting some research questions and positing some potential outcomes of the research. Finally, the structure of the remainder of the thesis will be described.

A number of research aims can now be presented. This thesis focuses on child behaviour given the established relationship between it and parental stress in the extant literature. Thus the first research question is whether the data are supportive of a relationship between child behaviour problems and increased parental stress. This thesis also takes account of any possible dual diagnosis in the child, and thus it is hypothesised that increased child psychopathology is positively correlated with parental stress. Accordingly, we might also expect to observe a negative correlation between child pro-social behaviour and parental stress. In addition, given previous research has found bi-directionality between child behaviour problems and parental stress, it is hypothesised that the longitudinal data will show that a transactional relationship exists between these variables.

Given the close association between parental stress and mental health that is implicit in the current literature, it is hypothesised that parental stress and measures of parental mental health will have a bi-directional positive relationship. The positive characteristics of the child such as pro-social behaviour are hypothesised to positively correlate with positive perceptions of the parent. Furthermore, parental positive perceptions are likely to be correlated with measures of positive well-being and life satisfaction.

Parental coping and support will be analysed as possible mediators or moderators of the relationships between other main study variables. In addition, the other variables in the middle layer (stress and positive perceptions) of the model will be analysed to see if they act as mediators or moderators between other variables. Given the lack of attention given to these processes in previous research, it is difficult to make specific predictions regarding expected findings. Thus, exploratory analyses will be employed to investigate potential mediation and moderation.

A further aim of the present research is to attempt to gather a more independent rating of child behaviour and thus direct in-home observations are to be collected. Two broad aims



can be identified for this aspect of the research. First, to explore potential associations between ratings of child behaviour gathered through observations and the ratings of child behaviour collected in the main study. Second, to analyse the relationships between the child and parent variables collected in the main study and data regarding both positive and negative parenting behaviours.

Finally, the present research will seek to collect, wherever possible, both mother and father variables. These data will be analysed separately and then the individual experiences of mothers and fathers compared and contrasted. We would expect to replicate findings such as mothers experiencing higher levels of stress and depression than fathers and differential use of coping strategies.

Finally, the organisation of this thesis is presented. The preceding two chapters have established that traditionally research has focused on the detrimental effects of having a child with an intellectual disability and its impact of the stress of the family and individuals within that family. The review of the literature identified that both negative and positive experiences are reported by many families, but the factors that affect this and the complexity of the relationships between them are less well explored. This thesis presents two pieces of research. The first is a major 12-month longitudinal study featuring data collected at two time points. The second is an observational study collected after completion of the second period of data collection for the first study. Chapter 4 describes the methodology adopted for the first study, with reviews of the measures used along with the pertinent reliability data. Chapter 5 provides analysis of the demographic data and an initial check of correlations between the variables to establish what to take forward to the next stage of analysis. Chapter 6 presents the cross-sectional data analysis using data collected at the first time point and focusing on the relationships in the working model presented at the end of Chapter 2. Chapter 7 presents the analysis and results from the longitudinal element of the research, integrating the data from the first and second time point. Chapter 8 features as a self-contained chapter focusing on the observational research study. Thus, an introduction, methodology, results and brief discussion are included. Finally, Chapter 9 functions as a general discussion of the thesis, addressing the results obtained and providing thoughts on clinical implications, limitations of the research and future directions of research within the area.

## Chapter 4

## Method

4.1 Introduction

This chapter introduces the methodology used for the first study. Given the nature of the methodology by way of inclusion of the perspectives of both mothers and fathers, the chapter opens with a presentation of the demographic data of the participating families. This includes information on mothers, fathers and the child with intellectual disability who was targeted by this research. Each measure used in the first study is introduced. For each measure, a similar structure is used to describe its background, content, and psychometric properties. The measure is introduced which includes information on the scale's development and history. The items are then described, how they are rated, what, if any, subscales exist and how these are comprised and how the item scores are combined to provide subscale and total scores (where applicable). Then the use of the measure in other intellectual disability research is summarised and any available psychometric data given. Finally, the psychometric properties of each measure from the present study are provided. Cronbach's Alpha is provided for internal consistency data and for measures of the child, inter-rater agreements are supplied.

4.2 Participating Families

The information presented in Table 4.1 relates to the demographic information collected about the participating families. Due to reliability concerns, the questionnaires were only available in English. As we did not correspond with people in Welsh, we did not collect data on the percentage of Welsh speakers taking part in the study.

Table 4.1

*Demographic Information on Participating Families*

| Variables  | <i>n</i>    | Percentage (%) |
|--|-------------|----------------|
| Living Arrangements  |             |                |
| Child with ID living at home                                 | 137         | 97.9%          |
| Child with ID living with other parent                       | 1           |                |
| Child with ID at residential school and at home for holidays | 1           |                |
| Availability of Respite Care                                 |             |                |
| Respite care available                                       | 68          | 48.6%          |
| Use it   | 47          | 69.1%          |
| Do not use it  | 21          | 30.9%          |
| No respite care available                                    | 72          | 51.4%          |
| Family Income  |             |                |
| No response  | 35          |                |
| <£15000  | 30          | 28%            |
| £16000 – 25000   | 29          | 27.1%          |
| £26000 – 35000   | 24          | 22.4%          |
| £36000 – 50000   | 16          | 15%            |
| £51000 – 75000   | 7           | 6.5%           |
| >£75000  | 1           | 0.9%           |
|  | Mean (SD)   | Range          |
| Number of Adults in Household                                | 1.89 (0.56) | 1 – 3          |
| Number of Children in Household                              | 2.23 (0.94) | 1 – 5          |

4.2.1 Participating Children

The information presented in Table 4.2 relates to the demographic information collected about the children with intellectual disabilities whose parents participated in the research. The research did not assess for intellectual disability, but relied on parental report to ascertain the child's condition. Furthermore, given that we used special schools to recruit participants, an assumption was made that any child involved in the research would have a statement of need with the school, thus ensuring that only children with intellectual disability were recruited.

Table 4.2

*Demographic Information on Participating Children*

| Variable                             | <i>n</i>      | Percentage (%) |
|--------------------------------------|---------------|----------------|
| Gender                               |               |                |
| Male                                 | 92            | 65.7%          |
| Female                               | 48            | 34.3%          |
| Nature of Disability                 |               |                |
| Intellectual Disabilities            | 47            | 33.6%          |
| Autism                               | 56            | 40%            |
| Cerebral Palsy                       | 12            | 8.6%           |
| Down Syndrome                        | 22            | 15.7%          |
| Unspecified                          | 1             |                |
| Autism & Down Syndrome               | 2             |                |
| Presence of Sensory Problems         |               |                |
| Yes                                  | 31            | 22.1%          |
| Hearing                              | 7             | 5%             |
| Vision                               | 13            | 9.3%           |
| Both                                 | 11            | 7.9%           |
| No                                   | 109           | 77.9%          |
| Presence of Epilepsy                 |               |                |
| Suffering from epilepsy              | 17            | 12.1%          |
| Not suffering from epilepsy          | 123           | 87.9%          |
| Presence of Mobility Problems        |               |                |
| Suffering from mobility problems     | 39            | 27.9%          |
| Not suffering from mobility problems | 101           | 72.1%          |
| Presence of other Health Problems    |               |                |
| Other health problems                | 46            | 27.9%          |
| No other health problems             | 94            | 67.1%          |
| Adaptive behaviour (Composite Score) |               |                |
| Adequate for age                     | 7             | 5.1%           |
| Mild deficits for age                | 16            | 11.7%          |
| Moderate deficits for age            | 43            | 31.4%          |
| Severe deficits for age              | 52            | 38%            |
| Profound deficits for age            | 19            | 13.9%          |
|                                      | Mean (SD)     | Range          |
| Age of child with ID                 | 10.59 (4.07)  | 3.58 – 17.95   |
| Adaptive behaviour composite score   | 41.49 (16.79) | 19 – 113       |

4.2.2 Participating Mothers

The information presented in Table 4.3 relates to the demographic data collected about the mothers taking part in the research. With regard to the information in the table regarding Life Events, mothers were asked about the number of life events they had experienced in the preceding six-month period. Life events were dichotomised into ‘three

or fewer events experienced' and 'more than three events experienced'. This process of dichotomisation is described in greater detail in Section 4.2.17.

Table 4.3

*Demographic Information on Participating Mothers*

| Variable  | <i>n</i>     | Percentage (%) |
|---|--------------|----------------|
| Mother Marital Status                                   |              |                |
| Mothers who were married                                | 88           | 63.8%          |
| Mothers who were living with a partner                  | 18           | 13%            |
| Mothers who were divorced and not living with a partner | 32           | 23.2%          |
| Mother Educational Level                                |              |                |
| No formal educational qualifications                    | 21           | 15.2%          |
| GCSE level education                                    | 49           | 35.5%          |
| A-level education                                       | 14           | 10.2%          |
| HND level education                                     | 24           | 17.4%          |
| Degree level education                                  | 28           | 20.3%          |
| Masters level education                                 | 2            | 1.4%           |
| Mother Occupational Status                              |              |                |
| Job outside the home                                    | 66           | 47.8%          |
| Full-time   | 17           | 12.3%          |
| Part-time   | 49           | 35.5%          |
| No job outside the home                                 | 72           | 52.2%          |
| Mother's Relationship to Child with ID                  |              |                |
| Biological mother                                       | 130          | 94.2%          |
| Stepmother  | 1            | 0.8%           |
| Adoptive mother   | 5            | 3.6%           |
| Foster mother   | 2            | 1.4%           |
|   | Mean (SD)    | Range          |
| Age of mother   | 39.50 (7.24) | 23 – 57        |

4.2.3 Participating Fathers

The information presented in Table 4.4 relates to the demographic data collected about the sample of fathers who participated in the research.

Table 4.4

*Demographic Information for Participating Fathers*

| Variable  | <i>n</i>     | Percentage |
|---|--------------|------------|
| Father Marital Status   |              |            |
| Fathers who were married  | 53           | 88.3%      |
| Fathers who were living with a partner  | 6            | 10%        |
| Fathers who were divorced and not living with a partner                       | 1            | 1.7%       |
| Was the father from a family where the mother also participated in the study? |              |            |
| Yes   | 58           | 96.7%      |
| No  | 2            | 3.3%       |
| Father Educational Level  |              |            |
| No formal educational qualifications  | 7            | 11.7%      |
| GCSE level education  | 16           | 26.6%      |
| A-level education   | 12           | 20%        |
| HND level education   | 7            | 11.7%      |
| Degree level education  | 12           | 20%        |
| Masters level education   | 6            | 10%        |
| Father Occupational Status  |              |            |
| Job outside the home  | 50           | 83.3%      |
| Full-time   | 45           | 75%        |
| Part-time   | 5            | 8.3%       |
| No job outside the home   | 10           | 16.7%      |
| Father's Relationship to Child with ID  |              |            |
| Biological father   | 55           | 91.6%      |
| Adoptive father   | 4            | 6.7%       |
| Foster father   | 1            | 1.7%       |
|   | Mean (SD)    | Range      |
| Age of father   | 42.08 (6.98) | 23 – 54    |

#### 4.3 Measures

In the forthcoming section, the instruments measuring various aspects of the child are presented first, followed by those that measure parental responses. In addition, data were collected on demographic data. This demographic questionnaire was included in the questionnaire booklet that was sent to parents who had consented to take part in the study. Either parent was able to complete it. The data obtained from this section of the questionnaire are presented in the preceding Participants section (Section 4.2) and the measure of life events is described at the end of this section. Psychometric properties of the measures included in this study are reported, where relevant, using data from Phase 1 of the data collection.

#### 4.4 Child Measures - Introduction

The following section provides information on the measures included in the research to obtain data on various aspects of the functioning of a child with an intellectual disability within a family. The domains assessed were child behaviour problems, child mental health symptoms, child pro-social functioning, and child adaptive behaviour. The four measures assessing these domains will be described in turn.

##### 4.4.1 Behavior Problems Inventory (BPI)

To establish the frequency and severity of any behavioural problems the child exhibited, the BPI was selected (Appendix A). The BPI is a narrow-band assessment tool for the rating of problem behaviours in people with intellectual disabilities, specifically challenging behaviours. In contrast, broad-band assessment instruments, such as the Aberrant Behaviour Checklist (ABC; Aman, Singh, Stewart & Field, 1985), are designed to capture a broad spectrum of psychopathology. Whilst their advantage lies in their usage as a screening tool, their disadvantage is the restriction of number of items for each topography of behaviour, thus increasing the potential for a subscale to be unreliable. The BPI was designed for a number of different functions including assessing people at risk for challenging behaviour, and as a treatment outcome measure.

The BPI has been developed over the previous two decades. Originally produced in German at the beginning of the 1980s (Edlinger, 1983, as cited in Rojahn, 1984), it was designed as a specialized assessment instrument for microanalyses of self-injuring and stereotypic behaviour. Most recently it has been modified by the addition of the independently developed “Stereotyped Behaviour Scale”, which replaced the five original stereotypic behaviour items (Rojahn, Matlock & Tasse, 2000).

The BPI contains 14 self-injurious behaviour items (e.g., “Self-biting”), 24 stereotypic items (e.g., “Waving or shaking arms”) and 11 aggressive /destructive behaviour items (e.g., “Hitting others”). In addition, each sub-scale had a generic item (e.g., “Other”) where additional behaviours could be listed and rated. To be scored, behaviours must have occurred at some time in the preceding two months. Items are scored on two scales, a five-point frequency scale (never = 0, monthly = 1, weekly = 2, daily = 3, hourly = 4) and a four-point severity scale (no problem = 0, a slight problem = 1, a moderate problem = 2, a severe problem = 3). If the behaviour did not meet criteria, “never” is checked by



the respondent. In addition to the short topographic descriptions that accompany each of the items, each of the three groups of behavioural problems has a generic definition prior to the items within that scale. According to the definitions provided for respondents, “self-injurious behaviours (SIB) causes damage to the person’s own body; i.e., damage has either already occurred, or it must be expected if the behaviour remained untreated. SIB occurs repeatedly in the same way over and over again, and they are characteristic for that person”. “Stereotyped behaviours look unusual, strange, or inappropriate to the average person. They are voluntary acts that occur repeatedly in the same way over and over again, and they are characteristic for that person. However, they do not cause damage to the person”. “Aggressive or destructive behaviours are offensive actions or deliberate overt attacks directed towards other individuals or objects. They occur repeatedly in the same way over and over again, and they are characteristic for that person”. Each subscale total is produced by adding the score for each item together. A total score is produced by adding together the two sub-scale scores.

Rojahn et al. (2001) reported the correlation between the frequency and severity scales. Frequency and severity data for the BPI full scale correlated at .90 and therefore they excluded severity data from the remainder of their paper and used the frequency data. The internal consistency of the frequency data was reported using Cronbach’s alphas (.83). The subscales had alphas of .61 (SIB), .79 (Stereotyped Behaviour) and .82 (Aggressive/ destructive behaviour). In the current research, correlations were calculated between the frequency and severity scales. For mothers, the alpha was .97 and for fathers, .95. Therefore, similar to previous research, severity data will be excluded and frequency data used for the measure of behaviour problems.

Internal consistency of the BPI was calculated in the current research for mothers and fathers. Cronbach’s alphas were calculated for the frequency scale of the BPI. The frequency scale of the BPI total score had an overall alpha of .94 for mothers and for fathers .93. For mothers, alphas for the subscales were .77 (SIB frequency), .92 (Stereotyped behaviour frequency), .89 (Aggressive/ Destructive behaviour frequency), .80 (SIB severity), .93 (Stereotyped behaviour severity), and .88 (Aggressive/ Destructive behaviour severity). For fathers, alphas for the subscales were .65 (SIB frequency), .92 (Stereotyped behaviour frequency), .88 (Aggressive/ Destructive behaviour frequency), .72 (SIB severity), .94 (Stereotyped behaviour severity), .89 (Aggressive/ Destructive

behaviour severity). Inter-rater agreement between mothers and fathers was calculated (Intraclass correlation coefficient = .93).

#### 4.4.2 Reiss Scales for Children's Dual Diagnosis

To measure the presence of any co-morbid mental health problems in the child with intellectual disabilities, the Reiss Scales for Children's Dual Diagnosis was selected (Appendix B). The development of the Reiss Scales for Children's dual diagnosis occurred due to a perceived need for a validated instrument for assessing mental health symptoms in children and adolescents between the ages of 4 and 21 (Reiss & Valenti-Hein, 1994). The measure was designed as a child variant of the established Reiss Screen for Maladaptive Behaviour (Reiss, 1988).

Possible items for the scale were generated from DS-III-R, Kessler's (1987) textbook on childhood psychopathology and the Reiss Screen for adults. Seventy-two initial items were produced. As caretakers and teachers, rather than people with formal professional training complete the scales, the items were modified to ensure that all raters understood the measure. Each item was constructed to include the name of the problem behaviour (e.g., confusing speech), a definition in non-technical language (e.g., poorly related or bizarre ideas or thoughts), and an specific example to aid the understanding (e.g., speech makes no sense, thinking hard to follow, expresses strange ideas, thoughts jump from one topic to another). Two psychiatrists and two clinical psychologists gave critical comments on the revisions. In the second part of the development of the scale, factor analysis was performed on the 72-item instrument. The desired length of the instrument was 60-items and after the creation of a depression sub-scale and the deletion of items that were not used in the scoring system a scale of the required length was produced.

The Reiss Scales can be used with children between the ages of 4 and 21 who have mild, moderate or severe intellectual disabilities. The authors suggest its suitability for use in a variety of services including community and state operated developmental disability units and mainstream schools as part of the establishment of their Statement of Educational Needs. They also assert the measure's potential role in initial evaluations at mental health centres, psychiatric facilities, and inpatient programmes. Finally, they suggest the application of the measure within research into intellectual disabilities.

The Reiss Scales for Children's Dual Diagnosis has ten empirically derived (from factor analysis, see Reiss & Valenti-Hein, 1994, for further details) scales (anger/ self-control, anxiety disorder, attention deficit, autism, conduct disorder, depression, poor self-esteem, psychosis, somatoform behaviours, withdrawn/ isolated). The Reiss Scales also assesses the presence of crying spells, enuresis/encopresis, hallucinations, involuntary movements, pica, sexual problems, lying, fire setting and verbal aggression. Carers, teachers and parents may rate each question on a three-point scale (No problem, problem, major problem). Each factor, or sub-scale yields its own score and a total score can be generated from the sum of all scores.

Reiss and Valenti-Hein (1994) reported internal consistency using Cronbach's alpha for two samples used to develop the instrument. The first sample of 313 children was used to develop the scoring system and make final revisions to the list of items. Cronbach's alpha for the total score in the first sample was .91. The second sample of 270 children was tested with the revised measure for an initial evaluation of psychometric properties and preliminary validity tests. Cronbach's alpha in the second sample was .92. In the current research, Cronbach's alpha was calculated for the total score at .95 and .93 for mothers and fathers respectively. These data indicate a very high degree of internal reliability. This high degree of internal reliability is consistent with the hypothesis that the total score derived from the Reiss Scales for Children's Dual Diagnosis is a reliable measure of the severity of psychopathology. Due to the high degree of internal reliability for the total score, this work shall use the total score exclusively and not the sub-scales. Including all the subscales in the analyses would also make the statistical enquiries far more complex, and given the number of measures already, excessively complex. Hence, no alphas have been presented for these sub-scale scores. Inter-rater reliability between mother and father reports was found to be excellent in the current research (Intraclass correlation coefficient = .93).

#### 4.4.3 Nisonger Child Behaviour Rating Form (NCBRF) – Pro-social Behaviour

To measure the child's pro-social behaviour, we selected the NCBRF social competence scale (Appendix C). The NCBRF is a modified version of a behaviour rating scale developed for children without disabilities. Aman, Tasse, Rojahn and Hammer (1996) identified the need for a standardised instrument for the assessment of behavioural problems in children with intellectual disabilities. Their goal was to design an instrument

that was brief enough to be completed in 7-8 minutes, capable of being completed by both parents and teachers, applicable to a broad age range of children and applicable to the wide variety of behaviour problems manifested by children with intellectual disabilities. Aman et al., (1996) selected the Child Behavior Rating Form (CBRF; Edelbrock, 1985) as a suitable instrument for modification.

To develop the NCBRF, a working group comprising three psychologists, two social workers and a speech therapist agreed on the modifications to be made to the existing CBRF. First, instructions were altered to assess both the behaviours of concern and the rate of occurrence. Second, four items were rewritten to make them more specific. Third, 16 items were added to the measure, reflecting the increased likelihood of self-injury (five items) and stereotypic behaviour (seven items). The remaining four additional items identified shy behaviours and arguing behaviour. Separate factor analysis on the parent and teacher ratings of 369 children with intellectual disabilities yielded the parent and teacher versions of the NCBRF, which contain different item pools and scoring schemes. The new version of the measure was named the Nisonger Child Behavior Rating Form.

The NCBRF has two constituent sections, the social competence scale and the problem behaviour scale. In the current research, a different measure of problem behaviour had been selected (see below). So as not to replicate questions on problem behaviours, only the social competence scale from the NCBRF was adopted for use in the current research. There are 10 items within the Social Competence scale, divided into two distinct sub-scales, all of which are rated on a 4-point Likert scale ranging from 0 (not true) to 3 (completely or always true). Participants are asked to base their responses on the last month. The compliant/ calm sub-scale consists of six items (e.g., "Accepted redirection") and the adaptive social sub-scale four items (e.g., "Expressed ideas clearly"). Sub-scale scores are derived by adding the scores given to each item together. Both sub-scale scores can then be added together to provide a total score for the Social Competence section of the NCBRF. Aman et al (1996) reported data suggesting that the NCBRF was quite sound psychometrically. Internal consistency for the Social Competence scale (all 10 items) was high, a median of .78 for the parent subscales and .84 for the teacher subscales). In the present research, the internal consistency of the NCBRF was calculated (Cronbach's Alphas = .87 for mothers and fathers). Inter-rater reliability between mothers and fathers was also assessed (Intraclass Correlation Coefficient = .88)

#### 4.4.4 Vineland Adaptive Behaviour Scales (VABS)

The Vineland Adaptive Behaviour Scales assess personal and social sufficiency of individuals from birth through adulthood. It is available for use with disabled and non-disabled individuals. The respondent must be an individual who is familiar with the person of interest's behaviour. Three versions of the Vineland Adaptive Behaviour Scales are available; the Interview Edition, Survey Form; the Interview Edition, Expanded Form; and the Classroom Edition.

In the current research, the Survey Form was selected for use. The Survey Form is shorter than the Interview Form, Expanded Edition, and is thus more suited to research. The Classroom Edition is for use exclusively in classroom settings. The Survey form contains 297 items and provides an assessment of adaptive behaviour, useful for determining areas of strength and weakness. It consists of four domains: socialization, communication, daily living skills and motor skills. The interviewer administers the survey form to a parent or care-giver of individuals ranging in age between birth and 18 (or a low functioning adult).

The format of the interview is semi-structured and typically lasts between 20 minutes and 1 hour. The Survey Form also includes a recording booklet, which is used by the interviewer to score items and make additional notes, where necessary. It also enables the interviewer to score the interview and subsequently profile the derived scores from the manual. The Vineland Adaptive Behaviour Scales identify what the child does in day-to-day life. Each domain is taken in turn and the questions asked of the parents or carer may be broad in nature. Items in each domain are developmentally ordered, that is, the initial questions refer to adaptive behaviour of a very young typically developing child. In the domain of Communication, a likely opening question might be, "Tell me what (insert child's name) reading and writing is like". From the answer, the interviewer may code the questionnaire appropriately. The individual questions may be used if the amount of information generated by the broad inquiry was insufficient. Individual questions are not typically used due to the length of time that it would take for the VABS to be administered. Basal and ceiling scores are obtained by identifying the five lowest and five highest scores on each of the subscales. Any additional questions needed are asked from items between these two points.



The information obtained from the Vineland Adaptive Behaviour Scales Manual (Sparrow, Ball & Cicchetti, 1984) includes normative referenced information based on the performance of representative national standardization samples of approximately 4800 typically developing individuals and individuals with various intellectual disabilities. Split-half coefficients were produced for each of the adaptive behaviour domains and the adaptive behaviour Composite score. The coefficient for the domain of communication was .89. For the domain of daily living skills, the coefficient was .90 and for the domain of socialization the coefficient was .81. For the adaptive behaviour composite, the coefficient was .94. The Test-retest reliability in the two to three weeks following the initial coding showed a figure of .86 for communication. The figure for the domain of daily living skills was recorded at .85 and socialization, .81. Sparrow et al. (1984) reported that the construct, content and criterion-related validity were all acceptable.

Reliability data taken from the VABS manual shows that internal consistency for the Adaptive Behaviour Composite was excellent, with split half reliability coefficients ranging from .89 to .98. With regards to the test-retest reliability, the Adaptive Behaviour Composite coefficients were .99, excellent scores. For inter-rater reliability, the Adaptive Behaviour Composite intraclass correlation coefficient was .98. In the present research, the composite score is used. This provides a composite of all the scales used in the VABS.

#### 4.5 Parental Measures - Introduction

The following section provides information on the measures included in the research to obtain data on various aspects of the mothers and fathers of the child with an intellectual disability. The domains assessed were parental stress, positive contributions made by the child with the intellectual disability to the family, mental health, parental life satisfaction, marital state, positive affect, perceptions of support and ways of coping. The measures assessing these domains are described in turn.

##### 4.5.1 Questionnaire on Resources and Stress-Short Form (QRS-SF)

To measure the stress experienced by the parents of a child with an intellectual disability, the QRS-SF was selected for inclusion in the study (Appendix D). The original QRS



(Holroyd, 1974) is a 285-item true-false instrument, of which 222-items are scored. It was developed as a way of measuring the impact of a developmentally delayed, handicapped, or chronically ill child on the members of their family. Considered to be a general measure of adaptation and coping, it contains both positively and negatively worded items that measure the negative impact of the child on the family. Positively worded items are then reversed scored. Previous research has demonstrated the applicability of the QRS as a measure that applies to parents of children with intellectual disability (e.g., Holroyd, Brown, Wikler & Simmons, 1975; Holroyd & McArthur, 1976).

Friedrich, Greenberg and Crnic (1983) identified a number of criticisms associated with the measure in its original format. First, the original QRS is reasonably lengthy, reducing the ease of which it may be administered. Second, no reports were available regarding the internal reliability of the measure. Third, questions remained over whether the 15 original scales were truly distinct and valid. Therefore, Friedrich et al. (1983) analysed the items of the QRS, reducing them to just 52, to form the Questionnaire on Resources and Stress – Short Form (QRS-F). Subsequent factor analysis identified four independent factors, the categories of Parent and Family Problems, Pessimism, Child Characteristics and Physical Incapacitation.

Thus, in the present research, the QRS-F (Friedrich et al., 1983) was included as a general measure of parental stress. The first subscale, Parent and Family Problems contains 20 items (e.g., “I can go and visit friends whenever I want”). The second subscale, Pessimism, contains 11 items (e.g., “My child will always be a problem to us”). The third subscale, Child Characteristics, contains 15 items (e.g., “My child can’t pay attention for very long”). The fourth and final subscale, Physical Incapacitation, consists of six items (e.g., “My child can walk without help”). Respondents score each item either ‘true’ or ‘false’, by circling their chosen answer. As mentioned previously, 33 positively worded items (e.g. “It is easy for me to relax”) from the scale are reverse scored. So, with normally scored items, ‘true’ responses are assigned a score of one and ‘false’ responses are assigned a score of zero, when the questionnaires are collated. If the item is one of the 33 that need reverse scoring, a ‘true’ response is assigned a score of zero and a ‘false’ response, a score of one. Thus, the researcher may obtain the subscale scores may simply

summing the items in each scale. A total score may also be derived from summing all items answered.

Prior to analysis, 5 items were removed from the QRS-F as they have been shown to be a good measure of depression in parents of families with intellectual disabilities (Glidden & Floyd, 1997). This was done to avoid an overlap between this measure and the Hospital Anxiety and Depression Scale. Whilst respondents completed the items for all four subscales, the decision was taken to use the Parent and Family Problems subscale as the 'stress' measure in this research. Other research such as Baker et al. (2003) has used this subscale as the measure of parenting stress, dropping the other subscales. The Parent and Family Problems subscale provides a measure of stress based on the impact the child has on the family. The Pessimism subscale is perhaps too focused for use as a broad measure of stress. The Child Characteristics subscale shares items with other measures taken by the study such as child behaviour and the demographic information. The final subscale, Physical Incapacitation, also has considerable overlap with items on the measure of adaptive behaviour included in this thesis, the Vineland Adaptive Behaviour Scales.

Friedrich et al. (1983) reported psychometrics in the development paper for the QRS-SF. Using Kuder-Richardson-20 reliability coefficients, the overall coefficient for the short form was .95. Scott, Sexton, Thompson and Wood (1989) investigated the measurement characteristics of the QRS-SF. Using Cronbach's alpha for total score, they reported a coefficient of .92. They also reported the alpha's for each of the four subscales, with the Parent and Family Problem subscale alpha being .84. For the present research, Kuder-Richardson-20 Coefficient's were reported for the Parent and Family Problem Subscale of the QRS-F ( $KD-20 = .83$  for both mothers and fathers). This result is similar to that reported in previous work.

#### 4.5.2 Positive Contribution Scale (PCS)

In the present research, the need was identified for a measure of the positive contribution that a child with an intellectual disability may make to the family/parent. To this end, the Positive Contributions Scale was selected (Appendix E). The PCS (Behr, Murphy & Summers, 1992) was designed for use by researchers in investigations of perceptions related to coping with the challenges of caring for individuals with special needs, not as a

clinical measure. Behr et al., (1992) identified that the term special needs included physical and mental impairments, neurological problems, developmental disabilities, and intellectual disabilities. The PCS is simple to use, being designed as a self-report instrument, easily filled out by parents. It can be administered through the mail or in person. It is one of the four measures of perception that comprise the Kansas Inventory of Positive Perceptions (KIPP; Behr, Murphy & Summers, 1992).

Through a three-stage process of refinement, Behr et al. (1992) modified the PCS until the present 50 items were established. All items in the instrument are divided into four sections. At the beginning of each section there is a sentence in which the respondent inserts the name of their child. The first is "My Child \_\_\_\_\_ Is:". The second is "I Consider My Child \_\_\_\_\_ To Be:". The third is "The Presence of My Child \_\_\_\_\_:". The fourth and final is "Because Of My Child \_\_\_\_\_:". Each of the four sections contains items from the nine dimensions that comprise the PCS. These are: Learning through experience with special problems (e.g., helps me understand people who are different); Happiness and fulfilment (e.g., kind and loving); Personal strength and family closeness (e.g., helps me to take things as they come); Understanding life's purposes (e.g., all children need to be loved); Awareness about future issues (e.g., realise importance of planning for family future); Personal growth and maturity (e.g., learned patience); Expanded social network (e.g., circle of friends is larger); Career or job growth (e.g., am more realistic about job); Pride and cooperation (e.g., pride in child's artistic accomplishments).

Each item is scored on a 4-point Likert scale, ranging from "Strongly Disagree" to "Strongly Agree". The higher the score on the subscales, one can infer greater awareness of positive contributions, stronger positive perceptions, or greater use of positive perceptions.. Behr, Murphy and Summers (1992) used two methods were used to assess the reliability of the PCS subscales. First, internal consistency coefficients (Cronbach's Alpha) were calculated. Coefficients ranged from .56 and .86, with a mean coefficient of .77. Second, a sub-sample of 100 respondents completed the measure six weeks after the initial administration. Stability coefficients ranged from .30 to .74, with a mean stability coefficient of .56. This relatively instability is not unexpected and suggest that perceptions at representative of a snapshot in time and are not suitable for extrapolation to global perceptions over time.

The internal consistency of the dimensions and the total was calculated. For mothers, the Cronbach's alphas for the dimensions were: Learning through experience with special problems was .74; Happiness and fulfillment was .83; Personal strength and family closeness was .81; Understanding life's purposes was .41; Awareness about future issues was .64; Personal growth and maturity was .81; Expanded social network was .81; Career or job growth was .82; Pride and cooperation was .79. The alpha for the total KIPP score was calculated at .92.

For fathers, the Cronbach's alphas for the dimensions were: Learning through experience with special problems was .75; Happiness and fulfillment was .87; Personal strength and family closeness was .78; Understanding life's purposes was .47; Awareness about future issues was .68; Personal growth and maturity was .83; Expanded social network was .83; Career or job growth was .78; Pride and cooperation was .80. The alpha for the total KIPP score was calculated at .94. Behr, Murphy and Summers (1992) used the total score for the PCS in their developmental research and this total score will be used in the present research. Again, this total score is preferred to limit the number of subscales to analyse.

#### 4.5.3 Hospital Anxiety and Depression Scale (HADS)

The HADS (Zigmond & Snaith, 1983) was included in the present research as a measure of mental health, taking into account the domains of both anxiety and depression (Appendix F). Zigmond and Snaith (1983) identified that there are emotional elements of illnesses and that hospital clinics did not have the time to understand the way they may contribute to the disorder or from what form of neurosis the patient is suffering. They posited that it would be of use to have a screening tool for psychiatric disorder. Existing measures, such as the General Health Questionnaire (Goldberg, 1972) were deemed to be disadvantageous in the fact that it took a considerable time to complete and also did not identify the psychiatric disorder. Thus, Zigmond and Snaith (1983) proposed to develop a short, self-assessment mood scale specifically designed for use in non-psychiatric settings.

The HADS is a 14-item scale developed to provide a measure of anxiety and depression. An example of an item on the Anxiety scale would be "Worrying thoughts go through my mind". An example of an item on the Depression scale is "I look forward with enjoyment

to things”. Items are scored on a four point Likert scale. A total score for each scale (anxiety and depression) is achieved by summing the scores on the subscale. Higher scores represent higher levels of anxiety or depression. The HADS, whilst developed for clinical use, has been employed successfully in community samples of parents of children with learning disabilities (Hastings & Brown, 2002). In the Hastings and Brown (2002) study, mothers and fathers of children with autism were interviewed. A reliability check confirmed that the Anxiety (Cronbach’s alpha = .86 for fathers and .89 for mothers), and Depression (Cronbach’s alpha = .74 for fathers and .86 for mothers) subscales had high levels of internal consistency. In the current research, internal consistency was analysed. Both anxiety (Cronbach’s alpha = .80 for mothers and .78 for fathers) and depression (Cronbach’s alpha = .79 for mothers and .80 for fathers) subscales were found to have good levels of internal reliability.

#### 4.5.4 Satisfaction With Life Scale (SWLS)

The SWLS (Diener, Emmons, Larsen & Griffin, 1985) was included in the present research as a brief global measure of life satisfaction (Appendix G). The SWLS was originally used to assess the life satisfaction of the individual with a brain injury. Life satisfaction is one factor in the general construct of subjective well-being. Whilst life satisfaction can be assessed specific to a particular domain of life such as work, the Satisfaction With Life Scale is a global measure.

The scale consists of five items and is a self-assessment tool, to be completed by the individual whose life satisfaction is being measured. It is a particularly brief measure, able to be completed in a few minutes. An example of an item for the measure is “In most ways, my life is close to my ideal”. Each item is scored on a 7-point scale, from “Strongly Disagree” to Strongly Agree”. The scores given by the respondent for each of the five items is summed to produce a total life satisfaction score.

Diener, Emmons, Larsen and Griffins (1985) showed strong internal reliability, reporting a coefficient alpha of .87 for the scale and a 2-month test-retest stability coefficient of .82. In the current research, internal consistency for the total score on the Satisfaction with Life Scale was good (Cronbach’s alpha = .87 for mothers and .88 for fathers).

#### 4.5.5 Golombok Rust Inventory of Marital State (GRIMS)

The GRIMS (Rust, Crowe & Golombok, 1988) was included in this research to provide a short and easily administered questionnaire to assess the overall quality of a couple's relationship and identify existing problems/ discord (Appendix H). To identify areas of potential distress, both marital therapists and their clients were used to gain information. The therapists were asked about both the areas they believe to be important in marital harmony and the specific areas they would assess during initial interview. Clients were asked to identify their specific targets for change (e.g., wanting their partners to change behaviours/habits that were felt to be irritating or unpleasant).

The authors identify that of the key advantages of the GRIMS over existing measures is its simplicity of administration. The participant is provided with the questionnaire sheet on which the 28-items are set out within a standardised format. The GRIMS may be used to give an objective and standardised view of the severity of any problems within the relationship between heterosexual partners who live in a co-habitation situation. The authors proposed that the companion measure to the GRIMS is the Golombok Rust Inventory of Sexual Satisfaction (GRISS; Rust & Golombok, 1985). The GRIMS does not include any measure of sexual dissatisfaction that may be an integral cause of marital disharmony. However, in the current research, it was deemed unethical to question the parents about the presence of any sexual dissatisfaction and that this would have reduced the number of participants willing to take part. It is a 28-item questionnaire, rated on a four-point scale, from "strongly disagree" to "strongly agree". There are no subscales and each item scores are summed to produce a total score. It is important to note that higher scores indicate more severe relationship problems. An example of an item from the questionnaire would be "I never have second thoughts about our relationship".

The reliability of the GRIMS was reported by Rust, Bennun, Crowe, and Golombok (1990) to be good (Cronbach's alpha in a standardized sample was .89 for females and .85 for males). A recent paper (Beck et al. (2004) reported a Cronbach's alpha of .87 for a sample of mothers of children with intellectual disabilities. In the current study, internal consistency of the measure was found to be very good. Mothers had a Cronbach's alpha of .91 and fathers, .92.



#### 4.5.6 Positive Affect Schedule (PAS)

The PAS (Watson, Clark & Tellegen, 1988) was included in the current research to provide a measure of the degree to which the respondent feels enthusiastic, active and alert at the time of completing the questionnaire (Appendix I). Watson, Clark and Tellegen (1988) identified the lack of a reliable and valid measure of positive and negative affect that was also brief and simple to administer. Positive and Negative affect have emerged as distinctive dimensions in research into affective structure (Watson & Tellegen, 1985). Positive affect reflects characteristics such as alertness, enthusiasm and energy. Negative affect however, reflects subjective distress that may include mood states such as anger, fear and contempt. These dimensions are not at opposite ends of the same spectrum. Rather, low positive affect may well include sadness or lethargy, whilst low negative affect would be indicated by a state of calmness.

In the selection of items to be included in the final measure, the researchers (Watson et al., 1988) highlighted the need to choose terms that were pure markers of either positive or negative affect, terms that had a significant loading on one factor but a almost zero loading on the other. It was established through reliability analyses that 10 items would be sufficient for the positive affect subscale. Twelve items were identified as possible and so 2 items (delighted, healthy) were removed as they had the highest secondary loadings on the negative affect scale. The negative affect scale had 25 potential items available. Again just 10 items were deemed necessary and so each of five triads (distressed, angry, fearful, guilty, jittery) were assigned 2 items each.

Participants were asked to read each item and circle a number on a five point Likert scale (1 = Very slight or not at all, 2 = A little, 3 = Moderate, 4 = Quite a bit, 5 = Extremely) which corresponds to the way they are feeling at the very moment they are completing the scale. The responses to the items are then summed to produce subscale scores for both the positive and negative affect domains. Watson et al. (1988) reported internal consistency. Cronbach's alphas were reported (positive affect scale = .89; negative affect scale = .85).

In the current research, only the positive affect scale was used. The decision to include just the positive scale of the measure was based on the fact that the thesis contains a number of negative adjustment measures, such as anxiety and depression measures and a

measure of family stress. The internal consistency for the positive affect scale in the current research was good (Cronbach's  $\alpha = .90$  for mothers,  $.88$  for fathers).

#### 4.5.7 Shortened Ways of Coping – Revised (SWC-R)

To measure the parent's coping mechanisms, we selected the SWC-R (Hatton & Emerson, 1995) to be included in the research (Appendix J). This has developed from the Ways of Coping Checklist (WCCL) and the Ways of Coping (Revised) Questionnaire (WCQ-R), developed by Folkman and Lazarus (1985). A more recent version of the WCQ-R was revised for use with a UK sample (Knussen, Sloper, Cunningham & Turner, 1992). This derivative is a self-report questionnaire contains 63-items and is scored on a four-point Likert scale. Hatton and Emerson (1995) identify that researchers typically factor analyse questionnaire items to produce a small number of subscales that are presumed to represent distinct ways of coping. However, a number of problems are associated with this approach. First, carers may not have the time to complete a 63-item questionnaire. Second, the numbers of carers used in such studies may render the factor analysis unreliable. Third, the reliance of factor analysis requires a significant use of statistical resources. Hatton and Emerson (1995) developed a shortened version of the WCQ-R, requiring that it was quick and simple to complete, and was robust enough to show reliable associations.

Hatton and Emerson (1995) identified five studies that used the WCCL or the WCQ-R with different populations (Folkman & Lazarus, 1985; Folkman et al., 1986; Knussen et al., 1992; Sloper & Turner, 1991; Vitaliano, Russo, Carr, Maiuro & Becker, 1987). All the studies factor analysed the questionnaires into a number of different sub-scales, to determine common Ways of Coping subscales that contained similar items and were reliably associated with outcome measures. Two subscales were found to be similar across all five studies. These were Practical Coping and Wishful Thinking.

The SWC-R contains 14 items that measure two independent subscales, Practical Coping and Wishful Thinking. Practical coping (e.g., "I draw on my past experiences") relates to coping with a stressful situation by attempting to change it; this coping style is related to a variety of positive outcomes for carers of people with learning disabilities such as satisfaction with life (Knussen et al., 1992). The subscale of wishful thinking (e.g., "I

wish the situation would go away or somehow be over with”), involves attempting to cope with one’s feelings about a stressful event whilst not trying to alter the situation. Each one of the 14 items is rated by the parents on a 4-point Likert scale, the options being ‘Not Used’, ‘Used Somewhat’, ‘Used Quite a Bit’ and ‘Used a Great Deal’. Each sub-scale contains seven items and sub-scale total scores are derived by summing the respondent’s scores on each item. Thus, one is left with two sub-scale total scores.

Hatton and Emerson (1995) reported internal reliability in the SWC-R development paper which assessed staff responses and not parents . Four services took part in the development including a residential homes, residential education centres and staffed homes. The average alpha for the practical coping sub-scale was .76 and the average alpha for the wishful thinking sub-scale was .65. Hatton and Emerson report that both sub-scales show adequate internal reliability compared to previous studies using full-length versions of the questionnaire. For the present research, internal consistency was generally good for the subscale scores. For mothers, the wishful thinking subscale had an alpha of .85 and the practical coping subscale had an alpha of .81. For fathers, the wishful thinking subscale had an alpha of .82 and the practical coping subscale had an alpha of .81.

#### 4.5.8 Support Functions Scale (SFS)

The inclusion of the SFS (Dunst & Trivette, 1985) in the research was to provide a measure of the social support that people find helpful (Appendix K). The SFS is a self-report instrument used to measure the extent of parents’ needs for different types of support. The scale is available in both an extended (20-item) and short (12-item) version. Both ask parents to rate the their need for financial, emotional, instrumental and informational support on a 5-point Likert scale. The parent answers to what extent he or she feels a need for each type of assistance by marking Never, Once in a While, Sometimes, Often, Quite Often. Due to the amount of data being collected in this study, the decision was taken to use the shorter version of the instrument, in order to reduce the amount of time the parent needed to spend on the questionnaire. The measure contains two subscales. The first, the practical support sub-scale contains seven items (e.g. “Someone who loans you money when you need it”). The second, the emotional support sub-scale, contains five items (e.g. “Someone to talk to about things that worry you”). The scores

given are then summed to provide a sub-scale score for both the practical and emotional scales.

Dunst and Trivette (1985) report internal consistency reliability (Cronbach's Alpha) of .87 for the total score. In the current research, internal consistency was good overall (Cronbach's alpha = .88 for mothers, .89 for fathers). The alpha for the practical subscale was .78 for mothers and .81 for fathers. For the emotional subscale, the alpha was .87 for both mothers and fathers. In the current research, both subscales will be used and not the total score.

#### 4.5.9 Social Readjustment Rating Scale - Life Events

The Social Readjustment Rating Scale (Holmes & Rahe, 1967) was included as a measure in the current research to establish what social events an individual may have experienced within a recent time period (Appendix L). This is due to the recognition within the literature of the impact that life events can have on stress, mental health and access to support.

The original Social Readjustment Rating Scale contained 43 life events empirically derived from clinical experience. Examples of these items include marriage, death of a close friend and divorce. In the original scale, each item was assigned a value. In the current research, the scale was adjusted for the needs of the research. Thus, respondents simply rated the items as present or absent within the last 12 months. This enables researchers to understand and potentially control for any significant life event that may have occurred and had an impact upon the results provided by the participant. To aid the ease of data analysis the life event data was dichotomised. This was done by taking a frequency count of the data and looking for a point where the data split into two approximately even groups. It was observed that 51.4 % of participants had experienced three or fewer life events in the previous 12 months. This was identified as an appropriate place to dichotomise the group. Thus, two groups were analysed in the data analysis, those who had experienced more than three life events in the previous year and those who had experienced three or fewer in the preceding year.

#### 4.6 Procedure

After receiving ethics approval from the University of Wales, Bangor's ethics committee, schools for children with special needs were contacted, asking if they would be willing to facilitate communication between the research team and parents of children attending their school. If the head-teacher agreed to the participation of the school, approximate numbers of families were obtained and suitable numbers of initial contact letters (Appendix M) were sent to the school. The school then took the responsibility of sending the letter home through established communication channels.

Parents were then able to read through the information provided on the Information Form (Appendix N) and decide on one of three courses of action. First, if they had considered the request and felt they had enough information to decide to take part, they could complete the consent form (Appendix O) and sent it back via a business reply envelope that gave initial consent for the research project to send them questionnaires. Second, the family could request further information by post or over the telephone, should they decide that the Initial Contact Form did not answer all of their questions. The third and final option gave the family the opportunity to decline taking part in the study. As part of the initial contact, all participants were assured that the decision they made on whether to take part would in no way affect the care that their children received and that the research project was not connected with either the school or the local authorities. At the same time, parents were informed that the aim was to collect data from them a second time, one year after they had completed the Time 1 questionnaires. To encourage participation at both time points, a payment system was devised that rewarded people who took part in both data collections. Mothers were paid £15 at Time One and an additional £25 if they took part at Time Two. Fathers were paid £10 at Time One and an additional £20 if they took part at Time Two.

Families who had agreed to participate in the study were sent either one or two questionnaires packs, depending on the number of parents in the home. These were accompanied by pre-paid business return envelopes. If the questionnaires sent out were not returned within two weeks, a reminder letter was sent to the family. The questionnaire for the mother contained a section to collect demographic data, followed by the measures outlined in the previous section. After the questionnaires had been returned, the respondents were telephoned at home to complete the remainder of the measures. These

were the VABS and the life events data. Once all the data were received and the telephone interviews completed, the families were sent letters of thanks and their payment.

#### 4.7 Time 2 Data Collection

Approximately one year after completion of the Time One, participants were sent the Information Sheet (Appendix N) and the second consent form (Appendix P). Once again, they had the same choice of one of three courses of action. One, they could complete the consent form (Appendix O) and sent it back via a business reply envelope agreeing to participate a second time. Two, the family could request further information by post or over the telephone, and three, the family could decline taking part in the study. Once again, it was made clear that the decision they made on whether to take part would in no way affect the care that their children received and that the research project was not connected with either the school or the local authorities. Families then received their questionnaire packs through the post. On receipt of the questionnaire packs, the families were sent letters of thanks and the second, final, element of their payment for participating in the research.



## Chapter 5

## Descriptive Analysis of Time 1 Data

5.1 Introduction

Chapter 5 presents descriptive analyses for both the parents and children involved in the study. These are considered in light of previous research findings and papers that have utilised the same measures, to establish broadly whether the sample used in this research is similar to that used in previous research. The suitability of the data for parametric analysis is explored before the analysis proceeds.

Once the data are analysed for suitability for parametric methodology, two stages of data investigation are presented. First, the demographic variables need to be checked to establish which are associated with child and parent outcome variables and so need to be controlled for in the main analysis. Second, bivariate associations are analysed to initially check relationships in the model.

5.1.1 Sample Size Estimate

Prior to beginning the analyses, sample sizes were estimated following Cohen's (1992) recommendations. We expected each multiple regression analysis to contain no more than eight predictors. Cohen suggests that a sample of 107 participants gives approximately 80% power to detect a medium effect size within a multiple regression at an alpha level of .05 when the regression contains eight predictors. Thus, we aimed to collect data from 140 families, to account for anticipated attrition in participation between Times 1 and 2.

5.2 Descriptive Analyses

In this section, descriptive information for both child and parent variables is presented in Tables, 5.1, 5.2 and 5.3. Where they are used, clinical cut-off scores are shown and compared to the data obtained in the present research. Table 5.1 presents means, standard deviations and actual range of child behaviour problems (BPI), child psychopathology (REISS), child pro-social behaviour (NCBRF) and child adaptive behaviour (VABS) scores, separately for mothers and fathers.

Table 5.1

*Child Variables as Rated by Mothers and Fathers*

|       | Mother (n = 138) |       |        | Father (n = 60) |       |       |
|-------|------------------|-------|--------|-----------------|-------|-------|
|       | Mean             | SD    | Range  | Mean            | SD    | Range |
| BPI   | 37.50            | 30.30 | 0-135  | 32.82           | 26.36 | 0-105 |
| REISS | 24.13            | 18.17 | 0-80   | 17.27           | 12.98 | 0-55  |
| NCBRF | 12.26            | 5.48  | 2-30   | 13.58           | 5.58  | 4-27  |
| VABS  | 41.49            | 16.79 | 19-113 | —               | —     | —     |

The manual for the Reiss Scales for Children's Dual Diagnosis provide clinical cut-off scores. For the total score, over 29 indicates clinically significant child psychopathology. In the present sample, 35.4% of the children reached or exceeded this score.

Table 5.2 illustrates the means, standard deviations and range of scores for parent outcomes variables, again presented separately for mothers and fathers.

Table 5.2

*Maternal and Paternal Outcomes*

|                   | Mother (n = 138) |       |        | Father (n = 60) |       |        |
|-------------------|------------------|-------|--------|-----------------|-------|--------|
|                   | Mean             | SD    | Range  | Mean            | SD    | Range  |
| Stress            | 5.15             | 3.50  | 0-14   | 4.52            | 3.59  | 0-13   |
| PCS               | 134.88           | 18.96 | 87-184 | 132.28          | 20.93 | 68-180 |
| Anxiety           | 8.78             | 3.81  | 0-20   | 7.30            | 3.95  | 0-19   |
| Depression        | 5.57             | 3.54  | 0-19   | 4.85            | 3.68  | 0-15   |
| Life Satisfaction | 20.68            | 7.22  | 5-35   | 21.37           | 6.76  | 5-35   |
| Marital State     | 29.31            | 12.51 | 8-71   | 26.30           | 11.95 | 7-57   |
| Positive Affect   | 33.12            | 7.87  | 10-49  | 34.02           | 7.10  | 10-50  |

For both Anxiety and Depression scores alike, scores between 8 and 10 identify mild cases, 11-15 moderate cases and 16 and above, severe cases. Means scores for mothers indicate mild anxiety, but depression within a normal range. For fathers both anxiety and depression were within normal ranges. The GRIMS also provides a measure of interpretation for scores. In the sample presented here, mothers scored 29.31 and fathers,

26.30. These both are within the ‘above average’ range, indicating that parents of children with intellectual disabilities report above average dissatisfaction with their relationships.

Table 5.3 presents the means, standard deviations and range of scores for parent resource variables, for both mothers and fathers.

Table 5.3

*Maternal and Paternal Resource Variables*

|                   | Mother (n = 138) |      |       | Father (n = 60) |      |       |
|-------------------|------------------|------|-------|-----------------|------|-------|
|                   | Mean             | SD   | Range | Mean            | SD   | Range |
| Wishful Thinking  | 12.64            | 4.77 | 7-28  | 10.78           | 3.89 | 7-25  |
| Practical Coping  | 19.25            | 4.25 | 7-28  | 18.05           | 4.30 | 9-28  |
| Practical Support | 16.83            | 5.83 | 7-35  | 15.27           | 5.45 | 5-25  |
| Emotional Support | 16.38            | 5.21 | 5-25  | 17.75           | 6.43 | 7-31  |

### 5.3 Confirmation of Data Distributions

To assess the suitability of the data for parametric statistical analyses, a series of one-sample Kolmogorov-Smirnov tests were performed for all measures and their subscales. A non-significant result indicates the data are reasonably normally distributed and thus suitable for parametric analyses.

Three scales were not normally distributed: Mother NCBRF Total, Mother Reiss Scale Total, and the Mother SWC-R Wishful Thinking subscale. Using histograms to assess the distribution, data transformations were performed on the three scales. With transformations, it is best to use the least severe transformation possible in order to obtain a non-significant Kolmogorov-Smirnov score (Tabachnick & Fidell, 2001).

For the mother NCBRF total and the mother Reiss Scale total, a square root transformation was performed. For the mother Wishful Thinking subscale of the Shortened Ways of Coping measure natural log transformation was used. All transformations resulted in non-significant Kolmogorov-Smirnov scores.

For data that were not normally distributed, analyses were conducted using non-transformed, as well as transformed scores, since non-transformed scores are easier to interpret. For following analyses, all tables contain data using non-transformed scores for all variables. However, results using transformed data for Mother NCBRF Total, Mother Reiss Scale Total, and the Mother SWC-R Wishful Thinking subscale are also discussed in the text throughout.

#### 5.4 Background Demographics

This section examines relationships among background demographic variables and the main study variables. This is to identify demographic variables that have an effect on main study variables, so they can be controlled for in later main analyses. This section is divided into two sub-sections; the first addresses continuous demographic variables while the second addresses categorical demographic variables.

##### 5.4.1 Continuous Demographic Variables

Pearson's product-moment correlation coefficients were used to determine potential associations for continuous demographic variables. Zero-order correlations for these variables are presented in Tables 5.4-5.6, with brief descriptions of relevant relationships following each table.

Table 5.4 shows mother age to be negatively correlated with mother BPI rating, mother Reiss scales total score and maternal anxiety as measured on the HADS. Thus, older mothers report fewer child behaviour problems, fewer child mental health problems and less of their own anxiety. The number of adults in the family was positively correlated with the mother score on the positive scale of the NCBRF measure, the mother total score of Life Satisfaction Scale and maternal positive affect. Therefore, mothers with more adults in the family report more child pro-social behaviour, greater life satisfaction and more positive affect. The number of adults in the family was negatively correlated with maternal stress, anxiety and depression, suggesting that mothers with fewer adults in the family report greater levels of stress, anxiety and depression.

Table 5.4

*Correlations between Demographic Information, and Maternal Resources, Maternal Outcomes and Maternal Ratings of Child Variables*

|                   | Mother age | No. of adults in family | No. of children in family | Mother education | Age of child |
|-------------------|------------|-------------------------|---------------------------|------------------|--------------|
| BPI               | -.27**     | -.16                    | -.01                      | -.03             | -.15         |
| REISS             | -.22*      | -.12                    | .02                       | -.06             | -.05         |
| NCBRF             | .10        | .20*                    | -.10                      | .07              | .10          |
| VABS              | -.15       | .02                     | .08                       | .06              | -.36**       |
| Stress            | -.08       | -.24**                  | -.00                      | .12              | -.07         |
| PCS               | -.04       | .10                     | .05                       | -.03             | -.05         |
| Anxiety           | -.22**     | -.30**                  | -.03                      | -.21*            | .03          |
| Depression        | -.13       | -.18*                   | -.04                      | -.13             | -.04         |
| Life Satisfaction | .05        | .19*                    | .10                       | .04              | .01          |
| Marital State     | -.05       | -.07                    | .04                       | -.14             | .01          |
| Positive Affect   | .03        | .19*                    | -.03                      | .02              | .03          |
| Wishful Thinking  | -.15       | -.20*                   | -.12                      | -.08             | .05          |
| Practical Coping  | .07        | -.08                    | -.16                      | .09              | -.06         |
| Practical Support | -.01       | .11                     | -.01                      | .00              | .16          |
| Emotional Support | -.01       | .07                     | .03                       | .06              | .03          |

*Note.* The pattern of significant relationships was identical when tests were run again using transformed variables. \* $p < .05$ , \*\* $p < .01$

Table 5.5 shows father scores correlated with the demographic data. Father age was negatively correlated with father score on the positive affect scale, suggesting older fathers tend to report less positive affect. The number of adults in the family was negatively correlated with paternal stress, thus the more adults in the family, the less stress is reported by fathers. The age of the child with special needs was positively correlated with the father score of the positive affect scale. Thus, fathers of older children report more positive affect.

Table 5.5

*Correlations between Demographic Information, and Paternal Resources, Paternal Outcomes and Paternal Ratings of Child Variables*

|                   | Father age | No. of adults in family | No. of children in family | Father education | Age of child |
|-------------------|------------|-------------------------|---------------------------|------------------|--------------|
| BPI               | -.25       | -.25                    | -.00                      | .17              | -.17         |
| REISS             | -.19       | -.03                    | .09                       | .16              | -.05         |
| NCBRF             | .19        | .24                     | -.07                      | -.02             | .17          |
| Stress            | .03        | -.27*                   | .14                       | .25              | .04          |
| PCS               | -.04       | .06                     | .16                       | -.13             | -.18         |
| Anxiety           | .07        | -.05                    | .08                       | .08              | .05          |
| Depression        | .21        | .07                     | -.02                      | -.01             | .10          |
| Life Satisfaction | -.05       | .11                     | .02                       | -.11             | -.13         |
| Marital State     | .01        | -.24                    | .13                       | .04              | -.14         |
| Positive Affect   | -.26*      | -.09                    | .14                       | .03              | -.35**       |
| Wishful Thinking  | .16        | .19                     | -.04                      | .05              | .23          |
| Practical Coping  | .12        | .19                     | .07                       | .00              | -.01         |
| Practical Support | -.06       | .09                     | .01                       | .03              | -.09         |
| Emotional Support | -.02       | .04                     | .14                       | .12              | -.06         |

\* $p < .05$ , \*\* $p < .01$

#### 5.4.2 Categorical Demographic Variables

A series of independent-sample t-tests (Tables 5.6 and 5.7) were conducted to investigate whether scores for child and parent variables differ significantly according to the presence or absence of a specific condition or syndrome (autism, Down syndrome and cerebral palsy). These analyses enabled the identification of variables that needed to be controlled for in subsequent analyses. Of the data completed by mothers, 56 children had diagnoses of autism, 22 had diagnoses of Down syndrome and 12 had diagnoses of cerebral palsy. In the data returned by fathers, 26 children had diagnoses of autism, 9 had diagnoses of Down syndrome and 2 had diagnoses of cerebral palsy.

A second set of independent-sample t-tests were conducted to examine group differences in child and parent variables for other dichotomous demographic variables (e.g., child



gender), as rated by mothers and fathers. The results of these analyses are presented in Tables 5.8 and 5.9.

Table 5.6 presents results of the t-tests performed to establish the effect of diagnostic group. Mothers of children with autism reported significantly lower levels of pro-social behaviour in their children than mothers of children without autism. Mothers of children with autism also reported more child behaviour problems and greater child psychopathology than mothers of children without autism. In terms of positive contributions the child makes to the family, mothers of children with autism reported significantly fewer contributions than mothers of children without autism. Mothers of children with autism also reported more stress and depression than mothers of children without autism. Finally, mothers of children with autism rated their own positive affect as lower than mothers of children who do not have autism.

Independent sample t-tests also revealed that mothers of children with Down syndrome reported significantly higher levels of pro-social behaviour than mothers of children without Down syndrome. In terms of behaviour problems and child psychopathology, mothers of children with Down syndrome reported less than mothers of children without Down syndrome. With regard to stress, mothers of children with Down syndrome reported significantly less than mothers of children without Down syndrome. The positive contributions made by the child with Down syndrome, their mother's life satisfaction and positive affect were significantly higher than mothers of children without Down syndrome. Finally, the presence of cerebral palsy was associated with lower maternal ratings of child behavioural problems and child psychopathology.

Independent samples t-test for paternal data are presented in Table 5.7. Fathers of children with autism reported significantly lower levels of pro-social behaviour compared to fathers of children without autism. Fathers of children with autism also report significantly more behaviour problems and child psychopathology and rate their stress as higher than fathers of children without autism. Fathers of children with Down syndrome report significantly higher levels of pro-social behaviour than fathers of children without Down syndrome. Fathers of children with Down syndrome also report lower levels of child behaviour problems, child psychopathology and stress when compared to fathers of

children without Down syndrome. Finally, fathers of children with cerebral palsy report significantly more stress than fathers of children without cerebral palsy.

A series of independent sample t-test were conducted to examine group differences for other dichotomous demographic variables (e.g., child gender). The results of these analyses are presented in Table 5.8, for maternal ratings, and in Table 5.9 for paternal ratings. Analyses indicated that mothers in households with an income from paid work have significantly higher scores on the wishful thinking subscale of the SWC-R than mothers with no income. The same pattern of results was observed when analyses contained the transformed mother SWC-R wishful thinking scores.

Mothers of male children provided significantly higher ratings of behavioural problems and child psychopathology than mothers of female children. The same pattern of results was observed using the transformed mother REISS score. There was a significant difference among mothers of male and female children in their scores on the wishful thinking subscale of the SWC-R, with mothers of male children reporting greater endorsement than mothers of female children. Again the same pattern of results was revealed for the transformed mother score on this construct. Finally, mothers of male children reported significantly higher marital dissatisfaction than mothers of female children.

Mothers of children with sensory impairments reported more pro-social behaviour, compared with mothers of children with no sensory problems. The same pattern of results was observed for the transformed NCBRF score. In addition, mothers of children with sensory problems reported fewer behavioural problems and less psychopathology than mothers of children without sensory problems. This pattern of results was also observed for the t-test using the transformed REISS score. Finally, mothers whose child suffers from sensory problems reported significantly greater marital dissatisfaction than mothers of children with no additional sensory impairments.

Table 5.6

*T-tests between Diagnostic Group and the Maternal Variables*

|                    | Autism         |                |      | Down Syndrome  |                |      | Cerebral Palsy |                |      |
|--------------------|----------------|----------------|------|----------------|----------------|------|----------------|----------------|------|
|                    | Yes (n = 56)   | No (n = 82)    | p    | Yes (n = 22)   | No (n = 116)   | p    | Yes (n = 12)   | No (n = 126)   | p    |
| Child Variables    |                |                |      |                |                |      |                |                |      |
| BPI                | 56.02 (31.39)  | 24.47 (21.60)  | .000 | 16.95 (15.96)  | 41.40 (30.84)  | .000 | 20.00 (17.25)  | 39.17 (30.79)  | .036 |
| REISS              | 35.04 (17.12)  | 16.46 (14.73)  | .000 | 9.23 (8.61)    | 26.96 (18.16)  | .000 | 13.25 (10.61)  | 25.17 (18.44)  | .030 |
| NCBRF              | 9.65 (4.55)    | 14.10 (5.35)   | .000 | 16.27 (3.72)   | 11.50 (5.43)   | .000 | 15.00 (5.69)   | 12.00 (5.41)   | .070 |
| VABS               | 41.28 (20.72)  | 41.64 (13.39)  | .901 | 46.95 (10.24)  | 40.50 (17.57)  | .105 | 34.00 (11.32)  | 42.20 (17.08)  | .106 |
| Maternal Variables |                |                |      |                |                |      |                |                |      |
| Stress             | 6.95 (3.62)    | 3.89 (2.80)    | .000 | 2.91 (2.78)    | 5.58 (3.47)    | .001 | 5.42 (2.47)    | 5.13 (3.59)    | .785 |
| PCS                | 129.25 (15.54) | 138.85 (20.19) | .003 | 145.64 (18.99) | 132.84 (18.33) | .003 | 143.42 (15.07) | 134.07 (19.14) | .103 |
| Anxiety            | 9.33 (4.17)    | 8.40 (3.52)    | .155 | 8.09 (4.08)    | 8.91 (3.76)    | .355 | 8.50 (2.11)    | 8.81 (3.94)    | .789 |
| Depression         | 6.58 (4.13)    | 4.85 (2.87)    | .004 | 4.50 (3.39)    | 5.77 (3.54)    | .124 | 5.42 (2.02)    | 5.58 (3.66)    | .880 |
| Life Satisfaction  | 19.37 (8.09)   | 21.60 (6.44)   | .073 | 23.68 (6.69)   | 20.11 (7.21)   | .033 | 19.00 (6.32)   | 20.84 (7.31)   | .401 |
| Marital State      | 29.20 (12.92)  | 29.39 (12.31)  | .935 | 32.24 (14.24)  | 28.79 (12.18)  | .298 | 31.44 (14.64)  | 29.13 (12.37)  | .596 |
| Positive Affect    | 30.96 (8.67)   | 34.64 (6.91)   | .006 | 36.27 (6.09)   | 32.53 (8.04)   | .040 | 34.83 (5.29)   | 32.96 (8.07)   | .433 |
| Wishful Thinking   | 14.35 (5.72)   | 11.43 (3.53)   | .000 | 10.64 (3.59)   | 13.02 (4.88)   | .031 | 10.83 (3.16)   | 12.81 (4.87)   | .171 |
| Practical Coping   | 19.53 (3.85)   | 19.05 (4.53)   | .519 | 20.31 (4.38)   | 19.04 (4.22)   | .199 | 18.67 (3.52)   | 19.30 (4.33)   | .623 |
| Practical Support  | 16.81 (5.24)   | 16.85 (6.25)   | .965 | 16.73 (6.45)   | 16.85 (5.74)   | .926 | 18.42 (7.95)   | 16.68 (5.61)   | .327 |
| Emotional Support  | 15.87 (4.94)   | 16.73 (5.39)   | .346 | 16.68 (5.16)   | 16.32 (5.24)   | .766 | 17.17 (5.51)   | 16.30 (5.19)   | .584 |

Table 5.7

*T-Tests between Diagnostic Group and Paternal Variables*

|                           | Autism         |                |      | Down Syndrome  |                |      | Cerebral Palsy |                |      |
|---------------------------|----------------|----------------|------|----------------|----------------|------|----------------|----------------|------|
|                           | Yes (n = 26)   | No (n = 34)    | p    | Yes (n = 2)    | No (n = 58)    | p    | Yes (n = 9)    | No (n = 51)    | p    |
| <b>Child Variables</b>    |                |                |      |                |                |      |                |                |      |
| BPI                       | 51.08 (23.97)  | 18.85 (18.53)  | .000 | 11.44 (11.60)  | 36.59 (26.49)  | .007 | 25.50 (13.44)  | 33.07 (26.72)  | .693 |
| REISS                     | 24.62 (12.59)  | 11.65 (10.29)  | .000 | 7.44 (6.44)    | 19.00 (13.10)  | .012 | 9.00 (8.49)    | 17.55 (13.06)  | .364 |
| NCBRF                     | 11.88 (5.35)   | 14.88 (5.48)   | .038 | 17.11 (4.51)   | 12.96 (5.56)   | .039 | 11.50 (10.61)  | 13.66 (5.49)   | .596 |
| <b>Paternal Variables</b> |                |                |      |                |                |      |                |                |      |
| Stress                    | 6.38 (3.31)    | 3.09 (3.15)    | .000 | 2.11 (2.85)    | 4.94 (3.56)    | .028 | 10.50 (0.71)   | 4.31 (3.47)    | .015 |
| PCS                       | 127.31 (14.04) | 132.56 (24.94) | .340 | 135.33 (19.56) | 129.39 (21.22) | .437 | 142.00 (28.28) | 129.88 (20.85) | .425 |
| Anxiety                   | 7.15 (3.79)    | 7.41 (4.12)    | .805 | 6.44 (4.36)    | 7.45 (3.90)    | .486 | 11.00 (5.66)   | 7.17 (3.88)    | .180 |
| Depression                | 4.31 (3.18)    | 5.26 (4.01)    | .323 | 6.11 (5.33)    | 4.63 (3.33)    | .269 | 9.00 (2.82)    | 4.71 (3.64)    | .105 |
| Life Satisfaction         | 22.08 (6.47)   | 20.82 (7.01)   | .481 | 23.56 (8.09)   | 20.98 (6.51)   | .296 | 19.50 (2.12)   | 21.43 (6.86)   | .695 |
| Marital State             | 25.96 (11.29)  | 26.56 (12.58)  | .850 | 29.11 (14.06)  | 25.80 (11.62)  | .449 | 37.00 (21.21)  | 25.93 (11.65)  | .200 |
| Positive Affect           | 33.65 (5.63)   | 34.29 (8.12)   | .732 | 35.22 (7.91)   | 33.80 (7.01)   | .585 | 31.00 (6.00)   | 7.11 (0.93)    | .546 |
| Wishful Thinking          | 10.50 (4.03)   | 11.00 (3.83)   | .626 | 10.22 (2.77)   | 10.88 (4.07)   | .643 | 13.00 (2.83)   | 10.71 (3.92)   | .417 |
| Practical Coping          | 17.50 (4.49)   | 18.47 (4.16)   | .390 | 18.22 (3.73)   | 18.02 (4.42)   | .898 | 17.50 (6.36)   | 18.09 (4.29)   | .856 |
| Practical Support         | 16.62 (5.38)   | 18.62 (7.08)   | .235 | 22.33 (6.67)   | 16.94 (6.10)   | .019 | 17.00 (9.90)   | 17.78 (6.41)   | .868 |
| Emotional Support         | 15.46 (4.92)   | 15.12 (5.89)   | .811 | 15.11 (5.93)   | 15.29 (5.42)   | .927 | 10.50 (6.36)   | 15.43 (5.40)   | .211 |

With regard to paternal ratings, fathers with jobs outside the home reported significantly more satisfaction with life, higher levels of positive affect, and lower scores for anxiety and depression than fathers with no job. Fathers in households with no income also had significantly higher anxiety scores than fathers in households with an income. Fathers of female children reported significantly higher levels of anxiety than fathers with male children.

Chi-Square tests were performed to investigate significant associations where both the dependent and independent variables were dichotomous. As a  $2 \times 2$  table was produced by the use of two sets of dichotomous variables, the Yates' Correction for Continuity was used. No significant relationships were identified, for both mother and paternal ratings.

### 5.5 Correlations among Child Variables, Parental Resources and Parental Outcomes

Zero-order correlations were conducted to examine the bivariate relationships between child variables, parental resources and parental outcomes. Table 5.10 summarises the results for mothers and Table 5.11 summarises the correlations for fathers. Mother ratings of the child's behaviour problems were positively correlated with maternal stress, anxiety and depression. Negative correlations were observed between the child behaviour problems and the positive contribution, life satisfaction and positive affect scales. Maternal ratings of child psychopathology were positively correlated with the measures of stress, marital state (higher scores indicate greater dissatisfaction within the relationship), anxiety and depression, and negative correlated with positive contributions, life satisfaction and positive affect. Maternal rating of the child's pro-social behaviour correlated positively with their score on the positive contribution, life satisfaction and positive affect scales and negatively with their score on the measures of stress, anxiety and depression. Maternal ratings of the child's adaptive behaviour were correlated positively with positive contributions, life satisfaction and positive affect, and negatively with maternal stress. Transformed scores did not alter the level of significance for any of the associations. Mothers' use of wishful thinking coping strategies were correlated positively with maternal ratings of stress, marital state, anxiety and depression, while wishful thinking was negatively correlated with maternal ratings of the positive contributions made by her child, her life satisfaction and positive affect. Finally, mothers' use of practical coping strategies was positively correlated with maternal ratings of the positive contributions made by her child, her life satisfaction and positive affect.

Correlations were also conducted using the transformed scores for wishful thinking and the same pattern of significant correlations was found. There were significant positive correlations between maternal ratings of practical support and ratings of the positive contributions made by her child, her life satisfaction and her positive affect. Negative correlations were observed between maternal ratings of practical support and her marital problems and depression. Maternal ratings of emotional support were positively correlated with her ratings of the positive contributions made by her child, her life satisfaction and positive affect. Negative correlations emerged between maternal ratings of emotional support, and stress, marital state, anxiety and depression.

Taking now the paternal data presented in Table 5.11, a positive correlation was observed between the paternal rating of the child's behaviour problems and stress. Father's ratings of child psychopathology were also positively correlated with paternal stress and a significant negative correlation was observed between the paternal rating of the child's pro-social behaviour and paternal stress. Father's use of wishful thinking coping strategies was correlated positively with stress, anxiety and depression and negatively with life satisfaction and positive affect. Finally, father's use of a practical coping strategy was positively correlated with their rating of the positive contribution made by their child and life satisfaction and negatively correlated with paternal anxiety and depression. Table 5.11 also shows a significant positive correlation between paternal ratings of practical support and their rating of the positive contribution made by their child. Paternal ratings of emotional support were also positively correlated with their rating of the positive contribution made by their child.



Table 5.8  
T-tests of Demographic Variables for Child and Maternal Variables

|                   | Mother co-habit   |                   | Mother Job        |                   | Income from work               |                                | Child Gender                   |                                | Life Events       |                   | Sensory Problems               |                                |
|-------------------|-------------------|-------------------|-------------------|-------------------|--------------------------------|--------------------------------|--------------------------------|--------------------------------|-------------------|-------------------|--------------------------------|--------------------------------|
|                   | Yes (n = 106)     | No (n = 32)       | Yes (n = 66)      | No (n = 72)       | Yes (n = 102)                  | No (n = 36)                    | Male (n = 91)                  | Female (n = 47)                | >3 (n = 67)       | <3 (n = 71)       | Yes (n = 30)                   | No (n = 108)                   |
| Child Variables   |                   |                   |                   |                   |                                |                                |                                |                                |                   |                   |                                |                                |
| BPI               | 37.54<br>(32.41)  | 37.38<br>(22.36)  | 35.15<br>(30.44)  | 39.65<br>(30.23)  | 35.93<br>(31.24)               | 41.94<br>(27.38)               | <b>42.14</b><br><b>(31.97)</b> | <b>28.51</b><br><b>(24.69)</b> | 38.00<br>(32.16)  | 37.69<br>(28.70)  | <b>24.67</b><br><b>(22.40)</b> | <b>41.06</b><br><b>(31.31)</b> |
| REISS             | 24.12<br>(18.88)  | 24.16<br>(15.96)  | 22.85<br>(16.16)  | 25.31<br>(19.91)  | 23.89<br>(18.66)               | 24.81<br>(17.00)               | <b>26.91</b><br><b>(19.57)</b> | <b>18.74</b><br><b>(13.82)</b> | 25.36<br>(19.29)  | 23.46<br>(17.00)  | <b>17.57</b><br><b>(14.28)</b> | <b>25.95</b><br><b>(18.78)</b> |
| NCBRF             | 12.13<br>(5.60)   | 12.69<br>(5.12)   | 11.82<br>(5.18)   | 12.67<br>(5.74)   | 12.29<br>(5.67)                | 12.17<br>(4.97)                | 11.85<br>(5.34)                | 13.06<br>(5.71)                | 11.54<br>(4.97)   | 12.82<br>(5.82)   | <b>14.07</b><br><b>(5.66)</b>  | <b>11.76</b><br><b>(5.34)</b>  |
| VABS              | 40.68<br>(16.14)  | 44.71<br>(19.05)  | 43.25<br>(18.03)  | 40.08<br>(15.69)  | <b>43.24</b><br><b>(17.07)</b> | <b>36.53</b><br><b>(15.14)</b> | 40.42<br>(17.57)               | 43.55<br>(15.15)               | 41.38<br>(16.94)  | 41.60<br>(16.77)  | 37.67<br>(12.68)               | 42.55<br>(17.67)               |
| Mother Variables  |                   |                   |                   |                   |                                |                                |                                |                                |                   |                   |                                |                                |
| Stress            | 5.05<br>(3.51)    | 5.50<br>(3.49)    | 5.00<br>(3.62)    | 5.29<br>(3.40)    | 6.00<br>(3.46)                 | 4.85<br>(3.48)                 | 5.37<br>(3.55)                 | 4.72<br>(3.39)                 | 5.04<br>(3.52)    | 5.34<br>(3.49)    | 4.80<br>(2.96)                 | 5.25<br>(3.64)                 |
| PCS               | 134.49<br>(19.06) | 136.19<br>(18.84) | 135.55<br>(16.17) | 134.28<br>(21.29) | 135.33<br>(22.15)              | 134.73<br>(17.82)              | 134.74<br>(19.55)              | 135.15<br>(17.96)              | 132.88<br>(18.19) | 136.70<br>(19.44) | 136.03<br>(16.38)              | 134.56<br>(19.67)              |
| Anxiety           | 8.46<br>(3.86)    | 9.84<br>(3.50)    | 8.62<br>(3.79)    | 8.93<br>(3.85)    | 8.45<br>(3.80)                 | 9.72<br>(3.75)                 | 9.09<br>(4.15)                 | 8.19<br>(2.30)                 | 8.87<br>(3.72)    | 8.75<br>(3.97)    | 8.83<br>(3.80)                 | 8.77<br>(3.83)                 |
| Depression        | 5.44<br>(3.56)    | 5.97<br>(3.51)    | 4.82<br>(3.43)    | 6.25<br>(3.52)    | 5.14<br>(3.34)                 | 6.78<br>(3.83)                 | 5.98<br>(3.90)                 | 4.77<br>(2.56)                 | 5.48<br>(3.73)    | 5.72<br>(3.34)    | 6.00<br>(2.88)                 | 5.44<br>(3.70)                 |
| Life Satisfaction | 21.00<br>(7.21)   | 19.63<br>(7.28)   | 21.03<br>(6.31)   | 20.36<br>(8.00)   | 18.83<br>(7.85)                | 21.33<br>(6.91)                | 20.11<br>(7.50)                | 21.79<br>(6.59)                | 21.84<br>(7.40)   | 19.49<br>(6.84)   | 20.33<br>(6.48)                | 20.78<br>(7.44)                |
| Marital State     | 28.81<br>(12.08)  | 36.86<br>(17.15)  | 30.78<br>(12.58)  | 27.95<br>(12.40)  | 29.43<br>(13.14)               | 29.28<br>(12.42)               | <b>31.41</b><br><b>(13.20)</b> | <b>25.05</b><br><b>(9.83)</b>  | 29.40<br>(12.15)  | 29.17<br>(13.10)  | <b>33.88</b><br><b>(11.96)</b> | <b>28.07</b><br><b>(12.43)</b> |
| Positive Affect   | 33.49<br>(7.45)   | 31.92<br>(9.14)   | 33.83<br>(6.88)   | 32.47<br>(8.67)   | 31.47<br>(9.18)                | 33.71<br>(7.31)                | 32.25<br>(8.45)                | 34.81<br>(6.34)                | 32.86<br>(7.64)   | 33.36<br>(8.25)   | 33.07<br>(6.41)                | 33.14<br>(8.25)                |
| Wishful Thinking  | 12.26<br>(4.69)   | 13.88<br>(4.88)   | 12.32<br>(4.43)   | 12.93<br>(5.08)   | <b>12.15</b><br><b>(4.39)</b>  | <b>14.03</b><br><b>(5.54)</b>  | <b>13.35</b><br><b>(5.16)</b>  | <b>11.26</b><br><b>(3.57)</b>  | 11.97<br>(4.90)   | 13.39<br>(4.61)   | 12.07<br>(3.93)                | 12.80<br>(4.98)                |
| Practical Coping  | 19.08<br>(4.44)   | 19.78<br>(3.59)   | 19.64<br>(3.96)   | 18.89<br>(4.50)   | 18.47<br>(4.05)                | 19.52<br>(4.31)                | 19.33<br>(4.31)                | 19.09<br>(4.20)                | 19.30<br>(3.93)   | 19.33<br>(4.57)   | 19.50<br>(3.82)                | 19.18<br>(4.38)                |
| Practical Support | 16.84<br>(5.64)   | 16.81<br>(6.52)   | 16.86<br>(5.51)   | 16.81<br>(6.15)   | 18.28<br>(6.73)                | 16.32<br>(5.42)                | 16.95<br>(5.90)                | 16.62<br>(5.75)                | 17.54<br>(5.99)   | 16.00<br>(5.54)   | 15.87<br>(5.53)                | 17.10<br>(5.91)                |
| Emotional Support | 16.45<br>(5.14)   | 16.13<br>(5.49)   | 16.64<br>(5.08)   | 16.14<br>(5.34)   | 16.19<br>(5.44)                | 16.44<br>(5.15)                | 15.95<br>(5.08)                | 17.21<br>(5.40)                | 17.23<br>(5.62)   | 15.51<br>(4.66)   | 15.67<br>(5.35)                | 16.57<br>(5.17)                |

Table 5.8 Continued

*T-tests of Demographic Variables for Child and Maternal Variables*

|                           | Hearing Problem   |                   | Visual Problem    |                  | Both sensory problems |                   | Epilepsy          |                   | Mobility Problems                |                                  | Other Health Problem |                   |
|---------------------------|-------------------|-------------------|-------------------|------------------|-----------------------|-------------------|-------------------|-------------------|----------------------------------|----------------------------------|----------------------|-------------------|
|                           | Yes (n = 6)       | No (n = 132)      | Yes (n = 13)      | No (n = 125)     | Yes (n = 11)          | No (n = 127)      | Yes (n = 17)      | No (n = 121)      | Yes (n = 39)                     | No (n = 99)                      | Yes (n = 45)         | No (n = 93)       |
| <b>Child Variables</b>    |                   |                   |                   |                  |                       |                   |                   |                   |                                  |                                  |                      |                   |
| NCBRF                     | 14.67<br>(6.56)   | 12.15<br>(5.43)   | 14.69<br>(5.42)   | 12.01<br>(5.44)  | 13.00<br>(5.85)       | 12.20<br>(5.46)   | 12.71<br>(6.95)   | 12.20<br>(5.27)   | 12.15<br>(5.85)                  | 12.30<br>(5.35)                  | 12.44<br>(4.71)      | 12.17<br>(5.83)   |
| BPI                       | 27.17<br>(30.96)  | 37.97<br>(30.31)  | 23.08<br>(23.81)  | 39.00<br>(30.59) | 25.18<br>(16.96)      | 38.57<br>(31.00)  | 32.53<br>(24.18)  | 38.20<br>(31.09)  | 36.62<br>(31.71)                 | 37.85<br>(29.88)                 | 32.69<br>(29.21)     | 39.83<br>(30.70)  |
| REISS                     | 21.67<br>(12.31)  | 24.24<br>(18.43)  | 17.85<br>(18.60)  | 24.78<br>(18.09) | 15.00<br>(9.14)       | 24.92<br>(18.58)  | 20.12<br>(16.58)  | 24.69<br>(18.39)  | 20.79<br>(16.42)                 | 25.44<br>(18.75)                 | 20.64<br>(17.81)     | 25.82<br>(18.22)  |
| VABS                      | 46.43<br>(15.12)  | 41.62<br>(17.25)  | 33.92<br>(10.92)  | 42.27<br>(17.13) | 36.40<br>(11.19)      | 41.88<br>(17.12)  | 34.35<br>(13.16)  | 42.49<br>(17.05)  | <b>35.74</b><br>( <b>11.57</b> ) | <b>43.67</b><br>( <b>17.96</b> ) | 41.76<br>(15.51)     | 41.35<br>(17.46)  |
| <b>Maternal Variables</b> |                   |                   |                   |                  |                       |                   |                   |                   |                                  |                                  |                      |                   |
| Stress                    | 5.14 (3.51)       | 5.50 (3.51)       | 5.21 (3.57)       | 4.62 (2.79)      | 4.64 (3.11)           | 5.20 (3.54)       | 4.53 (3.20)       | 5.24 (3.54)       | 5.44 (3.14)                      | 5.04 (3.64)                      | 4.80 (3.49)          | 5.32 (3.51)       |
| PCS                       | 134.68<br>(19.15) | 139.33<br>(14.68) | 134.94<br>(19.73) | 134.38<br>(9.06) | 136.18<br>(23.70)     | 134.77<br>(18.60) | 133.88<br>(18.76) | 135.02<br>(19.06) | 139.41<br>(18.11)                | 133.10<br>(19.08)                | 138.13<br>(20.85)    | 133.31<br>(17.88) |
| Anxiety                   | 8.86 (3.82)       | 7.00 (3.52)       | 8.78 (3.88)       | 8.84 (3.26)      | 9.81 (4.44)           | 8.69 (3.76)       | 7.47 (2.85)       | 8.97 (3.90)       | 9.18 (2.85)                      | 8.63 (4.13)                      | 8.40 (3.59)          | 8.97 (3.92)       |
| Depression                | 5.61 (3.57)       | 4.67 (2.80)       | 5.48 (3.66)       | 6.38 (1.94)      | 6.27 (3.77)           | 5.50 (3.53)       | 5.06 (3.03)       | 5.64 (3.61)       | 5.62 (2.58)                      | 5.55 (3.86)                      | 5.20 (3.43)          | 5.74 (3.60)       |
| Life Satisfaction         | 20.80<br>(7.32)   | 18.00<br>(4.15)   | 20.71<br>(7.31)   | 20.38<br>(6.61)  | 21.55<br>(7.46)       | 20.61<br>(7.23)   | 20.59<br>(7.12)   | 20.69<br>(7.27)   | 20.95<br>(6.74)                  | 20.58<br>(7.44)                  | 20.47<br>(6.65)      | 20.78<br>(7.52)   |
| Marital State             | 29.23<br>(12.65)  | 32.33<br>(6.11)   | 28.79<br>(12.60)  | 33.67<br>(11.26) | 34.67<br>(15.02)      | 28.84<br>(12.24)  | 28.94<br>(11.35)  | 29.38<br>(12.75)  | 29.50<br>(12.54)                 | 29.23<br>(12.58)                 | 29.31<br>(11.75)     | 29.32<br>(12.93)  |
| Positive Affect           | 33.19<br>(8.00)   | 31.67<br>(93.93)  | 33.15<br>(8.14)   | 32.85<br>(4.67)  | 34.09<br>(9.09)       | 33.04<br>(7.79)   | 33.41<br>(5.41)   | 33.08<br>(8.17)   | 35.15<br>(6.14)                  | 32.32<br>(8.34)                  | 34.36<br>(6.71)      | 32.53<br>(8.34)   |
| Wishful Thinking          | 12.72<br>(4.84)   | 10.83<br>(2.14)   | 12.55<br>(4.87)   | 13.46<br>(3.73)  | 11.09<br>(4.61)       | 12.77<br>(4.78)   | 12.00<br>(4.17)   | 12.73<br>(4.86)   | 11.79<br>(3.81)                  | 12.97<br>(5.08)                  | 11.60<br>(3.95)      | 13.14<br>(5.06)   |
| Practical Coping          | 19.23<br>(4.30)   | 19.67<br>(3.27)   | 19.25<br>(4.24)   | 19.23<br>(4.53)  | 19.72<br>(3.50)       | 19.20<br>(4.32)   | 19.53<br>(3.91)   | 19.21<br>(4.31)   | 19.69<br>(3.57)                  | 19.07<br>(4.50)                  | 19.76<br>(3.87)      | 19.00<br>(4.43)   |
| Practical Support         | 16.85<br>(5.91)   | 16.50<br>(4.14)   | 16.83<br>(5.89)   | 16.85<br>(5.43)  | 14.36<br>(6.38)       | 17.05<br>(5.76)   | 17.94<br>(6.46)   | 16.68<br>(5.75)   | 17.51<br>(6.71)                  | 16.57<br>(5.46)                  | 16.02<br>(6.03)      | 17.23<br>(5.72)   |
| Emotional Support         | 16.39<br>(5.15)   | 16.17<br>(6.97)   | 16.32<br>(5.27)   | 16.92<br>(4.68)  | 13.91<br>(5.19)       | 16.59<br>(5.17)   | 17.00<br>(4.90)   | 16.29<br>(5.26)   | 16.72<br>(5.27)                  | 16.24<br>(5.20)                  | 15.91<br>(4.84)      | 16.60<br>(5.39)   |

Note. Values in bold signify significant differences at  $p = .05$ . Values in bold and italics signify significant differences at  $p = .01$ .

Table 5.9

*T-tests of Demographic Variables for Child and Paternal Variables*

|                           | Father Co-habit               |                  | Father Job                     |                                | Income from work               |                                | Child Gender                 |                              | Life Events       |                   | Sensory Problems               |                                |
|---------------------------|-------------------------------|------------------|--------------------------------|--------------------------------|--------------------------------|--------------------------------|------------------------------|------------------------------|-------------------|-------------------|--------------------------------|--------------------------------|
|                           | Yes (n = 59)                  | No (n = 1)       | Yes (n = 50)                   | No (n = 10)                    | Yes (n = 52)                   | No (n = 8)                     | Male (n = 40)                | Female (n = 20)              | >3 (n = 67)       | <3 (n = 71)       | Yes (n = 13)                   | No (n = 47)                    |
| <b>Child Variables</b>    |                               |                  |                                |                                |                                |                                |                              |                              |                   |                   |                                |                                |
| BPI                       | 32.64<br>(26.55)              | 43.00 (–)        | 32.42<br>(24.86)               | 34.80<br>(34.44)               | 32.04<br>(24.88)               | 37.88<br>(36.25)               | 36.75<br>(28.69)             | 24.95<br>(19.25)             | 33.47<br>(26.52)  | 32.63<br>(26.98)  | <b>22.46</b><br><b>(22.94)</b> | <b>35.68</b><br><b>(26.75)</b> |
| REISS                     | 17.51<br>(12.95)              | 3.00 (–)         | 16.74<br>(12.49)               | 19.90<br>(15.68)               | 16.58<br>(12.55)               | 21.75<br>(15.65)               | 18.20<br>(14.55)             | 15.40<br>(9.12)              | 17.88<br>(13.38)  | 17.07<br>(12.66)  | 13.85<br>(12.48)               | 18.21<br>(13.08)               |
| NCBRF                     | <b>13.36</b><br><b>(5.34)</b> | <b>27.00 (–)</b> | 13.66<br>(5.49)                | 13.20<br>(6.32)                | 13.79<br>(5.47)                | 12.25<br>(6.50)                | 13.55<br>(5.45)              | 13.65<br>(5.98)              | 12.66<br>(5.85)   | 14.70<br>(5.25)   | 14.00<br>(6.23)                | 13.47<br>(5.46)                |
| VABS                      | 44.34<br>(18.05)              | 43.00 (–)        | 41.92<br>(16.03)               | 37.44<br>(15.74)               | <b>43.24</b><br><b>(17.07)</b> | <b>36.53</b><br><b>(15.14)</b> | 40.42<br>(17.57)             | 43.55<br>(15.15)             | 41.38<br>(16.94)  | 41.60<br>(16.77)  | 37.67<br>(12.68)               | 42.55<br>(17.67)               |
| <b>Paternal Variables</b> |                               |                  |                                |                                |                                |                                |                              |                              |                   |                   |                                |                                |
| Stress                    | 129.95<br>(20.95)             | 150.00 (–)       | 128.86<br>(20.10)              | 137.40<br>(24.62)              | 128.25<br>(19.79)              | 143.50<br>(24.68)              | 128.28<br>(21.44)            | 134.30<br>(19.80)            | 4.97<br>(3.61)    | 4.00<br>(3.64)    | 3.15<br>(2.94)                 | 4.89<br>(3.69)                 |
| PCS                       | 21.24<br>(6.74)               | 29.00 (–)        | 22.20<br>(6.95)                | 17.20<br>(3.68)                | 21.90<br>(6.69)                | 17.88<br>(6.53)                | 22.20<br>(6.66)              | 19.70<br>(6.80)              | 128.84<br>(19.40) | 132.33<br>(23.14) | 128.92<br>(15.27)              | 130.66<br>(22.37)              |
| Anxiety                   | 4.90<br>(3.69)                | 2.00 (–)         | <b>4.36</b><br><b>(3.17)</b>   | <b>7.30</b><br><b>(5.10)</b>   | <b>4.54</b><br><b>(3.52)</b>   | <b>6.88</b><br><b>(4.32)</b>   | <b>4.43</b><br><b>(3.62)</b> | <b>5.70</b><br><b>(3.76)</b> | 7.44<br>(3.60)    | 7.22<br>(4.44)    | 6.92<br>(2.63)                 | 7.40<br>(4.26)                 |
| Depression                | 32.64<br>(26.55)              | 43.00 (–)        | <b>32.42</b><br><b>(24.86)</b> | <b>34.80</b><br><b>(34.44)</b> | 32.04<br>(24.88)               | 37.88<br>(36.25)               | 36.75<br>(28.69)             | 24.95<br>(19.25)             | 4.44<br>(3.51)    | 5.33<br>(3.95)    | 3.62<br>(2.69)                 | 5.19<br>(3.87)                 |
| Life Satisfaction         | 33.88<br>(7.08)               | 42.00 (–)        | <b>35.16</b><br><b>(6.19)</b>  | <b>28.30</b><br><b>(8.84)</b>  | 34.54<br>(6.42)                | 30.63<br>(10.46)               | 33.35<br>(7.32)              | 35.35<br>(6.61)              | 21.56<br>(6.62)   | 21.26<br>(7.13)   | 21.54<br>(6.57)                | 21.32<br>(6.88)                |
| Marital State             | 7.37<br>(3.94)                | 3.00 (–)         | 6.72<br>(3.64)                 | 10.20<br>(4.34)                | 6.85<br>(3.65)                 | 10.25<br>(4.80)                | 6.55<br>(3.76)               | 8.80<br>(3.99)               | 26.09<br>(9.12)   | 26.37<br>(11.94)  | 22.77<br>(10.95)               | 27.28<br>(12.13)               |
| Positive Affect           | 10.85<br>(3.89)               | 7.00 (–)         | <b>10.36</b><br><b>(3.44)</b>  | <b>12.90</b><br><b>(5.38)</b>  | 10.42<br>(3.43)                | 13.13<br>(5.91)                | 10.50<br>(3.86)              | 11.35<br>(4.00)              | 25.38<br>(6.89)   | 32.19<br>(7.12)   | 35.85<br>(5.98)                | 33.51<br>(7.36)                |
| Wishful Thinking          | 18.10<br>(4.31)               | 15.00 (–)        | 18.24<br>(4.25)                | 17.10<br>(3.68)                | 17.98<br>(4.23)                | 18.50<br>(5.01)                | 17.80<br>(4.42)              | 18.55<br>(4.10)              | 10.03<br>(3.22)   | 11.81<br>(4.44)   | 9.85<br>(3.36)                 | 11.04<br>(4.02)                |
| Practical Coping          | 17.81<br>(6.47)               | 14.00 (–)        | 17.82<br>(6.54)                | 17.40<br>(6.19)                | 17.65<br>(6.15)                | 18.38<br>(8.50)                | 17.83<br>(6.25)              | 17.60<br>(6.94)              | 18.25<br>(4.13)   | 17.70<br>(4.59)   | 17.08<br>(3.30)                | 18.32<br>(4.53)                |
| Practical Support         | 15.32<br>(5.47)               | 12.00 (–)        | 15.56<br>(5.50)                | 13.80<br>(5.16)                | 15.48<br>(5.46)                | 13.88<br>(5.49)                | 15.73<br>(5.28)              | 14.35<br>(5.80)              | 17.91<br>(6.58)   | 17.77<br>(6.39)   | 16.15<br>(5.38)                | 18.19<br>(6.67)                |
| Emotional Support         | 26.58<br>(11.85)              | 10.00 (–)        | 26.38<br>(12.14)               | 25.90<br>(11.54)               | 26.48<br>(11.95)               | 25.13<br>(12.68)               | 26.50<br>(12.46)             | 25.90<br>(11.14)             | 16.38<br>(5.49)   | 14.22<br>(5.17)   | 14.46<br>(6.27)                | 15.49<br>(5.25)                |

Table 5.9 Continued  
*T-tests of Demographic Variables for Child and Paternal Variables*

|                           | Hearing           |                   | Visual            |                   | Both             |                   | Epilepsy          |                   | Mobility Problems       |                         | Other health problem |                   |
|---------------------------|-------------------|-------------------|-------------------|-------------------|------------------|-------------------|-------------------|-------------------|-------------------------|-------------------------|----------------------|-------------------|
|                           | Yes (n = 3)       | No (n = 57)       | Yes (n = 5)       | No (n = 55)       | Yes (n = 5)      | No (n = 55)       | Yes (n = 10)      | No (n = 50)       | Yes (n = 17)            | No (n = 43)             | Yes (n = 21)         | No (n = 39)       |
| <b>Child Variables</b>    |                   |                   |                   |                   |                  |                   |                   |                   |                         |                         |                      |                   |
| BPI                       | 24.00<br>(40.71)  | 33.28<br>(25.86)  | 25.00<br>(22.78)  | 33.53<br>(26.73)  | 19.00<br>(14.35) | 34.07<br>(26.92)  | 24.80<br>(13.20)  | 34.42<br>(28.09)  | 31.88<br>(25.71)        | 33.19<br>(26.90)        | 23.86<br>(17.90)     | 37.64<br>(29.02)  |
| REISS                     | 27.33<br>(18.15)  | 16.74<br>(12.64)  | 12.20<br>(8.53)   | 17.73<br>(13.27)  | 7.40<br>(6.19)   | 18.16<br>(13.09)  | 11.20<br>(9.39)   | 18.48<br>(13.33)  | 14.65<br>(13.16)        | 18.30<br>(12.91)        | 14.10<br>(11.30)     | 18.97<br>(13.63)  |
| NCBRF                     | 15.67<br>(8.50)   | 13.47<br>(5.48)   | 15.40<br>(6.35)   | 13.41<br>(5.54)   | 11.60<br>(5.32)  | 13.76<br>(5.62)   | 12.40<br>(6.40)   | 13.82<br>(5.45)   | 12.00<br>(6.08)         | 14.21<br>(5.32)         | 13.95<br>(3.77)      | 13.38<br>(4.65)   |
| VABS                      | 46.43<br>(15.12)  | 41.62<br>(17.25)  | 33.92<br>(10.92)  | 42.27<br>(17.13)  | 36.40<br>(11.19) | 41.88<br>(17.12)  | 34.35<br>(13.16)  | 42.49<br>(17.05)  | <b>35.74</b><br>(11.57) | <b>43.67</b><br>(17.96) | 41.76<br>(15.51)     | 41.35<br>(17.46)  |
| <b>Paternal Variables</b> |                   |                   |                   |                   |                  |                   |                   |                   |                         |                         |                      |                   |
| Stress                    | 4.00 (4.36)       | 4.54 (3.59)       | 3.20 (3.11)       | 4.64 (3.63)       | 2.60 (2.41)      | 4.69 (3.65)       | 3.90 (3.87)       | 4.64 (3.56)       | 4.88 (4.01)             | 4.37 (3.45)             | 3.71 (3.68)          | 4.95 (3.52)       |
| PCS                       | 136.67<br>(17.62) | 129.95<br>(21.17) | 138.40<br>(10.11) | 129.55<br>(21.55) | 114.80<br>(5.97) | 131.69<br>(21.26) | 131.90<br>(17.81) | 129.96<br>(21.65) | 130.00<br>(18.03)       | 130.40<br>(22.17)       | 129.90<br>(23.36)    | 130.49<br>(19.83) |
| Anxiety                   | 8.00 (3.61)       | 7.26 (3.99)       | 6.60 (3.29)       | 7.36 (4.02)       | 6.60 (1.52)      | 7.36 (4.10)       | 7.30 (3.43)       | 7.30 (4.08)       | 7.88 (4.88)             | 7.07 (3.55)             | 7.62 (4.03)          | 7.13 (3.95)       |
| Depression                | 4.33 (2.31)       | 4.88 (3.75)       | 2.00 (3.46)       | 5.11 (3.62)       | 4.80 (1.30)      | 4.85 (3.83)       | 4.20 (3.49)       | 4.98 (3.74)       | 5.12 (4.04)             | 4.74 (3.57)             | 6.00 (4.22)          | 4.23 (3.25)       |
| Life Satisfaction         | 17.00<br>(5.00)   | 21.60<br>(6.79)   | 24.00<br>(7.71)   | 21.13<br>(6.69)   | 21.80<br>(5.85)  | 21.33<br>(6.88)   | 21.70<br>(4.57)   | 21.30<br>(7.15)   | 21.94<br>(6.28)         | 21.14<br>(7.00)         | 20.00<br>(6.81)      | 22.10<br>(6.70)   |
| Marital State             | 22.67<br>(17.79)  | 26.49<br>(11.76)  | 19.60<br>(7.70)   | 26.91<br>(12.12)  | 26.00<br>(10.79) | 26.33<br>(12.14)  | 27.30<br>(10.72)  | 26.10<br>(12.27)  | 26.00<br>(11.39)        | 26.42<br>(12.29)        | 26.48<br>(11.85)     | 26.21<br>(12.15)  |
| Positive Affect           | 37.67<br>(6.66)   | 33.82<br>(7.13)   | 38.20<br>(6.14)   | 33.64<br>(7.11)   | 32.40<br>(4.83)  | 34.16<br>(7.29)   | 35.20<br>(5.75)   | 33.78<br>(7.37)   | 34.71<br>(8.86)         | 33.74<br>(6.38)         | 34.33<br>(6.61)      | 33.85<br>(1.19)   |
| Wishful Thinking          | 11.33<br>(3.06)   | 10.75<br>(3.95)   | 9.20<br>(4.38)    | 10.93<br>(3.86)   | 9.60<br>(2.79)   | 10.89<br>(3.98)   | 9.50<br>(2.99)    | 11.044<br>(4.03)  | 10.76<br>(4.71)         | 10.79<br>(3.58)         | 10.62<br>(3.15)      | 10.87<br>(4.27)   |
| Practical Coping          | 16.67<br>(2.08)   | 18.12<br>(4.38)   | 16.60<br>(3.58)   | 18.18<br>(4.36)   | 17.80<br>(4.09)  | 18.07<br>(4.35)   | 19.40<br>(4.65)   | 17.78<br>(4.22)   | 18.47<br>(4.16)         | 17.88<br>(4.39)         | 18.52<br>(5.10)      | 17.79<br>(3.85)   |
| Practical Support         | 17.00<br>(2.00)   | 17.79<br>(6.59)   | 17.20<br>(5.17)   | 17.80<br>(6.57)   | 14.60<br>(7.30)  | 18.04<br>(6.34)   | 18.60<br>(6.08)   | 17.58<br>(6.54)   | 17.88<br>(7.09)         | 17.69<br>(6.24)         | 17.95<br>(6.67)      | 17.64<br>(6.38)   |
| Emotional Support         | 16.33<br>(7.77)   | 15.21<br>(5.39)   | 16.20<br>(5.81)   | 15.18<br>(5.46)   | 11.60<br>(6.11)  | 15.60<br>(5.32)   | 15.70<br>(5.89)   | 15.18<br>(5.41)   | 14.29<br>(5.77)         | 15.65<br>(5.33)         | 14.76<br>(5.47)      | 15.54<br>(5.49)   |

Note. Values in bold signify significant differences at  $p = .05$ . Values in bold and italics signify significant differences at  $p = .01$ .

Table 5.10

*Bivariate Correlations between Child Variables as rated by Mothers and Maternal Variables*

|                   | 1      | 2      | 3      | 4     | 5      | 6     | 7      | 8      | 9      | 10     | 11     | 12     | 13    | 14    |
|-------------------|--------|--------|--------|-------|--------|-------|--------|--------|--------|--------|--------|--------|-------|-------|
| BPI               | —      |        |        |       |        |       |        |        |        |        |        |        |       |       |
| REISS             | .79**  | —      |        |       |        |       |        |        |        |        |        |        |       |       |
| NCBRF             | -.53** | -.54** | —      |       |        |       |        |        |        |        |        |        |       |       |
| VABS              | -.27** | -.12   | .27**  | —     |        |       |        |        |        |        |        |        |       |       |
| Stress            | .47**  | .50**  | -.52** | -.19* | —      |       |        |        |        |        |        |        |       |       |
| PCS               | -.21*  | -.25** | .27**  | .18*  | -.30** | —     |        |        |        |        |        |        |       |       |
| Anxiety           | .25**  | .41**  | -.21*  | -.09  | .33**  | -.01  | —      |        |        |        |        |        |       |       |
| Depression        | .27**  | .45**  | -.31** | -.11  | .50**  | -.21* | .64**  | —      |        |        |        |        |       |       |
| Life Satisfaction | -.19*  | -.27** | .19*   | .21*  | -.51** | .22** | -.39** | -.60** | —      |        |        |        |       |       |
| Marital State     | .11    | .19*   | -.11   | -.16  | .30**  | -.03  | .35**  | .53**  | -.52** | —      |        |        |       |       |
| Positive Affect   | -.20*  | -.32** | .25**  | .22*  | -.34** | .44** | -.34** | -.52** | .54**  | -.43** | —      |        |       |       |
| Wishful Thinking  | .33**  | .41**  | -.20*  | -.15  | .45**  | -.22* | .61**  | .62**  | -.58** | .29**  | -.43** | —      |       |       |
| Practical Coping  | .03    | .06    | -.04   | .16   | -.07   | .33** | .08    | -.08   | .20*   | -.13   | .37**  | .04    | —     |       |
| Practical Support | .07    | -.10   | .07    | -.12  | -.06   | .24** | -.02   | -.21*  | .21*   | -.21*  | .27**  | -.14   | .05   | —     |
| Emotional Support | -.13   | -.17*  | .09    | .04   | -.27** | .36** | -.17*  | -.38** | .38**  | -.32** | .37**  | -.31** | .27** | .65** |

\*p&lt;.05, \*\*p&lt;.01

Table 5.11

*Bivariate Correlations between Child Variables as rated by Fathers and Paternal Variables*

|                   | 1      | 2      | 3     | 4    | 5    | 6     | 7      | 8      | 9      | 10   | 11     | 12   | 13   | 14    |
|-------------------|--------|--------|-------|------|------|-------|--------|--------|--------|------|--------|------|------|-------|
| BPI               | —      |        |       |      |      |       |        |        |        |      |        |      |      |       |
| REISS             | .63**  | —      |       |      |      |       |        |        |        |      |        |      |      |       |
| NCBRF             | -.52** | -.45** | —     |      |      |       |        |        |        |      |        |      |      |       |
| VABS              | -.28*  | -.05   | .24   | —    |      |       |        |        |        |      |        |      |      |       |
| Stress            | .44**  | .50**  | -.31* | -.12 | —    |       |        |        |        |      |        |      |      |       |
| PCS               | -.03   | -.06   | .20   | .15  | -.10 | —     |        |        |        |      |        |      |      |       |
| Anxiety           | .01    | .10    | -.04  | .01  | .32* | .05   | —      |        |        |      |        |      |      |       |
| Depression        | -.14   | -.08   | .03   | .12  | .29* | -.04  | .65**  | —      |        |      |        |      |      |       |
| Life Satisfaction | .03    | -.11   | .19   | .09  | -.21 | .31*  | -.46** | -.43** | —      |      |        |      |      |       |
| Marital State     | .02    | .09    | -.09  | .13  | .25  | -.29* | .24    | .46**  | -.41** | —    |        |      |      |       |
| Positive Affect   | -.02   | -.17   | .21   | .05  | -.21 | .31*  | -.36** | -.49** | .46**  | -.18 | —      |      |      |       |
| Wishful Thinking  | -.19   | .00    | -.04  | .04  | .28* | .14   | .67**  | .65**  | -.40** | .03  | -.58** | —    |      |       |
| Practical Coping  | -.19   | -.06   | .04   | .10  | -.23 | .39** | -.27*  | -.35** | .37**  | -.26 | .25    | -.14 | —    |       |
| Practical Support | -.05   | .00    | .12   | .08  | -.08 | .52** | -.04   | .02    | .11    | .05  | .11    | .07  | .13  | —     |
| Emotional Support | -.00   | -.03   | .08   | .08  | -.14 | .50** | -.10   | -.23   | .11    | -.22 | .17    | .06  | .29* | .68** |

\*p&lt;.05, \*\*p&lt;.01



### 5.6 Summary

This chapter has served a number of functions. First, the means and standard deviations of the main study variables were presented, comparing and contrasting these data with previous research. Second, the distribution of the data was investigated, to establish whether the use of parametric data analyses was appropriate. Third, the relationships between demographic data and the main study variables were examined. Continuous demographic variables were analysed with correlations. Independent sample t-tests were used to analyse categorical demographic data. Finally, correlations were conducted among all the variables to examine any bivariate relationships, before they are investigated in detail in the next chapter.

## Chapter 6

## Cross-Sectional Analysis

6.1 Introduction

Chapter 2 saw the refinement of the conceptual model proposed in Chapter 1. We now return to this refined model:

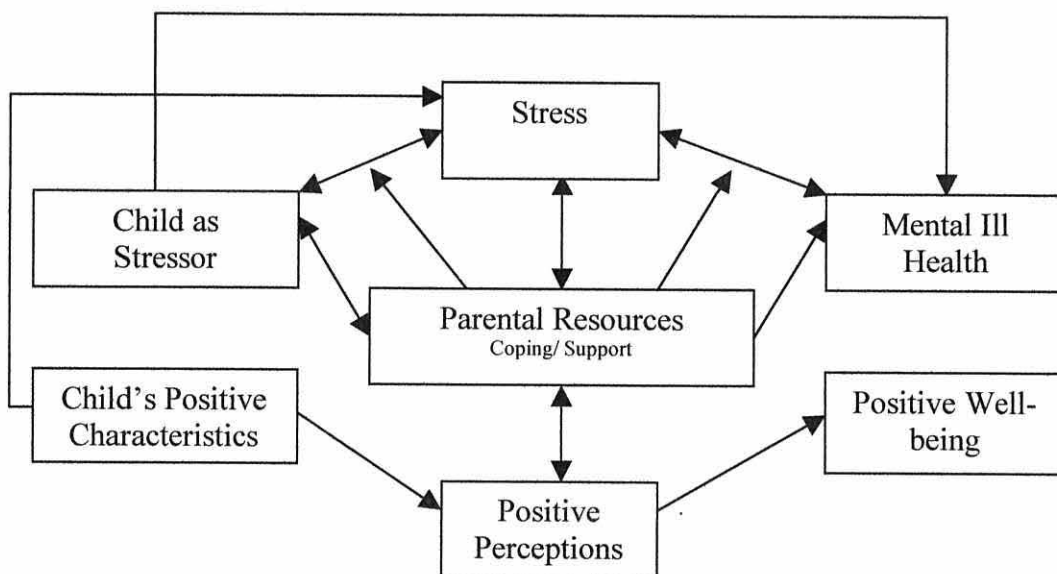


Figure 6.1 An Integrated Model of Stress and Coping in Parents of Children with Intellectual Disability

A number of pathways in this model were discussed in Chapters 2 and 3. The purpose of the present chapter is to investigate the nature of these relationships, taking into account the demographic variables that are significantly related to the main study variables in Chapter 5. This analysis of the cross-sectional data is important for Time 2 analyses as the cross-sectional regressions provide a framework of significant relationships that are examined longitudinally in the next chapter.

Three regression analysis techniques are employed in this chapter. Standard multiple regression was used to examine independent variables as predictors of dependent variables at the cross-sectional level. In this procedure, the unique contribution of each independent variable can be assessed (i.e., the amount of variance in the dependent variable accounted for by each independent variable is assessed as if it had entered the regression equation after

all the others). That is, all the potential predictors are evaluated together to establish their unique contribution. Standard multiple regression is used in this research to investigate a number of variables that may co-exist and the relative predictive contribution made by each. The regression analyses used to test mediating and moderating relationships followed the recommendations of Baron and Kenny (1986). These methods are discussed in detail, in the relevant sections of this chapter.

## 6.2 Child Variables as Predictors of Parental Outcomes

The first focus of this chapter is on child variables as predictors of parental outcomes. That is, we examined how indicators of the child as stressor and the child's positive characteristics predict mental ill health and positive well-being in parents. Each set of regression analyses is presented according to the criterion variable of interest. Within each set of analyses, two regressions are presented. In the first regression analysis, the demographic variables identified in Chapter 5 as significantly correlating with the criterion variable are entered into the first regression analysis. This regression establishes which of the demographic variables are predictive of the criterion variable. This allows identification of the most important demographic variables, which are then controlled for in the second regression. The second regression analysis contains the child variables as predictors of mental ill health and positive well-being while controlling for the demographic variables found to be significant predictors of the criterion in the first regression. The method of analysis described here is also employed to examine the relationships in the subsequent four sections.

### 6.2.1 Child Variables predicting Maternal Anxiety

As indicated in Table 6.1, no demographic variables significantly predicted maternal anxiety and therefore no demographic variables were controlled for in the next regression. The second regression analysis revealed child psychopathology to be the only significant (and positive) predictor of maternal anxiety.

Table 6.1

*Summary of Regression Analysis for Demographic Variables predicting Maternal Anxiety*

| Variable  | $\beta$ | p    |
|---|---------|------|
| Mother Age                                      | .25     | .432 |
| Number of Adults in Family                      | -.14    | .330 |
| Mother Education                                | -.22    | .091 |
| $R = .41, R^2 = .17, F(4, 53) = 2.68, p = .041$ |         |      |

Table 6.2

*Summary of Regression Analysis for Child Variables predicting Maternal Anxiety*

| Variable   | $\beta$ | p    |
|--|---------|------|
| NCBRF  | .02     | .855 |
| BPI  | -.24    | .074 |
| REISS  | .60     | .000 |
| VABS   | -.09    | .277 |
| $R = .44, R^2 = .19, F(4, 131) = 7.81, p < .000$ |         |      |

*Note.* Transformed scores did not change the pattern of significant results.

### 6.2.2 Child Variables predicting Maternal Depression

Table 6.3 shows that autism was the only significant demographic variable predictive of maternal depression. Therefore this variable was included in the second regression. Of the four child variables, child behaviour problems were a negative predictor of maternal depression, whereas child psychopathology positively predicted this construct (see Table 6.4).

Table 6.3

*Summary of Regression Analysis for Demographic Variables predicting Maternal Depression*

| Variable   | $\beta$ | p    |
|--|---------|------|
| Number of Adults in Family                       | -.16    | .062 |
| Autism   | .22     | .008 |
| $R = .29, R^2 = .08, F(5, 130) = 6.04, p = .003$ |         |      |

Table 6.4

*Summary of Regression Analysis for Child Variables predicting Maternal Depression*

| Variable | $\beta$ | p    |
|----------|---------|------|
| Autism   | .06     | .540 |
| NCBRF    | -.07    | .440 |
| BPI      | -.30    | .026 |
| REISS    | .61     | .000 |
| VABS     | -.10    | .242 |

$R = .49$ ,  $R^2 = .24$ ,  $F(5, 130) = 8.15$ ,  $p < .000$

*Note.* Transformed scores did not change the pattern of significant results.

6.2.3 Child Variables predicting Maternal Life Satisfaction

Down syndrome and the number of adults in the family were significant predictors of maternal life satisfaction (Table 6.5) and therefore were controlled for in the second regression. As can be seen in Table 6.6, child psychopathology was a negative predictor of maternal life satisfaction, while child adaptive behaviour was a positive predictor of this construct.

Table 6.5

*Summary of Regression Analysis for Demographic Variables predicting Maternal Life Satisfaction*

| Variable                      | $\beta$ | p    |
|-------------------------------|---------|------|
| Down Syndrome                 | .17     | .049 |
| Number of Adults<br>in Family | .17     | .040 |

$R = .25$ ,  $R^2 = .06$ ,  $F(2, 135) = 4.53$ ,  $p = .012$

Table 6.6

*Summary of Regression Analysis for Child Variables predicting Maternal Life Satisfaction*

| Variable                   | $\beta$ | P    |
|----------------------------|---------|------|
| Number of Adults in Family | .16     | .053 |
| Down Syndrome              | .06     | .531 |
| NCBRF                      | -.02    | .826 |
| BPI                        | .18     | .194 |
| REISS                      | -.36    | .011 |
| VABS                       | .21     | .016 |

$R = .38, R^2 = .14, F(6, 129) = 3.61, p = .002$

*Note.* Transformed scores did not change the pattern of significant results.

#### 6.2.4 Child Variables predicting Maternal Marital State

Both child gender and the presence of a sensory impairment were significant predictors of maternal marital state and thus were controlled for in the next regression (Table 6.7). In the second regression analysis, none of the child variables significantly predicted maternal marital state (Table 6.8).

Table 6.7

*Summary of Regression Analysis for Demographic Variables predicting Maternal Marital State*

| Variable                     | $\beta$ | P    |
|------------------------------|---------|------|
| Gender of Child              | -.25    | .007 |
| Presence of Sensory problems | -.20    | .027 |

$R = .32, R^2 = .10, F(2, 109) = 5.99, p = .003$



Table 6.8

*Summary of Regression Analysis for Child Variables predicting Maternal Marital State*

| Variable                     | $\beta$ | P    |
|------------------------------|---------|------|
| Gender of child              | -.21    | .029 |
| Presence of sensory problems | -.19    | .046 |
| NCBRF                        | -.30    | .802 |
| BPI                          | -.17    | .292 |
| REISS                        | .30     | .074 |
| VABS                         | -.11    | .272 |

$R = .39$ ,  $R^2 = .15$ ,  $F(6, 104) = 3.01$ ,  $p = .009$

*Note.* Transformed scores did not change the pattern of significant results.

#### 6.2.5 Child Variables predicting Maternal Positive Affect

As evident in Table 6.9, maternal positive affect was significantly predicted by autism and thus autism was included in the second regression. Table 6.10 present the results of the second regression. Maternal positive affect was predicted positively by child behavioural problems and adaptive behaviour and negatively by child psychopathology.

Table 6.9

*Summary of Regression Analysis for Demographic Variables predicting Maternal Positive Affect*

| Variable                   | $\beta$ | P    |
|----------------------------|---------|------|
| Number of Adults in Family | .16     | .061 |
| Autism                     | -.18    | .048 |
| Down Syndrome              | .10     | .282 |

$R = .30$ ,  $R^2 = .09$ ,  $F(3, 134) = 4.27$ ,  $p = .007$

Table 6.10

*Summary of Regression Analysis for Child Variables predicting Maternal Positive Affect*

| Variable | $\beta$ | p    |
|----------|---------|------|
| Autism   | -.15    | .136 |
| NCBRF    | .07     | .510 |
| BPI      | .30     | .036 |
| REISS    | -.41    | .003 |
| VABS     | .27     | .010 |

$R = .41$ ,  $R^2 = .17$ ,  $F(5, 130) = 5.36$ ,  $p < .000$

*Note.* Transformed scores changed the  $\beta$  for adaptive child behaviour (VABS) to a significance level of .05. Child behaviour problems (BPI) ceased to be a significant predictor of positive affect.

#### 6.2.6 Child Variables predicting Paternal Anxiety

None of the demographic variables included in Table 6.11 significantly predicted paternal anxiety, thus none of these variables was included in the next regression. No significant predictors of paternal anxiety were identified by the regression analysis shown in Table 6.12.

Table 6.11

*Summary of Regression Analysis for Demographic Variables predicting Paternal Anxiety*

| Variable         | $\beta$ | p    |
|------------------|---------|------|
| Father Employed  | .27     | .142 |
| Income from Work | -.06    | .751 |
| Gender of Child  | .25     | .051 |

$R = .42$ ,  $R^2 = .17$ ,  $F(3, 56) = 3.93$ ,  $p = .013$

Table 6.12

*Summary of Regression Analysis for Child Variables predicting Paternal Anxiety*

| Variable                                      | $\beta$ | p    |
|---|---------|------|
| NCBRF   | -.03    | .858 |
| BPI   | -.12    | .547 |
| REISS   | .15     | .401 |
| VABS  | -.01    | .939 |
| $R = .13, R^2 = .02, F(4, 54) = .22, p = .93$ |         |      |

#### 6.2.7 Child Variables predicting Paternal Depression

No demographic regression analyses were performed with paternal depression data as only a single demographic variable, paternal employment, was associated with paternal depression in preliminary analyses. None of the child variables emerged as significant predictors of paternal depression, as indicated in Table 6.13.

Table 6.13

*Summary of Regression Analysis for Child Variables predicting Paternal Depression*

| Variable                                       | $\beta$ | p    |
|--|---------|------|
| Father Employed                                | -.33    | .014 |
| NCBRF  | -.09    | .546 |
| BPI  | -.11    | .542 |
| REISS  | -.08    | .655 |
| VABS   | .15     | .284 |
| $R = .37, R^2 = .14, F(5, 53) = 1.68, p = .16$ |         |      |

#### 6.2.8 Child Variables predicting Paternal Life Satisfaction

Father employment status was the only significant demographic variable associated with paternal life satisfaction in preliminary analyses. It was not necessary, therefore, to perform a demographic regression analysis for paternal life satisfaction. Father employment was controlled for in the regression analysis presented in Table 6.14 in which none of the three child variables significantly predicted paternal life satisfaction.

Table 6.14

*Summary of Regression Analysis for Child Variables predicting Paternal Life Satisfaction*

| Variable   | $\beta$ | p    |
|------------|---------|------|
| Father Job | .26     | .048 |
| NCBRF      | .23     | .144 |
| BPI        | .28     | .126 |
| REISS      | -.17    | .322 |
| VABS       | .07     | .638 |

$R = .39, R^2 = .15, F(5, 53) = 1.87, p = .16$

#### 6.2.9 Child Variables predicting Paternal Marital State

No significant demographic variables were associated with paternal marital state.

Therefore, no regression analysis is presented for demographic data. Table 35 presents the results of the regression analysis to establish whether child variables predict paternal marital state. No significant predictors were found.

Table 6.15

*Summary of Regression Analysis for Child Variables predicting Paternal Marital State*

| Variable | $\beta$ | p    |
|----------|---------|------|
| NCBRF    | -.18    | .470 |
| BPI      | -.04    | .852 |
| REISS    | .07     | .699 |
| VABS     | .16     | .283 |

$R = .19, R^2 = .04, F(5, 54) = .52, p = .72$

#### 6.2.10 Child Variables predicting Paternal Positive Affect

Demographic regression analyses reported in Table 6.16 revealed father employment status as a predictor of positive affect in fathers. Consequently, this variable was controlled for in the next regression. None of the child variables in the second regression analysis (Table 6.17) significantly predicted paternal positive affect.

Table 6.16

*Summary of Regression Analysis for Demographic Variables predicting Paternal Positive Affect*

| Variable  | $\beta$ | P    |
|---|---------|------|
| Father Employed                                 | -.30    | .016 |
| Father Age                                      | -.02    | .897 |
| Child Age                                       | -.27    | .084 |
| $R = .46, R^2 = .21, F(3, 56) = 4.99, p = .004$ |         |      |

Table 6.17

*Summary of Regression Analysis for Child Variables predicting Paternal Positive Affect*

| Variable                                       | $\beta$ | p    |
|--|---------|------|
| Father Job                                     | .35     | .008 |
| NCBRF  | .24     | .111 |
| BPI  | .22     | .221 |
| REISS  | -.15    | .372 |
| VABS   | -.01    | .955 |
| $R = .44, R^2 = .20, F(5, 53) = 2.57, p = .04$ |         |      |

### 6.3 Child Variables as Predictors of Parental Stress and Positive Contributions

The second focus of this chapter is on the relationship between child variables and factors in the middle level of the model, parental stress and parental perceptions of the positive contributions the child makes to the family. Again, results are presented according to the criterion variable of interest and two regressions are conducted; the first concerning demographic variables predicting stress and positive contributions, and the second concerning child variables predicting stress and positive contributions, while controlling for the significant demographic predictors identified in the first regression. Analyses are presented for both mother and father data.

#### 6.3.1 Child Variables predicting Maternal Stress

Table 6.18 shows that autism and the number of adults in the family are significant predictors of maternal stress and therefore will be controlled for in the next regression analysis. Maternal stress was predicted negatively by child pro-social behaviour and

positively by child psychopathology (Table 6.19), while controlling for relevant demographic variables.

Table 6.18

*Summary of Regression Analysis for Demographic Variables predicting Maternal Stress*

| Variable  | $\beta$ | p    |
|---|---------|------|
| Autism  | .36     | .000 |
| Down Syndrome                                     | -.12    | .108 |
| Number of Adults<br>in Family                     | -.18    | .017 |
| $R = .49, R^2 = .24, F(3, 134) = 13.91, p < .001$ |         |      |

Table 6.19

*Summary of Regression Analysis for Child Variables predicting Maternal Stress*

| Variable  | $\beta$ | p    |
|---|---------|------|
| Autism  | .19     | .023 |
| Number of Adults<br>in family                     | -.13    | .067 |
| NCBRF   | -.25    | .004 |
| BPI   | .000    | .998 |
| REISS   | .24     | .045 |
| VABS  | -.09    | .255 |
| $R = .61, R^2 = .38, F(6, 129) = 12.91, p < .001$ |         |      |

*Note.* Transformed scores did not change the pattern of significant results.

### 6.3.2 Child Variables predicting Maternal Ratings of Child Positive Contributions

The criterion variable in this sub-section is maternal rating of the positive contributions made to the family by their child with an intellectual disability. The first regression presents demographic variables predicting maternal ratings of positive contributions. Only those demographic variables found to be significantly related to maternal ratings of positive contributions in Chapter 5 were included in this regression model. The second regression presents the child variables as rated by the mother predicting maternal ratings of the child's positive contribution scores, controlling for the significant demographic variables identified in Table 6.20.

Table 6.20 shows that autism and Down syndrome are significant predictors of maternal ratings of positive contributions and therefore need to be controlled for in the next regression analysis. Table 6.21 indicates that none of the child variables significantly predicted maternal ratings of the child's positive contributions.

Table 6.20

*Summary of Regression Analysis for Demographic Variables Predicting Maternal Positive Contribution Scores*

| Variable      | $\beta$ | p    |
|---------------|---------|------|
| Autism        | -.18    | .038 |
| Down Syndrome | .18     | .043 |

$R = .30, R^2 = .09, F(2, 135) = 6.75, p = .002$

Table 6.21

*Summary of Regression Analysis for Child Variables predicting Maternal Positive Contribution Scores*

| Variable      | $\beta$ | p    |
|---------------|---------|------|
| Autism        | -.15    | .137 |
| Down Syndrome | .10     | .283 |
| NCBRF         | .09     | .367 |
| BPI           | .10     | .498 |
| REISS         | -.14    | .318 |
| VABS          | .15     | .102 |

$R = .35, R^2 = .13, F(6, 129) = 3.06, p = .008$

*Note.* Transformed scores did not change the pattern of significant results.

### 6.3.3 Child Variables predicting Paternal Stress

From the regression analysis shown in Table 6.22, autism and cerebral palsy were identified as significant predictors of paternal stress and consequently were controlled for in the next regression analysis. In the second regression, child psychopathology was revealed as the only significant predictor of paternal stress, positively predicting this outcome (Table 6.23).



Table 6.22

*Summary of Regression Analysis for Demographic Variables predicting Paternal Stress*

| Variable  | $\beta$ | p    |
|---|---------|------|
| Number of Adults in Family                      | -.06    | .600 |
| Autism  | .48     | .000 |
| Cerebral Palsy                                  | .37     | .003 |
| Down Syndrome                                   | -.08    | .518 |
| $R = .61, R^2 = .37, F(4, 55) = 8.12, p < .001$ |         |      |

Table 6.23

*Summary of Regression Analysis for Child Variables predicting Paternal Stress*

| Variable  | $\beta$ | p    |
|---|---------|------|
| Autism  | .37     | .010 |
| Cerebral Palsy                                  | .41     | .000 |
| NCBRF   | .01     | .951 |
| BPI   | -.04    | .833 |
| REISS   | .39     | .005 |
| VABS  | -.10    | .381 |
| $R = .70, R^2 = .49, F(6, 52) = 8.31, p < .001$ |         |      |

#### 6.3.4 Child Variables predicting Paternal Ratings of Child Positive Contributions

No demographic regression analysis is provided for paternal ratings of child positive contributions, as no significant relationships emerged between demographic data and paternal ratings of child positive contributions in preliminary analyses. As indicated in Table 6.24, there were no significant predictors of paternal ratings of child positive contribution scores.

Table 6.24

*Summary of Regression Analysis for Child Variables predicting Paternal Positive Contribution Scores*

| Variable | $\beta$ | p    |
|----------|---------|------|
| NCBRF    | .22     | .181 |
| BPI      | .15     | .431 |
| Reiss    | -.06    | .753 |
| VABS     | .14     | .344 |

$R = .25$ ,  $R^2 = .06$ ,  $F(4, 54) = .88$ ,  $p = .48$

#### 6.4 Child Variables as Predictors of Parental Coping and Support

The third focus of this chapter is on the relationship between child variables and parental coping and support variables. Thus, we examine whether child variables predict the use of wishful thinking and practical coping strategies and practical and emotional support.

##### 6.4.1 Child Variables predicting Maternal Wishful Thinking

As evident in Table 6.25, autism was the only significant predictor of maternal wishful thinking. Table 6.26 presents the results of the second regression. Child psychopathology was the significant predictor of maternal wishful thinking, positively predicting this construct.

Table 6.25

*Summary of Regression Analysis Demographic Variables predicting Maternal Wishful Thinking*

| Variable                   | $\beta$ | p    |
|----------------------------|---------|------|
| Number of Adults in Family | -.13    | .143 |
| Family Income              | -.12    | .156 |
| Gender of Child            | -.14    | .100 |
| Autism                     | .23     | .013 |
| Down Syndrome              | -.05    | .540 |

$R = .39$ ,  $R^2 = .16$ ,  $F(5, 132) = 4.83$ ,  $p < .000$

Table 6.26

*Summary of Regression Analysis for Child Variables predicting Maternal Wishful Thinking*

| Variable | $\beta$ | p    |
|----------|---------|------|
| Autism   | .15     | .114 |
| NCBRF    | .10     | .301 |
| BPI      | -.12    | .386 |
| REISS    | .50     | .000 |
| VABS     | -.14    | .106 |

$R = .41, R^2 = .17, F(5, 130) = 5.36, p < .000$

#### 6.4.2 Child Variables predicting Maternal Practical Coping

No demographics variables were associated with maternal practical coping; therefore only the second regression is presented in Table 6.27. Maternal ratings of child adaptive behaviour significantly and positively predicted maternal use of practical coping.

Table 6.27

*Summary of Regression Analysis for Child Variables predicting Maternal Practical Coping*

| Variable | $\beta$ | p    |
|----------|---------|------|
| NCBRF    | -.06    | .565 |
| BPI      | .03     | .856 |
| REISS    | .01     | .937 |
| VABS     | .19     | .043 |

$R = .18, R^2 = .03, F(4, 131) = 1.13, p = .344$

#### 6.4.3 Child Variables predicting Maternal Practical Support

No demographic variables were associated with maternal practical support. Therefore, only the second regression is presented (Table 6.28). Maternal practical support was not significantly predicted by any of the child variables.

Table 6.28

*Summary of Regression Analysis for Child Variables predicting Maternal Practical Support*

| Variable | $\beta$ | p    |
|----------|---------|------|
| NCBRF    | .12     | .269 |
| BPI      | .21     | .158 |
| REISS    | -.12    | .402 |
| VABS     | -.11    | .235 |

$R = .19, R^2 = .04, F(4, 131) = 1.21, p = .311$

#### 6.4.4 Child Variables predicting Maternal Emotional Support

No demographic variables were associated with maternal use of emotional support. The results of the second regression in Table 6.29 show that maternal emotional support is not predicted by any of the child variables.

Table 6.29

*Summary of Regression Analysis for Child Variables predicting Maternal Emotional Support*

| Variable | $\beta$ | p    |
|----------|---------|------|
| NCBRF    | -.03    | .818 |
| BPI      | .04     | .808 |
| REISS    | -.22    | .138 |
| VABS     | .03     | .760 |

$R = .18, R^2 = .03, F(4, 131) = 1.12, p = .350$

#### 6.4.5 Child Variables predicting Paternal Wishful Thinking

No demographic variables were associated with paternal wishful thinking. Therefore, only one regression is presented (Table 6.30). Paternal wishful thinking was not predicted by any of the child variables.

Table 6.30

*Summary of Regression Analysis for Child Variables predicting Paternal Wishful Thinking*

| Variable  | $\beta$ | p    |
|---|---------|------|
| NCBRF   | .03     | .850 |
| BPI   | .004    | .983 |
| REISS   | -.004   | .980 |
| VABS  | .04     | .800 |
| $R = .05, R^2 = .00, F(4, 54) = 0.04, p = .997$ |         |      |

#### 6.4.6 Child Variables predicting Paternal Practical Coping

No demographic variables were associated with paternal practical coping and therefore only one regression analysis is presented. The results presented in Table 6.31 indicate that none of the child variables significantly predicted paternal practical coping.

Table 6.31

*Summary of Regression Analysis for Child Variables predicting Paternal Practical Coping*

| Variable  | $\beta$ | p    |
|---|---------|------|
| NCBRF   | -.06    | .708 |
| BPI   | -.26    | .176 |
| REISS   | .09     | .604 |
| VABS  | .05     | .728 |
| $R = .21, R^2 = .05, F(4, 54) = 0.64, p = .635$ |         |      |

#### 6.4.7 Child Variables predicting Paternal Practical Support

Only one demographic variable, the presence of Down syndrome, was associated with paternal practical support and therefore was entered into the second regression along with the child variables. The results presented in Table 6.32 show that no child variable predicts paternal practical support.

Table 6.32

*Summary of Regression Analysis for Child Variables predicting Paternal Practical Support*

| Variable      | $\beta$ | p    |
|---------------|---------|------|
| Down syndrome | .32     | .030 |
| NCBRF         | .09     | .562 |
| BPI           | .06     | .736 |
| REISS         | .10     | .589 |
| VABS          | .06     | .658 |

$R = .33, R^2 = .11, F(5, 53) = 1.27, p = .290$

#### 6.4.8 Child Variables predicting Paternal Emotional Support

No demographic variables were associated with paternal emotional support and therefore only the second regression was required (Table 6.33). No child variables significantly predicted paternal emotional support.

Table 6.33

*Summary of Regression Analysis for Child Variables predicting Paternal Emotional Support*

| Variable | $\beta$ | p    |
|----------|---------|------|
| NCBRF    | .07     | .663 |
| BPI      | .10     | .620 |
| REISS    | -.08    | .667 |
| VABS     | .09     | .544 |

$R = .13, R^2 = .02, F(4, 54) = 0.22, p = .928$

#### 6.5 Stress and Positive Contributions as Predictors of Parental Outcomes

The fourth section investigates the relationships between variables in the middle layer of the model and parental negative and positive outcomes. Given the nature of the variables, stress and positive contributions are considered together and parental resources are considered in the next section. Relationships between demographic variables and parental outcomes were established in Section 6.2; therefore only one regression is presented for each outcome, with stress and positive contributions as predictors of parental mental ill

health and positive well-being, controlling for demographic variables when relevant. Mother data are considered first and father data presented second.

#### 6.5.1 Stress and Positive Contributions predicting Maternal Anxiety

None of the demographic variables significantly predicted maternal anxiety. Therefore, the regression analysis presented in Table 6.34 does not include demographic variables. Maternal stress emerged as the only significant predictor of maternal anxiety, positively predicting this outcome.

Table 6.34

*Summary of Regression Analysis for Stress and Positive Contributions predicting Maternal Anxiety*

| Variable        | $\beta$ | p    |
|-----------------|---------|------|
| Maternal Stress | .36     | .000 |
| Maternal PCS    | .10     | .234 |

$R = .34, R^2 = .118, F(2, 135) = 9.07, p < .001$

#### 6.5.2 Stress and Positive Contributions predicting Maternal Depression

Maternal depression was significantly predicted by autism and therefore this demographic variable was controlled for in the regression analysis. As indicated in Table 6.35, depression in mothers was positively predicted by maternal stress.

Table 6.35

*Summary of Regression Analysis for Stress and Positive Contributions predicting Maternal Depression*

| Variable        | $\beta$ | p    |
|-----------------|---------|------|
| Autism          | .02     | .793 |
| Maternal Stress | .47     | .000 |
| Maternal PCS    | -.06    | .427 |

$R = .50, R^2 = .25, F(3, 134) = 15.15, p < .001$



### 6.5.3 Stress and Positive Contributions predicting Maternal Life Satisfaction

The number of adults in the family and the presence of Down syndrome were found to be the only demographic variables to significantly predict maternal life satisfaction and thus were controlled for in the next regression. Maternal stress was found to negatively predict life satisfaction in mothers (Table 6.36).

Table 6.36

*Summary of Regression Analysis for Stress and Positive Contributions predicting Maternal Life Satisfaction*

| Variable                   | $\beta$ | p    |
|----------------------------|---------|------|
| Number of Adults in Family | .07     | .366 |
| Down Syndrome              | .03     | .716 |
| Maternal Stress            | -.46    | .000 |
| Maternal PCS               | .07     | .378 |

$R = .52, R^2 = .27, F(4, 133) = 12.15, p < .001$

### 6.5.4 Stress and Positive Contributions predicting Maternal Marital State

The gender of the child and the presence of any sensory impairments were significant demographic predictors of maternal marital state. Therefore, this was controlled for in the regression analysis presented in Table 6.37. As can be seen, maternal marital state (higher scores denote more dissatisfaction) is positively predicted by maternal stress.

Table 6.37

*Summary of Regression Analysis for Stress and Positive Contributions predicting Maternal Marital State*

| Variable                       | $\beta$ | p    |
|--------------------------------|---------|------|
| Gender of Child                | .23     | .009 |
| Presence of Sensory Impairment | .21     | .021 |
| Maternal Stress                | .30     | .001 |
| Maternal PCS                   | .04     | .644 |

$R = .43, R^2 = .18, F(4, 107) = 5.93, p < .001$

### 6.5.5 Stress and Positive Contributions predicting Maternal Positive Affect

Autism was the only demographic variable found to be a significant predictor of maternal positive affect. Therefore, this was controlled for in the regression analysis. The regression analysis presented in Table 6.38 revealed that maternal positive affect was negatively predicted by maternal stress and positively predicted by maternal ratings of the child's positive contributions to the family.

Table 6.38

*Summary of Regression Analysis for Stress and Positive Contributions predicting Maternal Positive Affect*

| Variable        | $\beta$ | p    |
|-----------------|---------|------|
| Autism          | -.05    | .542 |
| Maternal Stress | -.20    | .018 |
| Maternal PCS    | .36     | .000 |

$R = .49, R^2 = .24, F(3, 134) = 14.10, p < .001$

### 6.5.6 Stress and Positive Contributions predicting Paternal Anxiety

No demographic variables were significant predictors of paternal anxiety. Consequently the regression analysis presented in Table 6.39 does not contain any demographic variables. Paternal stress was found to be the only significant predictor of anxiety in fathers, positively predicting this construct.

Table 6.39

*Summary of Regression Analysis for Stress and Positive Contributions predicting Paternal Anxiety*

| Variable        | $\beta$ | p    |
|-----------------|---------|------|
| Paternal Stress | .33     | .011 |
| Paternal PCS    | .08     | .535 |

$R = .33, R^2 = .11, F(2, 57) = 3.52, p = .04$

### 6.5.7 Stress and Positive Contributions predicting Paternal Depression

Father employment status was controlled for in the present regression analysis, as this demographic variable was found to be a significant predictor of paternal depression in

preliminary analyses. Paternal stress was revealed as a positive predictor of paternal depression.

Table 6.40

*Summary of Regression Analysis for Stress and Positive Contributions predicting Paternal Depression*

| Variable                                       | $\beta$ | p    |
|--|---------|------|
| Father employed                                | .31     | .015 |
| Paternal Stress                                | .28     | .025 |
| Paternal PCS                                   | -.06    | .615 |
| $R = .42, R^2 = .18, F(3, 56) = 3.98, p = .01$ |         |      |

#### 6.5.8 Stress and Positive Contributions predicting Paternal Life Satisfaction

Father employment was found to be a significant predictor of paternal positive affect in preliminary analyses and so this variable was controlled for in the regression analysis below (Table 6.41). Paternal ratings of positive contributions made by the child significantly (and positively) predicted life satisfaction in fathers.

Table 6.41

*Summary of Regression Analysis for Stress and Positive Contributions predicting Paternal Life Satisfaction*

| Variable  | $\beta$ | p    |
|---|---------|------|
| Father employed                                 | -.33    | .008 |
| Paternal Stress                                 | -.18    | .135 |
| Paternal PCS                                    | .34     | .006 |
| $R = .48, R^2 = .23, F(3, 56) = 5.70, p = .002$ |         |      |

#### 6.5.9 Stress and Positive Contributions predicting Paternal Marital State

No demographic variables were found to significantly predict paternal marital state. Paternal ratings of the positive contributions made by the child significantly (and negatively) predicted marital state in fathers. Thus, the fewer positive contributions the father perceived the child to make, the more dissatisfied fathers are within their relationships.

Table 6.42

*Summary of Regression Analysis for Stress and Positive Contributions predicting Paternal Marital State*

| Variable        | $\beta$ | p    |
|-----------------|---------|------|
| Paternal Stress | .22     | .082 |
| Paternal PCS    | -.27    | .034 |

$R = .36, R^2 = .13, F(2, 57) = 4.34, p = .018$

#### 6.5.10 Stress and Positive Contributions predicting Paternal Positive Affect

Father employment was the only demographic variable to significantly predict positive affect in fathers. As a result, this variable was controlled for in the regression analysis. As indicated in Table 6.43, paternal ratings of their child's positive contributions positively predicted paternal positive affect.

Table 6.43

*Summary of Regression Analysis for Stress and Positive Contributions predicting Paternal Positive Affect*

| Variable        | $\beta$ | p    |
|-----------------|---------|------|
| Father employed | -.42    | .001 |
| Paternal Stress | -.17    | .132 |
| Paternal PCS    | .36     | .002 |

$R = .55, R^2 = .30, F(3, 56) = 8.04, p < .001$

#### 6.6 Parental Resources as Predictors of Parental Outcomes

This section focuses on the direct relationships between parental resources and outcomes. The regression analyses in this section examine whether parental resources, that is, coping and support strategies, predict parental outcomes concerning mental ill health and positive well-being. Again, correlation and regression analyses have been conducted in previous sections to identify the demographic variables that significantly predict parental outcomes. Therefore, only one regression is presented with parental resources as predictors of parental outcomes, while controlling for relevant demographic variables.

### 6.6.1 Maternal Resources predicting Maternal Anxiety

No demographic variables were significantly associated with maternal anxiety. As indicated in Table 6.44, maternal wishful thinking was a significant positive predictor of anxiety in mothers.

Table 6.44

*Summary of Regression Analysis for Maternal Resources predicting Maternal Anxiety*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Wishful Thinking  | .60     | .000 |
| Practical Coping  | .07     | .334 |
| Practical Support | .11     | .235 |
| Emotional Support | -.08    | .440 |

$R = .62, R^2 = .38, F(4, 133) = 20.76, p < .001$

### 6.6.2 Maternal Resources predicting Maternal Depression

Previous regression analyses revealed that autism was a significant predictor of maternal depression and was therefore entered in the current regression analysis. The results in Table 6.45 show that maternal wishful thinking significantly and positively predicted depression in mothers.

Table 6.45

*Summary of Regression Analysis for Maternal Resources predicting Maternal Depression*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Autism            | -.06    | .390 |
| Wishful Thinking  | .55     | .000 |
| Practical Coping  | -.04    | .619 |
| Practical Support | .01     | .944 |
| Emotional Support | -.19    | .060 |

$R = .65, R^2 = .42, F(6, 131) = 15.97, p < .001$

### 6.6.3 Maternal Resources predicting Maternal Life Satisfaction

Previous regressions for demographic variables established that maternal life satisfaction was significantly predicted by the number of adults in the family and the presence of

Down syndrome. Therefore, these were entered into the regression with maternal resources to predict maternal life satisfaction (Table 6.46). Maternal life satisfaction was predicted negatively by wishful thinking predicted and positively by practical coping.

Table 6.46

*Summary of Regression Analysis for Maternal Resources predicting Maternal Life Satisfaction*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Number of Adults  | .08     | .248 |
| Down syndrome     | .06     | .400 |
| Wishful Thinking  | -.52    | .000 |
| Practical Coping  | .16     | .030 |
| Practical Support | .01     | .931 |
| Emotional Support | .15     | .142 |

$R = .64$ ,  $R^2 = .41$ ,  $F(6, 131) = 15.12$ ,  $p < .001$

#### 6.6.4 Maternal Resources predicting Maternal Marital State

Previous analyses established that the gender of the child and the presence of any sensory problems significantly predicted maternal marital state, therefore these variables were entered into the regression to control for their effects. Table 6.47 presents the results of the regression. Maternal wishful thinking was found to significantly and positively predict marital state, bearing in mind that higher scores indicate greater dissatisfaction.

Table 6.47

*Summary of Regression Analysis for Maternal Resources predicting Maternal Marital State*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Gender of Child   | -.20    | .023 |
| Sensory Problems  | -.19    | .028 |
| Wishful Thinking  | .23     | .012 |
| Practical Coping  | -.10    | .284 |
| Practical Support | -.06    | .630 |
| Emotional Support | -.16    | .203 |

$R = .48, R^2 = .23, F(6, 105) = 5.20, p < .001$

#### 6.6.5 Maternal Resources predicting Maternal Positive Affect

Previous analyses indicated that autism was a significant demographic predictor of maternal positive affect and so this variable was controlled for in the regression presented in Table 6.48. Maternal positive affect was predicted negatively by wishful thinking and positively by practical coping.

Table 6.48

*Summary of Regression Analysis for Maternal Resources predicting Maternal Positive Affect*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Autism            | -.14    | .068 |
| Wishful Thinking  | -.38    | .000 |
| Practical Coping  | .35     | .000 |
| Practical Support | .17     | .072 |
| Emotional Support | .02     | .864 |

$R = .60, R^2 = .36, F(5, 132) = 14.91, p < .001$

#### 6.6.6 Paternal Resources predicting Paternal Anxiety

No demographic variables were associated with paternal anxiety and so only the paternal resources were entered into the regression analysis presented in Table 6.49. Paternal wishful thinking was found to be a significant and positive predictor of paternal anxiety.



Table 6.49

*Summary of Regression Analysis for Paternal Resources predicting Paternal Anxiety*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Wishful Thinking  | .64     | .000 |
| Practical Coping  | -.14    | .182 |
| Practical Support | .003    | .981 |
| Emotional Support | -.10    | .470 |

$R = .69, R^2 = .47, F(4, 55) = 12.16, p < .001$

#### 6.6.7 Paternal Resources predicting Paternal Depression

Father employment status was the only demographic variable associated with paternal depression and so was entered into the regression analysis presented in Table 6.50.

Paternal wishful thinking and practical support significantly and positively predicted paternal depression and paternal emotional support negatively predicted this outcome.

Table 6.50

*Summary of Regression Analysis for Paternal Resources predicting Paternal Depression*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Father Job        | .09     | .328 |
| Wishful Thinking  | .62     | .000 |
| Practical Coping  | -.15    | .123 |
| Practical Support | .31     | .014 |
| Emotional Support | -.43    | .001 |

$R = .77, R^2 = .59, F(5, 54) = 15.47, p < .001$

#### 6.6.8 Paternal Resources predicting Paternal Life Satisfaction

Father employment status was found to be the only significant demographic predictor of paternal life satisfaction. In order to control for its effects, father employment status was entered into the regression alongside the paternal resource variables. Table 6.51 presents the results of this regression analysis. Paternal wishful thinking was a significant negative predictor of paternal life satisfaction.

Table 6.51

*Summary of Regression Analysis for Paternal Resources predicting Paternal Life Satisfaction*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Father Job        | -.17    | .162 |
| Wishful Thinking  | -.35    | .006 |
| Practical Coping  | .22     | .083 |
| Practical Support | .12     | .468 |
| Emotional Support | -.05    | .772 |

$R = .52, R^2 = .27, F(5, 54) = 3.91, p = .004$

#### 6.6.9 Paternal Resources predicting Paternal Marital State

No demographic variables were associated with paternal marital state. The regression analysis presented in Table 6.52 indicates that paternal marital state is predicted positively by paternal practical support and negatively by emotional support.

Table 6.52

*Summary of Regression Analysis for Paternal Resources predicting Paternal Marital State*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Wishful Thinking  | .02     | .861 |
| Practical Coping  | -.15    | .252 |
| Practical Support | .42     | .016 |
| Emotional Support | -.46    | .010 |

$R = .42, R^2 = .18, F(4, 55) = 2.91, p = .029$

#### 6.6.10 Paternal Resources predicting Paternal Positive Affect

Previous regression analyses identified that father employment status was a significant demographic predictor of paternal positive affect and therefore was entered into the regression analysis presented in Table 6.53. Paternal wishful thinking was found to be a significant and negative predictor of paternal positive affect.

Table 6.53

*Summary of Regression Analysis for Paternal Resources predicting Paternal Positive Affect*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Father Job        | -.21    | .054 |
| Wishful Thinking  | -.53    | .000 |
| Practical Coping  | .06     | .575 |
| Practical Support | .08     | .596 |
| Emotional Support | .09     | .537 |

$R = .65$ ,  $R^2 = .42$ ,  $F(5, 54) = 7.89$ ,  $p < .001$

### 6.7 Parental Resources as Predictors of Stress and Positive Contributions

The relationships between parental resources, and stress and positive contributions are not a primary focus of the thesis. However, it is necessary to examine whether parental resources predict stress and perceptions of positive contributions, to enable the planning of mediational analyses later in this chapter.

#### 6.7.1 Maternal Resources predicting Maternal Stress

Earlier regressions analyses established that the number of adults in the family and autism were significant demographic predictors of maternal stress. Therefore, these were entered into the regression analysis presented in Table 6.54 where maternal resources were predicting maternal stress. Maternal stress was positively predicted by maternal wishful thinking and negatively by maternal emotional support.

Table 6.54

*Summary of Regression Analysis for Maternal Resources predicting Maternal Stress*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Number of Adults  | -.15    | .043 |
| Autism            | .31     | .000 |
| Wishful Thinking  | .29     | .000 |
| Practical Coping  | -.04    | .565 |
| Practical Support | .15     | .114 |
| Emotional Support | -.22    | .039 |

$R = .59, R^2 = .35, F(6, 131) = 11.90, p < .001$

### 6.7.2 Maternal Resources predicting Maternal Ratings of Child Positive Contributions

Previous regression analyses found that autism and Down syndrome were significant demographic predictors of maternal ratings of child positive contributions. Therefore, they were entered into the regression analysis presented in Table 6.55 in order to control for their effects. Maternal practical coping was found to significantly and positively predict her perceptions of the positive contributions made by the child.

Table 6.55

*Summary of Regression Analysis for Maternal Resources predicting Maternal Positive Contributions*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Autism            | -.18    | .028 |
| Down syndrome     | .13     | .101 |
| Wishful Thinking  | -.06    | .450 |
| Practical Coping  | .29     | .000 |
| Practical Support | .11     | .264 |
| Emotional Support | .17     | .122 |

$R = .53, R^2 = .28, F(6, 131) = 8.42, p < .001$

### 6.7.3 Paternal Resources predicting Paternal Stress

Paternal stress was found to be significantly predicted by the demographic variables of autism and cerebral palsy and so these variables were controlled for in the regression analysis. Paternal wishful thinking was found to positively predict paternal stress.

Table 6.56

*Summary of Regression Analysis for Paternal Resources predicting Paternal Stress*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Autism            | .55     | .000 |
| Cerebral Palsy    | .34     | .002 |
| Wishful Thinking  | .25     | .018 |
| Practical Coping  | -.10    | .346 |
| Practical Support | .15     | .296 |
| Emotional Support | -.20    | .192 |

$R = .69$ ,  $R^2 = .47$ ,  $F(6, 53) = 7.80$ ,  $p < .001$

### 6.7.4 Paternal Resources predicting Paternal Positive Contributions

No demographic variables were associated with paternal ratings of child positive contributions and therefore no demographic variables were included in the regression analysis (Table 6.57). Both paternal practical coping and paternal practical support were positive predictors of paternal perceptions of the positive contributions made by his child.

Table 6.57

*Summary of Regression Analysis for Paternal Resources predicting Paternal Positive Contributions*

| Variable          | $\beta$ | p    |
|-------------------|---------|------|
| Wishful Thinking  | .12     | .266 |
| Practical Coping  | .27     | .022 |
| Practical Support | .38     | .012 |
| Emotional Support | .13     | .389 |

$R = .61$ ,  $R^2 = .37$ ,  $F(4, 55) = 7.93$ ,  $p < .001$

### 6.8 Summary of Direct Cross-Sectional Relationships

Figures 6.2 and 6.3 represent a summary of the relationships that have been established among the main study variables so far, through a series of simultaneous regression analyses. Figures 6.4 and 6.5 represent a summary of the relationships identified between parental resources and the other variables in the model. These relationships provide the basis for analyses in the following section, which investigate coping and support variables as possible mediators and moderators of relationships between other variables in the model.

### 6.9 Mediated and Moderated Relationships

In Chapter 3, mediating and moderating relationships were discussed with specific regard to their conceptual and statistical considerations. Before analysing the potential mediated and moderated relationships that may be present in the model, it is pertinent to briefly return to the theoretical basis for these concepts. The procedure/process for analysing mediation is considered first, followed by the analysis of potential mediating relationships within the presented model. Moderating relationships are then considered, with a discussion of the procedure for analysing moderating relationships, followed by analysis of potential moderation relationships present within the model.

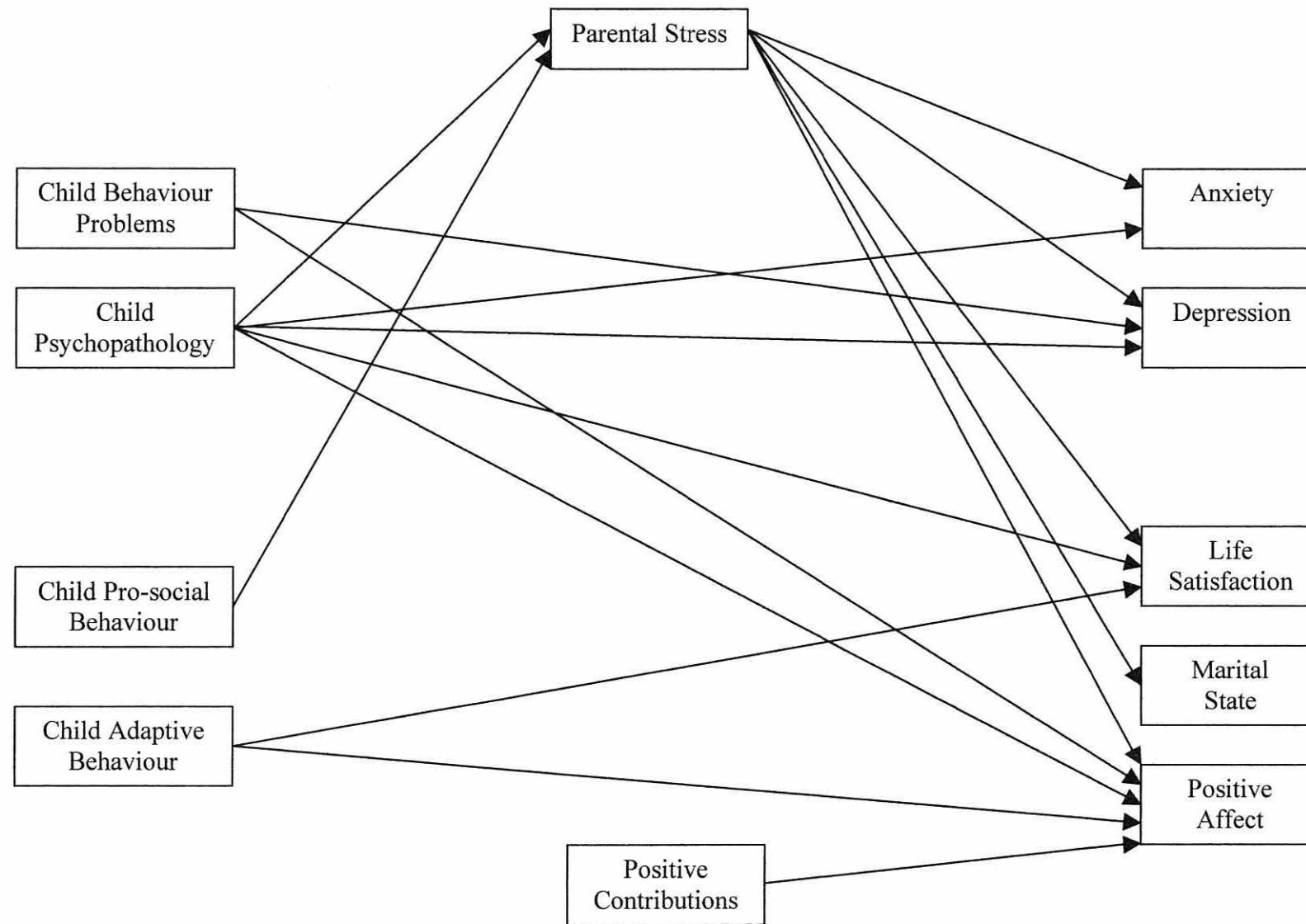


Figure 6.2 Relationships between the main study variables established by regression (Mothers)



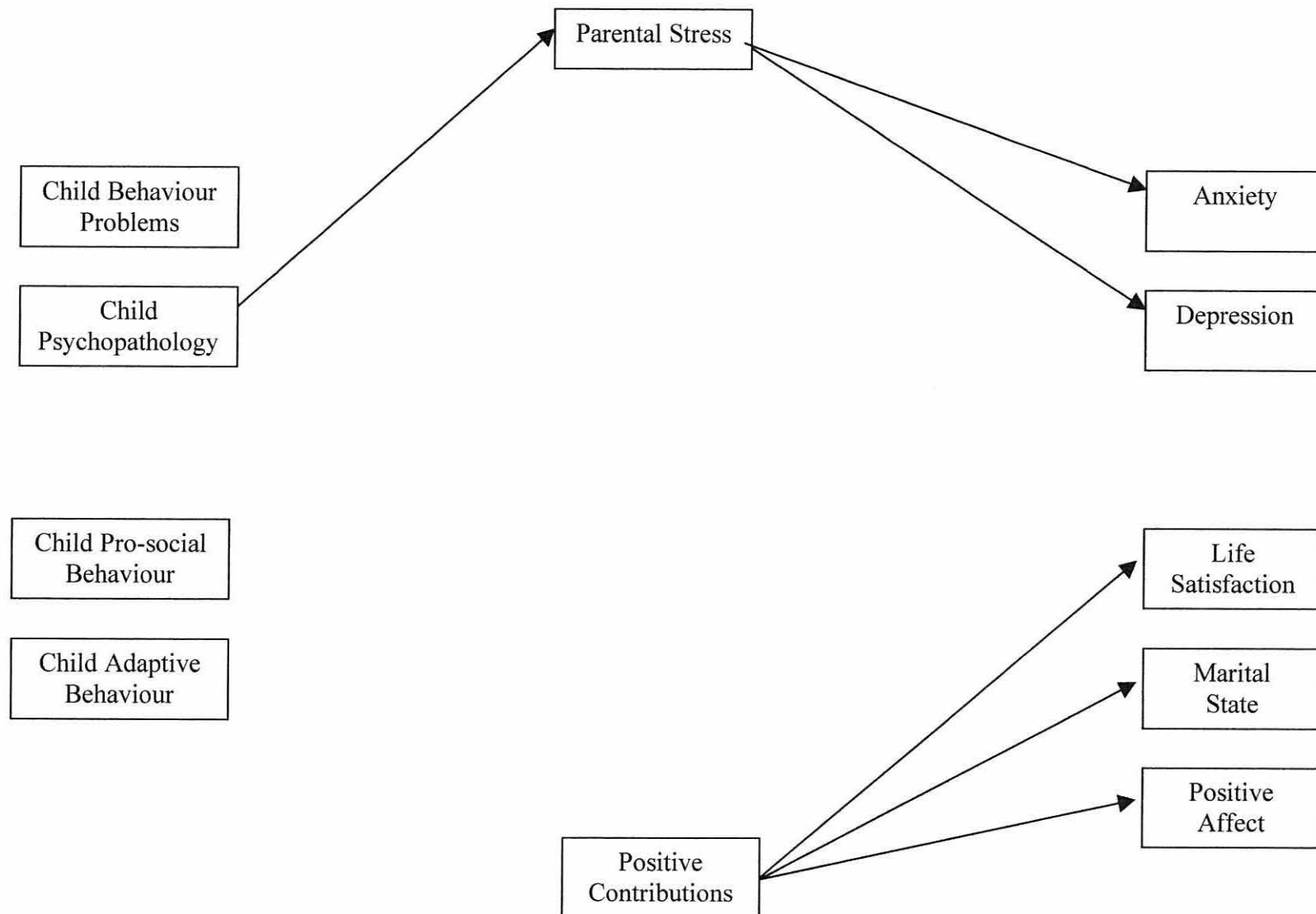
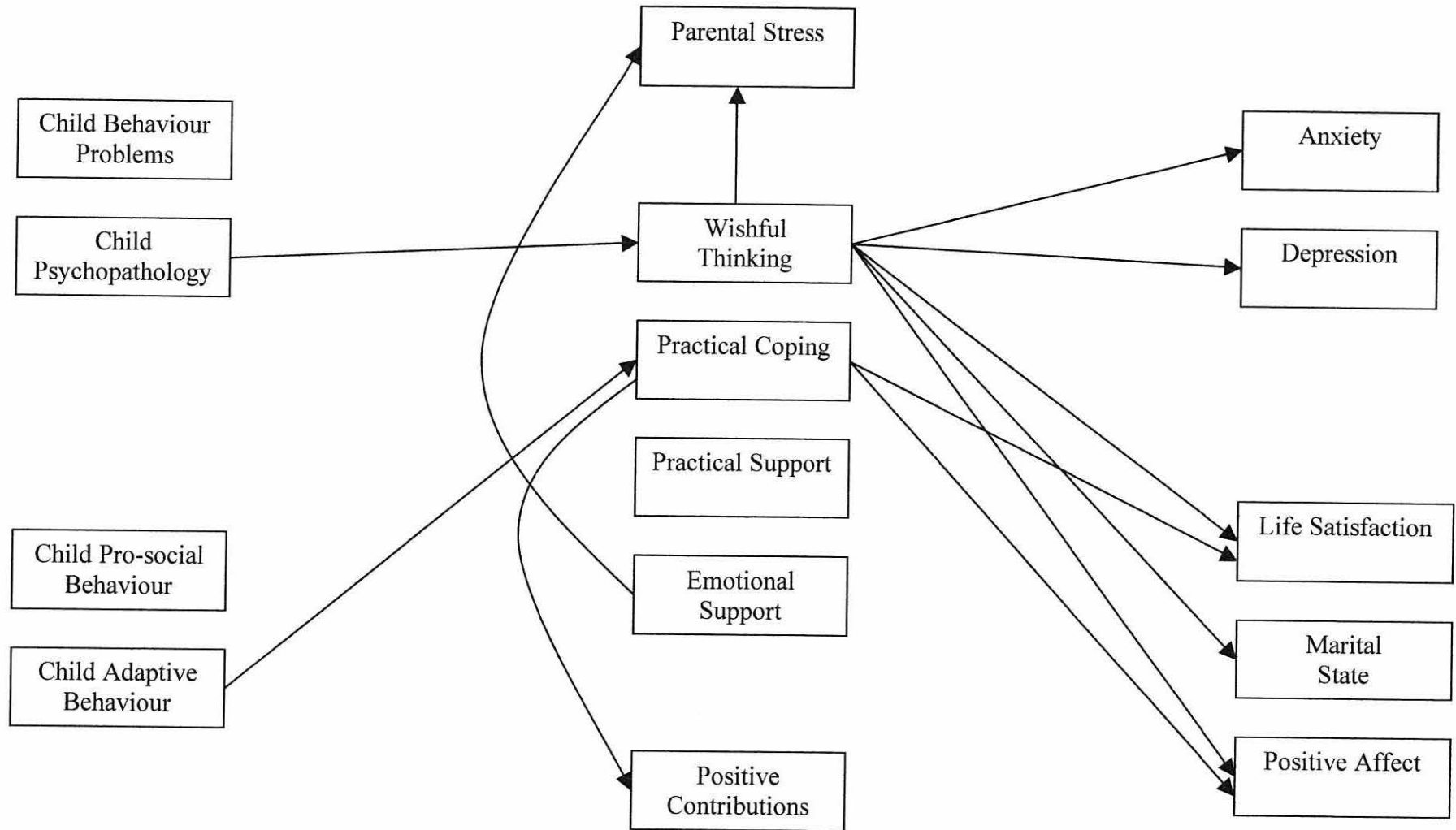


Figure 6.3 Relationships between the main study variables established by regression (Fathers)



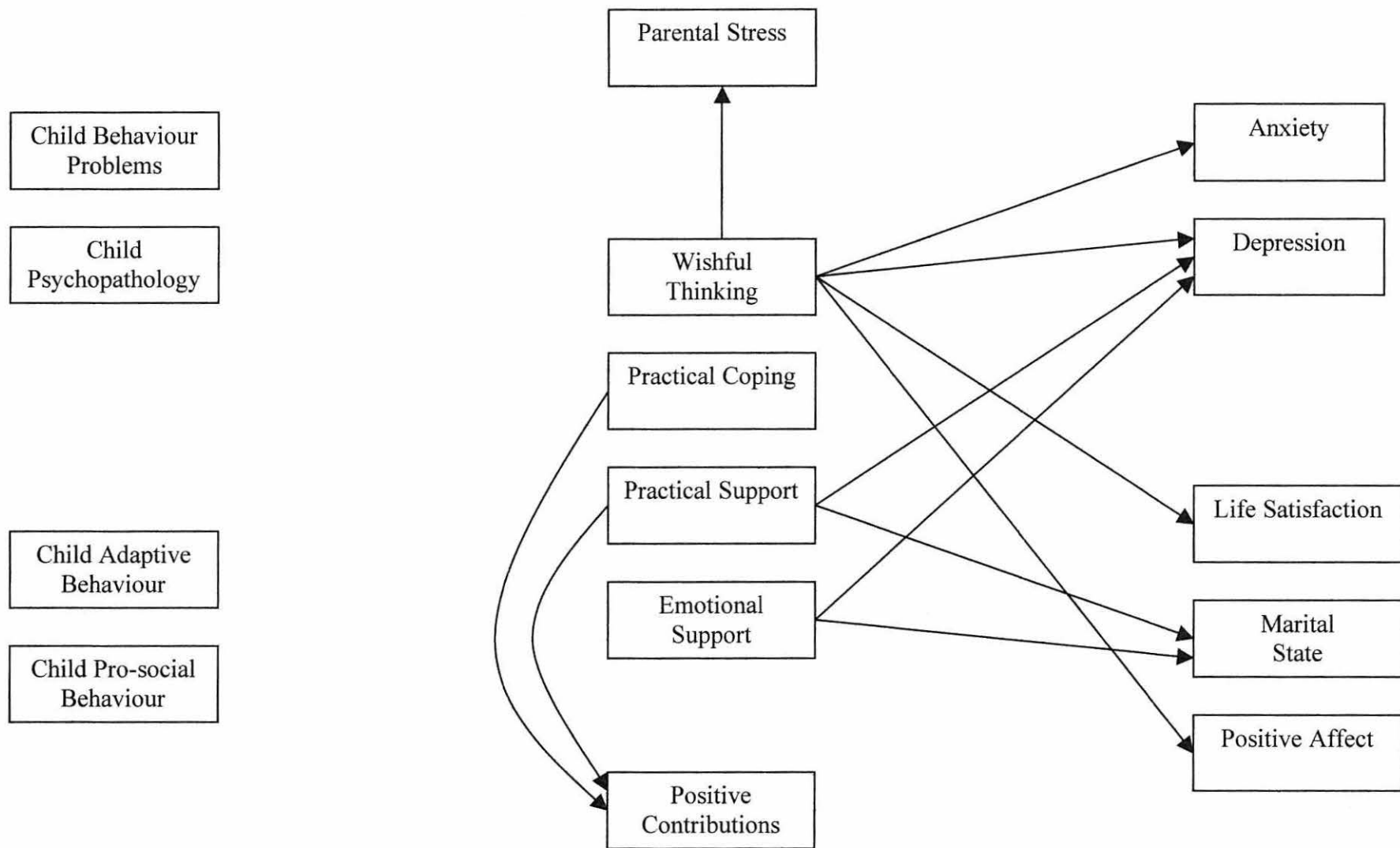


Figure 6.5 Relationships between the resource variables and main study variables established by regression (Fathers)

### 6.10 Mediation

Following the Baron and Kenny (1986) steps required to ascertain the presence of mediation, evidence of three relationships is needed. This is illustrated in the diagram below:

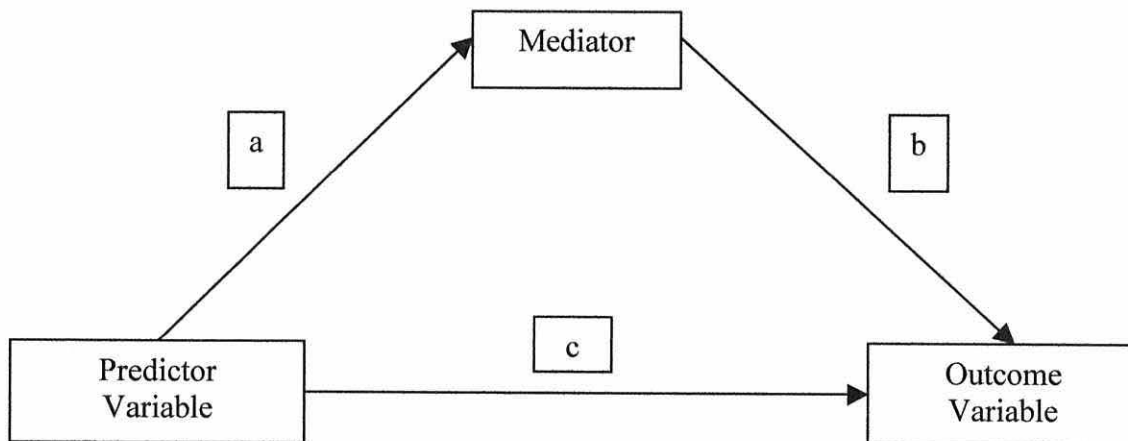


Figure 6.6 Mediation Model (Based on Baron and Kenny, 1986)

With a three-variable system, two causal paths feed into the outcome variable: the direct impact of the predictor variable (path c) and the impact of the mediator (path b). There also exists a path from the predictor variable to the mediator (path a). Judd and Kenny (1981) recommend that a series of regression models should be estimated to test for mediation: First, the mediator is regressed onto the predictor variable; second, the outcome variable is regressed onto the predictor variable; and third, the outcome variable is regressed onto both the predictor variable and the mediator. For mediation to hold, three conditions must be met: 1) the predictor variable must affect the mediator in the first equation; 2) the predictor variable must be shown to affect the outcome variable in the second equation; 3) the mediator must affect the outcome variable in the third equation. The effect of the predictor variable on the outcome variable must be less in the third equation than in the second. Perfect mediation occurs if the independent variable has no effect when the mediator is controlled.

From the results presented in Figures 6.2-6.5 it is possible to identify a number of relationships that satisfy the requirements for mediation. For example, relationships have been identified between child psychopathology and maternal stress, between child

psychopathology and maternal anxiety, and between maternal stress and maternal anxiety. According to the recommendations of Baron and Kenny (1986), the presence of these three relationships indicates that maternal stress may be functioning as a mediator of the relationship between child psychopathology and maternal anxiety. This example is analysed in full in the next section (6.10.1). Regressions investigating subsequent mediating relationships are presented in a briefer format, since all mediation analyses follow the format presented in Figure 6.6.

First, parental stress is examined as mediator of the relationship between child variables and parental outcomes (i.e., mental ill health and positive well-being), where direct relationships were identified in the preceding regressions. Theoretically, we would also examine positive contributions as a mediator of the relationship between child variables and parental outcomes. However, previous regressions did not identify any of the child variables as predictors of positive contributions, meaning that the prerequisites for testing mediation were not satisfied.

### 6.11 Stress as a Mediator in Mothers

#### 6.11.1 Stress as Mediator of the Child Psychopathology-Maternal Anxiety Relationship

Regression 1, presented in Table 6.58, shows a significant relationship between child psychopathology and maternal anxiety, which has also been established in preceding regression analyses. A significant relationship between child psychopathology and maternal stress emerged in Regression 2. In Regression 3, both child psychopathology and maternal stress were entered together as predictor variables to predict the outcome variable, maternal anxiety. If maternal stress mediates the effect of child psychopathology on maternal anxiety, we would expect to see a reduction in the beta weight from Regression 1 to Regression 3. This is indeed the case, as evident in Table 6.58. Partial mediation is indicated, as the beta weight for Reiss in Regression 3 is not equal to zero. This is sufficient to establish partial mediation of the child psychopathology-maternal anxiety relationship. A Sobel test was consequently conducted, which established that maternal stress is not a significant partial mediator of the relationships between child psychopathology and maternal anxiety, that is, the *indirect effect* was non-significant.

Table 6.58

*Regression Analyses for Stress as Mediator of the Child Psychopathology-Maternal Anxiety Relationship*

| Regression | Predictors | Outcome | B (SE)      | $\beta$ | t       |
|------------|------------|---------|-------------|---------|---------|
| 1          | REISS      | Anxiety | 0.09 (0.02) | 0.41    | 5.31*** |
| 2          | REISS      | Stress  | 0.10 (0.01) | 0.50    | 6.73*** |
| 3          | REISS      | Anxiety | 0.07 (0.02) | 0.33    | 3.72*** |
|            | Stress     | Anxiety | 0.18 (0.10) | 0.17    | 1.84    |
| SOBELS     |            |         |             |         | 1.78**  |

\*p<.05, \*\*p<.01, \*\*\*p<.001

6.11.2 Stress as Mediator of the Child Psychopathology-Maternal Depression Relationship

If maternal stress mediates the effect of child psychopathology on maternal depression, we would expect to see a reduction in the beta weight from Regression 1 to Regression 3. Table 6.59 indicates this to be the case. Partial mediation is indicated the child psychopathology-maternal depression relationship, as the beta weight for child psychopathology in Regression 3 is not equal to zero. A Sobel test was consequently conducted, which was non-significant. Thus, the indirect effect of the predictor variable on the outcome variable via the mediator is non-significant.

Table 6.59

*Regression Analyses for Stress as Mediator of the Child Psychopathology-Maternal Depression Relationship*

| Regression | Predictors | Outcome    | B (SE)      | $\beta$ | t       |
|------------|------------|------------|-------------|---------|---------|
| 1          | REISS      | Depression | 0.08 (0.02) | 0.44    | 5.69*** |
| 2          | REISS      | Stress     | 0.10 (0.01) | 0.50    | 6.73*** |
| 3          | REISS      | Depression | 0.05 (0.07) | 0.27    | 3.25**  |
|            | Stress     | Depression | 0.35 (0.09) | 0.35    | 4.11*** |
| SOBELS     |            |            |             |         | 0.41    |

\*p<.05, \*\*p<.01, \*\*\*p<.001

### 6.11.3 Stress as Mediator of the Child Psychopathology-Maternal Life Satisfaction Relationship

If maternal stress mediates the effect of child psychopathology on maternal life satisfaction, we would expect to see a reduction in the beta weight from Regression 1 to Regression 3. Table 6.60 indicates this to be the case. Given that the beta weight for child psychopathology in Regression 3 is so close to zero, full mediation is indicated in the child psychopathology-maternal life satisfaction relationship. A Sobel test was consequently conducted. The Sobel statistic revealed that the indirect effect of the predictor variable on the outcome variable via the mediator is significant. Therefore, maternal stress mediates the relationship between child psychopathology and maternal life satisfaction.

Table 6.60

*Regression Analyses for Stress as Mediator of Child Psychopathology-Maternal Life Satisfaction Relationship*

| Regression | Predictors | Outcomes          | B (SE)        | $\beta$ | t        |
|------------|------------|-------------------|---------------|---------|----------|
| 1          | REISS      | Life Satisfaction | -0.08 (0.04)  | -0.21   | -2.42*   |
| 2          | REISS      | Stress            | 0.10 (0.01)   | 0.50    | 6.73***  |
| 3          | REISS      | Life Satisfaction | -0.001 (0.04) | -0.003  | -0.04    |
|            | Stress     | Life Satisfaction | -0.99 (0.18)  | -0.48   | -5.40*** |
| SOBELS     |            |                   |               |         | -4.24*** |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

### 6.11.4 Stress as Mediator of the Child Psychopathology-Maternal Positive Affect Relationship

If maternal stress mediates the effect of child psychopathology on maternal positive affect, we would expect to see a reduction in the beta weight from Regression 1 to Regression 3. Table 6.61 indicates this to be the case. Partial mediation is indicated the child psychopathology-maternal positive affect relationship, as the beta weight for child psychopathology in Regression 3 is not equal to zero. A Sobel test was consequently conducted and maternal stress emerged as a significant mediator of the relationship between child psychopathology and maternal positive affect.



Table 6.61

*Regression Analyses for Stress as Mediator of Child Psychopathology-Maternal Positive Affect Relationship*

| Regression | Predictors | Outcome         | B (SE)       | $\beta$ | t       |
|------------|------------|-----------------|--------------|---------|---------|
| 1          | REISS      | Positive Affect | -0.12 (0.04) | -0.27   | -2.83** |
| 2          | REISS      | Stress          | 0.10 (0.01)  | 0.50    | 6.73*** |
| 3          | REISS      | Positive Affect | -0.08 (0.04) | -0.18   | -1.83   |
|            | Stress     | Positive Affect | -0.51 (0.21) | -0.23   | -2.38*  |
| SOBELS     |            |                 |              |         | -2.24** |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

6.12 Maternal Coping and Support as Mediators

The next set of analyses focuses on the potential mediating effects of parental resource variables of coping and support. Where previous regression analyses established the necessary direct relationships, parental use of wishful thinking and practical coping, and practical and emotional support strategies are examined as mediators of the relationships between child variables and parental outcomes, between child variables and stress/positive contributions, and between stress/ positive contributions and parental outcomes.

6.12.1 Wishful Thinking as Mediator of the Child Psychopathology-Maternal Anxiety Relationship

If maternal wishful thinking coping strategy mediates the effect of child psychopathology on maternal anxiety, we would expect to see a reduction in the beta weight from Regression 1 to Regression 3. Table 6.62 indicates this to be the case. Partial mediation is indicated the child psychopathology-maternal anxiety relationship, as the beta weight for Reiss in Regression 3 is not equal to zero. A Sobel test was consequently conducted, indicating that the indirect effect of the predictor variable on the outcome variable via the mediator is significant. Thus, the relationship between child psychopathology and maternal anxiety is partially mediated by maternal wishful thinking.

Table 6.62

*Regression Analyses for Wishful Thinking as Mediator of Child Psychopathology-Maternal Anxiety Relationship*

| Regression | Predictors       | Outcome          | B (SE)       | $\beta$ | t       |
|------------|------------------|------------------|--------------|---------|---------|
| 1          | REISS            | Anxiety          | 0.07 (0.02)  | 0.41    | 5.31*** |
| 2          | REISS            | Wishful Thinking | 0.12 (0.02)  | 0.44    | 5.77*** |
| 3          | REISS            | Anxiety          | 0.037 (0.02) | 0.18    | 2.39*   |
|            | Wishful Thinking | Anxiety          | 0.43 (0.06)  | 0.53    | 7.17*** |
| SOBELS     |                  |                  |              |         | 4.53*** |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

6.12.2 Wishful thinking as Mediator of the Child Psychopathology-Maternal Depression Relationship

If maternal wishful thinking coping strategy mediates the effect of child psychopathology on maternal depression, we would expect to see a reduction in the beta weight from Regression 1 to Regression 3. Table 6.63 indicates this to be the case. Partial mediation is indicated in the child psychopathology-maternal depression relationship, as the beta weight for Reiss in Regression 3 is not equal to zero. The Sobel test was significant indicating that the partially mediated relationship is significant.

Table 6.63

*Regression Analyses for Wishful Thinking as Mediator of Child Psychopathology-Maternal Depression Relationship*

| Regression | Predictors       | Outcome          | B (SE)      | $\beta$ | t       |
|------------|------------------|------------------|-------------|---------|---------|
| 1          | REISS            | Depression       | 0.09 (0.02) | 0.44    | 5.69*** |
| 2          | REISS            | Wishful Thinking | 0.12 (0.02) | 0.44    | 5.77*** |
| 3          | REISS            | Depression       | 0.04 (0.01) | 0.22    | 2.98**  |
|            | Wishful Thinking | Depression       | 0.38 (0.06) | 0.51    | 6.91*** |
| SOBELS     |                  |                  |             |         | 4.44*** |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

### 6.12.3 Wishful Thinking as Mediator of the Child Psychopathology-Maternal Life Satisfaction Relationship

If mothers' use of wishful thinking coping strategies mediates the effect of child psychopathology on maternal life satisfaction, we would expect to see a reduction in the magnitude of the beta weight from Regression 1 to Regression 3. Table 6.64 indicates that this is the case. The table shows that when the mediator is included in Regression 3, the absolute value of the beta weight decreases to almost zero, indicating that full mediation is occurring. A Sobel test was consequently conducted, confirming maternal wishful thinking as a significant mediator of the relationship between child psychopathology and maternal life satisfaction. Thus, high child psychopathology increases the use of wishful thinking, which reduces maternal life satisfaction.

Table 6.64

*Regression Analyses for Wishful Thinking as Mediator of Child Psychopathology–Maternal Life Satisfaction Relationship*

| Regression | Predictors       | Outcome           | B (SE)        | $\beta$ | t        |
|------------|------------------|-------------------|---------------|---------|----------|
| 1          | REISS            | Life Satisfaction | -0.08 (0.04)  | -0.21   | -2.42*   |
| 2          | REISS            | Wishful Thinking  | 0.12 (0.02)   | 0.44    | 5.77***  |
| 3          | REISS            | Life Satisfaction | 0.0089 (0.03) | 0.02    | 0.27     |
|            | Wishful Thinking | Life Satisfaction | -0.85 (0.12)  | -0.56   | -7.13*** |
| SOBELS     |                  |                   |               |         | -4.50*** |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

### 6.12.4 Wishful thinking as Mediator of the Child Psychopathology-Maternal Positive Affect Relationship

A reduction in the beta weight from Regression 1 to Regression 3 was observed, indicating that maternal wishful thinking coping strategy mediates the effect of child psychopathology on maternal positive affect. Table 6.65 shows a reduction in the negativity of the beta. Partial mediation is indicated in the child psychopathology-positive affect relationship, as the beta weight for child psychopathology in Regression 3 is not equal to zero. The indirect effect of child psychopathology on positive affect via the wishful thinking is significant, as revealed by the significant Sobel test.

Table 6.65

*Regression Analyses for Wishful Thinking as Mediator of Child Psychopathology-Maternal Positive Affect Relationship*

| Regression | Predictors       | Outcome          | B (SE)       | $\beta$ | t        |
|------------|------------------|------------------|--------------|---------|----------|
| 1          | REISS            | Positive Affect  | -0.12 (0.04) | -0.27   | -2.83**  |
| 2          | REISS            | Wishful Thinking | 0.12 (0.02)  | 0.44    | 5.77***  |
| 3          | REISS            | Positive Affect  | -0.06 (0.04) | -0.13   | -1.35    |
|            | Wishful Thinking | Positive Affect  | -0.59 (0.14) | -0.36   | -4.12*** |
| SOBELS     |                  |                  |              |         | -3.36*** |

\*p<.05, \*\*p<.01, \*\*\*p<.001

#### 6.12.4 Practical Coping as Mediator of the Child Adaptive Behaviour-Maternal Life Satisfaction Relationship

Table 6.66 shows a slight decrease in beta weight from Regression 1 to Regression 3 indicating partial mediation of the child adaptive behaviour-maternal life satisfaction relationship. A Sobel test was consequently conducted, which was non-significant and therefore there is no significant indirect effect of the predictor variable on the outcome variable via the mediator.

Table 6.66

*Regression Analyses for Practical Coping as mediator of the Child Adaptive Behaviour-Maternal Life Satisfaction Relationship*

| Regression | Predictors       | Outcome           | B (SE)      | $\beta$ | t     |
|------------|------------------|-------------------|-------------|---------|-------|
| 1          | VABS             | Life Satisfaction | 0.08 (0.04) | 0.19    | 2.30* |
| 2          | VABS             | Practical Coping  | 0.04 (0.02) | 0.16    | 1.91  |
| 3          | VABS             | Life Satisfaction | 0.07 (0.04) | 0.17    | 2.03* |
|            | Practical Coping | Life Satisfaction | 0.25 (0.14) | 0.15    | 1.72  |
| SOBELS     |                  |                   |             |         | 1.29  |

\*p<.05, \*\*p<.01, \*\*\*p<.001

### 6.12.5 Practical Coping as Mediator of the Child Adaptive Behaviour-Maternal Positive Affect Relationship

Table 6.67 shows a slight decrease in the beta weight for child adaptive behaviour indicating partial mediation of the child adaptive behaviour-maternal positive affect relationship. The Sobel test was non-significant and therefore no partial mediation was occurring.

Table 6.67

*Regression Analyses for Practical Coping as Mediator of Adaptive Behaviour–Maternal Positive Affect Relationship*

| Regression | Predictors       | Outcome          | B (SE)      | $\beta$ | t       |
|------------|------------------|------------------|-------------|---------|---------|
| 1          | VABS             | Positive Affect  | 0.10 (0.04) | 0.21    | 2.58*   |
| 2          | VABS             | Practical Coping | 0.04 (0.02) | 0.16    | 1.91    |
| 3          | VABS             | Positive Affect  | 0.07 (0.04) | 0.16    | 2.01*   |
|            | Practical Coping | Positive Affect  | 0.62 (0.15) | 0.33    | 4.19*** |
| SOBELS     |                  |                  |             |         | 1.77    |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

### 6.12.6 Wishful Thinking as Mediator of the Child Psychopathology-Maternal Stress Relationship

A wishful thinking coping strategy in mothers was found to partially mediate the child psychopathology-maternal stress relationship, as a reduction in the beta weight for child psychopathology was evident from Regression 1 to Regression 3 (Table 6.68). The Sobel test was significant and therefore the indirect effect via wishful thinking was significant.

Table 6.68

*Regression Analyses of Wishful Thinking as Mediator of Child Psychopathology-Maternal Stress Relationship*

| Regression | Predictors       | Outcome          | B (SE)      | $\beta$ | t       |
|------------|------------------|------------------|-------------|---------|---------|
| 1          | REISS            | Stress           | 0.07 (0.02) | 0.36    | 4.39*** |
| 2          | REISS            | Wishful Thinking | 0.12 (0.02) | 0.44    | 5.77*** |
| 3          | REISS            | Stress           | 0.05 (0.02) | 0.27    | 3.15**  |
|            | Wishful Thinking | Stress           | 0.18 (0.06) | 0.25    | 3.19**  |
| SOBELS     |                  |                  |             |         | 2.81*** |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

6.12.7 Wishful Thinking as Mediator of the Maternal Stress-Maternal Anxiety Relationship

Mediation was indicated in the maternal stress-anxiety relationship as the beta weight for maternal stress reduced from Regression 1 to Regression 3 (Table 6.69). Given that the beta weight in the third regression reduced to almost zero, the relationship between maternal stress and maternal anxiety appears to be almost completely mediated by the mothers' use of wishful thinking coping strategies. A Sobel test revealed that the indirect effect of the mediator was significant and so wishful thinking mediates the relationship between maternal stress and anxiety.

Table 6.69

*Regression Analyses for Wishful Thinking as Mediator of Stress-Maternal Anxiety Relationship*

| Regression | Predictors       | Outcome          | B (SE)      | $\beta$ | t       |
|------------|------------------|------------------|-------------|---------|---------|
| 1          | Stress           | Anxiety          | 0.36 (0.09) | 0.33    | 4.08*** |
| 2          | Stress           | Wishful Thinking | 0.62 (0.10) | 0.46    | 6.00*** |
| 3          | Stress           | Anxiety          | 0.07 (0.08) | 0.06    | 0.83    |
|            | Wishful Thinking | Anxiety          | 0.47 (0.06) | 0.58    | 7.64*** |
| SOBELS     |                  |                  |             |         | 4.80*** |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

### 6.12.8 Wishful Thinking as Mediator of the Maternal Stress-Maternal Depression Relationship

As shown in Table 6.70, maternal wishful thinking coping strategy partially mediates the effect of stress on maternal depression. The indirect effect of the predictor variable on the outcome variable via the mediator was found to be significant in a subsequent Sobel test.

Table 6.70

*Regression Analyses for Wishful Thinking as Mediator of the Stress–Maternal Depression Relationship*

| Regression | Predictors       | Outcome          | B (SE)      | $\beta$ | t       |
|------------|------------------|------------------|-------------|---------|---------|
| 1          | Stress           | Depression       | 0.49 (0.08) | 0.48    | 6.31*** |
| 2          | Stress           | Wishful thinking | 0.62 (0.10) | 0.46    | 6.00*** |
| 3          | Stress           | Depression       | 0.27 (0.07) | 0.27    | 3.66*** |
|            | Wishful thinking | Depression       | 0.37 (0.05) | 0.49    | 6.75*** |
| SOBELS     |                  |                  |             |         | 4.49*** |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

### 6.12.9 Wishful Thinking as Mediator of the Maternal Stress-Maternal Life Satisfaction Relationship

In Table 6.71 it is indicated that maternal wishful thinking coping strategy partially mediates the effect of maternal stress on maternal life satisfaction. A subsequent Sobel test was significant and therefore the indirect effect of a mother's stress on her life satisfaction via wishful thinking is significant.



Table 6.71

*Regression Analyses for Wishful Thinking as Mediator of Stress-Maternal Life Satisfaction Relationship*

| Regression | Predictors       | Outcome           | B (SE)       | $\beta$ | t        |
|------------|------------------|-------------------|--------------|---------|----------|
| 1          | Stress           | Life Satisfaction | -0.99 (0.16) | -0.48   | -6.04*** |
| 2          | Stress           | Wishful Thinking  | 0.62 (0.10)  | 0.46    | 6.00***  |
| 3          | Stress           | Life Satisfaction | -0.61 (0.16) | -0.30   | -3.80*** |
|            | Wishful thinking | Life Satisfaction | -0.67 (0.11) | -0.44   | -5.84*** |
| SOBELS     |                  |                   |              |         | -4.19*** |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

#### 6.12.10 Wishful Thinking as Mediator of the Maternal Stress-Maternal Positive Affect Relationship

Table 6.72 shows a reduction in the beta weight for maternal stress between the two regressions (1 and 3). Partial mediation is indicated in the maternal stress-positive affect relationship, as the beta weight for stress in Regression 3 is not equal to zero and the significant Sobel test indicates that this indirect effect is significant.

Table 6.72

*Regression Analyses for Wishful Thinking as Mediator of Stress–Maternal Positive Affect Relationship*

| Regression | Predictors       | Outcome          | B (SE)       | $\beta$ | t        |
|------------|------------------|------------------|--------------|---------|----------|
| 1          | Stress           | Positive Affect  | -0.65 (0.20) | -0.29   | -3.23**  |
| 2          | Stress           | Wishful thinking | 0.62 (0.10)  | 0.46    | 6.00***  |
| 3          | Stress           | Positive Affect  | -0.34 (0.21) | -0.15   | -1.65    |
|            | Wishful thinking | Positive Affect  | -0.56 (0.14) | -0.34   | -3.93*** |
| SOBELS     |                  |                  |              |         | -3.30*** |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

### 6.12.11 Practical Coping as Mediator of the Child Positive Contributions-Maternal Positive Affect Relationship

The use of practical coping strategies by mothers was found to partially mediate the effect of the child positive contributions on maternal positive affect. As shown in Table 6.73, the beta weight for child positive contributions decreased from Regression 1 to Regression 3. The subsequent Sobel test revealed that the indirect effect was significant.

Table 6.73

*Regression Analyses for Practical Coping as Mediator of Positive Contributions–Maternal Positive Affect Relationship*

| Regression | Predictors       | Outcome          | B (SE)      | $\beta$ | t       |
|------------|------------------|------------------|-------------|---------|---------|
| 1          | PCS              | Positive Affect  | 0.17 (0.03) | 0.41    | 5.13*** |
| 2          | PCS              | Practical Coping | 0.08 (0.02) | 0.34    | 4.23*** |
| 3          | PCS              | Positive Affect  | 0.13 (0.03) | 0.31    | 3.80*** |
|            | Practical Coping | Positive Affect  | 0.45 (0.15) | 0.24    | 3.02**  |
| SOBELS     |                  |                  |             |         | 2.47**  |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

### 6.13 Mediation for Paternal Variables

Mediation analyses were not conducted for stress, the positive contributions the child makes to the family and parental resources as mediators of the child variable–father outcome relationships as there were no significant relationships found between the child variables and paternal outcomes in the regression analyses. Only three mediation analyses were potentially supported by paths in the model for fathers.

#### 6.13.1 Wishful Thinking as Mediator of the Paternal Stress-Paternal Anxiety Relationship

If paternal wishful thinking coping strategy mediates the effect of paternal stress on paternal anxiety, we would expect to see a reduction in the beta weight from Regression 1 to Regression 3. Table 6.74 shows a reduction in the beta weight between the two regressions. Partial mediation is indicated in the paternal stress-anxiety relationship, as the beta weight for stress in Regression 3 is not equal to zero. A Sobel test was consequently conducted, which was significant and therefore the indirect effect of paternal stress on paternal anxiety via the wishful thinking was significant.

Table 6.74

*Regression Analyses for Wishful Thinking as Mediator of Stress–Paternal Anxiety Relationship*

| Regression | Predictors       | Outcome          | B (SE)      | $\beta$ | t       |
|------------|------------------|------------------|-------------|---------|---------|
| 1          | Stress           | Anxiety          | 0.35 (0.14) | 0.32    | 2.59*   |
| 2          | Stress           | Wishful Thinking | 0.29 (0.14) | 0.27    | 2.09*   |
| 3          | Stress           | Anxiety          | 0.18 (0.11) | 0.16    | 1.57    |
|            | Wishful Thinking | Anxiety          | 0.62 (0.10) | 0.62    | 6.06*** |
| SOBELS     |                  |                  |             |         | 1.98*   |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

### 6.13.2 Wishful Thinking as Mediator of the Paternal Stress-Paternal Depression Relationship

#### Relationship

A wishful thinking strategy in fathers was found to partially mediate the relationship between paternal stress and depression, as there was a decrease in the beta weight for paternal stress from Regression 1 to Regression 3. As indicated in Table 6.75, the t-statistic for the Sobel test was significant and therefore the indirect effect via wishful thinking was significant.

Table 6.75

*Regression Analyses for Wishful Thinking as Mediator of Stress–Paternal Depression Relationship*

| Regression | Predictors       | Outcome          | B (SE)      | $\beta$ | t       |
|------------|------------------|------------------|-------------|---------|---------|
| 1          | Stress           | Depression       | 0.29 (0.12) | 0.29    | 2.37*   |
| 2          | Stress           | Wishful Thinking | 0.29 (0.13) | 0.26    | 2.12*   |
| 3          | Stress           | Depression       | 0.14 (0.10) | 0.13    | 1.32    |
|            | Wishful Thinking | Depression       | 0.55 (0.10) | 0.58    | 5.54*** |
| SOBELS     |                  |                  |             |         | 1.96*   |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

### 6.13.3 Practical Support as Mediator of the Child Positive Contributions-Paternal Marital State Relationship

If paternal practical support mediates the effect of paternal ratings of child positive contributions on marital state, we would expect to see a reduction in the beta weight from Regression 1 to Regression 3. Table 6.76 shows an increase in the beta weight between the two regressions; thus, no mediation is indicated.

Table 6.76

*Regression Analyses for Practical Support as Mediator of Positive Contributions–Paternal Marital State Relationship*

| Regression | Predictors        | Outcome           | B (SE)       | $\beta$ | t       |
|------------|-------------------|-------------------|--------------|---------|---------|
| 1          | PCS               | Marital State     | -0.17 (0.07) | -0.29   | -2.31*  |
| 2          | PCS               | Practical Support | 0.16 (0.04)  | 0.51    | 4.57*** |
| 3          | PCS               | Marital State     | -0.17 (0.07) | -0.31   | -2.36*  |
|            | Practical Support | Marital State     | 0.09 (0.29)  | 0.04    | 0.31    |

### 6.14 Moderation

A moderator is a variable that affects the direction and/or the strength of the relation between an independent variable and a dependent variable. Baron and Kenny (1986) present a diagram of the moderator model.

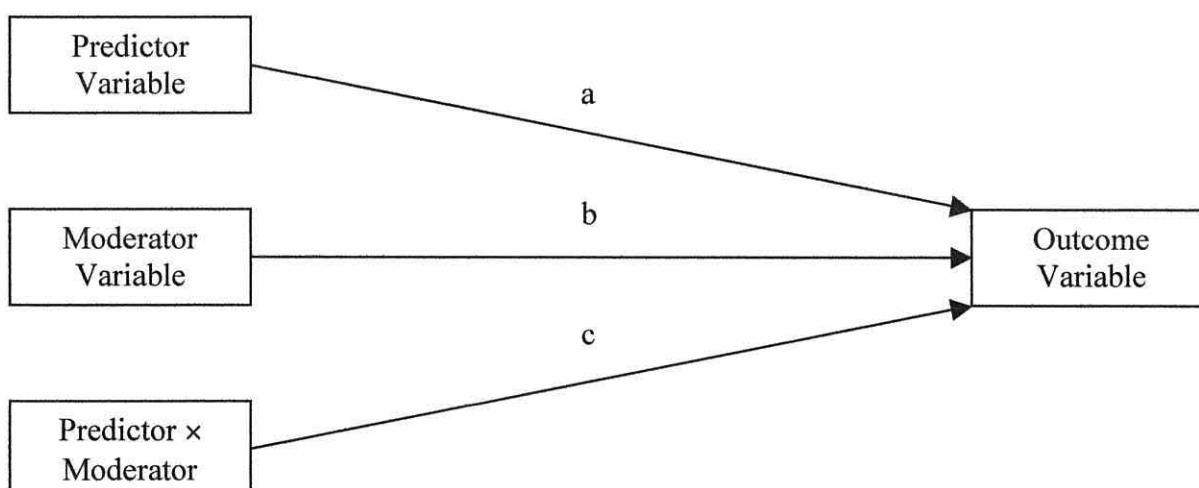


Figure 6.7 Moderator Model (adapted from Baron & Kenny, 1986)

Moderation refers to the examination of the statistical interaction between two independent variables in predicting a dependent variable. Whilst the statistical interaction between two or more independent categorical variables can be examined in ANOVA and MANOVA, moderation can investigate independent variables that are continuous in nature. Moderation implies that a relation between two variables changes as a function of a moderator variable.

One uses multiple regression to test whether certain independent (predictor) variables are significant predictors of the dependent (outcome) variable. A hierarchical regression is computed which includes three distinct steps. The main effect of the predictor variable is entered first, the main effect of the moderator is entered second and the interaction term between the two is entered third. This interaction term is calculated by generating z-scores for the variables and multiplying them together (i.e., centring the variables first).

The resultant data table includes three models. In the first model, the significant demographic variables are entered. In the second model, the demographic variables and the predictor and putative moderator variables are included. In the third model, the demographic variables, the predictor and putative moderator and the interaction term are entered. To interpret the result of the moderation analyses, the beta for the interaction term cannot be understood directly and requires an additional analysis. Following the guidelines proposed by Aiken and West (1991), the putative moderator variable is trichotomised (high, medium and low). The medium figure is the mean, the high figure is one standard deviation above the mean and the low is one standard deviation below the mean. The predictor variable is dichotomised into low and high categories. These relate to the minimum and maximum observed scores for the variable. These are then used to generate a graphical representation of the observed interaction, which may then be interpreted. For the sake of brevity, only significant moderations have been displayed.

### 6.15 Maternal Moderations

Analyses where variables were found to significantly moderate relationships for maternal data are presented below.

#### 6.15.1 Practical Coping as a Moderator of the Child Pro-Social Behaviour-Maternal Stress Relationship

As indicated in Table 6.76, autism and the number of adults in the family were entered in the first step of the model to control for their effects, as these demographic variables were found to predict maternal stress in preliminary analyses. The centred main effect terms for child pro-social behaviour and practical coping were entered in Step 2. The interaction term for these latter two variables was entered in Step 3. Child pro-social behaviour significantly predicted maternal stress in Step 2, indicating a main effect for this predictor variable. That is, mothers who perceived their child to display more pro-social behaviour reported lower stress. The interaction term in Step 3 significantly predicted additional variance in maternal stress, indicating that practical coping moderates the relationship between child pro-social behaviour and maternal stress. Specifically, low maternal ratings of child pro-social behaviour were associated with high maternal stress, regardless of the use of a practical coping strategy. High maternal ratings of child pro-social behaviour were associated with lower levels of stress in mothers. When these high ratings were coupled with high use of practical coping, mothers reported even lower stress levels, than when high pro-social behaviour was coupled with low use of practical coping. That is, a practical coping strategy enhances the adaptive effects of high pro-social behaviour on maternal stress. This interaction is presented in Figure 6.8.

Table 6.77

*Hierarchical Regression Analyses of Practical Coping as Moderator of Child Pro-social Behaviour-Maternal Stress Relationship*

| Step/Predictor                  | $\beta$ | p    | R <sup>2</sup> | F Change |
|---------------------------------|---------|------|----------------|----------|
| <b>Step 1</b>                   |         |      | 0.22           | 19.32*** |
| Autism                          | 0.41    | .000 |                |          |
| Number of Adults in Family      | -0.19   | .014 |                |          |
| <b>Step 2</b>                   |         |      | 0.35           | 13.29*** |
| Autism                          | 0.27    | .001 |                |          |
| Number of Adults                | -0.14   | .053 |                |          |
| NCBRF                           | -0.39   | .000 |                |          |
| Practical Coping                | -0.10   | .173 |                |          |
| <b>Step 3</b>                   |         |      | 0.37           | 4.08*    |
| Autism                          | .026    | .001 |                |          |
| Number of Adults                | -0.14   | .052 |                |          |
| NCBRF                           | -0.41   | .000 |                |          |
| Practical Coping                | -0.08   | .272 |                |          |
| NCBRF $\times$ Practical Coping | -0.14   | .045 |                |          |

\*p<.05, \*\*p<.01, \*\*\*p<.001



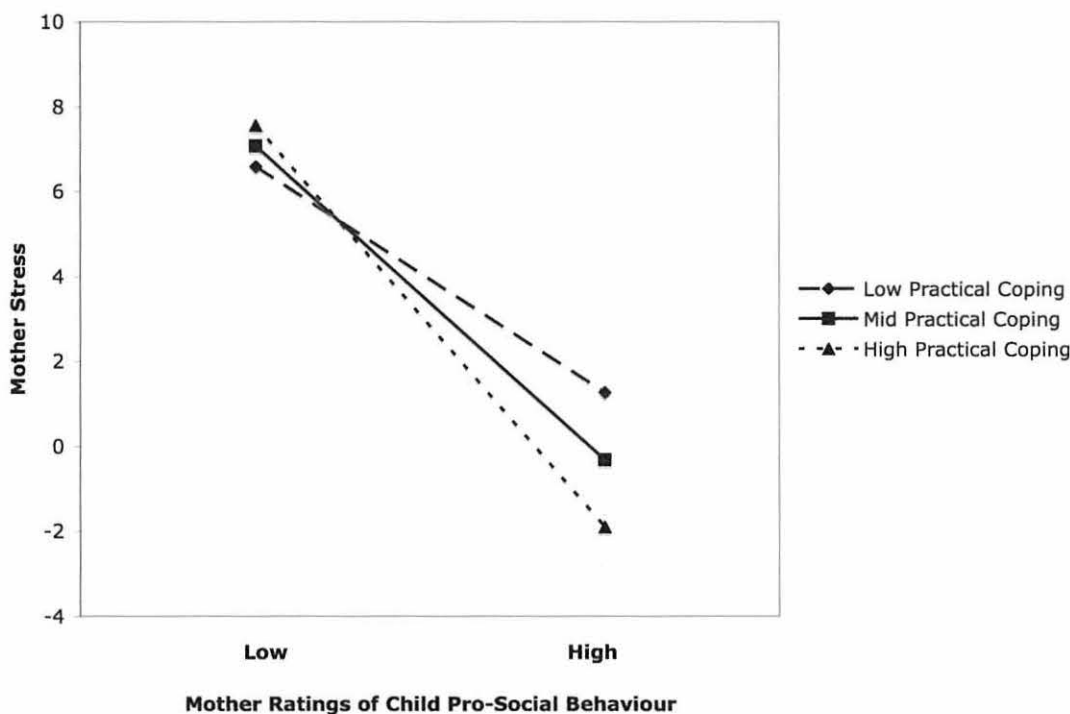


Figure 6.8 Interpretation of the moderating effect of practical coping on the relationship between child pro-social behaviour and maternal stress

#### 6.15.2 Wishful Thinking as Moderator of the Child Positive Contributions-Maternal Positive Affect Relationship

Autism, as the only significant demographic variable, was entered into Step 1 to control for its effects. As shown in Table 6.77, both child positive contributions and wishful thinking were significant predictors of maternal positive affect when entered in Step 2. Thus, mothers reported greater positive affect when they perceived their child to make more positive contribution to the family, while a wishful thinking coping strategy was predictive of lower positive affect in mothers. The interaction term entered in Step 3 significantly predicted additional variance in maternal positive affect. As indicated in Figure 6.9, high ratings of child positive contributions were associated with high positive affect in mothers, regardless of wishful thinking scores. The level of wishful thinking moderated the relationship between child positive contributions and positive affect, such that positive affect scores were even lower when low ratings of child positive contributions were accompanied by greater use of a wishful thinking coping strategy.

Table 6.78

*Hierarchical Regression Analyses of Wishful Thinking as Moderator of Positive Contributions-Maternal Positive Affect Relationship*

| Step/Predictor                | $\beta$ | p    | $R^2$ | F Change |
|-------------------------------|---------|------|-------|----------|
| <b>Step 1</b>                 |         |      | 0.05  | 7.67**   |
| Autism                        | -0.23   | .006 |       |          |
| <b>Step 2</b>                 |         |      | 0.32  | 25.66*** |
| Autism                        | -0.04   | .642 |       |          |
| PCS                           | 0.36    | .000 |       |          |
| Wishful thinking              | -0.35   | .000 |       |          |
| <b>Step 3</b>                 |         |      | 0.34  | 5.76*    |
| Autism                        | -0.02   | .794 |       |          |
| PCS                           | 0.35    | .000 |       |          |
| Wishful thinking              | -0.29   | .000 |       |          |
| PCS $\times$ Wishful thinking | 0.18    | .018 |       |          |

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

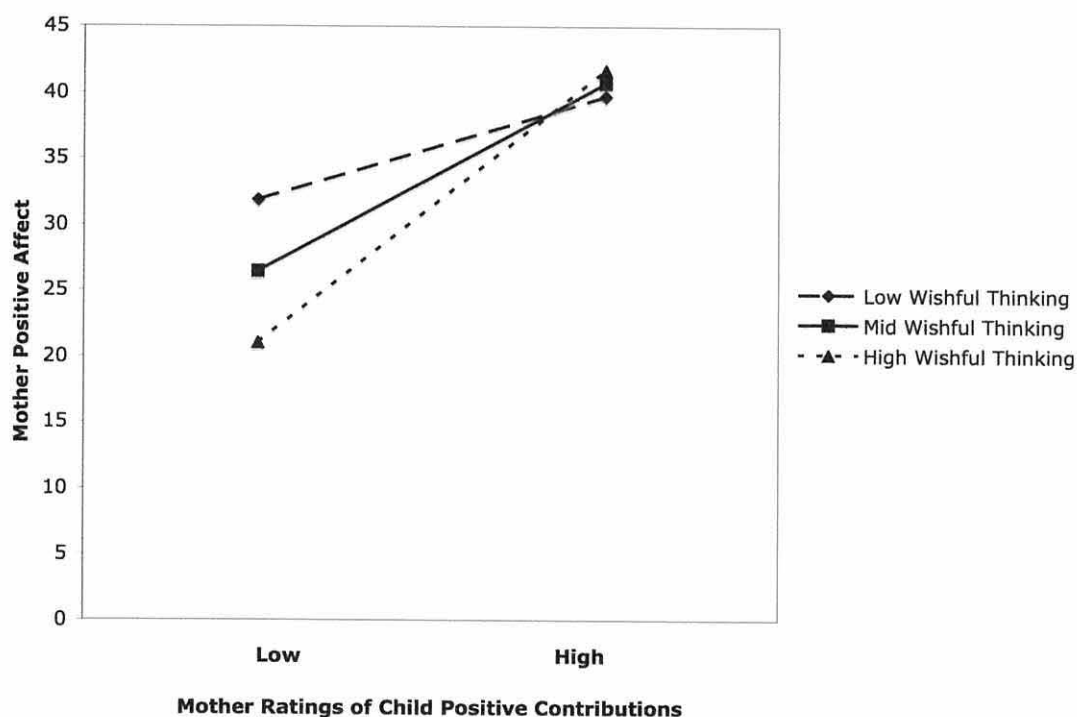


Figure 6.9 Interpretation of the moderating effect of wishful thinking on the relationship between child positive contributions and maternal positive affect

### 6.16 Paternal Moderations

Only interaction one was found to be significant in the analysis of paternal data. This is presented below.

#### 6.16.1 Practical Coping as Moderator of the Paternal Stress-Paternal Anxiety

##### Relationship

Child gender was included in Step 1, to control for its effects. As shown in Table 6.78, the main effects for paternal stress and practical coping significantly predicted anxiety in fathers. Specifically, stress scores were associated with greater anxiety in fathers, while the use of a practical coping strategy predicted less paternal anxiety. The interaction term entered in Step 3 predicted significant variance above and beyond the main effects in Step 2. As indicated in Figure 6.10, low ratings of stress were associated with moderate anxiety in fathers, regardless of the levels of practical coping they use. High paternal stress was also associated with moderate anxiety when coupled with high levels of practical coping, but with high anxiety when coupled with low levels of practical coping. Thus, the use of a practical coping strategy appears to buffer the negative effects of high paternal stress on anxiety, indicating a classic protective effect.

Table 6.79

*Hierarchical Regression Analyses of Practical Coping as Moderator of Stress-Paternal Anxiety Relationship*

| Step/Predictor                   | $\beta$ | p    | R <sup>2</sup> | F Change |
|----------------------------------|---------|------|----------------|----------|
| <b>Step 1</b>                    |         |      | 0.07           | 4.59*    |
| Gender of Child                  | -0.27   | .036 |                |          |
| <b>Step 2</b>                    |         |      | 0.22           | 5.42**   |
| Gender of Child                  | -0.29   | .016 |                |          |
| Stress                           | 0.27    | .029 |                |          |
| Practical Coping                 | -0.22   | .080 |                |          |
| <b>Step 3</b>                    |         |      | 0.29           | 5.51*    |
| Gender                           | -0.28   | .017 |                |          |
| Stress                           | 0.21    | .093 |                |          |
| Practical Coping                 | -0.29   | .020 |                |          |
| Stress $\times$ Practical Coping | -0.28   | .023 |                |          |

\*p<.05, \*\*p<.01, \*\*\*p<.001

In preliminary analyses, the beta weight for child gender approached significance ( $p = .051$ ) and thus was retained in the final model.

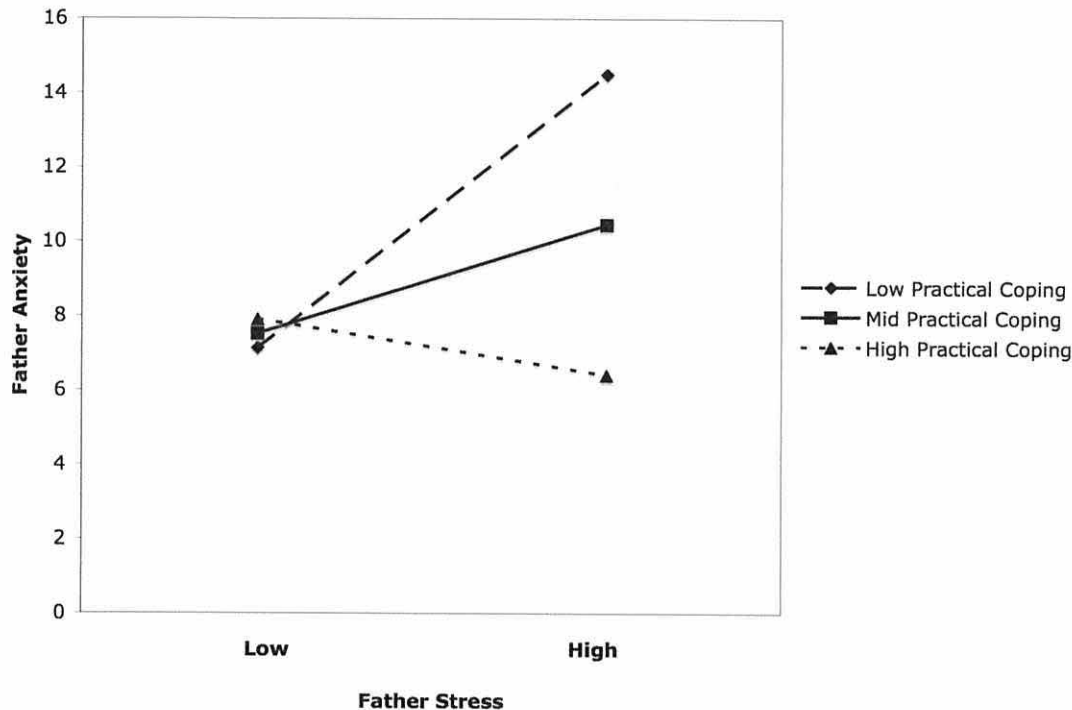


Figure 6.10 Interpretation of the moderating effect of practical coping on the relationship between paternal stress and paternal anxiety

### 6.17 Summary

This chapter has methodically presented regression analyses for all cross-sectional data, for both mothers and fathers of children with an intellectual disability. First, a series of simultaneous regressions were conducted for demographics predicting the main study variables and resource variables. Second, relationships among the main study variables were analysed. Specifically, child variables were analysed as predictors of parental outcomes, child variables were analysed as predictors of the parental ratings of stress and child positive contributions, and parental ratings of stress and child positive contributions were analysed as predictors of parental outcomes. Child variables were also examined as predictors of parental resources, while parental resources were investigated as predictors of parental stress, PCS, mental ill health and positive well-being. The significant relationships among the main study variables are summarised in Figures 6.2 and 6.4 for mothers, and in Figures 6.3 and 6.5, for fathers. Third, a series of regression analyses were used to examine stress as a mediator of the relationships between child variables and parental outcomes. Coping and support variables were analysed as mediators of a number of relationships: between child variables and parental outcomes, between child variables

and stress/child positive contributions, and between stress/child positive contributions and parental outcomes. Finally, coping and support were analysed as moderators of the relationships between main study variables, through a series of moderated hierarchical regressions. A summary of the significant results of these mediations and moderations are presented in Figures 6.11 to 6.18.

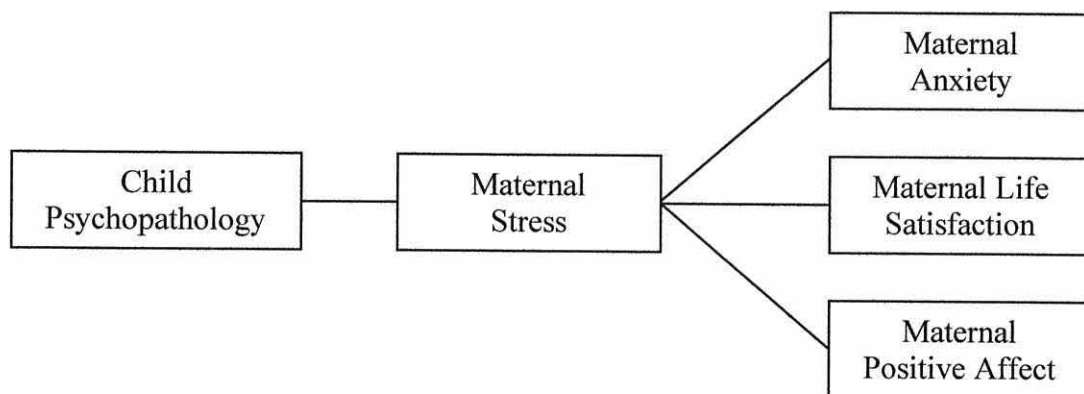


Figure 6.11 Summary of significant mediation analyses where the mediator variable is Maternal Stress and the predictor variable is Child Psychopathology

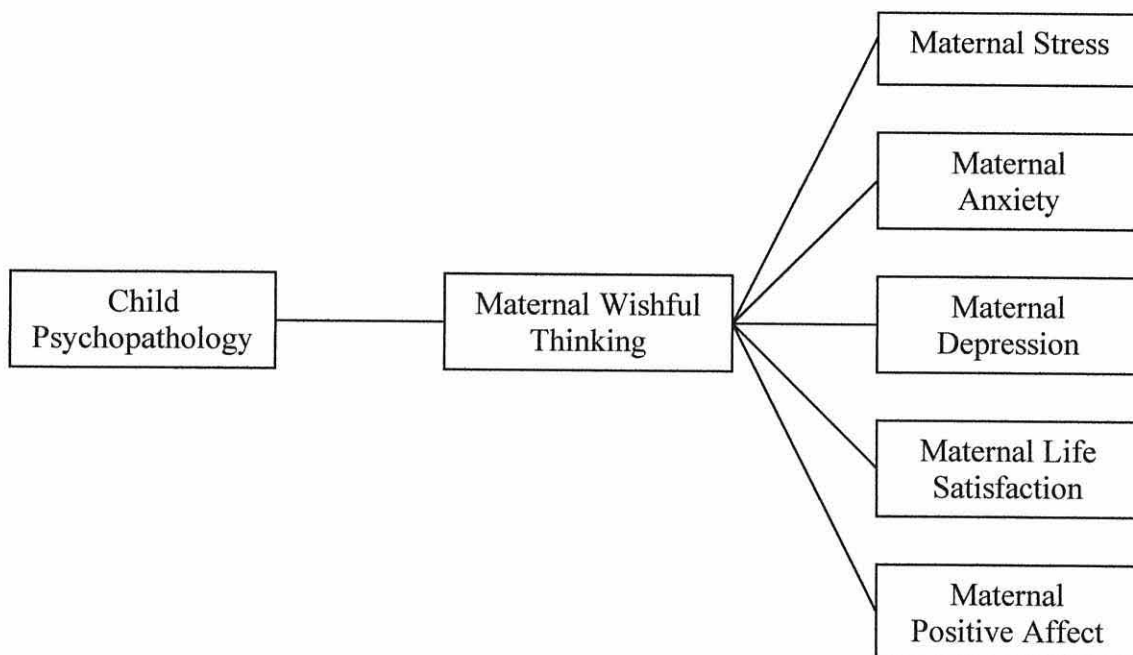


Figure 6.12 Summary of mediation analyses where the mediator variable is Maternal Wishful Thinking and the predictor variable is Child Psychopathology

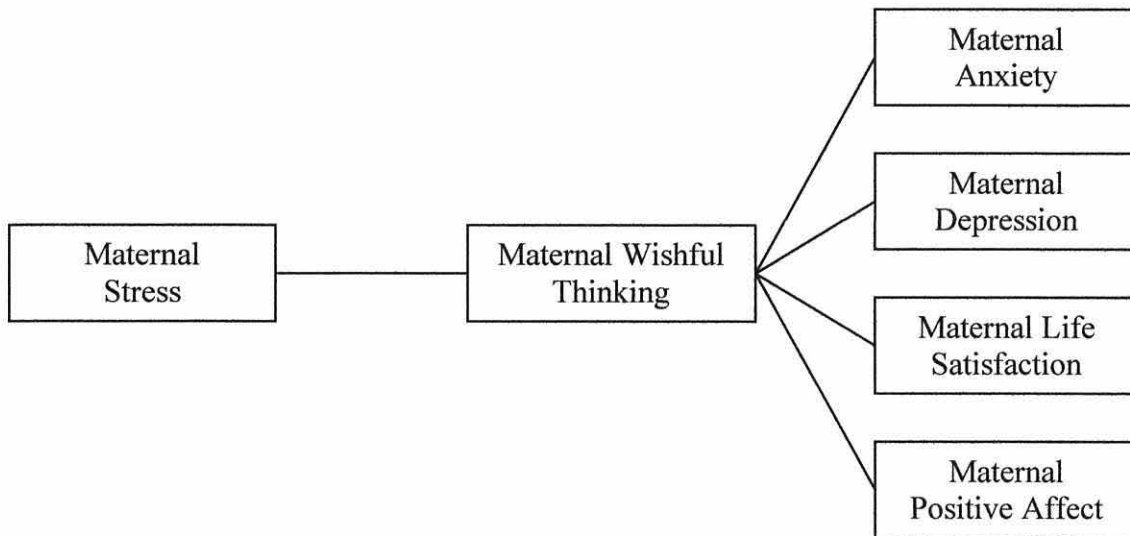


Figure 6.13 Summary of significant mediation analyses where the mediator variable is Maternal Wishful Thinking and the predictor variable is Maternal Stress

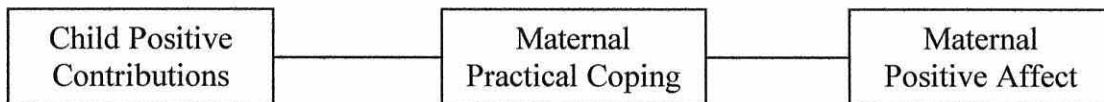


Figure 6.14 Summary of significant mediation analyses where the mediator variable is Maternal Practical Coping and the predictor variable is Child Positive Contributions

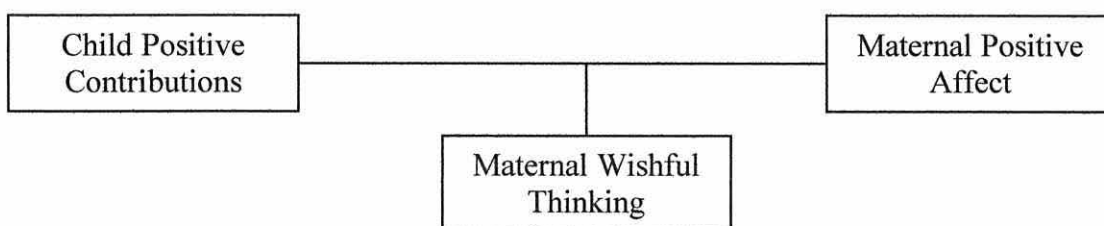


Figure 6.15 Summary of significant moderation analyses where the moderator variable is Maternal Wishful Thinking and the predictor variable is Child Positive Contributions



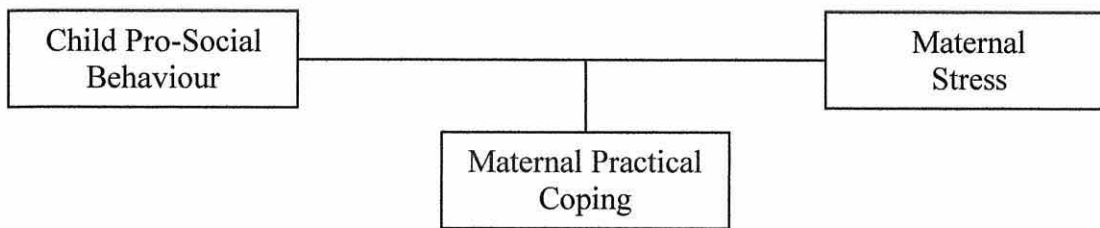


Figure 6.16 Summary of significant moderation analysis where the moderator variable is Maternal Practical Coping and the predictor variable is Child Pro-Social Behaviour

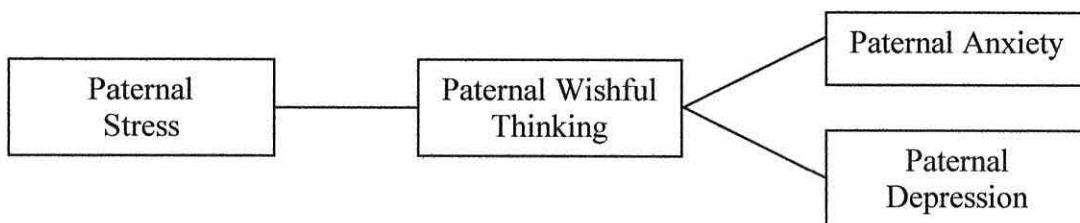


Figure 6.17 Summary of significant mediation analysis where the mediator variable is Paternal Wishful Thinking and the predictor variable is Paternal Stress

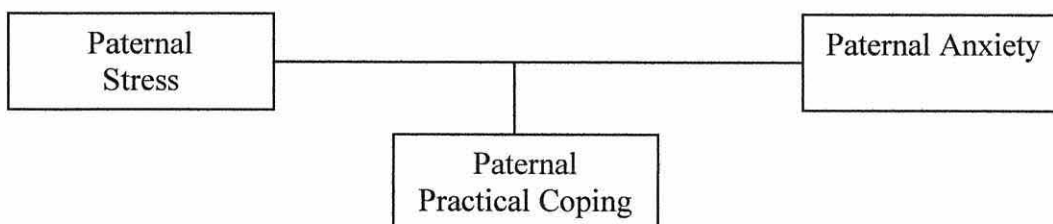


Figure 6.18 Summary of significant moderation analysis where the moderator variable is Paternal Practical Coping and the predictor variable is Paternal Stress

## Chapter 7

## Longitudinal Data Analysis

7.1 Introduction

Chapter 6 described the analysis of cross-sectional data and concluded with an explication of the mediating and moderating processes amongst the variables in the model. The aim of Chapter 7 is to establish the nature of any longitudinal relationships that may exist. The significant relationships identified in Chapter 6 serve as a guide for longitudinal data analysis. Thus, only significant relationships at the Time 1 cross-sectional level are analysed at the longitudinal level. This methodology, using Time 1 data for cross-sectional analyses, allowed the largest possible sample to be analysed cross-sectionally. While it would be possible to reanalyse cross-sectional relationships using Time 2 data, the main focus of this chapter is on testing relationships longitudinally. There was an attrition rate of 19% for mothers and 8.3 % for fathers over the 12 months between data collections, with 113 mother and 50 fathers participating at Time 2. This reduction of the dataset would lead to its own problems for cross-sectional analyses at Time 2, namely a loss of power when conducting so many analyses with the smaller sample. Thus the approach taken in this chapter is a pragmatic one, which allows for the number of relationships tested at Time 2 to be reduced, minimising the chance of committing a Type I error.

A second consent form was completed for participation in this phase of the research (Appendix P). Tables 7.1 to 7.3 illustrate descriptive analyses for the Time 2 data. In Table 7.1 the means, standard deviations and ranges are presented for the child variables, as rated by mothers and fathers.

Table 7.1

*Child Variables as Rated by Mothers and Fathers*

|       | Mother (n = 113) |       |       | Father (n = 50) |       |       |
|-------|------------------|-------|-------|-----------------|-------|-------|
|       | Mean             | SD    | Range | Mean            | SD    | Range |
| BPI   | 34.78            | 27.77 | 0-111 | 27.90           | 22.75 | 0-82  |
| REISS | 17.29            | 13.16 | 0-53  | 15.44           | 12.74 | 0-43  |
| NCBRF | 12.75            | 5.03  | 3-30  | 13.76           | 5.66  | 3-30  |

Table 7.2 illustrates the means, standard deviations and range of scores for parent outcomes variables, again presented separately for mothers and fathers.

Table 7.2

*Maternal and Paternal Outcomes*

|                   | Mother (n = 113) |       |        | Father (n = 50) |       |        |
|-------------------|------------------|-------|--------|-----------------|-------|--------|
|                   | Mean             | SD    | Range  | Mean            | SD    | Range  |
| Stress            | 5.10             | 3.74  | 0-15   | 3.55            | 3.64  | 0-14   |
| PCS               | 134.96           | 17.94 | 88-187 | 130.78          | 21.26 | 74-174 |
| Anxiety           | 8.43             | 3.80  | 0-18   | 6.12            | 4.45  | 0-20   |
| Depression        | 5.12             | 3.52  | 0-14   | 3.90            | 3.23  | 0-14   |
| Life Satisfaction | 20.69            | 6.95  | 5-35   | 21.92           | 7.08  | 5-33   |
| Marital State     | 27.57            | 14.01 | 3-67   | 22.58           | 11.54 | 1-55   |
| Positive Affect   | 32.60            | 8.05  | 14-50  | 33.78           | 7.67  | 13-50  |

For both Anxiety and Depression scores alike, scores between 8 and 10 identify mild cases, 11-15 moderate cases and 16 and above, severe cases. As with Time One scores, the means for mothers indicate mild anxiety, but depression within a normal range. For fathers both anxiety and depression were within normal ranges.

Table 7.3 presents the means, standard deviations and range of scores for parent resource variables, for both mothers and fathers.

Table 5.3

*Maternal and Paternal Resource Variables*

|                   | Mother (n = 113) |      |       | Father (n = 50) |      |       |
|-------------------|------------------|------|-------|-----------------|------|-------|
|                   | Mean             | SD   | Range | Mean            | SD   | Range |
| Wishful Thinking  | 12.25            | 4.61 | 7-27  | 10.94           | 3.85 | 7-26  |
| Practical Coping  | 19.53            | 4.04 | 7-28  | 19.08           | 4.27 | 12-28 |
| Practical Support | 17.20            | 5.18 | 7-33  | 17.04           | 5.81 | 7-31  |
| Emotional Support | 15.92            | 4.03 | 5-25  | 13.50           | 4.76 | 5-25  |

Longitudinal mediation and moderation are also tested based on Baron and Kenny's (1986) recommendations. Thus, longitudinal mediation was only investigated when all three requisite pathways were present over time. Further information regarding the examination of relationships over time can be found in Cohen, Cohen, West, and Aiken (2003). The significant variables in the cross-sectional mediation and moderation analyses were presented in Figures 6.11 to 6.18, at the end of Chapter 6.

Though significant demographic variables were controlled for in the cross-sectional data, demographic variables are not controlled for in longitudinal analyses. This methodology is in accord with previous researchers (e.g. Lecavalier et al., 2006), who argue that controlling for demographic data at the cross-sectional level precludes the need to additionally control for it at the longitudinal level. That is, we know relationships are still significant despite the relevant demographics being controlled for in the cross-sectional regression analyses. Thus, longitudinal findings from both mothers and fathers are presented, establishing whether and to what extent bi-directional relationships exist between variables in the sample. A second, and perhaps more substantial, observation is that the longitudinal analyses are essentially repeated measures on the same participants. Thus, if one controls already for the Time 1 score on the relevant outcome variable when predicting its Time 2 score, any impact of control variables are already accounted for and do not need to be added again.

With regard to longitudinal analysis there are two questions that are of interest: First, are the results observed at a cross-sectional level, also observed over time? Second, are bi-directional relationships observed? For example, does child psychopathology at Time 1 predict parenting stress at Time 2 and conversely does parenting stress at Time 1 predict child psychopathology at Time 2? The presentation of results follows the same format as Chapter 6. Thus, the results are presented as follows (where cross-sectional results support the analyses), testing relationships over time. Where relevant, these relationships are also tested for bi-directionality:

1. Child variables predicting parental outcomes.
2. Child variables predicting stress and positive contributions.
3. Child variables predicting parental resources.
4. Stress and positive contributions predicting parent outcomes.

## 5. Parental resources predicting parental outcomes.

Where the cross-sectional regressions indicate the presence of a relationship, a regression analysis is conducted to test this relationship longitudinally. No table is presented when the longitudinal relationship is non-significant. The section titled 'Non-significant longitudinal regressions' lists those analyses that identified non-significant relationships over time. However, results are presented in table format when longitudinal regression supports a relationship over time. For the significant relationship identified over time another regression analysis is conducted to ascertain whether a bi-directional relationship exists between the variables. Results for significant bi-directional relationships are reported in a second table, but no table is presented if a bi-directional relationship is not found.

### 7.2 Non-Significant Longitudinal Regressions

For mothers, 12 relationships found to be significant predictors at the cross-sectional level were not significant predictors over time. These were child behaviour problems predicting maternal depression and positive affect; child psychopathology predicting maternal anxiety, depression, positive affect and wishful thinking; child adaptive behaviour predicting maternal life satisfaction, positive affect and practical coping; maternal practical coping predicting maternal life satisfaction and positive affect; and finally, maternal emotional support predicting maternal stress.

For fathers, seven relationships found to be significant predictors at the cross-sectional level were not significant predictors over time. These were paternal ratings of child positive contributions predicting paternal life satisfaction and positive affect; paternal wishful thinking predicting paternal positive affect; paternal practical support predicting paternal depression and marital state; paternal practical support predicting paternal ratings of child positive contributions; and finally, paternal emotional support predicting paternal depression and marital state.

### 7.3 Mother Longitudinal Analysis

#### 7.3.1 Longitudinal Relationship between Child Psychopathology and Maternal Stress

The first regression analysis examines child psychopathology at Time 1 as a predictor of maternal stress at Time 2. Following the methodology used in previous studies (e.g., Lecavalier et al., 2006) the change in child psychopathology scores from Time 1 to Time 2 was also included as a predictor variable. Positive change scores for all variables indicate an increase in the scores for the construct being measured. Thus a greater positive change score for stress would indicate an increase in the level of parenting stress over the one-year period.

Maternal stress at Time 1 was included to control for its effects and to ensure that, if significant, Time 1 child psychopathology and change scores for child psychopathology predict unique variance in the outcome. Table 7.4 shows that child psychopathology at Time 1 is a significant predictor of stress at Time 2. The change in child psychopathology over time is not a significant predictor. Thus, although stress scores were stable over the 12-month period, the child's initial psychopathology accounted for unique variance in maternal stress at Time 2. Therefore, child psychopathology exacerbated stress over the one-year period.

Table 7.4

*Longitudinal Regression Analyses for Time 1 Child Psychopathology and Child Psychopathology Change Predicting Time 2 Maternal Stress*

| Variable   | $\beta$ | p    |
|--|---------|------|
| T1 Stress  | .62     | .000 |
| T1 REISS   | .28     | .001 |
| REISS change score                               | .05     | .51  |
| $R = .76, R^2 = .58, F(2, 108) = 6.96, p = .001$ |         |      |

Maternal stress at Time 1 and the change score for maternal stress were also analysed as predictors of child psychopathology at Time 2, to investigate the bi-directionality of the relationship between child psychopathology and maternal stress. Neither Time 1 stress or stress change emerged as a significant predictor of Time 2 child psychopathology,

suggesting there is no bi-directional relationship between child psychopathology and stress in mothers.

### 7.3.2 Longitudinal Relationship between Child Psychopathology and Maternal Life Satisfaction

Two regressions are presented in Tables 7.5 and 7.6. The first regression shows the results of Time 1 child psychopathology and child psychopathology change predicting life satisfaction at Time 2, whilst controlling for life satisfaction at Time 1. While life satisfaction was stable over the 12-month period, Time 1 child psychopathology and child psychopathology change accounted for unique variance in this construct. Child psychopathology attenuated life satisfaction over the one-year period. In other words, high levels of child psychopathology at Time 1 and an increase in child psychopathology over time predict maternal life satisfaction at Time 2.

Table 7.5

*Longitudinal Regression Analyses for Time 1 Child Psychopathology and Child Psychopathology Change Predicting Time 2 Maternal Life Satisfaction*

| Variable             | $\beta$ | p    |
|----------------------|---------|------|
| T1 Life satisfaction | .74     | .000 |
| T1 REISS             | -.18    | .025 |
| REISS change score   | -.21    | .007 |

$R = .77, R^2 = .59, F(2, 108) = 4.05, p = .02$

Turning to the analysis of the bi-directional relationship, Table 7.6 shows Time 2 child psychopathology as the outcome variable. Child psychopathology was stable over the 12-month period. While initial levels of life satisfaction did not account for any unique variance, the change in life satisfaction between Time 1 and Time 2 attenuated child psychopathology scores at Time 2. Therefore, a decrease in maternal life satisfaction over time predicts higher child psychopathology at Time 2. Thus a bi-directional relationship between child psychopathology and maternal life satisfaction is supported.



Table 7.6

*Longitudinal Regression Analyses of Time 1 Maternal Life Satisfaction and Life Satisfaction Change Predicting Time 2 Child Psychopathology*

| Variable                       | $\beta$ | p    |
|--------------------------------|---------|------|
| T1 REISS                       | .83     | .000 |
| T1 Life satisfaction           | -.06    | .313 |
| Life satisfaction change score | -.15    | .007 |

$R = .85, R^2 = .73, F(2, 108) = 3.74, p = .027$

### 7.3.3 Longitudinal Relationship between Child Pro-Social Behaviour and Maternal Stress

Two regressions are presented in Tables 7.7 and 7.8. The first table shows the results of the regression analysis for Time 1 child pro-social behaviour and child pro-social behaviour change predicting maternal stress at Time 2, whilst controlling for stress at Time 1. Both child pro-social behaviour at Time 1 and the increase over time were found to negatively predict stress at Time 2. Therefore, although stress scores were stable over the 12-month period, the initial levels of the child's pro-social behaviour and the increase in pro-social behaviour accounted for unique variance. Thus, high initial child pro-social behaviour and increasing pro-social behaviour over time attenuates maternal stress over a one-year period.

Table 7.7

*Longitudinal Regression Analyses of Time 1 Child Pro-Social Behaviour and Child Pro-Social Change Predicting Time 2 Maternal Stress*

| Variable           | $\beta$ | P    |
|--------------------|---------|------|
| T1 Stress          | .62     | .000 |
| T1 NCBRF           | -.28    | .001 |
| NCBRF change score | -.20    | .006 |

$R = .76, R^2 = .58, F(2, 108) = 6.76, p = .002$

Table 7.8 shows the analysis to establish whether a bi-directional relationship exists between the variables. As can be seen, Time 1 stress and an increase in maternal stress negatively predict Time 2 child pro-social behaviour. While child pro-social behaviour was stable over the measured period, stress and stress change accounted for unique

variance in the outcome. Therefore, initial high stress and increasing stress over time both have a negative impact on child pro-social behaviour over the one-year period. Thus, a bi-directional relationship exists between child pro-social behaviour and maternal stress.

Table 7.8

*Longitudinal Regression Analyses for Time 1 Maternal Stress and Maternal Stress Change Predicting Time 2 Child Pro-Social Behaviour*

| Variable   | $\beta$ | p    |
|--|---------|------|
| T1 NCBRF   | .56     | .000 |
| T1 Stress  | -.17    | .047 |
| Stress change score                              | -.21    | .006 |
| $R = .69, R^2 = .48, F(2, 108) = 4.59, p = .012$ |         |      |

#### 7.3.4 Longitudinal Relationship between Maternal Stress and Maternal Anxiety

The first regression, presented in Table 7.9, shows the results of Time 1 stress and stress change predicting anxiety at Time 2, whilst controlling for anxiety at Time 1. While anxiety was stable over the 12-month period, Time 1 stress and stress change accounted for unique variance in maternal anxiety at Time 2. These two variables exacerbated anxiety over the 12-month period. In other words, high maternal stress at Time 1 and an increase in stress over time both predicted high levels of maternal anxiety at Time 2.

Table 7.9

*Longitudinal Regression Analyses for Time 1 Maternal Stress and Stress Change Predicting Time 2 Maternal Anxiety*

| Variable   | $\beta$ | p    |
|--|---------|------|
| T1 Anxiety                                       | .67     | .000 |
| T1 Stress  | .17     | .014 |
| Stress change score                              | .27     | .000 |
| $R = .77, R^2 = .59, F(2, 108) = 9.40, p = .000$ |         |      |

Table 7.10 shows the results of the second regression. Although stress was stable over the 12-month period, the initial levels of maternal anxiety and change in anxiety accounted for unique variance in Time 2 maternal stress. Thus, anxiety exacerbated stress over the

year. In other words, high levels of anxiety at Time 1 and an increase in maternal anxiety over time predict high maternal stress scores at Time 2. The significant relationships for both regressions support the presence of a bi-directional relationship between stress and anxiety.

Table 7.10

*Longitudinal Regression Analysis of Time 1 Maternal Anxiety and Anxiety Change Predicting Time 2 Maternal Stress*

| Variable             | $\beta$ | P    |
|----------------------|---------|------|
| T1 Stress            | .67     | .000 |
| T1 Anxiety           | .19     | .008 |
| Anxiety change score | .27     | .000 |

$R = .77, R^2 = .59, F(2, 108) = 9.14, p = .000$

### 7.3.5 Longitudinal Relationship between Maternal Stress and Maternal Depression

The regression presented in Table 7.11 shows the results of Time 1 stress and stress change predicting depression at Time 2, whilst controlling for depression at Time 1. While depression was stable over the 12-month period, Time 1 stress and stress change accounted for unique variance in maternal depression at Time 2. Thus, high levels of stress at Time 1 and an increase in stress over time were both associated with high levels of maternal depression at Time 2.

Table 7.11

*Longitudinal Regression Analysis for Time 1 Maternal Stress and Stress Change Predicting Time 2 Maternal Depression*

| Variable            | $\beta$ | p    |
|---------------------|---------|------|
| T1 Depression       | .50     | .000 |
| T1 Stress           | .20     | .018 |
| Stress change score | .31     | .000 |

$R = .67, R^2 = .45, F(2, 108) = 9.21, p = .000$

With regard to testing the bi-directional relationship between the variables, Table 7.12 shows the results of the second regression. Although stress was stable over the 12-month

period, the initial levels of depression and change in depression accounted for unique variance in maternal stress at Time 2. In other words, high depression at Time 1 and an increase in maternal depression scores over time were predictive of high maternal stress at Time 2. Taken together, the significant results in the two regressions support the presence of a bi-directional relationship between maternal stress and depression.

Table 7.12

*Longitudinal Regression Analysis for Time 1 Maternal Depression and Depression Change Predicting Time 2 Maternal Stress*

| Variable  | $\beta$ | P    |
|---|---------|------|
| T1 Stress   | .64     | .000 |
| T1 Depression                                       | .25     | .001 |
| Depression change score                             | .27     | .000 |
| R = .78, $R^2 = .60$ , F (2, 108) = 10.42, p = .000 |         |      |

### 7.3.6 Longitudinal Relationship between Maternal Stress and Maternal Life Satisfaction

The first regression for maternal stress and life satisfaction is presented in Table 7.13.

While life satisfaction was stable over the 12-month period, stress change accounted for unique variance in this outcome. A decrease in maternal stress over time was a significant predictor of higher maternal life satisfaction at Time 2. In other words, the initial levels of stress did not significantly predict life satisfaction at Time 2, whilst the change in stress did attenuate life satisfaction over the 12-month period.

Table 7.13

*Longitudinal Regression Analysis for Time 1 Maternal Stress and Stress Change Predicting Time 2 Maternal Life Satisfaction*

| Variable   | $\beta$ | p    |
|--|---------|------|
| T1 Life satisfaction                               | .70     | .000 |
| T1 Stress  | -.12    | .086 |
| Stress change score                                | -.25    | .000 |
| R = .79, $R^2 = .62$ , F (2, 108) = 8.41, p = .000 |         |      |

Table 7.14 shows the results of the second regression. Although stress was stable over the 12-month period, the initial levels of life satisfaction and the change in life satisfaction accounted for unique variance in Time 2 maternal stress. Therefore, high maternal life satisfaction scores at Time 1 and an increase in life satisfaction over time significantly predicted lower maternal stress at Time 2. The significant results identified in both regressions supports the presence of a bi-directional relationship between maternal stress and life satisfaction.

Table 7.14

*Longitudinal Regression Analysis for Time 1 Maternal Life Satisfaction and Life Satisfaction Change Predicting Time 2 Maternal Stress*

| Variable                       | $\beta$ | p    |
|--------------------------------|---------|------|
| T1 Stress                      | .67     | .000 |
| T1 Life satisfaction           | -.18    | .018 |
| Life satisfaction change score | -.27    | .000 |

$R = .77, R^2 = .59, F(2, 108) = 8.81, p = .000$

### 7.3.7 Longitudinal Relationship between Maternal Stress and Maternal Positive Affect

The first regression, presented in Table 7.15, shows the results of Time 1 maternal stress and stress change predicting maternal positive affect at Time 2, whilst controlling for positive affect at Time 1. Although positive affect was stable over the 12-month period, the change in stress over time predicted unique variance in Time 2 maternal positive affect. Therefore, a decrease in maternal stress over time was associated with higher maternal ratings of positive affect at Time 2.

Table 7.15

*Longitudinal Regression Analysis for Time 1 Maternal Stress and Stress Change Predicting Time 2 Maternal Positive Affect*

| Variable            | $\beta$ | p    |
|---------------------|---------|------|
| T1 Positive Affect  | .64     | .000 |
| T1 Stress           | -.03    | .691 |
| Stress change score | -.17    | .023 |

$R = .68, R^2 = .46, F(2, 108) = 2.71, p = .071$

Table 7.16 shows the results of the second regression. Whilst stress was stable over the 12-month period, the initial levels of positive affect and the change in positive affect accounted for unique variance in maternal stress at Time 2. In other words, low maternal positive affect at Time 1 and a decrease in positive affect over time predicted greater maternal stress at Time 2. The results of the two regressions support the presence of a bi-directional relationship between stress and positive affect.

Table 7.16

*Longitudinal Regression Analysis for Time 1 Maternal Positive Affect and Positive Affect Change Predicting Time 2 Maternal Stress*

| Variable   | $\beta$ | p    |
|--|---------|------|
| T1 Stress  | .69     | .000 |
| T1 Positive Affect                               | -.17    | .016 |
| Positive Affect change score                     | -.16    | .023 |
| $R = .75, R^2 = .56, F(2, 108) = 4.33, p = .016$ |         |      |

### 7.3.8 Longitudinal Relationship between Maternal Ratings of Child Positive Contributions and Maternal Positive Affect

Though a significant relationship was found between child positive contributions and maternal positive affect at a cross-sectional level, positive contributions made by the child was not found to be a significant predictor of positive affect over time. A second regression analysis was conducted to establish whether positive affect was predictive of child positive contributions over time. The results of this analysis are presented in Table 7.17. Although positive contribution scores were stable over the 12-month period, maternal positive affect at Time 1 was found to account for unique variance in Time 2 positive contribution scores. Thus the results suggest a uni-directional relationship exists between these variables. That is, high maternal positive affect at Time 1 predicts higher ratings of the child's positive contributions to the family at Time 2.

Table 7.17

*Longitudinal Regression Analysis for Time 1 Maternal Positive Affect and Positive Affect Change Predicting Time 2 Maternal Ratings of Positive Contributions*

| Variable                     | $\beta$ | p    |
|------------------------------|---------|------|
| T1 Positive Contributions    | .63     | .000 |
| T1 Positive Affect           | .22     | .004 |
| Positive Affect change score | .10     | .918 |

$R = .74, R^2 = .55, F(2, 108) = 4.56, p = .013$

### 7.3.9 Longitudinal Relationship between Maternal Wishful Thinking and Maternal Anxiety

The first regression for the longitudinal relationship between maternal wishful thinking and maternal anxiety is presented in Table 7.18. Although anxiety was stable over the 12-month period, change in the amount of wishful thinking was a significant predictor of anxiety at Time 2 accounting for unique variance this outcome. In other words, the mother's increase in the use of a wishful thinking coping strategy over the 12-month period was associated with high maternal anxiety at Time 2.

Table 7.18

*Longitudinal Regression Analysis for Time 1 Maternal Wishful Thinking and Wishful Thinking Change Predicting Time 2 Maternal Anxiety*

| Variable                      | $\beta$ | p    |
|-------------------------------|---------|------|
| T1 Anxiety                    | .67     | .000 |
| T1 Wishful thinking           | .12     | .147 |
| Wishful thinking change score | .23     | .001 |

$R = .75, R^2 = .56, F(2, 108) = 5.86, p = .004$

The second regression is presented in Table 7.19. Although wishful thinking was stable over the 12-month period, the initial levels of anxiety and the change in anxiety accounted for unique variance in this construct indicating that anxiety exacerbated the use of wishful thinking over the year. That is, high Time 1 maternal anxiety and an increase in anxiety over time predicted greater use of a wishful thinking coping strategy at Time 2.



The results of the two regressions support the presence of a bi-directional relationship between the use of wishful thinking coping strategies and anxiety.

Table 7.19

*Longitudinal Regression Analyses for Time 1 Maternal Anxiety and Anxiety Change Predicting Time 2 Maternal Wishful Thinking*

| Variable   | $\beta$ | p    |
|--|---------|------|
| T1 Wishful thinking                              | .63     | .000 |
| T1 Anxiety                                       | .20     | .020 |
| Anxiety change score                             | .24     | .001 |
| $R = .74, R^2 = .54, F(2, 108) = 6.71, p = .002$ |         |      |

#### 7.3.10 Longitudinal Relationship between Maternal Wishful Thinking and Maternal Depression

Two regressions are presented in Tables 7.20 and 7.21. The results presented in Table 7.20 indicate that both wishful thinking and wishful thinking change were significant predictors of depression at Time 2. These two predictors accounted for unique variance in this Time 2 depression, despite the stability in maternal depression over the 12-month period. Thus, high levels of maternal wishful thinking at Time 1 and an increase in the mothers' use of wishful thinking over the 12-month period predicted higher maternal depression at Time 2.

Table 7.20

*Longitudinal Regression Analysis for Time 1 Maternal Wishful Thinking and Wishful Thinking Change Predicting Time 2 Maternal Depression*

| Variable   | $\beta$ | p    |
|--|---------|------|
| T1 Depression                                    | .49     | .000 |
| T1 Wishful thinking                              | .25     | .013 |
| Wishful thinking change score                    | .28     | .000 |
| $R = .66, R^2 = .44, F(2, 108) = 7.80, p = .001$ |         |      |

The second regression, presented in Table 7.21, indicated that wishful thinking was stable over the 12-month period. However, initial levels of depression and the change in

depression accounted for unique variance in the use of wishful thinking coping strategies by mothers. Therefore, high maternal depression at Time 1 and an increase in depression over time were predictive of greater use of a wishful thinking coping strategy at Time 2. These two regressions provide support for the hypothesis of a bi-directional relationship between the use of wishful thinking coping strategies and depression.

Table 7.21

*Longitudinal Regression Analysis for Time 1 Maternal Depression and Depression Change Predicting Time 2 Maternal Wishful Thinking*

| Variable   | $\beta$ | p    |
|--|---------|------|
| T1 Wishful thinking                              | .61     | .000 |
| T1 Depression                                    | .20     | .033 |
| Depression change score                          | .26     | .000 |
| $R = .74, R^2 = .54, F(2, 108) = 7.15, p = .001$ |         |      |

### 7.3.11 Longitudinal Relationship between Maternal Wishful Thinking and Maternal Life Satisfaction

The regression presented in Table 7.22 indicates that both wishful thinking and wishful thinking change negatively predict life satisfaction at Time 2. Therefore, although life satisfaction was stable over the 12-month period, the initial amount of wishful thinking and the change in amount of wishful thinking use accounted for unique variance in Time 2 life satisfaction. That is, low initial levels of wishful thinking and a decrease in mothers' use of a wishful thinking coping strategy over time significantly predicted high maternal life satisfaction at Time 2.

Table 7.22

*Longitudinal Regression Analysis for Time 1 Maternal Wishful Thinking and Wishful Thinking Change Predicting Time 2 Maternal Life Satisfaction*

| Variable  | $\beta$ | p    |
|---|---------|------|
| T1 Life satisfaction                              | .67     | .000 |
| T1 Wishful thinking                               | -.20    | .009 |
| Wishful thinking change score                     | -.29    | .000 |
| $R = .80, R^2 = .64, F(2, 108) = 11.64, p = .000$ |         |      |

Table 7.23 shows that initial levels of maternal life satisfaction and the change in life satisfaction over the year negatively predict use of wishful thinking coping strategies. Although wishful thinking was stable over the 12-month period, life satisfaction at Time 1 and the change in life satisfaction accounted for unique variance in the outcome variable. Thus, low maternal life satisfaction at Time 1 and a decrease in life satisfaction over time were associated with greater use of a wishful thinking coping strategy at Time 2. Together with the first regression, these results support the presence of a bi-directional relationship between the use of wishful thinking coping strategies and life satisfaction.

Table 7.23

*Longitudinal Regression Analysis for Time 1 Maternal Life Satisfaction and Life Satisfaction Change Predicting Time 2 Maternal Wishful Thinking*

| Variable                       | $\beta$ | p    |
|--------------------------------|---------|------|
| T1 Wishful thinking            | .61     | .000 |
| T1 Life satisfaction           | -.23    | .006 |
| Life satisfaction change score | -.32    | .000 |

$R = .76$ ,  $R^2 = .58$ ,  $F(2, 108) = 11.88$ ,  $p = .000$

#### 7.3.12 Longitudinal Relationship between Maternal Wishful Thinking and Maternal Marital State

Table 7.24 shows the regression analysis for Time 1 wishful thinking and wishful thinking change predicting marital state at Time 2, whilst controlling for marital state at Time 1. These results must be interpreted in light of the fact that the higher the score on the marital state measure, the more dissatisfied the respondent is with their relationship. Both high use of wishful thinking at Time 1 and an increase in the use of wishful thinking over time were significant predictors of high maternal dissatisfaction in the marital relationship at Time 2. Time 1 wishful thinking and wishful thinking change accounted for unique variance in this construct, although marital state was stable over the 12-month period.

Table 7.24

*Longitudinal Regression Analysis of Time 1 Maternal Wishful Thinking and Wishful Thinking Change Predicting Time 2 Maternal Marital State*

| Variable                      | $\beta$ | p    |
|-------------------------------|---------|------|
| T1 Marital state              | .72     | .000 |
| T1 Wishful thinking           | .16     | .040 |
| Wishful thinking change score | .15     | .040 |

$R = .79, R^2 = .62, F(2, 84) = 3.42, p = .037$

As can be seen in Table 7.25, the change in marital state predicted use of wishful thinking at Time 2. Though wishful thinking was stable over the 12-month period, the change in marital dissatisfaction accounted for unique variance this construct. Thus, an increase in mothers' marital dissatisfaction over the year predicted greater use of wishful thinking at Time 2. When considered in conjunction with the first regression, these results indicate a bi-directional relationship exists between the use of wishful thinking coping strategies and the amount of dissatisfaction in the mother's relationship.

Table 7.25

*Longitudinal Regression Analysis for Time 1 Maternal Marital State and Marital State Change Predicting Time 2 Maternal Wishful Thinking*

| Variable                   | $\beta$ | p    |
|----------------------------|---------|------|
| T1 Wishful thinking        | .72     | .000 |
| T1 Marital state           | .08     | .302 |
| Marital state change score | .15     | .040 |

$R = .78, R^2 = .61, F(2, 84) = 2.36, p = .101$

### 7.3.13 Longitudinal Relationship between Maternal Wishful Thinking and Maternal Positive Affect

The regression presented in Table 7.26 shows the results of Time 1 wishful thinking and wishful thinking change predicting positive affect at Time 2, whilst controlling for positive affect at Time 1. While positive affect was stable over the 12-month period, wishful thinking change accounted for unique variance. Thus, a decrease in the mothers'

use of wishful thinking coping strategies over the 12-month period predicted high maternal positive affect at Time 2.

Table 7.26

*Longitudinal Regression Analysis for Time 1 Maternal Wishful Thinking and Wishful Thinking Change Predicting Time 2 Maternal Positive Affect*

| Variable                      | $\beta$ | p    |
|-------------------------------|---------|------|
| T1 Positive Affect            | .63     | .000 |
| T1 Wishful thinking           | -.14    | .082 |
| Wishful thinking change score | -.17    | .022 |

$R = .68, R^2 = .46, F(2, 108) = 3.30, p = .041$

With regard to testing the bi-directional relationship between the variables, Table 7.27 shows the results of the second regression. Although wishful thinking was stable over the 12-month period, change in positive affect accounted for unique variance in wishful thinking at Time 2. In other words, a decrease in maternal positive affect over time was associated with greater use of wishful thinking at Time 2. Taken together, the significant results of the two regressions support the presence of a bi-directional relationship between the mother's use of wishful thinking coping strategies and their positive affect.

Table 7.27

*Longitudinal Regression Analysis for Time 1 Maternal Positive Affect and Positive Affect Change Predicting Time 2 Maternal Wishful Thinking*

| Variable                     | $\beta$ | p    |
|------------------------------|---------|------|
| T1 Wishful thinking          | .68     | .000 |
| T1 Positive affect           | -.05    | .525 |
| Positive affect change score | -.17    | .022 |

$R = .71, R^2 = .51, F(2, 108) = 2.72, p = .071$

#### 7.3.14 Longitudinal Relationship between Maternal Wishful Thinking and Maternal Stress

The first regression for the longitudinal relationship between maternal wishful thinking and maternal stress is presented in Table 7.28. Time 1 wishful thinking and the change in

wishful thinking predicting maternal stress at Time 2, whilst controlling for Time 1 maternal stress. Stress was stable over the year and both the use of wishful thinking coping strategies at Time 1 and the change in the use of wishful thinking accounted for unique variance. Thus, high levels of maternal wishful thinking at Time 1 and an increase in the mothers' use of wishful thinking over the 12-month period predicted higher maternal stress at Time 2.

Table 7.28

*Longitudinal Regression Analysis for Time 1 Maternal Wishful Thinking and Wishful Thinking Change Predicting Time 2 Maternal Stress*

| Variable  | $\beta$ | p    |
|---|---------|------|
| T1 Stress   | .70     | .000 |
| T1 Wishful thinking                               | .21     | .003 |
| Wishful Thinking Change Score                     | .28     | .000 |
| $R = .78, R^2 = .61, F(3, 108) = 55.58, p < .001$ |         |      |

The second regression, presented in Table 7.29, indicated that maternal wishful thinking was stable over the 12-month period. However, initial levels of maternal stress and the change in stress accounted for unique variance in the use of wishful thinking coping strategies by mothers. Therefore, high maternal stress at Time 1 and an increase in stress over time were predictive of greater use of a wishful thinking coping strategy at Time 2. These two regressions provide support for the hypothesis of a bi-directional relationship between the use of wishful thinking coping strategies and maternal stress.

Table 7.29

*Longitudinal Regression Analysis for Time 1 Maternal Stress and Stress Change Predicting Time 2 Maternal Wishful Thinking*

| Variable  | $\beta$ | p    |
|---|---------|------|
| T1 Wishful thinking                               | .66     | .000 |
| T1 Stress   | .06     | .430 |
| Stress Change Score                               | .29     | .000 |
| $R = .78, R^2 = .61, F(3, 108) = 55.58, p < .001$ |         |      |

### 7.3.15 Longitudinal Relationship between Maternal Practical Coping and Maternal Ratings of Child Positive Contributions

Table 7.30 presents the regression analysis for Time 1 maternal practical coping and change in practical coping predicting maternal ratings of child positive contributions at Time 2, whilst controlling for maternal ratings of child positive contributions at Time 1. Although maternal ratings of child positive contributions were stable over the 12-month period, the in use of practical coping strategies by mothers accounted for unique variance in Time 2 maternal ratings of child positive contributions. Thus, an increase in the use of practical coping strategies by mothers was predictive of higher ratings of child positive contributions by the mother at Time 2.

Table 7.30

*Longitudinal Regression Analysis for Time 1 Maternal Practical Coping and Practical Coping Change Predicting Time 2 Maternal Ratings Of Child Positive Contributions*

| Variable  | $\beta$ | p    |
|---|---------|------|
| T1 PCS  | .70     | .000 |
| T1 Practical Coping                               | .09     | .300 |
| Practical Coping Change Score                     | .16     | .044 |
| $R = .73, R^2 = .53, F(3, 108) = 39.84, p < .001$ |         |      |

The second regression, presented in Table 7.31, indicates that maternal practical coping was stable over the 12-month period. However, the change in maternal ratings of child positive contributions accounted for unique variance in the use of practical coping strategies by mothers. An increase in mother ratings of the positive contributions made by their child over time was predictive of greater use of practical coping strategies at Time 2. Together, the regression presented in Tables 7.30 and 7.31 provide support for the hypothesis of a bi-directional relationship between the use of wishful thinking coping strategies and maternal mother ratings of the positive contributions made by their child.



Table 7.31

*Longitudinal Regression Analysis for Time 1 Maternal Ratings of Child Positive Contributions and Positive Contribution Change Predicting Time 2 Maternal Practical Coping*

| Variable            | $\beta$ | p    |
|---------------------|---------|------|
| T1 Practical Coping | .63     | .000 |
| T1 PCS              | .13     | .127 |
| PCS Change Score    | .16     | .044 |

$R = .68, R^2 = .46, F(3, 108) = 30.26, p < .001$

### 7.3.16 Summary of Maternal Relationships

So far, a series of longitudinal regressions have been presented for maternal variables.

Before we turn to paternal variables, a summary of the maternal data is presented.

Table 7.32

*Summary of Maternal Relationships*

| Predictor Variable                      | Criterion Variable   |
|---|--|
| Time 1 Child Psychopathology            | Time 2 Stress (+)<br>Time 2 Life Satisfaction (-)  |
| Child Psychopathology Change Score      | Time 2 Life Satisfaction (-)   |
| Time 1 Life Satisfaction                | Time 2 Stress (-)<br>Time 2 Wishful Thinking (-)   |
| Life Satisfaction Change Score          | Time 2 Child Psychopathology (-)<br>Time 2 Stress (-)  |
| Time 1 Child Pro-social behaviour       | Time 2 Stress (-)  |
| Child Pro-social behaviour change score | Time 2 Stress (-)  |
| Time 1 Stress                           | Time 2 Child Pro-social behaviour (-)<br>Time 2 Anxiety (+)<br>Time 2 Depression (+)                                 |
| Stress change score                     | Time 2 Child Pro-social behaviour (-)<br>Time 2 Anxiety (+)<br>Time 2 Depression (+)<br>Time 2 Life Satisfaction (-) |

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|  |  |
|--|--|
|  | Time 2 Positive Affect (-)             |
|  | Time 2 Wishful Thinking (+)            |
| Time 1 Anxiety                           | Time 2 Stress (+)                      |
|  | Time 2 Wishful Thinking (+)            |
| Anxiety change score                     | Time 2 Stress (+)                      |
|  | Time 2 Wishful Thinking (+)            |
| Time 1 Depression                        | Time 2 Stress (+)                      |
|  | Time 2 Wishful Thinking (+)            |
| Depression change score                  | Time 2 Stress (+)                      |
|  | Time 2 Wishful Thinking (+)            |
| Time 1 Positive Affect                   | Time 2 Stress (-)                      |
|  | Time 2 Positive Contribution Score (+) |
| Positive Affect change score             | Time 2 Stress (-)                      |
|  | Time 2 Positive Contribution Score (+) |
|  | Time 2 Wishful Thinking (-)            |
| Time 1 Wishful Thinking                  | Time 2 Depression (+)                  |
|  | Time 2 Life Satisfaction (-)           |
|  | Time 2 Marital State (+)               |
|  | Time 2 Stress (+)                      |
| Wishful Thinking change score            | Time 2 Anxiety (+)                     |
|  | Time 2 Depression (+)                  |
|  | Time 2 Life Satisfaction (-)           |
|  | Time 2 Marital State (+)               |
|  | Time 2 Positive Affect (-)             |
|  | Time 2 Stress (+)                      |
| Marital Satisfaction change score        | Time 2 Wishful Thinking (+)            |
| Practical Coping change score            | Time 2 Positive Contribution Scale (+) |
| Positive Contribution Scale change score | Time 2 Practical Coping (+)            |

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#### 7.4 Father Longitudinal Analyses

##### 7.4.1 Longitudinal Relationship between Child Psychopathology and Paternal Stress

Table 7.33 presents the regression analysis for initial levels of child psychopathology and change in child psychopathology predicting paternal stress at Time 2, whilst controlling

for paternal stress at Time 1. Although stress was stable over the 12-month period, Time 1 child psychopathology accounted for unique variance in Time 2 stress indicating that high paternal ratings of child psychopathology at Time 1 are associated with high paternal stress at Time 2.

Table 7.33

*Longitudinal Regression Analysis for Time 1 Paternal Child Psychopathology and Child Psychopathology Change Predicting Time 2 Paternal Stress*

| Variable           | $\beta$ | p    |
|--------------------|---------|------|
| T1 Stress          | .45     | .000 |
| T1 REISS           | .40     | .002 |
| REISS change score | .22     | .058 |

$R = .71$ ,  $R^2 = .50$ ,  $F(2, 45) = 6.11$ ,  $p = .004$

Paternal stress at Time 1 and the change score for paternal stress were also analysed as predictors of child psychopathology at Time 2. Neither Time 1 paternal stress nor stress change emerged as a significant predictor of Time 2 child psychopathology, suggesting the relationship between child psychopathology and paternal stress is only uni-directional.

#### 7.4.2 Longitudinal Relationship between Paternal Stress and Paternal Anxiety

Table 7.34 illustrates the results of the regression analysis for Time 1 paternal stress and stress change predicting anxiety at Time 2, whilst controlling for paternal anxiety at Time 1. The change in paternal stress was a significant predictor of anxiety at Time 2. Although anxiety was stable over the 12-month period, the change in stress accounted for unique variance in Time 2 paternal anxiety indicating that an increase in paternal stress over the year predicts Time 2 paternal anxiety.

Table 7.34

*Longitudinal Regression Analysis for Time 1 Paternal Stress and Stress Change  
Predicting Time 2 Paternal Anxiety*

| Variable  | $\beta$ | p    |
|---|---------|------|
| T1 Anxiety  | .77     | .000 |
| T1 Stress   | .05     | .648 |
| Stress change score                               | .33     | .003 |
| R = .77, $R^2 = .59$ , F (2, 45) = 5.21, p = .009 |         |      |

As indicated in Table 7.35, the change in anxiety was found to significantly predict stress at Time 2. Although stress was stable over the 12-month period, the change in anxiety accounted for unique variance in Time 2 stress. Thus, an increase in paternal anxiety over the 12-month period predicts high paternal stress at Time. The significant results for the two regressions support the presence of a bi-directional relationship between paternal stress and anxiety.

Table 7.35

*Longitudinal Regression Analysis for Time 1 Paternal Anxiety and Anxiety Change  
Predicting Time 2 Paternal Stress*

| Variable  | $\beta$ | p    |
|---|---------|------|
| T1 Stress   | .67     | .000 |
| T1 Anxiety  | -.03    | .797 |
| Anxiety change score                              | .35     | .003 |
| R = .70, $R^2 = .48$ , F (2, 45) = 5.44, p = .008 |         |      |

#### 7.4.3 Longitudinal Relationship between Paternal Stress and Paternal Depression

Table 7.36 presents the results of the regression analysis for Time 1 paternal stress and stress change predicting paternal depression at Time 2, whilst controlling for depression at Time 1. While depression was stable over the year, stress change accounted for unique variance in the outcome. In other words, an increase in paternal stress over time was predictive of high paternal depression at Time 2.

Table 7.36

*Longitudinal Regression Analysis for Time 1 Paternal Stress and Stress Change  
Predicting Time 2 Paternal Depression*

| Variable  | $\beta$ | P    |
|---|---------|------|
| T1 Depression                                     | .49     | .000 |
| T1 Stress   | .06     | .685 |
| Stress change score                               | .43     | .003 |
| R = .58, $R^2 = .34$ , F (2, 45) = 5.56, p = .007 |         |      |

As shown in Table 7.37, Time 2 paternal stress was significantly predicted by change in depression. Although stress was stable over the 12-month period, depression accounted for unique variance in this construct, indicating that an increase in paternal depression over time is associated with high paternal stress at Time 2. Thus, a bi-directional relationship exists between stress and depression in fathers.

Table 7.37

*Longitudinal Regression Analysis for Time 1 Paternal Depression and Depression  
Change Predicting Time 2 Paternal Stress*

| Variable  | $\beta$ | P    |
|---|---------|------|
| T1 Stress   | .67     | .000 |
| T1 Depression                                     | .20     | .160 |
| Depression change score                           | .45     | .003 |
| R = .70, $R^2 = .48$ , F (2, 45) = 5.36, p = .008 |         |      |

#### 7.4.4 Longitudinal Relationship between Paternal Ratings of Child Positive Contributions and Paternal Marital State

The regression analysis for positive contributions and positive contribution change predicting Time 2 paternal marital state is presented in Table 7.38. The change in paternal ratings of positive contributions was found to significantly and negatively predict marital state scores at Time 2 (higher scores on the marital state measure indicate more severe relationship problems). While marital state scores were stable over the 12-month period, the change in paternal ratings of child positive contributions accounted for unique variance in Time 2 marital satisfaction. Thus, a decrease in fathers' perceptions of child

positive contributions predicted greater Time 2 paternal dissatisfaction with the state of the marital relationship. Time 1 marital state and marital state change scores were not found to significantly predict Time 2 ratings of child positive contributions in the second regression. Therefore, no evidence was found for a bi-directional relationship.

Table 7.38

*Longitudinal Regression Analysis for Time 1 Paternal Ratings of Positive Contributions and Positive Contribution Change Predicting Time 2 Paternal Marital State*

| Variable  | $\beta$ | p    |
|---|---------|------|
| T1 Marital state                                | .66     | .000 |
| T1 Positive contribution                        | -.17    | .170 |
| Positive contribution change score              | -.26    | .029 |
| $R = .72, R^2 = .51, F(2, 46) = 2.70, p = .078$ |         |      |

#### 7.4.5 Longitudinal Relationship between Paternal Wishful Thinking and Paternal Anxiety

Table 7.39 shows the results of the regression analysis for Time 1 wishful thinking and change in amount of wishful thinking predicting anxiety at Time 2, whilst controlling for anxiety at Time 1. Although anxiety was stable over the year, Time 1 wishful thinking and change in amount of wishful thinking accounted for unique variance in Time 2 anxiety. In high use of wishful thinking coping strategies and an increase in the use of these strategies over time predicted greater paternal anxiety at Time 2.

Table 7.39

*Longitudinal Regression Analysis for Time 1 Paternal Wishful Thinking and Wishful Thinking Change Predicting Time 2 Paternal Anxiety*

| Variable  | $\beta$ | p    |
|---|---------|------|
| T1 Anxiety                                      | .55     | .000 |
| T1 Wishful thinking                             | .36     | .008 |
| Wishful thinking change score                   | .44     | .000 |
| $R = .81, R^2 = .65, F(2, 46) = 9.64, p = .000$ |         |      |

Table 7.40 presents the regression investigating the existence of a bi-directional relationship between the variables. Both the initial levels and change in paternal anxiety significantly predicted the use of wishful thinking coping strategies at Time 2, accounting for unique variance in the outcome. That is, high paternal anxiety at Time 1 and an increase in anxiety over the year were both associated with more use of wishful thinking coping strategies at Time 2. Taken with the previous regression, these findings support the presence of a bi-directional relationship between wishful thinking and anxiety for fathers.

Table 7.40

*Longitudinal Regression Analysis for Time 1 Paternal Anxiety and Anxiety Change Predicting Time 2 Paternal Wishful Thinking*

| Variable             | $\beta$ | p    |
|----------------------|---------|------|
| T1 Wishful thinking  | .40     | .003 |
| T1 Anxiety           | .36     | .010 |
| Anxiety change score | .45     | .000 |

$R = .74$ ,  $R^2 = .55$ ,  $F(2, 46) = 10.56$ ,  $p = .000$

#### 7.4.6 Longitudinal Relationship between Paternal Wishful Thinking and Paternal Depression

Table 7.41 presents the regression analysis for wishful thinking predicting depression at Time 2, whilst controlling for depression at Time 1. While depression was stable over the 12-month period, Time 1 wishful thinking and wishful thinking change accounted for unique variance in Time 2 depression. Thus, high use of wishful thinking at Time 1 and an increase in fathers' use of wishful thinking over time predicted high levels of paternal depression Time 2.



Table 7.41

*Longitudinal Regression Analysis for Time 1 Paternal Wishful Thinking and Wishful Thinking Change Predicting Time 2 Paternal Depression*

| Variable                      | $\beta$ | p    |
|-------------------------------|---------|------|
| T1 Depression                 | .20     | .173 |
| T1 Wishful thinking           | .60     | .000 |
| Wishful thinking change score | .45     | .001 |

$R = .66, R^2 = .44, F(2, 46) = 10.53, p = .000$

The second regression (Table 7.42) examines whether paternal depression predicts wishful thinking at Time 2. Although wishful thinking was stable over the year, depression accounted for unique variance in this outcome. Therefore, high paternal depression at Time 1 and an increase in exacerbated the use of wishful thinking coping strategies over the year. The results of these two regressions provide support for the presence of a bi-directional relationship between wishful thinking and depression for fathers.

Table 7.42

*Longitudinal Regression Analysis for Time 1 Paternal Depression and Depression Change Predicting Time 2 Paternal Wishful Thinking*

| Variable                | $\beta$ | p    |
|-------------------------|---------|------|
| T1 Wishful thinking     | .44     | .004 |
| T1 Depression           | .39     | .041 |
| Depression change score | .52     | .001 |

$R = .70, R^2 = .49, F(2, 46) = 6.55, p = .003$

#### 7.4.7 Longitudinal Relationship between Paternal Wishful Thinking and Paternal Life Satisfaction

Table 7.43 illustrates the results of the regression analysis for paternal wishful thinking and wishful thinking change predicting life satisfaction at Time 2, whilst controlling for life satisfaction at Time 1. Although paternal life satisfaction was stable over the 12-month period, wishful thinking change accounted for unique variance indicating a

decrease in fathers' use of wishful thinking coping strategies over 12 months predicted high paternal life satisfaction at Time 2.

Table 7.43

*Longitudinal Regression Analysis for Time 1 Paternal Wishful Thinking and Wishful Thinking Change Predicting Time 2 Paternal Life Satisfaction*

| Variable  | $\beta$ | p    |
|---|---------|------|
| T1 Life satisfaction                            | .54     | .000 |
| T1 Wishful thinking                             | -.25    | .070 |
| Wishful thinking change score                   | -.35    | .006 |
| $R = .70, R^2 = .48, F(2, 46) = 4.24, p = .020$ |         |      |

As can be seen in Table 7.44 both the initial levels and change in life satisfaction were significant predictors of fathers' use of wishful thinking coping strategies at Time 2. Although wishful thinking was stable over the 12-month period, life satisfaction accounted for unique variance in Time 2 wishful thinking. Therefore, high Time 1 life satisfaction and an increase in paternal life satisfaction over time both predicted less paternal use of wishful thinking coping strategies at Time 2. A bi-directional relationship between wishful thinking and life satisfaction is supported by the results of these two regressions.

Table 7.44

*Longitudinal Regression Analysis for Time 1 Paternal Life Satisfaction and Life Satisfaction Change Predicting Time 2 Paternal Wishful Thinking*

| Variable  | $\beta$ | p    |
|---|---------|------|
| T1 Wishful thinking                             | .50     | .000 |
| T1 Life satisfaction                            | -.28    | .046 |
| Life satisfaction change score                  | -.34    | .006 |
| $R = .67, R^2 = .45, F(2, 46) = 4.60, p = .015$ |         |      |

#### 7.4.8 Longitudinal Relationship between Paternal Practical Coping and Paternal Ratings of Child Positive Contributions

Two regressions are presented in Tables 7.45 and 7.46. The first table shows the results of a regression for fathers' use of practical coping strategies at Time 1 and the change in use of practical coping strategies predicting paternal ratings of child positive contributions at Time 2, whilst controlling for child positive contributions at Time 1. Although paternal ratings of the positive contributions made by their child were stable over the 12-month period, practical coping change accounted for unique variance indicating that an increase in fathers' use of practical coping strategies over 12 months predicted high paternal ratings of the child positive contributions at Time 2.

Table 7.45

*Longitudinal Regression Analysis for Time 1 Paternal Practical Coping and Practical Coping Change Predicting Time 2 Paternal Ratings of Child Positive Contributions*

| Variable   | $\beta$ | p    |
|--|---------|------|
| T1 PCS   | .66     | .000 |
| T1 Practical Coping                              | .13     | .317 |
| Practical Coping Change Score                    | .33     | .010 |
| $R = .72, R^2 = .52, F(3, 46) = 16.89, p < .001$ |         |      |

Table 7.46 presents the results of the second regression. Although practical coping was stable over the 12-month period, the change in paternal ratings of child positive contributions accounted for unique variance in paternal use of practical coping strategies at Time 2. Therefore, an increase in paternal ratings of the positive contributions made by their child predicted more use of practical coping strategies by fathers at Time 2. A bi-directional relationship between paternal practical coping and their ratings of the positive contributions made by their child is supported by the results of these two regressions.

Table 7.46

*Longitudinal Regression Analysis for Time 1 Paternal Ratings of Child Positive Contributions and Positive Contribution Change Predicting Time 2 Paternal Practical Coping*

| Variable            | $\beta$ | p    |
|---------------------|---------|------|
| T1 Practical Coping | .50     | .000 |
| T1 PCS              | .22     | .119 |
| PCS Change Score    | .35     | .010 |

$R = .60$ ,  $R^2 = .35$ ,  $F(3, 46) = 8.42$ ,  $p < .001$

#### 7.4.9 Summary of Paternal Relationships

The following table presents the results of longitudinal regressions based on the paternal data. A summary of the paternal data is presented.

Table 7.47

*Summary of Paternal Relationships*

| Predictor Variable                       | Criterion Variable                     |
|--|--|
| Time 1 Child Psychopathology             | Time 2 Stress (+)                      |
| Stress change score                      | Time 2 Anxiety (+)                     |
|  | Time 2 Depression (+)                  |
| Time 1 Anxiety                           | Time 2 Wishful Thinking (+)            |
| Anxiety change score                     | Time 2 Stress (+)                      |
|  | Time 2 Wishful Thinking (+)            |
| Time 1 Depression                        | Time 2 Wishful Thinking                |
| Depression change score                  | Time 2 Stress (+)                      |
|  | Time 2 Wishful Thinking (+)            |
| Positive Contribution Scale change score | Time 2 Marital State (-)               |
|  | Time 2 Practical Coping (+)            |
| Time 1 Wishful Thinking                  | Time 2 Anxiety (+)                     |
|  | Time 2 Depression (+)                  |
| Wishful Thinking change score            | Time 2 Anxiety (+)                     |
|  | Time 2 Depression (+)                  |
|  | Time 2 Life Satisfaction (-)           |
| Time 1 Life Satisfaction                 | Time 2 Wishful Thinking (-)            |
| Life Satisfaction change score           | Time 2 Wishful Thinking (-)            |
| Practical Coping change score            | Time 2 Positive Contribution Scale (+) |

### 7.5 Longitudinal Mediation Analysis

Given that this research has the advantage of having a longitudinal element to its design, it is possible to explore the existence of longitudinal mediation and moderation in the mother and father data. A literature search uncovered no previous research within the intellectual disability field where this design was evident, thus the analyses are inherently exploratory in nature. We employed a procedure similar to that used in the analysis of cross-sectional mediation and moderation to establish whether mediating or moderating relationships exist over time.

As we have already established in previous chapters, following the Baron and Kenny (1986) steps, cross-sectional mediation requires the presence of three relationships. First, the mediator is regressed on the predictor variable; second, the outcome variable is regressed on the predictor variable; and third, the outcome variable is regressed on both the predictor variable and the mediator. There are few established guidelines for testing longitudinal mediation. In the current research, there are three hypothetical candidates that may function as a mediator variable: First, we could use the score for the mediator at Time 1; second, we could use the score for the mediator at Time 2; third, we could use the change score for the mediator variable. Cohen et al. (2003) suggest two ways of evaluating longitudinal mediation, one using the mediator as measured at Time 1 and one using the mediator as measured at Time 2. They identify limitations to these methods; if using the measurement of the mediator at Time 1, the effects of the mediator may be underestimated, whilst using the measurement of the mediator at Time 2 may be overestimated, as its relationship with the outcome variable at Time 2 may be due to the causal effect of the outcome variable at Time 1 on the mediator.

From the regressions conducted in the first part of this chapter, a potential longitudinal mediating relationship was identified. Direct longitudinal relationships were identified among child psychopathology, maternal stress and life satisfaction. Specifically, these relationships suggest that maternal stress may mediate the longitudinal relationship between child psychopathology and maternal life satisfaction. Both the Time 1 score and the change score for child psychopathology predicted Time 2 maternal life satisfaction, thereby satisfying the first step in Baron and Kenny's (1986) recommendations. Child psychopathology at Time 1 predicted a possible mediator in this analysis, Time 2 maternal stress, thus potentially satisfying the second step of the recommendations.

Finally, the change score for maternal stress predicted life satisfaction at Time 2, potentially fulfilling the final step of the recommendations.

However, on closer inspection it is evident that the regression analyses presented in the first part of this chapter are not sufficient to provide the basis for analysing longitudinal mediation. Initial levels of stress are conceptually different from stress change scores and only the change in maternal stress predicted Time 2 life satisfaction. The Baron and Kenny (1986) recommendations would require that stress change is examined as an outcome variable in the first step of testing mediation. This was not investigated earlier in the chapter, as the variable does not exist at Time 1. Therefore it is necessary to conduct an additional regression analysis for Time 1 child psychopathology predicting stress change, to confirm this pathway. The results of this analysis are presented in Table 7.48. Time 1 child psychopathology was not found to significantly predict stress change. Thus, the three conditions for mediation are not satisfied and we conclude that the change in maternal stress does not mediate the longitudinal relationship between maternal ratings of child psychopathology and maternal life satisfaction.

Table 7.48

*Longitudinal Mediation Analyses for Stress Change Mediating the Relationship Between Time 1 Child Psychopathology and Time 2 Maternal Life Satisfaction*

| Regression | Predictor     | Outcome              | B (SE)       | $\beta$ | t      |
|------------|---------------|----------------------|--------------|---------|--------|
| 1          | T1 Reiss      | T2 Life Satisfaction | -0.009 (.04) | -.22    | -2.40* |
| 2          | T1 Reiss      | Stress Change        | 0.002 (.03)  | .02     | .07    |
| 3          | T1 Reiss      | T2 Life Satisfaction | .11 (.06)    | .24     | 1.88   |
|            | Stress Change | T2 Life Satisfaction | -1.15 (.45)  | -.33    | -2.56* |

(Time 1 Life Satisfaction was controlled for in the third regression)

Bearing in mind these concerns, two further exploratory longitudinal mediation models were conducted, first with stress measured at Time 1 and second with stress measured at Time 2. Time 1 stress did not significantly predict Time 2 life satisfaction, thus Time 1 stress was discounted as a possible mediator. However, Time 2 stress was a significant predictor of life satisfaction at Time 2 and thus all three pathways were significant to allow for the testing of mediation. The quasi-longitudinal mediation analysis for Time 2

stress as a mediator of the relationship between Time 1 child psychopathology and Time 2 life satisfaction is shown in Table 7.49.

Table 7.49

*Longitudinal Mediation Analyses of Time 2 Stress Mediating the Relationship Between Time 1 Child Psychopathology and Time 2 Maternal Life Satisfaction*

| Regression | Predictor | Outcome              | B (SE)      | $\beta$ | t       |
|------------|-----------|----------------------|-------------|---------|---------|
| 1          | T1 Reiss  | T2 Life Satisfaction | -0.09 (.04) | -.22    | -2.40*  |
| 2          | T1 Reiss  | T2 Stress            | .12 (.02)   | .51     | 6.23**  |
| 3          | T1 Reiss  | T2 Life Satisfaction | 0.02 (.03)  | .06     | .88     |
|            | T2 Stress | T2 Life Satisfaction | -.47 (.14)  | -.25    | -3.40** |
| SOBEL      |           |                      |             |         | .13     |

(Time 1 Life Satisfaction was controlled for in the third regression)

As can be seen in Table 7.49, the beta coefficient for Time 1 child psychopathology decreased from the Regression 1 to Regression 3, indicating that Time 2 stress partially mediates the relationship between Time 1 child psychopathology and Time 2 maternal life satisfaction. However, the Sobel test revealed that the indirect effect of the predictor variable on the outcome variable via the mediator is not significant. No other mediating relationships are observed for either mothers or fathers.

### 7.6 Longitudinal Moderation Analysis

Similar to the previous section, no previous research was revealed in a literature search for longitudinal moderation analysis in the domain of intellectual disability. Thus, the moderation analyses presented here are also exploratory in nature. Using the procedures set out by Baron and Kenny (1986), two moderation analyses were presented in Chapter 6 for maternal data and one moderation analysis was presented for father data. In each longitudinal moderation analysis, the Time 1 score for the outcome variable was entered in the first step of the analysis to control for its effects. Time 1 scores for the predictor variable were entered in the second step, alongside Time 1 scores and change scores for the moderator variable. Finally, two product terms were entered in the final step of the regression, representing the interaction between Time 1 scores for the predictor variable and Time 1 scores for the moderator, and the interaction between Time 1 scores for the



predictor variable and the change scores for the moderator. All predictor and moderator scores were centred prior to calculating the interaction terms and being entered in the regression analysis, following the recommendations by Aiken and West (1991). The three moderations presented in Chapter 6 at the cross-sectional level were analysed using the longitudinal data and no significant interactions were observed, indicating that moderating effects were not occurring.

### 7.7 Summary

This chapter has presented the results of a series of regression analyses investigating the nature and extent of direct relationships over time, as well as longitudinal mediating and moderating factors. The issue of bi-directionality was also explored. These analyses conclude the investigation of the data from Time 1 and Time 2 of the survey study. All variables in this and the preceding chapters were measured by means of self-report. Chapter 8 presents an exploratory analysis of observation of parent-child interactions in order to attempt to gather both independent reports of child behaviour and to begin to provide an examination of the link between parental behaviour and child behaviour.

## Chapter 8

## Observational Study

8.1 Introduction

Thus far, this thesis has used a working model to guide the research. We now briefly return to this.

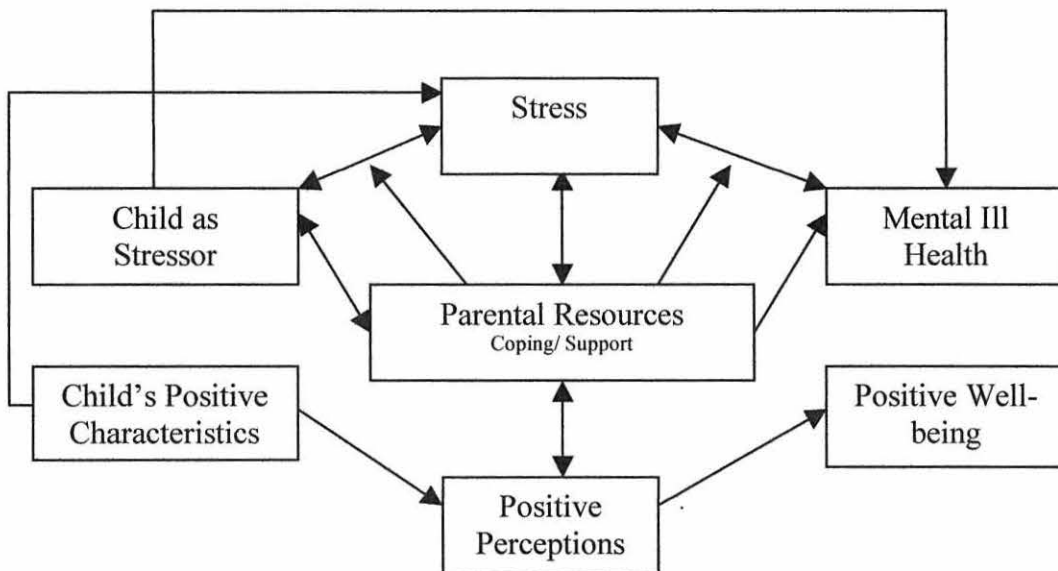


Figure 8.1 An Integrated Model of Stress and Coping in Parents of Children with Intellectual Disability

A bi-directional relationship was posited between the variables of 'Child as Stressor' and 'Stress' in the model. This hypothesis was based on a number of previous longitudinal studies, which have found a bi-directional relationship between child behaviour problems and parental stress in parents of children with intellectual disabilities (e.g. Baker et al., 2002; Lecavalier et al., 2006). Despite this established link, these studies have not examined the potential mechanisms underlying bi-directional relationships between the child as a stressor and parental stress. Thus, the key aim of the current study was to examine one possible mechanism of effect. If parent stress is causing increases in their child's behaviour, how is this happening? One likely explanation is that the stress experienced by a parent causes the parent to adopt certain parenting behaviours that then tend to influence or reinforce the behaviour problems exhibited by the child. The potential relationship between these variables is illustrated in Figure 8.2.

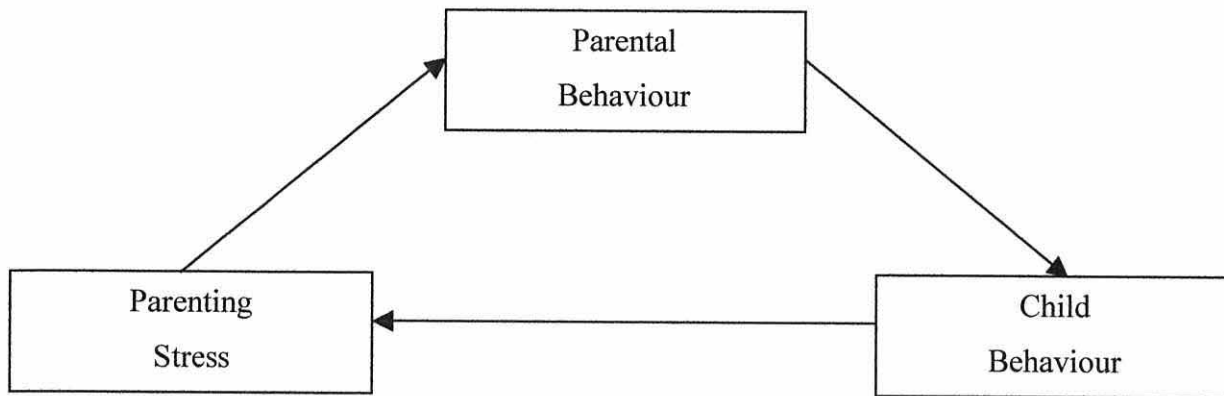


Figure 8.2 Relationships between parenting stress, parental behaviour, and child behaviour.

This chapter reviews the evidence for the relationships posited in the model depicted in Figure 8.2. First, the link between parental behaviour and child behaviour is discussed with reference to research and observational studies with parents of children with intellectual disability. Second, an emotional dimension of parenting behaviour, Expressed Emotion is introduced and discussed. Third, the hypothesised link between parenting stress and parental behaviour is reviewed. The more established link between child behaviour and parenting stress has been discussed at length earlier in this thesis (see Chapter 2) and will not be repeated here.

Parent-child interaction is an important factor in child development. Negative parental interactions, such as poor emotional support and low levels of affection and warmth, have been shown to correlate with diagnoses of conduct disorders (Kazdin, 1997). Positive parental interaction, such as warmth and supportive play, can encourage development of communication and social skills (Webster-Stratton & Herbert, 1994). For children with an intellectual or developmental disability, parental interaction may play an even more significant role, since children with delayed development are often highly dependent upon their parents. Parents, therefore, have a powerful influence on their child with an intellectual disability (McConachie, 1989).

Two broad areas may be identified as influential on the parent-child interaction: child characteristics and parental characteristics. Corter, Pepler, Stanhope and Abramovitch (1992) reported in their research of interactions with mothers, children with Down syndrome and their typically developing siblings, that the gender of the child was not a

significant factor in the interactions between the child with Down syndrome and the mother. They also found a significant positive correlation between the child's positive behaviour and maternal directive behaviour and a significant negative correlation between the child's positive behaviour and maternal negative behaviour.

Observations of children with autism indicate that these children rarely initiate others around them in social interaction, or example, they rarely display an interest in sharing with others, including both events and items (e.g. Loveland & Landry, 1986; Sigman, Mundy, Sherman & Ungerer, 1986). Furthermore, children with autism are less likely to exhibit expressions of happiness and may therefore give the person with whom they are interacting the impression they are disinterested in the interaction (Kasari, Sigman, Mundy & Yirmiya, 1990). Bell (1971) posited that these characteristics of children with autism may have an impact on the behaviour of partners engaged in social interaction with them. In a sample of children with autism, Kasari and Sigman (1997) found a significant association between perceptions and interactions. Caregivers of children with autism who rated their child to be more difficult temperamentally were observed to be less engaged with their children during the interactions.

The studies reviewed thus far in this chapter have excluded a key dimension of the relationship between parents and children: the emotional dimension. Expressed Emotion (EE) is a construct used to measure family life (Kuipers, 1994). It is a gauge of the family climate (Stubbe, Zahner, Goldstein & Leckman, 1993) and can be used as a method of measuring the nature of the emotional relationship that exists between parent and child (e.g. Beck et al., 2004; Hastings et al., 2004). Parental EE is typically dichotomised into 'high' and 'low'. Parents who are high in EE typically display a negative emotional relationship and intrusive over concern toward their child. 'High' parental EE (i.e., where parents make critical comments about their child or are emotionally over-involved) has been associated with a number of conditions in childhood including asthma (Wambolt, O'Conner, Wambolt & Klinnert, 2000), eating disorders (Schmidt, Humfress, & Treasure, 1997), obsessive compulsive disorders (Steketee, Van Noppen, Lam & Shapiro, 1998) and schizophrenia (Hamilton, Asarnow, & Tompson, 1999).

Parental EE has also been found to be associated with child behaviour problems. EE is typically coded along two dimensions: parental criticism and emotional over-

involvement. Emotional over-involvement may be the function of several different behaviours including evidence of overprotective behaviour, emotional display during the interview process, expressions of very strong love for the child or a willingness to do anything for the child in the future. In research that has looked at children without intellectual disabilities, the dimension of criticism rather than the dimension of emotional over-involvement is shown to relate to child behaviour problems. Furthermore, this is strongest for externalising behaviours, such as conduct problems/disorders and hyperactivity, as opposed to internalising behaviour, such as emotional symptoms (e.g. Baker et al., 2000; McCarty & Weisz, 2002; Peris & Baker, 2000). McCarty, Lau, Valeri & Weisz (2004) found that parents who scored highly on the criticism dimension engaged in more negative parenting behaviours. The same relationship was not observed for emotional over-involvement. Thus, EE through the dimension of criticism, is thought to show these relationships because it provides a good proxy measure of parenting behaviour.

Far fewer studies of EE have been carried out with families of children with intellectual disabilities. Beck, Daley Hastings and Stevenson (2004), and Lam, Giles and Lavander (2003) investigated EE within this population. Both studies found that mothers who were high in EE had children with more severe behaviour problems. However, neither of these studies clearly separated out the dimensions of criticism and emotional over-involvement that were identified by previous research as having differential associations with child behaviour problems and parenting behaviour. Dossetor, Nicol, Stretch and Rajikhowa (1994) found that children whose mothers had high emotional over-involvement showed more behaviour problems in public, whilst mothers who were critical had children with fewer overall behaviour disturbances. Recent work by Hastings, Daley, Burns and Beck (2006) has further tested EE. Identifying that only one previous study had done so (Dossetor et al., 1994), they clearly distinguished between the two dimensions of criticism and emotional over-involvement. In addition, they investigated whether associations with EE are specific to externalising behaviour in children with intellectual disabilities. The research design utilised a longitudinal methodology, thus allowing temporal precedence to be established. The study found that mothers high in criticism reported more distress and more externalising behaviour problems in their children. In contrast, emotional over-involvement was unrelated to maternal distress or children's behaviour problems. Internalising behaviour problems was additionally reported to be

unrelated to criticism. In the Hastings et al. (in press) study, the sample investigated mothers only, preferring to exclude fathers from the design.

EE as a construct appears to be a good measure of familial interaction for use with families where a young child has a developmental disability. However, it is not without its limitations. When first developed, EE was used as a retrospective measure with families of schizophrenic adults as they returned to live in the community following a period of hospitalisation (Hooley, 1985). The same criteria are now applied to families where a young child is indexed (McCarty & Weisz, 2002). These criteria may not be appropriate for use with families of very young children, whether they are developmentally disabled or typically developing. In particular, the constructs of emotional over-involvement (EOI) and quality of relationship appear to be problematic when studying families of young children (Daley *et al.*, 2003). The construct of EOI measures the extent of personal sacrifice and the extent of overprotection of one family member towards another. In the case of a parent and child relationship, this would be a measure of something that may be fundamental to the parenting role. Whilst with an adult child, it may not be appropriate to sacrifice personal goals, outside interests, etc., a parent may regard protection and a certain degree of sacrifice as parental duties. Thus, they may not only display these behaviours willingly, but they may also take a pride in them. Families of children with intellectual disabilities may choose to make even greater sacrifices and regard overprotection as an essential part of their responsibilities as a parent.

EOI, therefore, may not be a good reflection of high EE in parents of very young children. Perhaps it is best to view EOI as a construct that is situation-specific. Behaviours that may be viewed as inappropriate with an adolescent child may be normative with a school aged or pre-school child. Similarly, parents of children who have an illness or disability may be expected to show higher levels of protective and sacrificing behaviours that may, for their particular family situation, be normative. Thus, the point at which a family is surveyed takes on significance. For example, if a child with a disability has recently started at a new school, and the mother is concerned, levels of overprotection may be significantly higher than if the measurement was taken at a time of stability for both the parent and child. Other potentially confounding variables for the validity of EOI include the health and behaviour of the child at the time of interview. Although the



interviewer instructs the parent to only talk about their relationship with their child over the last six months, recent diagnoses, behavioural challenges and developmental milestones may confound EOI ratings, in that over protectiveness and personal sacrifice may be a transient reaction to current circumstances, rather than a typical familial pattern. In the current research, the two dimensions of Criticism and Emotional Over-involvement are analysed and interpreted separately in relation to observed child-parent interactions, as well as child variables and parent stress and mental health outcomes from the main study. Previous research involving typically developing children has found that Criticism rather than Emotional Over-involvement is related to children's behaviour (e.g. Baker, Heller, & Henker, 2000; McCarty & Weisz, 2002; Peris & Baker, 2000). Hastings et al. (2005) suggests that Criticism in particular may be thought of as a good proxy measure of parenting behaviour.

So far, we have reviewed the link between parenting behaviour/EE and child behaviour. The association between parenting stress and parenting behaviour has received less research attention, even outside the literature concerning intellectual disabilities. Generally, the research suggests that parents who show more stress also show poorer parenting (e.g. Baldwin, Brown, & Milan, 1995; Belsky, Woodworth, & Crnic, 1996). Deater-Deckard, Pinkerton and Scarr (1996) tested parenting behaviour as a mediator between parenting stress and child behaviour problems. High levels of stress were found to correlate with more authoritarian parenting discipline, which in turn was found to correlate with more behaviour problems amongst children. Baker, Heller and Henker (2000) found strong associations between EE and parental stress in their study of EE, stress and adjustment in mothers of children with behaviour problems. However, it is not clear whether stress drives parental EE or whether EE is a determinant of stress. In addition, these data were not collected on families of children with intellectual disability. Kasari and Sigman (1997) demonstrated that there were significant differences in the caregiver perceptions of the behaviour of children with autism, children with intellectual disabilities and typically developing children. Although parents perceived the characteristics of children with Down syndrome and typically developing children differently, there is no evidence of a strong association of caregiver perceptions with the parental-child interactions within this sample. However, in the sample of children with autism, a significant association between perceptions and interactions was reported. Caregivers of children with autism who rated their child to be more difficult



temperamentally were observed to be less engaged with their children during the interactions. Interestingly, children with autism who were reported to be temperamentally more difficult were also observed to be less responsive in their interactions with the experimenter. Kasari and Sigman (1997) suggest that these differences may potentially be explained by caregiver perceptions influencing the caregiver behaviour in addition to the child behaviour. One reason they suggest for this is that high parental stress may lead to differences in the interaction behaviour of the caregiver. However, Kasari and Sigman identify that it is impossible to say whether caregiver perceptions directly influence parent-child interactions or whether those perceptions are a result of interactions due to the design of the study being correlational and thus not able to investigate causation. However, they suggest the likelihood being that both perceptions and interactions influence one another in a bidirectional relationship. Thus, it appears as though there is still relatively little known about the relationship between parenting stress and parenting behaviour/EE.

Thus, the research presented in this chapter uses direct observations to examine the mechanisms involved in social interaction, providing a measure of processes including parenting strategies and child behaviour. Whilst direct observations may be used in a variety of naturalistic settings, the focus of interest is within the home as this is likely to be the environment where the majority of parent-child interaction takes place. Whilst the parental reports obtained in previous chapters are naturally of central importance to research, obtaining a more independent measure of the interactions between a parent and their child may be of benefit. Parents may define behaviour in different ways to those of the research team, experience them differently and be more easily influenced by biases relating to their mood or any preconceptions they may have about the intervention (Eddy, Dishion & Stoolmiller, 1998; Prescott et al., 2000). Bias due to expectancy effects has been found to be less likely with observational measures (Johnson & Lobitz, 1974; as cited in Aspland & Gardner, 2003).

This chapter details a small, exploratory observation-based study with five aims. First, to explore potential associations between ratings of child behaviour gathered through observations and the ratings of child behaviour collected in the main study. Second, to analyse the relationships between the child and parent variables collected in the main study and data regarding both positive and negative parenting behaviours. Third, to

explore any associations between child and parenting behaviour collected through observation and the dimensions of EE. Fourth, to explore associations between child behaviour data collected in the main study and the dimensions of EE. Fifth, to analyse any relationships between parent variables collected in the main study and the dimensions of EE.

## 8.2 Method

The following sections introduce the methodology used for the observational data collection. This includes details of the participants, the measures used, the design and the procedure. In addition, reliability data for the measures is presented.

### 8.2.1 Participants

22 families consented to participate in the observational study. These families were a sub-sample of the families who participated in the research outlined in the previous chapters. From an initial sample size of 142 families, who have participated in previous research, a sub-set of 22 mother/child dyads were recruited by telephone for the observational study.

Participants were selected according to availability to participate, proximity to the University of Wales, Bangor and according to scores on the Vineland Adaptive Behavior Scale (Sparrow, Balla & Cicchetti, 1984), where motor skills age scores of 2 years or above was a requirement to ensure that the children would be capable of physically manipulating the toys used in the tasks. Participants were paid £30 for taking part in this observational study. The researchers ensured that families were aware that the decision not to take part in the observation study would make no difference to their participation in the main research and more importantly, would have no bearing on the care they received from health or social services. Information sheets were provided to all participants and consent forms were read and signed by all participants (Appendices Q & R).

In terms of demographic data, the mean age of the mothers was 37.59 years ( $SD = 8.15$ , range = 24–55 years) and 9 mothers (40.9%) were employed either full or part-time, whilst the remaining 13 mothers (59.1%) were full-time carers for their child. The mean age of the children was 8 years ( $SD = 1.94$  years, range = 4.7–11.20 years). Fifteen of the children in the study were boys (68.2%) and seven were girls (32.8%). All of the children

had received a diagnosis of intellectual disability and the sample included 8 children with Autism (36.4%), 8 children with Down syndrome (36.4%) and 6 children with intellectual disabilities (27.3%). VABS scores ranged between 2 years and 5.11 years ( $M = 3.64$ ,  $SD = 1.29$ ).

### 8.2.2 Materials

A digital video camera and tripod were used to record the in-home mother/child interaction tasks. A stopwatch was used for timing the tasks. A laminated instruction sheet (Appendix S) was shown to each mother and 2 laminated photographs of a Duplo model (Appendix T) were required for the Lego building task. Score sheets (Appendix U & V) were used to code interactions.

The play materials required for the tasks were 6 toy cars, 4 plastic boats, a draw-string bag containing 12 plastic farm animals, and a Duplo set containing approximately 70 bricks of various sizes, shapes and colours in a large plastic container. Although original Lego is typically used for the Lego task, Duplo (the larger version of Lego) was used because it was felt to be more appropriate for the sample where the mean motor skills age was 3.6 years.

### 8.2.3 Measures

#### *Observations*

The Parent-Child Interaction Task (PCIT) (FASTTRACK program) (McMahon & Estes, 1994) was used as a measure for the observations. The PCIT involves four separate sections; a Child's Game, a Parent's Game, a Lego Task and a Tidy-up Task. Each task has a semi-structured element allowing for observation of specific behaviours.

The Child's Game consists of free play with the toys provided (the cars, animals and boats) and is controlled by the child, with the parent taking the lead from the child. The second section is the Parent's Game when the parent chooses the toys and play progresses according to the parent's rules. During the Lego Task, the Duplo blocks and two pictures of a figure (one front on and the other sideways on) are provided and the child must build the figure from the Duplo whilst the parent gives verbal help only. At no point during the Lego Task is the parent allowed to touch the bricks in order to help the child build the figure. However, the parent is allowed to point a certain blocks to assist the child. The

final task consists of the child clearing away the toys into their relevant boxes or bags. Each play task lasts for five minutes and the Tidy-up Task lasts for a maximum of three minutes; the task is stopped if the child finishes prior to the three-minute limit and the recording ends.

### *Coding – Behaviour Coding System*

Having collected video data, the Behaviour Coding System (BCS; Forehand & McMahon, 1981) was used to code mother/child interactions (See appendix for copies of a typical scoring sheet). Observers were trained until they reached an inter-rater reliability criterion greater than 70%, a figure suggested by Estes (1994) in the PCIT Resource Manual.

The BCS was developed for use with parents and children, both in-home and in clinical settings. Scoring is recorded sequentially for up to 10 parent and 10 child behaviours per 30-second interval, thus allowing observation of parental antecedent behaviours and child responses.

Three parenting behaviours were coded (commands, positive attention, and negative attention). These codes are mutually exclusive and were only coded if the behaviour was directed to, or included, the target child. The category of commands includes the following distinctions; Alpha Commands are those to which compliance is recorded and comprise direct commands, indirect commands, question commands, permission statements and rules, conditional statements, warnings and chain commands. Beta Commands are those to which compliance is not recorded and comprise no opportunity for compliance, conditional statements offering a choice and vague commands.

There are three forms of positive attention; attends, praise and positive physical attention. Three forms of negative attention are also coded; criticism, threats and negative physical attention. Two categories of child behaviour are coded, these being, compliance and non-compliance. Child deviant behaviour is coded as present or absent during each 30-second interval. No reliability data has thus far been reported within the literature.

### *Coding Systems – The Interaction Rating Scales*

The Interaction Rating Scales (Forehand & McMahon, 1981) were also used to code the

video data (See appendix for a copy of the IRS). The IRS is often used alongside the BCS to provide a richer, qualitative analysis of data. However, as for the BCS, no reliability data is currently available. The IRS comprises 5 rating scales, each of which is rated on a 5-point Likert scale. Ratings for parent and child are made independently. The first of the scales is the Gratification From Interaction Scale. This scale quantifies the amount of pleasure that the parent and child derive from the interaction. Gratification refers to enjoyment and satisfaction as well as pleasure and is indicated by positive affect, positive comments, laughter, and close physical proximity. The Parental Sensitivity Scale is coded for the parent's behaviour only and refers to the parent's ability to be sensitive to the needs of the child, to respond to cues and then to act accordingly. A sensitive parent helps only when needed whereas an insensitive parent is ignorant to their child's needs or is intrusive. The Involvement Scale measures how much the parent and child interact with each other during each play session. Involvement includes physical play and also visual attention and is the only quantitative measure in the IRS in that it measures the extent to which the mother and child were involved with each other. The IRS is coded independently of the BCS, so that if no codes are made for the BCS, coding still occurs for the IRS. Coding for the IRS takes place straight after each task has been completed and before the next task begins. Inter-rater reliability for the IRS was  $r = .98$ .

#### *Coding – The Choice of the BCS and IRS*

The BCS and the IRS were used together during the FASTTRACK programme data collection (Forehand & McMahon, 1981). These observation schedules were selected in preference to others as the time taken to train observers to code to collected data is substantially less than for other coding systems. Furthermore, as Aspland and Gardner (2003) identify, training time for the BCS is directly dependent on the number of behaviours of interest that the researchers wish to code. Given the relatively limited number of behaviours of interest in the current study, coder training time was not prohibitively long. In addition, the BCS contains codes for positive attention and the IRS contains codes for gratification, sensitivity and involvement, all of which may be important elements of positive parental perceptions, an element of the conceptual model proposed at the end of Chapter Three.

#### *Expressed Emotion*

We now turn to describe the assessment of EE in greater detail. To assess EE, caregivers

talk about their child and are then rated for EE based on the interview content (Baker, Heller & Henker, 2000). Levels of EE are rated as high or low depending on levels of criticism and hostility and emotional overinvolvement (EOI) displayed during the interview. Thus, measurement of EE is dependent on self-report measures and observational data (McCarty & Weisz, 2002). Two main methods exist for the measurement of EE. These are the Camberwell Family Interview (CFI) and the Five Minute Speech Sample (FMSS). The CFI (Brown, Carstairs & Topping, 1958) is a semi-structured interview that takes between one and two hours to administer and between five to six hours to score (Vaughn & Leff, 1976; Van Humbeeck, Van Audenhove, De Hert, Pieters & Storms, 2002). Whilst typically regarded as the “Golden Standard” of EE measures (Van Humbeeck *et al.*, 2002), the CFI is a cumbersome measurement tool. With practicality and simplicity being of importance in many research projects, the FMSS (Magana, Goldstein, Karno, Milkowitsz, Jenkins & Falloon, 1986) was developed to allow for a quicker, easier, yet valid assessment of EE.

The FMSS is essentially a monologue, during which the respondent describes their relationship with the patient (Peris & Hinshaw, 2003). In the case of this research, the parent is instructed to talk freely about their relationship with the child over the past six months for five minutes, and is told that the interviewer will not interrupt or intervene (Baker *et al.*, 2000). The FMSS is audio taped to allow for coding at a later stage, though coding is possible at the time of the interview. The FMSS was developed because data show that most critical, hostile and/or overprotective statements are made during the initial stages of the CFI interview (McGuire & Earls, 1994). Scoring is based on both content and vocal tone (Wamboldt *et al.*, 2000).



Table 8.1: Coding the FMSS

| Code                             | Sub-code                         | Example Statement                                     |
|----------------------------------|----------------------------------|---|
| Initial Statement                | Positive                         | “Colin is a lovely child”                             |
|                                  | Neutral                          | “Colin is nine years old”                             |
|                                  | Negative                         | “Colin is always irritating me”                       |
| Relationships                    | Positive                         | “Colin and I love to play football”                   |
|                                  | Neutral                          | “Colin is my son”                                     |
|                                  | Negative                         | “I don’t like taking Colin swimming”                  |
| Criticism                        | Negative comments<br>(frequency) | “Colin’s behaviour makes me hate him”                 |
| Positive Remarks                 | Positive comments<br>(frequency) | “Colin is really fun to be around                     |
| Dissatisfaction                  | Present or absent                | “I find it irritating when Colin doesn’t listen”      |
| EOI – Self-sacrificing behaviour | Present or absent                | “I gave up work to look after Colin”                  |
| EOI – Emotional Display          | Present or absent                | Cries or is unable to speak through emotion           |
| EOI – Excessive Detail           | Present or Absent                | When substantial detail about the past is provided    |
| EOI – Statement of Attitude      | Present or Absent                | “I will do whatever it takes for Colin in the future” |

As can be seen from Table 8.1, the initial statement and relationship quality items are rated as positive, neutral or negative. Criticism is based on a frequency count and EOI is rated as present or absent.

For the purposes of analysis, we used two dichotomous scores from the FMSS; Criticism and EOI. The FMSS coding manual was used to classify mothers as high or low on criticism. To be classified as high on criticism, mothers had one or more of the following during their five-minute speech sample; their first statement about the child was negative, they described the relationship with their child in negative terms, and/or they made one or



more critical comments about the child. In terms of EOI, mothers were dichotomised the same way, high or low. Mothers who were classified as high in EOI had one or more of the following; evidence of self-sacrificing behaviour, emotional display during the sample, and/ or two or more of three additional codes. These additional codes were: five or more positive comments about the child, excessive detail, the expression of very strong feelings of love for the child or a willingness to do anything for the child in the future. Previous research has reported reliability data for the FMSS. Hastings et al., (2005) reported agreement levels for code-recode and inter-rater reliability. For criticism, code-recode was 100% and inter-rater was 83%. For EOI, code-recode was 82% and inter-rater was 94%.

Van Humbeeck, Van Audenhove, De Hert, Pieters, and Storms (2002) found internal consistency of the Five Minute Speech Sample to be .80 and the test-retest reliability of overall EE to be .64. In the Beck et al. (2004) study, good agreement was found for the code-recode reliability data of overall EE, .83. A figure of .79 was found for the inter-rater reliability of overall EE, suggesting good agreement between both raters on all dimensions.

### *Other Measures*

In addition to the data collected through the measures outlined above, the observation study also included a number of measures from the main research study. The measures included from the main study were taken from the data collected at the second data point. This was because the observational home visits took place after the completion of the main project and so the measures taken at Time 2 would be a more accurate representation of the mother's attitudes and perceptions at the time of the home visit. There was a delay of approximately 8 weeks between the time of the second data collection by post and the home visit.

Three child measures were used, these being the Behavior Problems Inventory, the Reiss Scales for Children's Dual Diagnosis and the Vineland Adaptive Behavior Scales. Two maternal measures were also used: the Hospital Anxiety and Depression Scales and the Questionnaire on Resources and Stress – Short Form. Full descriptions and reliability data for these measures can be found in Chapter 4.

#### 8.2.4 Observers

The same two observers were present at all 22 observation sessions and coded all the video data. Observer 1 was a male PhD student at the University of Wales, Bangor and Observer 2 was a female Masters student at the same institution. During the data collection phase of the study, neither observer was trained to code the Behaviour Coding System or the Interaction Rating Scales. Therefore, whilst both observers were trained in the data collection, the fact that they were as yet untrained in the coding, allowed for unbiased data collection. Coder training for the BCS and IRS took place in four one-hour sessions using practice videotapes of parent/child interaction tasks until the coders were reliable to an inter-rater reliability criterion of greater than 70%. Coding of the data gathered during this study then took place and relevant analyses were carried out. Frequent reliability checks were employed throughout.

#### 8.2.5 Design

Due to the sensitivities of children with intellectual disabilities to changes in routines and environments, an observational design based at participant's homes was selected, thus providing the most natural setting for both parent and child. Observational data, rather than the self-report data used in the first two studies of this thesis, allows the researcher to independently define and code the behaviour exhibited by both parent and child, which may differ from a parental perception. This design complies with the ethical standards set by the University of Wales, Bangor.

#### 8.2.6 Procedure

The families, as selected by the criteria already identified, were telephoned approximately one month after participants had taken part in the second phase of the main data collection. They were asked as to whether they would be interested in taking part in a further observational study, which was based at their homes. If the family were willing to participate, an appointment for a home visit was arranged and an appointment pack, containing further details, contact numbers and addresses and a consent form (See appendix for a copy of the appointment pack) was mailed to the home address. Appointments were made for either 10.30 am or 2.30 pm during school holidays and no more than two appointments were made for any day, to facilitate travel to the destinations and allow extra time at addresses should the need arise.

On arrival at the home of the participant, the observers introduced themselves and familiarised themselves with the family for a short time, answering questions, describing the procedure and playing with the child. The observers then brought the equipment (video camera, toys, audio recorder) into the house. The observations took place in the lounge room of each home. The cars, boats and animals were placed on the floor approximately 1 metre apart. A laminated instruction sheet was given to the mother to read (See appendix for a copy of the instruction sheet) and verbal explanations of each task were given by Observer 2. Parents were then asked by Observer 2 to begin the first task (the Child's Game). During all tasks, Observer 1 video recorded the data whilst Observer 2 gave instructions and timed the interaction periods. For task 1, Observer 2 gave the following verbal instructions to the parent: *"In a minute you and (Child's name) are going to play with the toys on the floor. For the next five minutes, (Child's name) is in charge of play. He/She may choose to play with any of the toys and you must follow along. Play with (Child's name) just as you would normally, and try to forget we are here. We are not looking at right or wrong ways to play; we just want to see what goes on between parents and children. You may stop playing at any point if you or (Child's name) feel unhappy or uncomfortable. Do you have any questions before we begin?"*

If mother and child were happy to proceed, Observer 2 asked them to begin the game and timed the play for 5 minutes. Observer 2 remained in the doorway of the room where she was able to move out of sight should the child become distracted by her presence.

Observer 1 videotaped the play session from the furthest corner of the room. During observation sessions, both observers attempted to maintain as little contact with the participants as possible, answering questions briefly and avoiding eye contact. At the end of the five minute observation period Observer 2 stopped the play by saying *"That was a really great game you both played. Shall we have a little rest and then play some more games?"* The video camera was switched off and a 1-minute break followed.

Following the break, Observer 2 began the next video taped play session by saying: *"The next game we are going to play is Mum's Game. You can both play with any of the toys on the floor, but this time Mum will make up some rules for you both to follow. Try to play with all of the toys."* Again, Observer 2 moved slightly out of sight while Observer 1 videotaped the interaction. After 5 minutes, the play session was stopped and the Lego Task was then introduced by Observer 2 putting the Duplo container on the floor and tipping half of the bricks out onto the floor. She then showed both the mother and the

child two photographs of a Duplo figure (see appendix B). Observer 2 introduced the game by saying: “*This game is a bit different from the ones that you just played. For the next game, we are going to use these bricks to make a little girl like the one in my pictures. Mum can help in any way she likes; she can point to pieces and give lots of suggestions for which piece to use next, but the one thing that Mum can’t do in this game is to touch any of the bricks at all. This is really hard for Mum to do. In fact, this is a really hard game to play. It doesn’t matter if you can’t build the girl in the picture, but you can have lots of fun together trying. If you get stuck and can’t finish, it doesn’t matter.*” The videotaping then recommenced. After 5 minutes elapsed, Observer 2 ended the Lego Task by saying “*Well done, that was some really great building, but we have run out of time for today. Can Mum look on her sheet and ask (Child’s name) to do the last task on the sheet please? I don’t want to say aloud what you will do next, but I would like Mum to say the words to (Child’s name).*” Observer 2 indicated the instructions for the Tidy-up Task on the instruction sheet (appendix B) and told the mother “*You may help your child in any way and begin when you are ready.*” The task was timed for 3 minutes, or until the toys were packed away into the relevant boxes or bags. The videotaping was then stopped. While one of the researchers stayed with the child, the other researcher went to another room with the mother to record the Five Minute Speech Sample. After setting up the audio recording equipment the mother was given the following instructions, taken from Magana et al. (1986):

*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 five 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?*

On completion of this, the equipment was collected and the researchers left the participants home.

When all of the in-home observations had been conducted, both observers were trained to code the audio and videotapes according to the schedules previously described (BCS and IRS).

### 8.3 Results

The domains of Criticism and Emotional Over-Involvement were dichotomised into high and low. Following the precedent set by previous research (e.g. Beck et al., 2005), borderline results were collapsed into the 'low' code. Table 8.2 presents the descriptive analysis of the FMSS data when split into the two codes.

Table 8.2

#### *Descriptive Statistics for EE Domains*

| Emotional Over-Involvement |          | Criticism |          |
|----------------------------|----------|-----------|----------|
| High                       | Low      | High      | Low      |
| (n = 1)                    | (n = 21) | (n = 6)   | (n = 16) |
| 4.5%                       | 95.5%    | 27.3%     | 72.7%    |

Given that only one mother was high in Emotional Over-Involvement, this dimension is not included in further analyses, as little interpretation of the results can be made.

Previous researchers who have used EE (e.g. McCarty & Weiss, 2002) have suggested that the use of the Emotional Over-Involvement dimension may not be appropriate in research with children who have intellectual disabilities. This is because emotional over-involvement may be necessary for parents of these children, who are more dependent and require more emotional support. High EE is scored for any mother who makes one or more critical comment about her child. Therefore, the criticism dimension above is equivalent to high EE; mothers who are high in criticism are also high in EE. As can be seen in Table 8.2, 27.3% of the sample had high EE. This is considerably lower than previous published research of mothers whose children have intellectual disabilities. Beck et al. (2004) reported that 60% mothers of children with intellectual disabilities in their sample had high EE. However, the figure found in the present research is still higher than normal controls in a study by Hibbs et al. (1991) who found 13% of mothers of typically developing children had high EE.

The Criticism dimension of EE, along with BCS and IRS scores were initially analysed using one-sample Kolmogorov-Smirnov tests to assess the variables for normal distribution. The results were non-significant, indicating that the data were normally distributed and therefore could be analysed using parametric tests.

### 8.3.1 Behavior Coding System

Inter-rater reliability was calculated for the dimensions of the BCS. These data are reported in Table 8.3. These data were generated according the guidelines described in the PCIT manual (Estes, 1994). Good agreement was indicated for all the dimensions used in this study.

Table 8.3

#### *Reliability of the BCS*

| BCS Codes            | Inter-Observer Agreement (n = 20) |
|----------------------|-----------------------------------|
| Commands             | 86.5%                             |
| Positive Attention   | 86.3%                             |
| Negative Attention   | 100%                              |
| Compliance           | 85.2%                             |
| Non-compliance       | 76.3%                             |
| Disruptive Behaviour | 100%                              |

A series of correlation matrices were generated to establish the presence and extent of any relationships that existed between the BCS and the measures of mother stress and mental health, child variables and the criticism dimension of EE.

Table 8.4

#### *Correlations between the BCS and Child Variables*

| BCS Codes            | BPI  | REISS |
|----------------------|------|-------|
| Commands             | .03  | .02   |
| Alpha Commands       | .28  | .40   |
| Beta Commands        | -.13 | -.19  |
| Positive Attention   | .13  | .36   |
| Negative Attention   | .11  | .04   |
| Compliance           | .19  | .33   |
| Non-compliance       | -.31 | -.29  |
| Disruptive Behaviour | .02  | -.06  |

In Table 8.4, no significant correlations were found between the codes of the BCS and the child variables of child behaviour problems and child psychopathology.

Table 8.5

*Correlations between the BCS and Mother Stress and Mental Health*

| BCS Codes            | Stress | Anxiety | Depression |
|----------------------|--------|---------|------------|
| Commands             | -.18   | .23     | -.25       |
| Alpha Commands       | -.02   | .19     | -.20       |
| Beta Commands        | -.21   | .08     | -.26       |
| Positive Attention   | -.06   | -.01    | -.31       |
| Negative Attention   | .28    | .01     | .15        |
| Compliance           | -.11   | .22     | -.16       |
| Non-compliance       | -.13   | .19     | -.01       |
| Disruptive Behaviour | .12    | .13     | .37        |

Table 8.5 shows no significant correlations between parental stress and any of the domains of the BCS or mental health and any of the domains of the BCS.

Table 8.6

*Independent Samples T-test between the BCS and Criticism*

| BCS Codes            | Criticism    |              | p   |
|----------------------|--------------|--------------|-----|
|                      | High (n = 6) | Low (n = 16) |     |
| Commands             | 4.70 (0.98)  | 5.13 (2.02)  | .63 |
| Alpha Commands       | 1.38 (0.84)  | 1.91 (0.88)  | .23 |
| Beta Commands        | 3.12 (1.34)  | 3.06 (1.95)  | .95 |
| Positive Attention   | 1.41 (0.63)  | 2.25 (0.92)  | .06 |
| Negative Attention   | 0.01 (0.02)  | 0.02 (0.05)  | .62 |
| Compliance           | 1.64 (0.80)  | 1.87 (0.82)  | .57 |
| Non-compliance       | 0.67 (0.34)  | 0.86 (0.66)  | .52 |
| Disruptive Behaviour | 0.11 (0.09)  | 0.10 (0.15)  | .73 |

The results of the independent samples t-test indicate that there is no significant difference between mothers with high or low EE on the dimensions of the BCS.



### 8.3.2 Interaction Rating Scale

The inter-rater reliability of the IRS was investigated using Kappa and percentage agreement. The results presented in Table 8.7 indicate good agreement for the dimensions of mother gratification, mother involvement and child involvement. However, the dimensions of child gratification and mother sensitivity were found to have poor to moderate inter-rater reliability.

Table 8.7

#### *Reliability of the IRS*

| IRS Codes            | Inter-observer Agreement (n = 20) |
|----------------------|-----------------------------------|
| Mother Gratification | .64**                             |
| Child Gratification  | 47.4%                             |
| Mother Involvement   | 63.7%                             |
| Child Involvement    | 1.0**                             |
| Mother Sensitivity   | .37**                             |

\*\* <.001

Correlations are presented between the IRS and mother stress, anxiety and depression, child variables and mother EE.

Table 8.8

#### *Correlations between IRS and Child Variables*

| IRS Codes            | BPI | REISS |
|----------------------|-----|-------|
| Mother Gratification | .33 | .02   |
| Child Gratification  | .25 | -.03  |
| Mother Involvement   | .19 | -.11  |
| Child Involvement    | .03 | -.21  |
| Mother Sensitivity   | .16 | -.09  |

Table 8.8 shows no significant correlations between the codes of the IRS and the child variables of child behaviour problems and child psychopathology.

Table 8.9

*Correlations between IRS and Mother Stress and Mental Health*

| IRS Codes            | Stress | Anxiety | Depression |
|----------------------|--------|---------|------------|
| Mother Gratification | .50*   | .45     | .60**      |
| Child Gratification  | .30    | .03     | .42        |
| Mother Involvement   | .36    | .19     | .69**      |
| Child Involvement    | .27    | .09     | .49*       |
| Mother Sensitivity   | .58*   | .27     | .68**      |

Table 8.9 presents significant correlations between depression and the IRS domains of mother gratification, mother involvement, child involvement and mother sensitivity. Mother gratification and mother sensitivity were also significantly correlated with stress.

Table 8.10

*Independent Sample T-tests between IRS and Criticism*

| IRS Codes            | Criticism    |              | p   |
|----------------------|--------------|--------------|-----|
|                      | High (n = 6) | Low (n = 16) |     |
| Mother Gratification | 9.80 (2.95)  | 7.57 (2.93)  | .16 |
| Child Gratification  | 8.20 (2.59)  | 7.64 (2.84)  | .71 |
| Mother Involvement   | 8.80 (4.21)  | 6.50 (3.32)  | .50 |
| Child Involvement    | 13.00 (4.24) | 10.14 (3.96) | .23 |
| Mother Sensitivity   | 5.20 (1.48)  | 4.57 (1.83)  | .19 |

Independent sample t-tests were conducted to investigate whether mothers with high or low EE differed significantly in the dimensions of the IRS.

8.3.3 Expressed Emotion

The reliability of the Criticism dimension was investigated using intra-class correlations. Good agreement was found for both code-recode and inter-rater reliability.

Table 8.11

*Reliability of the Criticism dimension of EE*

|           | Code-Recode (n = 22) | Inter-rater (n = 22) |
|-----------|----------------------|----------------------|
| Criticism | .71**                | .77**                |

\*\* &lt;.001

To examine the differences between mothers with high criticism compared to low criticism, independent sample t-tests were performed. As the t-tests with the BCS and IRS were presented in sections 8.3.1 and 8.3.2, they are not been included here.

Table 8.12

*Independent Sample T-tests between Child Variables and Criticism*

| Child Variables | Criticism     |               | p   |
|-----------------|---------------|---------------|-----|
|                 | High (n = 6)  | Low (n = 16)  |     |
| BPI             | 34.00 (25.76) | 41.75 (28.89) | .57 |
| REISS           | 12.67 (6.35)  | 20.44 (13.76) | .20 |

Again, no significant differences were found between mothers with high criticism compared to mothers with low criticism in the domains of behaviour problems and child psychopathology.

Table 8.13

*Independent Sample T-tests between Mother Variables and Criticism*

| Mother Variables | Criticism    |              | p   |
|------------------|--------------|--------------|-----|
|                  | High (n = 6) | Low (n = 16) |     |
| Stress           | 4.00 (2.53)  | 4.13 (3.42)  | .94 |
| Anxiety          | 8.17 (2.71)  | 7.50 (2.61)  | .60 |
| Depression       | 6.83 (2.71)  | 4.88 (3.36)  | .22 |

No significant differences were observed between mothers with high criticism in terms of stress, anxiety and depression and mothers with low criticism.

#### 8.4 Discussion

The observation study presented in this chapter examined the relationships between observations of child and mother behaviour, EE in mothers, child variables from the main study and mother stress and mental health variables, also from the main study. The study was largely exploratory in nature, with the focus of the study on observed behavioural interactions in 22 mother/child dyads. Thus, Pearson's product moment correlations were used to investigate the relationships among the BCS and the IRS and child variables and parental outcomes from the main research project. Relationships between EE and the BCS, IRS, child behaviour from the main study and parent outcomes from the main study were explored using independent samples t-tests, as the dimension of Criticism was dichotomized for the analysis. This study represents the first examination of the BCS in a sample of children with intellectual disabilities, therefore no a priori hypotheses were offered for these relationships. The introduction (see Section 8.1) posited a number of aims for this observational study.

We found no evidence that observed maternal behaviour was significantly associated with maternal stress, anxiety or depression. The BCS also provides codings of compliance, non-compliance and disruptive behaviour in the child, which may be thought of as the observational analogue of the child behaviour measures used in the main study. Since a number of significant relationships were found between child variables, and mother stress, anxiety and depression in the main study, significant correlations might be expected between compliance, non-compliance and disruptive behaviour, and mother stress and mental health. However, no significant relationships were identified. This suggests that the behavioural observations might not have been sensitive enough to detect maternal or child behaviour. Visiting a family for an hour provides the researchers with a 'snapshot' of life at home. The behaviour that occurs within that time frame may not be representative of life within that household at other times. Given the environmental change that occurs when two researchers enter the home and ask the family to do something that they have never done before, it is perhaps understandable that a similar pattern of relationships was not identified when compared to results in the main study. Mothers may behave in a socially desirable way as they feel under pressure from the presence of strangers watching them. Other times of the day may be particular flashpoints for the family for behaviour problems, or indeed may be more representative of the mother/child dyad's interactions. One potential way of overcoming this would be to take

observations at multiple time points. However, this may pose additional problems; the PCIT uses a set of tasks that would need to be repeated if multiple measurements were taken. Depending on the frequency of these measurements, a potential issue could be the familiarization of the participant to the assessment, thus skewing the results.

No significant results were observed between child and parent behaviour collected through the observational data and the dimension of Criticism. One result was close to significance; mothers with higher Criticism gave less positive attention to their child. However, caution should be exercised when considering these results. Only six mothers were found to have high Criticism scores, thus potentially reducing the power of the analyses. The data collected in the main study on child behaviour was also analysed with the dimension of Criticism. Furthermore, no significant findings were observed between child behaviour data collected in the main study and the dimension of Criticism or between parent variables collected in the main study and the dimension of Criticism. Similarly, these findings must be interpreted in light of the small sample of mothers of expressed high EE/Criticism. As mentioned, the results for the dimension of Criticism were dichotomised into high and low, with borderline critical results being subsumed into the 'low' category. However, it is important to mention that only 6 mothers were in the 'high' category and 5 were in the 'low' category. The remaining 11 mothers obtained 'borderline' scores. This may affect the results obtained.

Using the IRS coding system, a number of significant correlations were identified in the coding dimensions but prove difficult to explain. Mother stress and depression are positively correlated with gratification, involvement and sensitivity. Given the small sample size, these results may be found by chance.

The current study contains both strengths and weaknesses. The small sample size means that the presented results should be treated with some caution. The small sample size may also mean that relatively large correlations are not significant, despite the effect size. By using a structured observation system, the efforts of the mother to spontaneously engage their child were unable to be assessed. A number of advantages and limitations were found with the measures used. The BCS allows for a more detailed breakdown of the behavioural interactions taking place between mother and child and is comparatively simple in terms of the ease of coding and speed at which coders can become conversant in

its use. However, as the tasks are semi-structured, a danger is that ecological validity may have been sacrificed (Gardner, Ward, Burton & Wilson, 2003). The BCS was developed for use with typically developing children. Children with intellectual disabilities typically have communicative problems and are frequently less vocal than their typically developing counterparts. Therefore, the results might bear this out in terms of less responses and potentially greater discontent on the part of the mothers. An interesting avenue for future research would be to compare mothers with just a child with intellectual disabilities to mothers with both a child who is typically developing and a child who has intellectual disabilities. Mothers of children with typical development may exhibit different behaviour, as they would be able to compare the progress and abilities of their children. Eheart (1982) found that children with an intellectual disability responded to maternal initiations less than typically developing children. Intellectually disabled children responded to an average of 56% of interactions, whereas typically developing children responded an average of 78% of the time. In the present study, one child did not vocalize at all during the observation periods.

Other areas of concern included the coding of behaviours across intervals. Each of the intervals was 5-seconds and given that children with intellectual disabilities often take longer to respond than typically developing children, the 5-second response criteria imposed by the BCS may need reviewing for future use of the BCS within the intellectual disability population. The BCS also needs to be more specific in regards to behaviours that occur across intervals, as it was in these areas that reliability was most compromised. However, the BCS does appear to be a valid tool for use with observational studies such as this. It is a well-established coding system and, as there several tasks, the content validity is high.

The IRS coding system is limited by the fact that it is a purely subjective scale. It relies upon the subjective opinion of the observers and thus, it is inappropriate for the observers to act as coders, since they have already met the families and have formed subjective opinions of familial dynamics prior to coding the data. A possible way to combat this in future research would be to have the data coded by researchers blind to the study. Thus, one team of researchers collect the data and another team code the data.

This observational study aimed to explore the link between parenting stress and parenting behaviour and parenting behaviour and child behaviour. Unfortunately, perhaps due to the limitations discussed above, little support was found for these links in the observational study, but the use of larger sample research in future observation studies of mother-child interactions is recommended.



## Chapter 9

## General Discussion

9.1 Introduction

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 in a clinical context and to discuss theoretical and conceptual issues. The following chapter takes the following structure: First, the broad aims of the thesis are reviewed. Second, each of the main sections of the model is presented. For each section, correlational, cross-sectional and longitudinal analyses, and where appropriate, findings from the observational study are presented and discussed in light of previous research. For each of these main sections, any future research directions are discussed. Third, the limitations inherent in the research are presented, together with more general critical issues and methodological problems. Four and finally, the clinical implications of the work are discussed.

As discussed in Chapter Three, a number of aims for the thesis were identified, which focused on the links between child factors and parental stress, coping and well-being. A proposed model provided a framework within which cross-sectional and longitudinal relationships were tested (Figure 9.1).

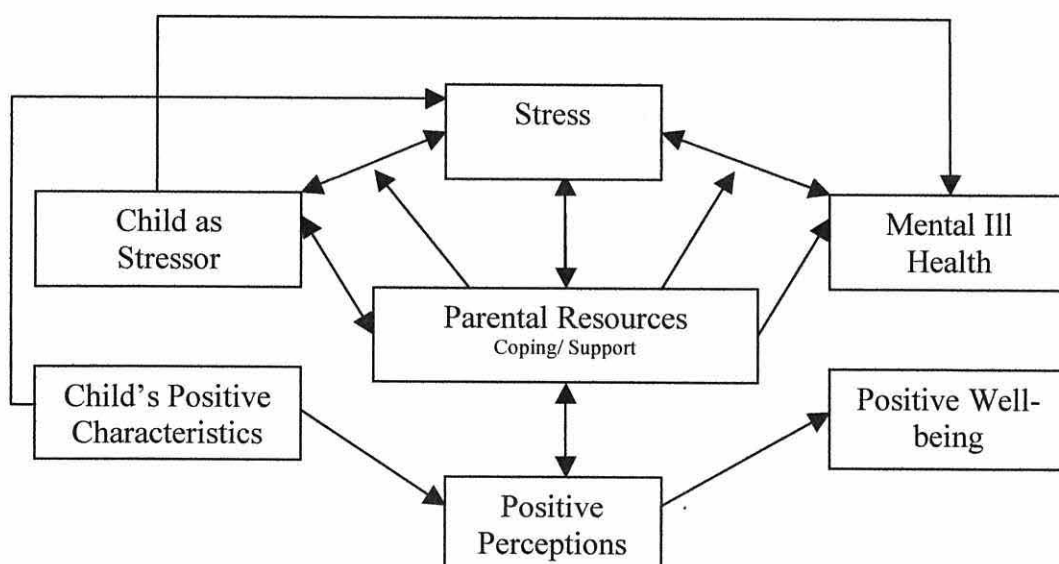


Figure 9.1 An Integrated Model of Stress and Coping in Parents of Children with Intellectual Disability

A second aim of the research was to investigate possible differential experiences of mothers and fathers. That is, do the relationships in the model differ according to the gender of the parent? To aid interpretation of the findings, each of the following sections includes pictorial summaries of significant relationships. Due to the size of the model and the number of relationships included in it, figures present only the relevant parts of the model, rather than the model as a whole. This approach also facilitates interpretation of differential results for mothers and fathers.

In this thesis, two forms of predictor were used to examine for evidence of longitudinal relationships. First, Time 1 independent variables were investigated as predictors of Time 2 outcomes. Second, the change score for the independent variable from Time 1 to Time 2 was also entered into the regression analyses. Where support for a longitudinal relationship comes exclusively from change scores, this is highlighted in the text.

## 9.2 Relationship between Child Variables and Parental Stress

Chapter Two identified the importance of child variables, particularly child behaviour, on the stress experienced by parents. The relationships between child behaviour and parental stress are considered first, given previous research that has found strong associations between these variables (e.g., Quine & Pahl, 1985; Sloper et al., 1991). Relationships between child variables and other parental variables, such as anxiety and depression are examined in later sections.

The first research question centred on whether data supported a relationship between child behaviour problems and increased parental stress. The present research contained the BPI, a traditional measure of behaviour problems in children with intellectual disability, and the Reiss Scales for Children's Dual Diagnosis, a measure that is used to assess for the presence of psychopathology in children with intellectual disability. However, the Reiss Scales are also for use in identifying behaviour problems and the measure has been employed in such a way in previous research (e.g., Feldman et al., 2000). In the current thesis, parental stress was correlated with both measures of child behaviour problems. Cohen (1988) suggests that a correlation coefficient of .1 represents small effects, .3 moderate effects and .5 large effects. According to these criteria, BPI was correlated with stress with a moderate-to-large effect size and Reiss was correlated with

stress with a large effect size. Child pro-social behaviour was negatively correlated with parental stress. Mother and father scores evidenced the same pattern of correlations, with similar effect sizes, indicating that at a correlational level, results do not differ according to parental gender.

The variables depicted as 'Child as Stressor' in the proposed model (i.e., child behaviour problems and child psychopathology) are hypothesised to positively predict parental stress. Regression analysis using the cross-sectional data found that both maternal and paternal stress was significantly predicted by child psychopathology. However, for both mothers and fathers, child behaviour problems did not significantly predict any unique variance when entered into the regression analyses with the other child variables. This may be due to shared variance between scores for child psychopathology and child behaviour problems. Indeed, the two measures were highly correlated (.79 for mothers, .63 for fathers). While the Reiss Scales for Children's Dual Diagnosis are primarily a measure of child psychopathology, the questionnaire can also be used to assess conduct disorder, hyperactivity and behavioural problems. It is possible that there is some overlap in the constructs operationalised in the Reiss Scales and the BPI. The results for this analysis indicate the same pattern of relationships for mothers and fathers, echoing those found in the corresponding correlations and providing further support for the similar impact of stressful child variables on both maternal and paternal stress.

The variables depicted as 'Child's Positive Characteristics' (i.e., child pro-social behaviour and adaptive behaviour) were hypothesised to negatively predict parental stress. Child pro-social behaviour was found to predict maternal stress but not paternal stress when entered into the regression analyses alongside all the child variables. The finding that child pro-social behaviour independently predicted maternal stress when entered in a regression analysis with child psychopathology, was a somewhat similar finding to that of Beck et al. (2004) who found that behaviour problems and child pro-social behaviour independently predicted maternal stress. Thus, mothers of children with intellectual disabilities at most risk of stress may be those whose children show high levels of child psychopathology and low levels of pro-social behaviour. Child adaptive behaviour was the final child variable included in the study, which was not found to significantly predict stress in either mothers or fathers. This finding is similar to that reported by Hastings (2002) whose review paper concluded that adaptive behaviour was

less important a predictor of stress than child behaviour problems. The differential results for child pro-social behaviour in predicting maternal and paternal stress indicate that child pro-social behaviour plays a more important role in whether mothers experience stress. The null finding for the child pro-social behaviour – father stress relationship may be due to a number of reasons. First, fathers may have a less accurate picture of their child's pro-social behaviour, as they may spend less time in the home than mothers. In the current sample, 75% of fathers had a full-time job outside the home compared to only 47.8% of mothers. Future researchers may wish to consider the amount of time each parent spends caring for their child with intellectual disabilities. Second, it may simply be the case that the child's positive characteristics are less important than other variables, such as child behaviour problems, in predicting paternal stress.

Next, longitudinal relationships between child variables and parental stress were examined. The bi-directionality of these relationships was also investigated. As outlined in Chapter Six, only significant relationships from cross-sectional regressions were examined over time. Therefore, the relationships between child psychopathology and maternal and paternal stress, and child pro-social behaviour and maternal stress were tested longitudinally. A number of studies (e.g., Lecavalier et al., 2006; Baker et al., 2003; Nihira, Mink & Meyers, 1985; Orsmond et al., 2003) have used a similar longitudinal design to assess the bi-directionality of a number of variables, but have paid particular attention to the relationship between child behaviour and parental stress. The Reiss Scales were included in the longitudinal analyses and were found to significantly predict both maternal and paternal stress at Time 2. Unlike the previous research, only a uni-directional relationship was observed between child psychopathology and parental stress. This may be attributable to a number of factors. Given that the present research used a sample of 113 mothers and 50 fathers in the longitudinal data analysis, and the relatively large number of measures included in the research, the probability of committing Type II errors due to diminished power is increased. A larger sample may enable bi-directional relationships to be identified. Another possible explanation for this finding may concern the questionnaires used to measure child behaviour problems and parental stress. The measures in the current research differ from those used in previous research. For example, the parent and family problems subscale of the QRS-SF asks parents to rate the impact that their child with intellectual disabilities has on family life. It may be that stress operationalised in this way does not predict child behaviour problems

as strongly as stress defined in terms of how the parent feels as an individual and their ability to manage the difficulties posed by their child. One example of this latter definition is the Parenting Stress Index – Short Form (Abidin, 1990) as used by Lecavalier et al. (2006) who identified a bi-directional relationship between child behaviour problems and stress. Future research may look to compare different measures of parental stress in the prediction of child behaviour problems.

Another relationship investigated over time was that between child pro-social behaviour and maternal stress. Both longitudinal and bi-directional relationships were found between these variables. This supports previous research (e.g. Lecavalier et al., 2006) which has identified that pro-social behaviours are negatively associated with parental stress. The findings support the presence of a transactional relationship between child pro-social behaviour and maternal stress, indicating that children with intellectual disabilities are more likely to demonstrate high pro-social behaviour when their mother has low levels of stress. Of course, it is also important to consider that mothers with low stress levels may tend to perceive their child as displaying more pro-social behaviour, even if objective measures indicate that this is not the case. This highlights the need for future studies to obtain independent measures of the child's behaviour where possible.

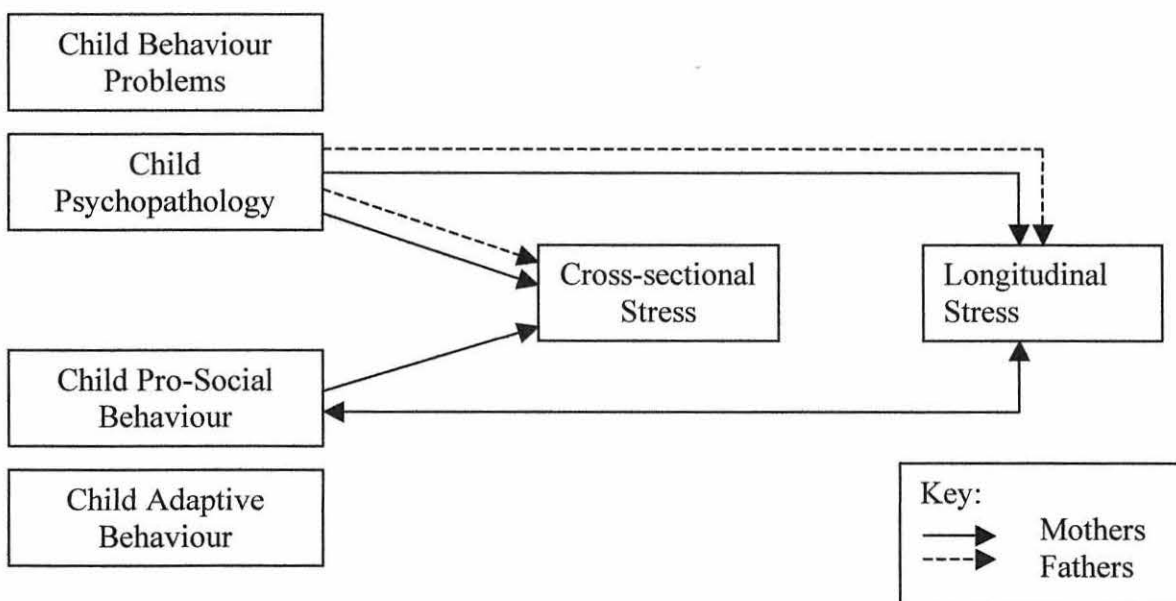


Figure 9.2 Relationships between Child Variables and Parental Stress

A summary of the relationships between child variables and parental stress identified through regression analyses is presented in Figure 9.2. This figure includes significant findings for both mothers and fathers, at both the cross-sectional and longitudinal level. For longitudinal analyses, arrows with a single head illustrate a uni-directional relationship and arrows with two heads indicate a bi-directional relationship.

With regard to possible future directions for research investigating child behaviour and parental stress, a delineation of the behaviours exhibited by the children into externalising and internalising behaviour may provide useful data. This distinction was originally made by Achenbach (Achenbach & Edelbrock, 1983). Externalising behaviour include conduct problems/disorders and hyperactivity, whereas internalising behaviour relates to emotional symptoms such as depression. This distinction may also be of use in research into intellectual disabilities. The Reiss Scales for Children's Dual Diagnosis - the current measure of child psychopathology – contains items that measure both internalising and externalising behaviours. Lecavalier et al. (2006) found that externalised behaviours may be most strongly associated with parent stress. Future work might look to either further break down the Reiss Scales into items measuring internalising and externalising behaviours or use an existing measure that separates these dimensions of the child behaviour. This would enable the nature of the relationship between child behaviour and parental stress to be better understood. Researchers could then begin to identify whether mothers and fathers are differentially affected by certain behaviours and thus ultimately guide interventions for parents.

### 9.3 Relationship between Child Variables, Parental Ratings of Child Positive Contributions and Parental Resources

This section examines the relationships between child variables and parental ratings of child positive contributions and parental resources. All child variables were significantly related to mothers' ratings of the positive contributions made to the family by the child. Specifically, child pro-social behaviour and adaptive behaviour were positively correlated with child positive contributions, while child behaviour problems and psychopathology were negatively correlated with this variable. In terms of the proposed model, it was hypothesised that child pro-social behaviour would be predictive of parental positive perceptions (measured by the ratings of child positive contributions). When entered in a cross-sectional analysis along with demographic variables and other child variables, the



overall model significantly predicted 13% of the variance in mother ratings of child positive contributions. However, inspection of the individual regression coefficients indicates that none of the variables explained unique variance in this outcome. Thus it would appear that there is a substantial degree of shared variance between the main study variables in predicting mother ratings of the positive contributions made by the child. No association was found between child variables and father ratings of the child's positive contributions. It might be that the child variables are not important for the fathers in the current research, or for fathers of children with intellectual disabilities in general. Other variables might be more important predictors of father ratings of child positive contributions. For example, of all the variables examined in the present research, father ratings of child positive contributions were most strongly correlated with practical and emotional support. It is beyond the scope of this thesis to examine these relationships in depth but this is clearly an interesting avenue for further investigation.

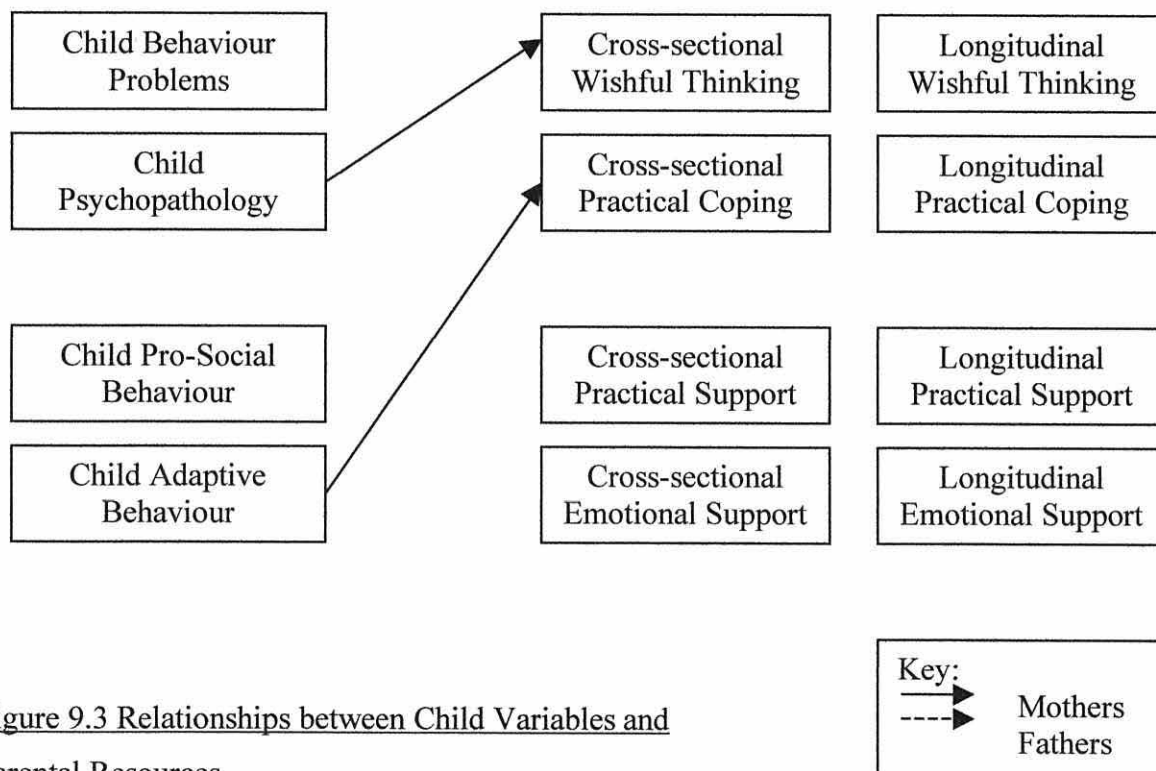
The proposed model also included potential pathways between child behaviour problems and child psychopathology, and parental resource variables. A number of significant correlations emerged among these variable for mothers. Child behaviour problems and child psychopathology were negatively correlated with mothers' use of wishful thinking as a coping strategy. Child pro-social behaviour was negatively correlated with maternal wishful thinking while child psychopathology correlated negatively with maternal emotional support. In cross-sectional regression analyses, we found evidence that child psychopathology positively predicted maternal use of wishful thinking coping strategies, supporting the correlational results. Child adaptive behaviour was found to positively predict mother practical coping. Thus, the negative child variables predicted maladaptive coping strategies, whereas the positive child variables predicted more adaptive coping in mothers. These relationships were not found over time and thus no bi-directional support was investigated.

Maternal practical and emotional support were not predicted by any child variables. This finding was contrary to the proposed model. One might expect mothers to receive less support from others when their child has more severe problems as others may not feel they have the skills needed to support mother. For example, practical support may not be offered as people may feel that they are not capable of looking after a child with complex needs. Similarly, emotional support may not be forthcoming as people may feel they are



unable to relate to or understand the difficulties faced by the family. Additionally, parents may perceive others to offer less emotional support, as they do not expect people to understand their difficulties. On the other hand, significant others may not offer support when the child has less severe problems, as they perceive that the parents do not require the help, but are more willing to offer support when they perceive that parents need it, due to increased behaviour problems and psychopathology in the child. Therefore, it is possible that the experiences of practical and emotional support differ between individual families, depending on the parents' perceptions of support and other peoples' perceptions of the need for support. In addition, other variables may exert a greater influence than child variables on whether a mother uses and perceives practical and emotional support, such as the size of their friendship groups or the availability of professional support within their locality.

The significant cross-sectional and longitudinal findings for the relationships between child variables and parental resource variables are summarised in Figure 9.3.



**Figure 9.3 Relationships between Child Variables and Parental Resources**

For fathers, there were no correlation or predictive relationships between the child variables and the resource variables. The mean scores for ratings of child behaviour

problems and child psychopathology were lower for fathers than for mothers. There was less variance, indicated by standard deviation, in paternal scores for these variables and a smaller range of scores. This may mean that the predictive utility of these variables in explaining perceptions of child positive contributions and paternal resources was limited by the lack of variability in the scores. Future research may seek to investigate other potential antecedents of practical and emotional support in mothers and fathers, such as the size of social support networks, family structure and access to professional support.

#### 9.4 Relationship between Parental Stress, Parental Ratings of Child Positive Contributions and Parental Outcomes

We turn now to the relationships between parental stress and parental anxiety and depression. As discussed in Chapter 2, researchers have tended to view parental mental health and stress in families of children with intellectual disabilities as relatively interchangeable measures of parental well-being. To address this issue, Hastings et al. (2006) used separate measures of stress and mental health. The current research replicates this methodology.

For mothers, stress correlated positively with the variables of anxiety, depression and marital state and negatively with the variables of life satisfaction and positive affect. When examined with cross-sectional regressions, maternal stress positively predicted anxiety, depression, marital state and negatively predicted life satisfaction and positive affect. Significant relationships were also observed over time. Bi-directional relationships were found between maternal stress and anxiety and maternal stress and depression. When change scores were used, a bi-directional relationship was also found with maternal stress change and life satisfaction and life satisfaction predicting maternal stress. Maternal stress change also predicted maternal positive affect and positive affect predicted maternal stress. The number of significant relationships between stress and parental outcomes highlights the key role that stress plays in maternal well-being. The bi-directional relationships suggest that the impact of anxiety, depression, positive affect and life satisfaction a mother experiences are also important to consider when looking to reduce stress.

With regard to maternal ratings of the positive contributions made by the child, this variable correlated negatively with maternal depression and positively with maternal life

satisfaction and positive affect. Cross-sectional regressions indicated that the maternal ratings of the positive contributions of the child were predictive of positive affect but this relationship was not observed longitudinally. The correlational analyses indicate that child positive contributions may have consequences for both negative and positive maternal outcomes. However when stress was included alongside positive contributions as a predictor of maternal outcomes, the relationships between positive contributions and anxiety, depression and life satisfaction did not hold. These findings suggest that stress is more important than child positive contributions in predicting maladaptive maternal outcomes and life satisfaction, whereas stress and child positive contributions both play an important role in whether mothers experience positive affect.

For the sample of fathers, there were positive correlations between stress, and anxiety and depression and cross-sectional regressions identified paternal stress as a predictor of these outcomes. The longitudinal regressions revealed a bi-directional relationship between paternal stress change and anxiety, and between paternal anxiety change and stress. A second set of regressions found a bi-directional relationship between paternal stress change and depression, and between paternal depression change and stress. Thus, stress in fathers appears to only be important for negative parental outcomes.

In terms of the paternal ratings of the child's positive contributions, this variable correlated positively with paternal life satisfaction and positive affect, and negatively with marital state (as higher scores on this measure indicate greater marital dissatisfaction). Cross-sectional regression supported the correlational findings with father ratings of child positive contributions predicting these three outcomes in the expected direction.

For both mothers and fathers, the hypothesis posited in Chapter Three that parental positive perceptions would be correlated with measures of positive well-being are supported by this research for both mothers and fathers. Furthermore, a key hypothesis, that parental stress would hold a bi-directional relationship with parental mental health measures, is supported by this research. A summary of the relationships between stress and parental outcomes and between child positive contributions and parental outcomes are provided in Figures 9.4 and 9.5, respectively.

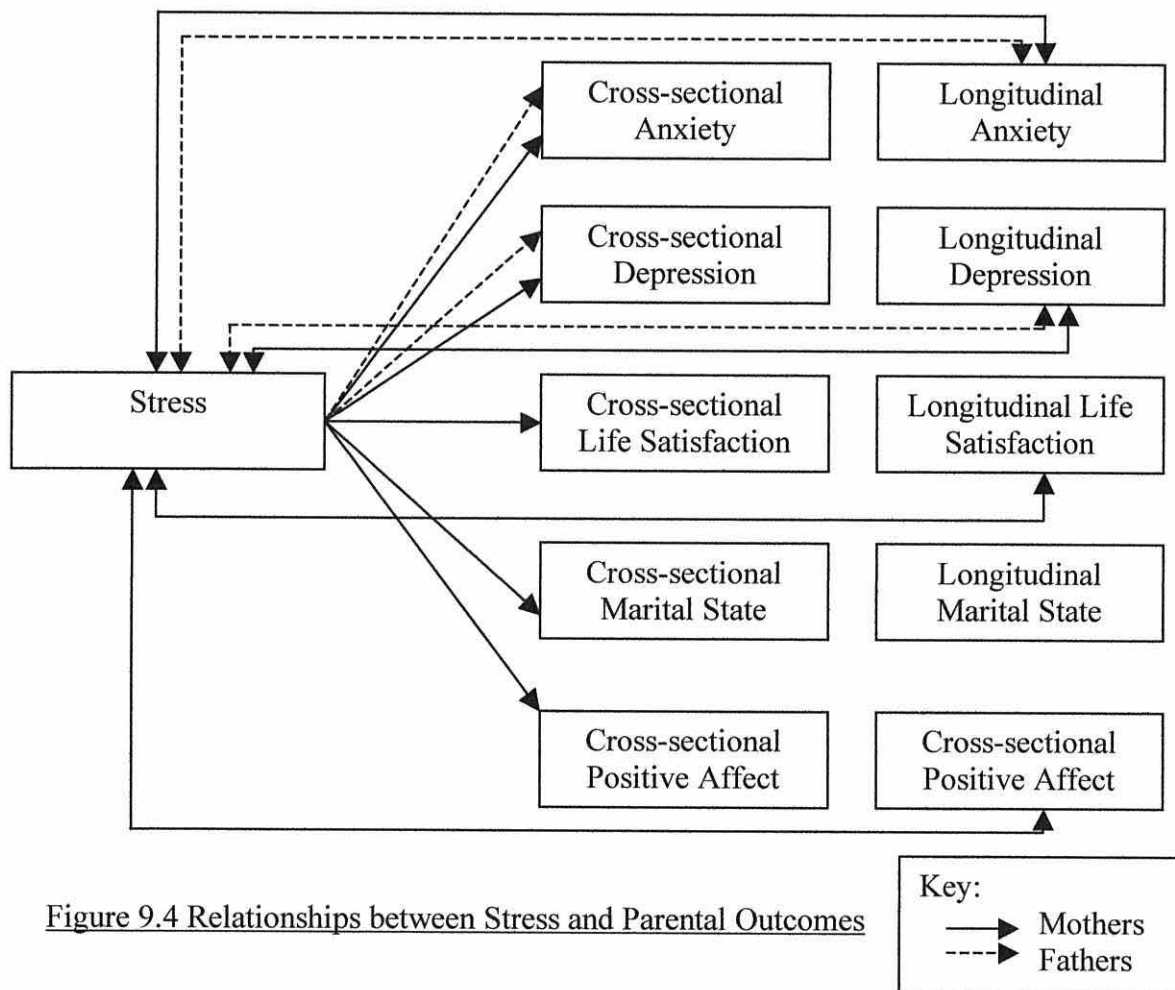


Figure 9.4 Relationships between Stress and Parental Outcomes

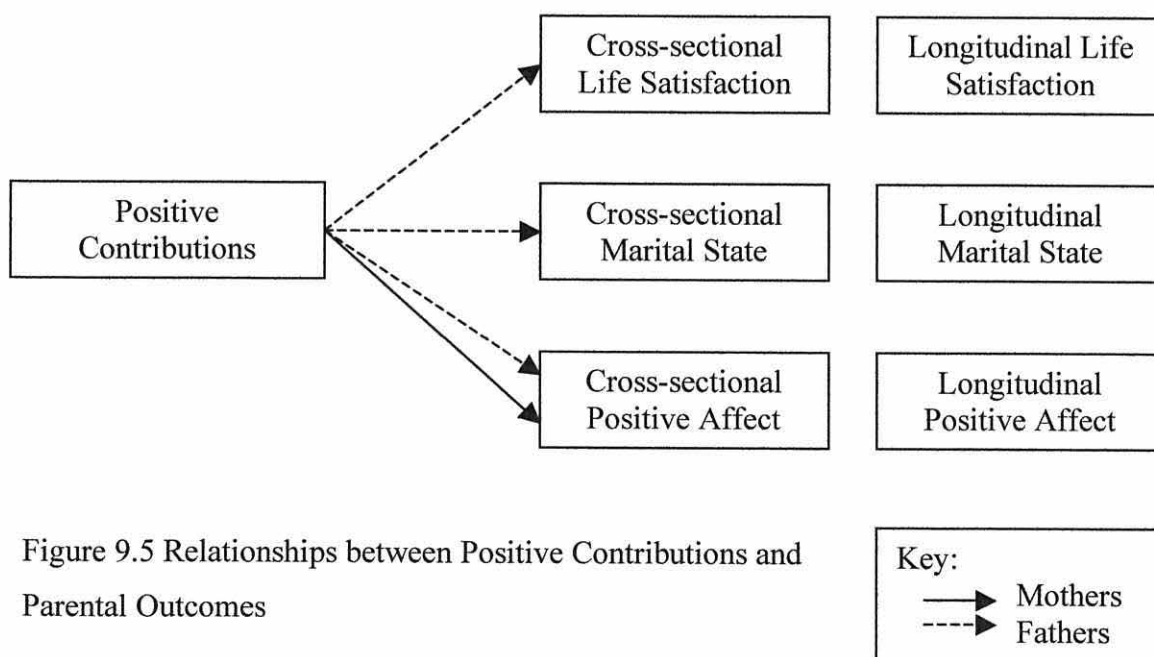


Figure 9.5 Relationships between Positive Contributions and Parental Outcomes

The results of the research presented in this thesis found similar results to Hastings and colleagues (2006). Bi-directional relationships between mother stress, and anxiety and depression were found. Furthermore, the present research also found support of a bi-directional relationship for the same variables for fathers, thus extending the work of Hastings and colleagues. Therefore, parental stress and anxiety/depression may function as mutual risk factors, in both mothers and fathers. Future research might also wish to continue to delineate stress and mental health to allow these to be studied as risk factors for one another.

Maternal stress also was found to have bi-directional relationships with the outcome variables of life satisfaction and positive affect. These results are unsurprising, as we might suggest that the more satisfied a person is with life, the less stress they report, and if they perceive themselves to be under little stress, then they may be more satisfied in their lives.

An interesting contrast between the mother and father data is seen in relation to the predictive value of the positive contributions of the child on parental outcomes at the cross-sectional level. Whereas mother ratings of the positive contributions of the child predicted only their positive affect, father's ratings of the positive contributions of the child predicted paternal life satisfaction, marital state and positive affect. Further research might look towards further investigation of this differential experience of mothers and fathers and perhaps look at different pathways operating for their experiences.

#### 9.5 Relationship between Parental Resources and Parental Outcomes

Parental resources, represented in this thesis by coping and support variables, were found to have a number of significant relationships with parental outcomes. A number of correlational relationships were observed in the mother data. Wishful thinking was correlated positively with anxiety, depression and marital state, and negatively with life satisfaction and positive affect. Practical coping was positively correlated with life satisfaction and positive affect. Practical support was negatively related to depression and marital state, and positively related to life satisfaction and positive affect. Finally, emotional support correlated negatively with anxiety, depression and marital state, and positively with life satisfaction and positive affect.

At the cross-sectional level, regression analyses indicated that wishful thinking significantly predicted all maternal outcomes. Specifically, wishful thinking positively predicted the maladaptive maternal outcomes and negatively predicted adaptive maternal outcomes, indicating that wishful thinking is not an adaptive coping strategy. Previous research (Sloper et al., 1991) found that the use of a wishful thinking coping strategy significantly predicted poor mental health in mothers and the present research supports this finding. The findings indicate bi-directional longitudinal relationships between wishful thinking and depression, life satisfaction and marital state. When using change scores, bi-directional relationships over time were revealed between wishful thinking and anxiety and positive affect. Thus, the findings suggest that mental ill-health may cause mothers to employ wishful thinking coping strategies, as well as these coping strategies leading to a lack of mental well-being. Therefore, the work by Sloper et al. (1991) has been supported and extended by the current research, showing the impact of wishful thinking coping strategies over time and the transactional relationship it holds with other key measures of well-being.

The present study also found mother life satisfaction was positively predicted at a cross-sectional level by practical coping, suggesting this strategy is effective in promoting maternal well-being. Sloper et al. (1991) reported that the use of a practical coping strategy by mothers was found to significantly predict their satisfaction with life and thus the research reported in this thesis supports their findings. A summary of the relationships between maternal resources and outcomes is presented in Figure 9.6.

Turning now to the paternal data, wishful thinking evidenced positive correlations with anxiety and depression, and negative correlations with life satisfaction and positive affect. Practical coping was correlated negatively with anxiety and depression and positively with life satisfaction. Practical and emotional support were unrelated to any of the parental outcomes in fathers. Paternal wishful thinking also emerged as a cross-sectional predictor of anxiety, depression, life satisfaction and positive affect, positively predicting the first two outcomes and negative predicting the latter two. The relationships between paternal wishful thinking, and anxiety and depression were further supported in bi-directional longitudinal analyses, indicating that these relationships are transactional. Longitudinal regressions also revealed a bi-directional relationship between paternal wishful thinking and life satisfaction, with wishful thinking change scores predicting life



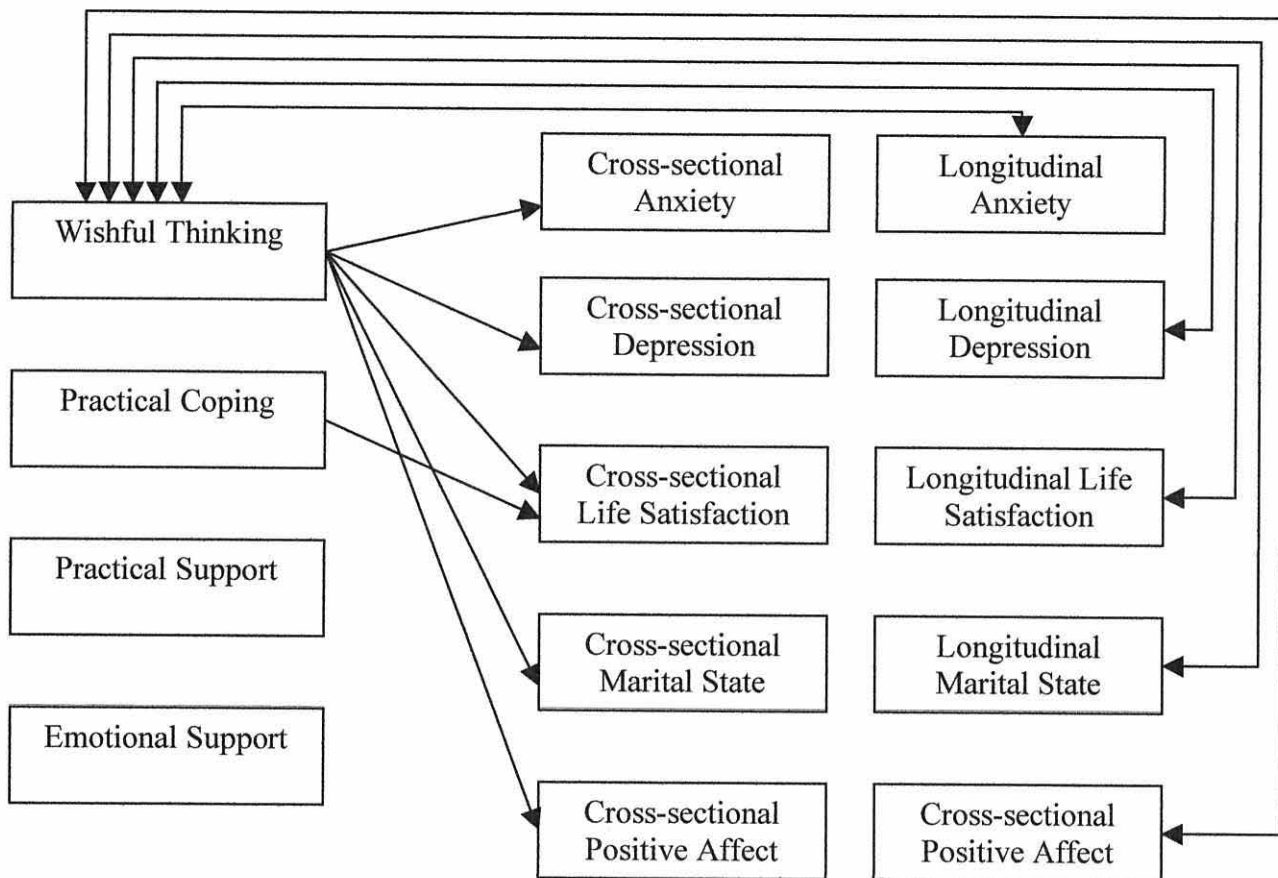


Figure 9.6 Relationships between Maternal Resource Variables and Maternal Outcome Variables

satisfaction, and Time 1 life satisfaction predicting wishful thinking. The significant findings for the relationships between coping strategies and paternal outcomes are in contrast to previous research by Sloper et al. (1991), who did not find coping strategies to predict mental health in fathers. Sloper et al. (1991) did not provide a specific rationale for their null findings, however the diagnostic group may play a part in these relationships for fathers. Specifically, participants in the Sloper et al. (1991) were parents of children with Down Syndrome, whereas participants in the current research were parents of children with a variety of diagnoses, with autism being the most common. A summary of the findings for the relationships between parental resources and outcomes in fathers is presented in Figure 9.7.



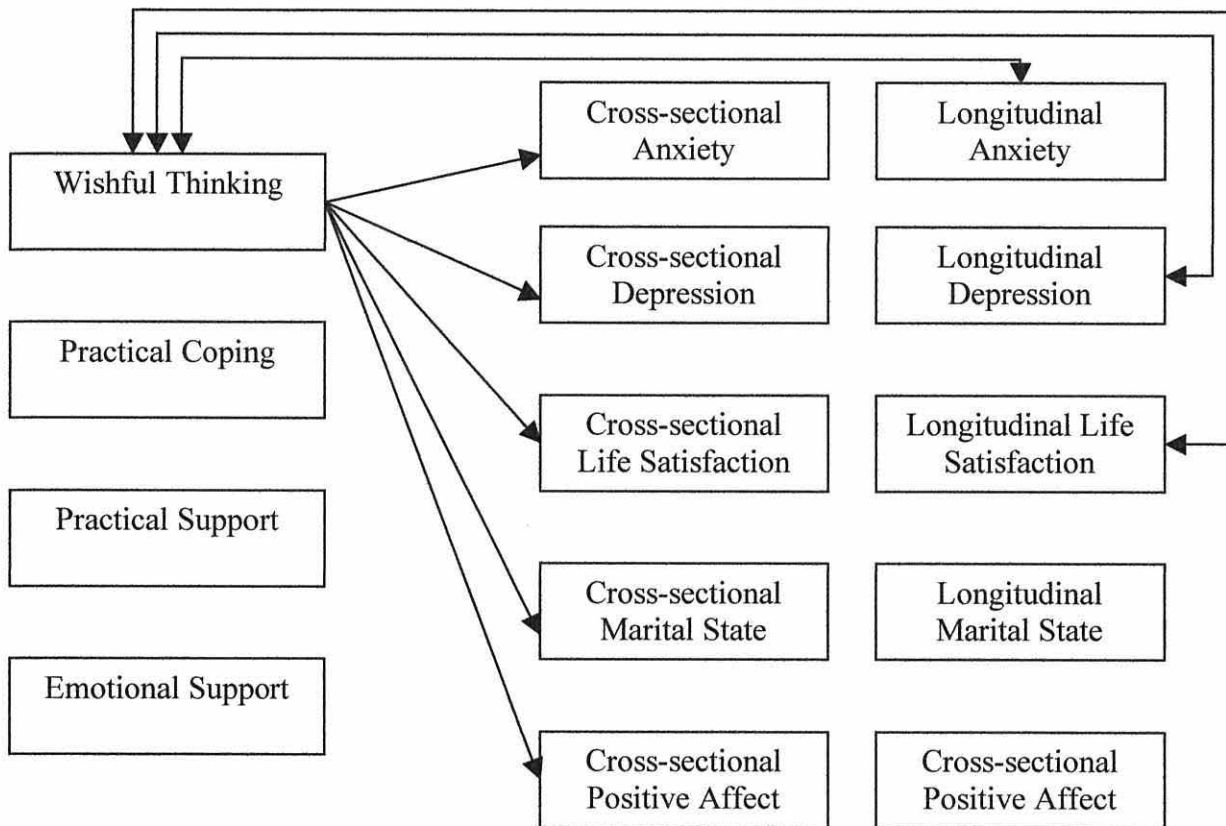


Figure 9.7 Relationships between Paternal Resource Variables and Paternal Outcome Variables

From these data, wishful thinking as a coping strategy in particular emerged as an important variable in the prediction of many outcome variables, for both mothers and fathers. We should also note a possible conceptual issue that exists with the measure of marital state as used in this research. While we conceptualised it as a parental outcome, other researchers have included it as a coping strategy. Brown and Hepple (1989) found that talking to a spouse was the most frequently mentioned strategy employed by parents of children with disabilities, which in turn indicates a satisfactory relationship between the two parents. Further research might wish to conceptualise the state of the parent's relationship as a resource variable, to assess its impact on other outcomes.

#### 9.6 Relationships between Parental Resources and Parental Stress and Ratings of Child Positive Contributions

The next aspect of the model is the relationships between parental resources, and stress and child positive contributions. For mothers, stress was correlated positively with wishful thinking and negatively with emotional support. Mother rating of the child's

positive contributions were related to all four of the parental resource variables. Specifically, child positive contributions were correlated negatively with wishful thinking and positively with practical coping, practical support and emotional support. When entered into cross-sectional regression analyses, wishful thinking was a positive predictor of maternal stress, while emotional support negatively predicted this variable. Practical coping was the only maternal resource found to (positively) predict maternal ratings of the positive contributions made by the child.

The significant relationships identified in the cross-sectional analyses were then examined using longitudinal regressions. The proposed model hypothesised that pathways between parental resources and stress, and between resources and child positive contributions would be bi-directional. Wishful thinking predicted maternal stress over time and stress change predicted wishful thinking, thus supporting the presence of a bi-directional relationship. The change in maternal practical coping scores predicted mothers' perceptions of the positive contributions made by the child. The change in child positive contributions also predicted practical coping strategies over time, again indicating the presence of a transactional relationships. Maternal emotional support was not found to predict maternal stress longitudinally.

For fathers, wishful thinking was positively correlated with stress, while practical coping, practical support and emotional support were all positively correlated with paternal perceptions of the positive contributions made by their child. Cross-sectional regressions indicated that practical coping and practical support both predicted paternal perceptions of the child's positive contributions. Longitudinally, practical coping change predicted child positive contributions, and change scores for positive contributions predicted practical coping, supporting the presence of a bi-directional relationship between these variables. No longitudinal relationship was found between practical support and positive contributions. A summary of the findings discussed in this section is presented in Figure 9.8.

One similarity between the findings for mothers and fathers is the relationship between practical coping and ratings of positive contributions made by the child. However, a more adaptive pattern of results emerged for fathers, with the positive relationship between practical support and positive contributions in fathers. On the other hand, the wishful

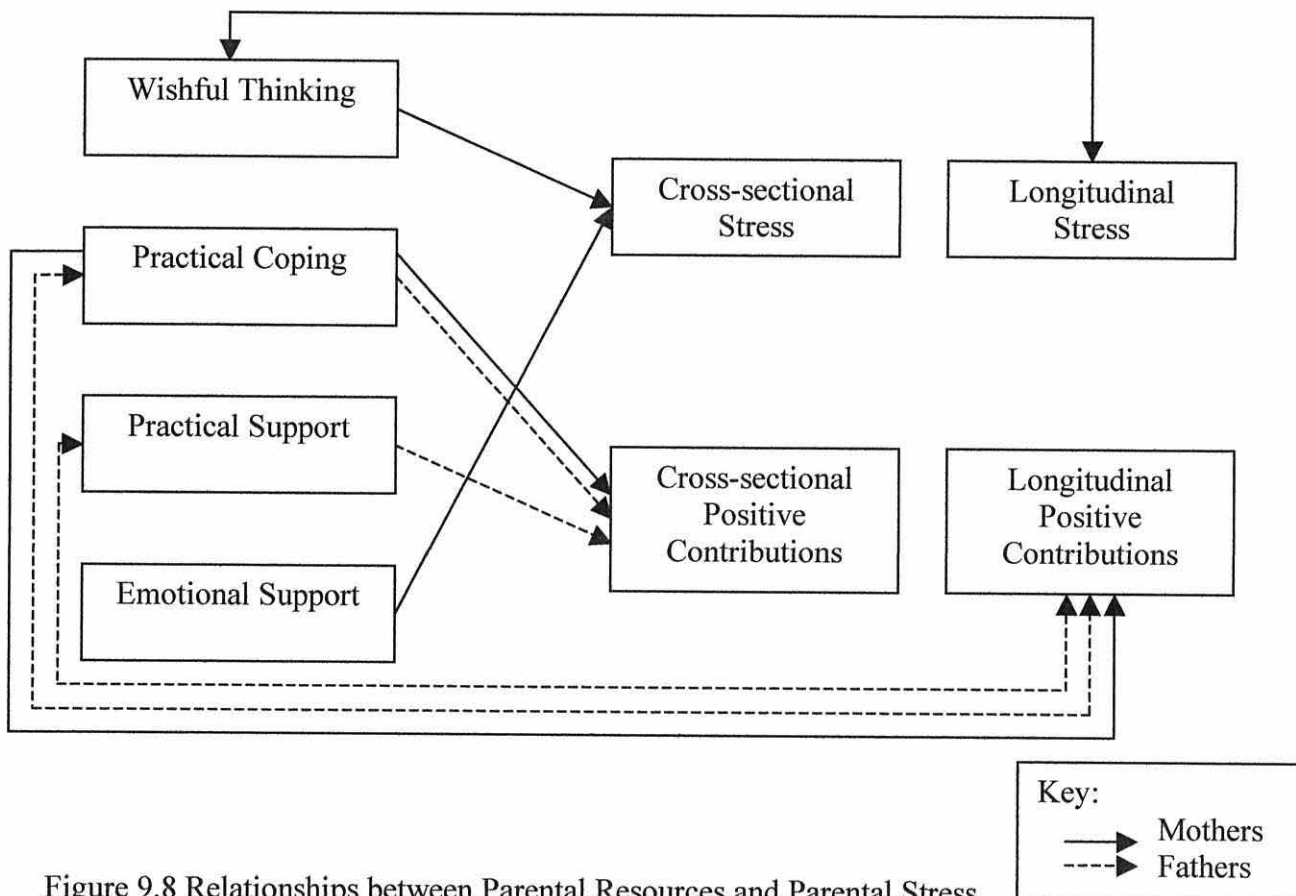


Figure 9.8 Relationships between Parental Resources and Parental Stress and Parental Ratings of the Positive Contributions made by their Child

thinking-stress relationship in mothers is less adaptive. These findings suggest that the impact of parental resources on stress and child positive contributions differs between mothers and fathers of children with intellectual disabilities. This has consequences in terms of interventions. Specifically, with regard to stress, the findings indicate that intervention in terms of parental resources may be more beneficial for mothers than for fathers.

A number of bi-directional relationships were revealed, suggesting that fathers' ratings of their child's positive contribution impact upon their use of practical coping and their perception of practical support. It is not clear why the relationship was found to operate in this direction. Hastings et al. (2002) suggest that contact with positive attitudes may help parents to make a positive attitude shift, and that positive perceptions of the child may help parents to cope with and adapt to children with intellectual disabilities. Thus, our findings may be a case of 'positivity breeding positivity'. When a father views their child positively, this may help him to make use of more positive resources. There is also the

possibility that this positivity about their child causes fathers to have more positive perceptions regarding coping and support, even if independent measurement indicates that use of these resources is not elevated. Both possibilities deserve further investigation.

### 9.7 Mediating and Moderating Relationships

The proposed model identified that variables in the ‘middle’ layer of the model may function as mediator or moderator variables. Parental stress, the parental perceptions of the positive contributions made by their child, coping and support were first investigated as possible mediators of the relationships between child variables and parental outcomes. As can be seen from the proposed model, parental resources were also hypothesised to moderate the relationships between child psychopathology and child behaviour problems, and parental stress, and between parental stress and parental anxiety and depression.

The most notable finding was the consistent role of wishful thinking as a mediator between child psychopathology and maternal outcomes and between maternal stress and maternal outcomes. Maternal wishful thinking mediated the relationships between child psychopathology and maternal stress, anxiety, depression, life satisfaction and positive affect. So, taking first the relationships of child psychopathology to maternal stress and mental health outcomes, high child psychopathology was found to lead to greater use of wishful thinking coping strategies, which leads to high stress, anxiety and depression, and lower life satisfaction and positive affect in mothers. This finding is similar to that of previous research. Quine and Pahl (1991) and Orr et al. (1991) found that child behaviour problems were mediated by parental coping strategies. Hastings et al. (2005) found that more severe child behaviour problems led to less problem-focused and more emotion-focused coping by parents, which negatively impacted upon stress. The wishful thinking coping strategy of the present research is similar to the emotion-focused coping strategy used by Hastings et al. (2005), thus supporting previous research. The construct of wishful thinking appeared to be a significant factor in a number of relationships. Many of the wishful thinking items are essentially avoidance items and thus it appears that avoidance cognitions are related to psychopathology.

Wishful thinking also acted as mediator between maternal stress and the outcomes of maternal anxiety, depression, life satisfaction and positive affect. In contrast to the maternal data, wishful thinking only mediated two relationships between paternal

variables. The relationship between paternal stress and paternal anxiety and depression was mediated by father's use of wishful thinking coping strategies. These findings again suggest that mothers may use wishful thinking coping strategies more often than fathers. Future research may continue to assess the importance of coping strategies in the lives of parents of children with intellectual disabilities. Practical coping has been linked to positive outcomes for parents (Sloper et al., 1991) and future research might investigate the positive outcomes with which practical coping strategies help to mediate. This analysis might inform interventions, which will be discussed in more detail in the clinical implications section of this general discussion.

Three significant moderating relationships were also observed. Maternal practical coping strategies moderated the relationship between child pro-social behaviour and maternal stress. The interaction between child pro-social behaviour and a practical coping strategy revealed that the use of this strategy enhances the adaptive effects of high pro-social behaviour on maternal stress. Maternal wishful thinking moderated the relationship between mother ratings of the positive contributions made by her child and maternal positive affect. The perception that the child makes few positive contributions to the family was associated with low positive affect. The use of a wishful thinking coping strategy exacerbated this relationship, that is, mothers who perceived their child to make few positive contributions *and* reported high use of wishful thinking had even lower positive affect. Paternal practical coping moderated the relationship between paternal stress and anxiety. When fathers experience high stress, the use of a practical coping strategy appears to offer a protective effect against paternal anxiety. That is, fathers with high stress experienced high anxiety when coupled with low levels of practical coping, whereas lower anxiety was experienced when fathers with high stress reported greater use of a practical coping strategy. Further research might look to replicate these findings. If the use of practical coping strategies increases the effect of child pro-social behaviour on maternal stress then it would be interesting to test the effect using a measure of 'personal' stress rather than the measures of stress used here, which assesses by way of parent and family problems. However, one issue requiring further thought is the limited number of coping strategies used in the present research. In order to include a short measure of coping, the 14-item SWC-R was used. This measures just two, broad coping strategies. Previous research has found that collapsing emotion-focused coping strategies into a single category was associated with poor adjustment (Thompson et al., 1992). However,

Bregman (1980) found that parents used certain emotion-focused coping strategies effectively and perceived them as helpful. Thus, collapsing different emotion-focused coping strategies under a single heading may be limiting the researchers' ability to explain the impact of the different strategies. Future research might want to use a longer measure of coping to more comprehensively investigate the impact of different strategies. In terms of other variables in the middle layer of the model acting as mediators or moderators, we found that maternal stress functioned as a mediator between maternal anxiety, life satisfaction and positive affect. Child positive contributions were not found to mediate any relationships between other variables.

A unique element to the research presented in this thesis was the analysis of longitudinal mediation and moderation. No evidence was found to support the presence of longitudinal mediation or moderation, but the exercise highlighted a number of methodological concerns in using this statistical approach. First, the literature that is available on longitudinal investigation of mediation and moderation specifies that one would ideally have more than two data points. Different problems are encountered if one takes the mediator from either the first time point measurement or the second time point measurement. Second, greater measurement error is included in the model when change scores are employed, as the change score contains measurement error from both Time 1 and Time 2 scores.

### 9.8 Relationships between Child Variables and Parental Outcomes

The final aspect of the proposed model was the hypothesised relationship between child variables and parental outcomes. It was suggested that child stressor variables (child behaviour problems and child psychopathology) would have a direct influence on parental anxiety and depression. Although not explicitly stated within the model, the data provided the opportunity to examine three other possible sets of relationships: between negative child variables and parental life satisfaction, marital state and positive affect; between positive child variables and these outcomes; and between positive child variables and parental anxiety and depression. Specific hypotheses were not formulated for these relationships, however mediational regressions necessitated the examination of these relationships.



Taking mother data first, child behaviour problems were correlated positively with anxiety and depression, and negatively with life satisfaction and positive affect. In the cross-sectional regression analyses, this variable was a positive predictor of maternal depression and a negative predictor of life satisfaction. None of these relationships were significant over time. Maternal ratings of child psychopathology were correlated positively with anxiety, depression and marital state, and negatively with life satisfaction and positive affect. At a cross-sectional level, this variable predicted maternal anxiety, depression, life satisfaction and positive affect, in the expected directions. Furthermore, a bi-directional relationship was revealed at the longitudinal level, between child psychopathology and life satisfaction. For maternal ratings of pro-social behaviour, significant relationships were only identified at the correlation level; this variable correlated negatively with anxiety and depression and positively with life satisfaction and positive affect. Finally, adaptive behaviour ratings were positively related with life satisfaction and positive affect in correlations and cross-sectional regressions. Taken together, this set of results indicates that child variables impact directly on maternal outcomes, as well as asserting their influence through variables such as stress and maternal resources. This finding suggests that practitioners wanting to improve parental outcomes could make use of interventions that focus on modifying the child variables, as well as intervening at the middle layer of the model. The bi-directional relationship between child psychopathology and life satisfaction also suggests that mothers' satisfaction with life may influence the conduct of their child with an intellectual disability. The mechanism for this effect is unclear. Future research might examine whether independent ratings of child psychopathology are predicted by maternal life satisfaction. It may be the case that parents high in indicators of well-being tend to have more positive perceptions of their children, even if objective measures do not indicate this to be so. If parental perceptions of child psychopathology are indeed accurate, future work would do well to examine the potential processes underpinning this relationship, in particular, with a focus on the impact of parental behaviour upon child variables.

No significant findings were identified between the child variables and parental outcomes in fathers. This suggests that other factors may be more important for fathers' well-being, such as their perception of the stress they are experiencing and the support they receive from others. Clearly, looking at the relationships in Figure 9.9 data, there is a contrast between the maternal and paternal data. It would appear that child variables play a greater



role in influencing maternal well-being than they do influencing paternal well-being. As discussed, this may be in part due to the roles traditionally taken on by mothers. Fathers are likely to have less contact with their children and thus may be less influenced by their behaviour, whether it be positive or negative.

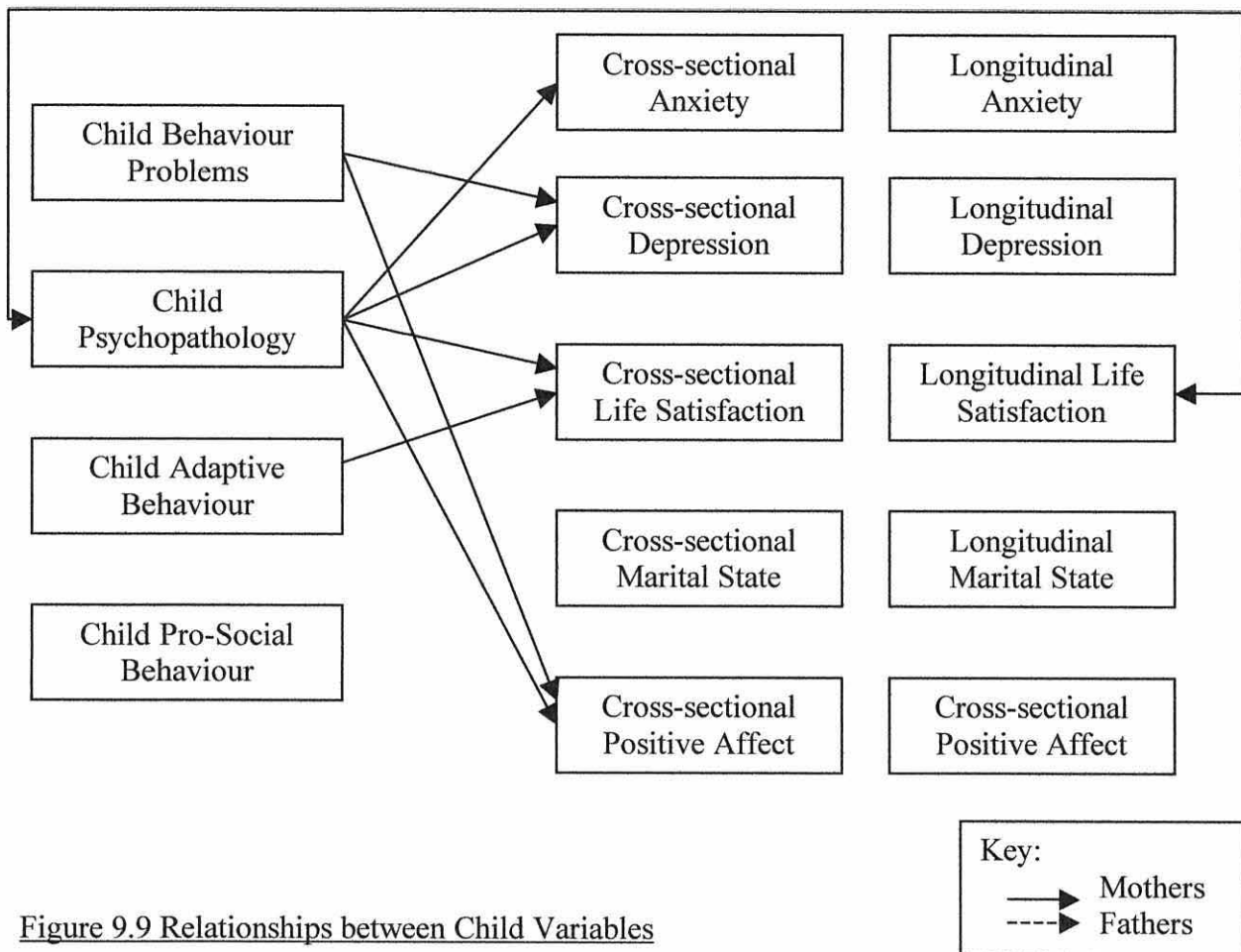


Figure 9.9 Relationships between Child Variables and Parental Outcomes

### 9.9 Summary of Findings

Throughout this thesis an integrated model has guided the examination of stress and coping in parents of children with intellectual disabilities. The proposed model was reiterated at the start of this chapter. In Figure 9.10, an updated model is presented, summarising the significant relationships identified in this thesis. When the proposed and updated models are compared, both similarities and differences are apparent. First, a number of hypothesised links were supported, for example, between child as a stressor, stress and mental ill health, between child as a stressor, parental resources and mental ill-

health and between the variables in the middle layer of the model. One relationship not supported was that between child positive characteristics and positive perceptions of the child, indicating that child positive characteristics may not have a direct impact on this outcome.

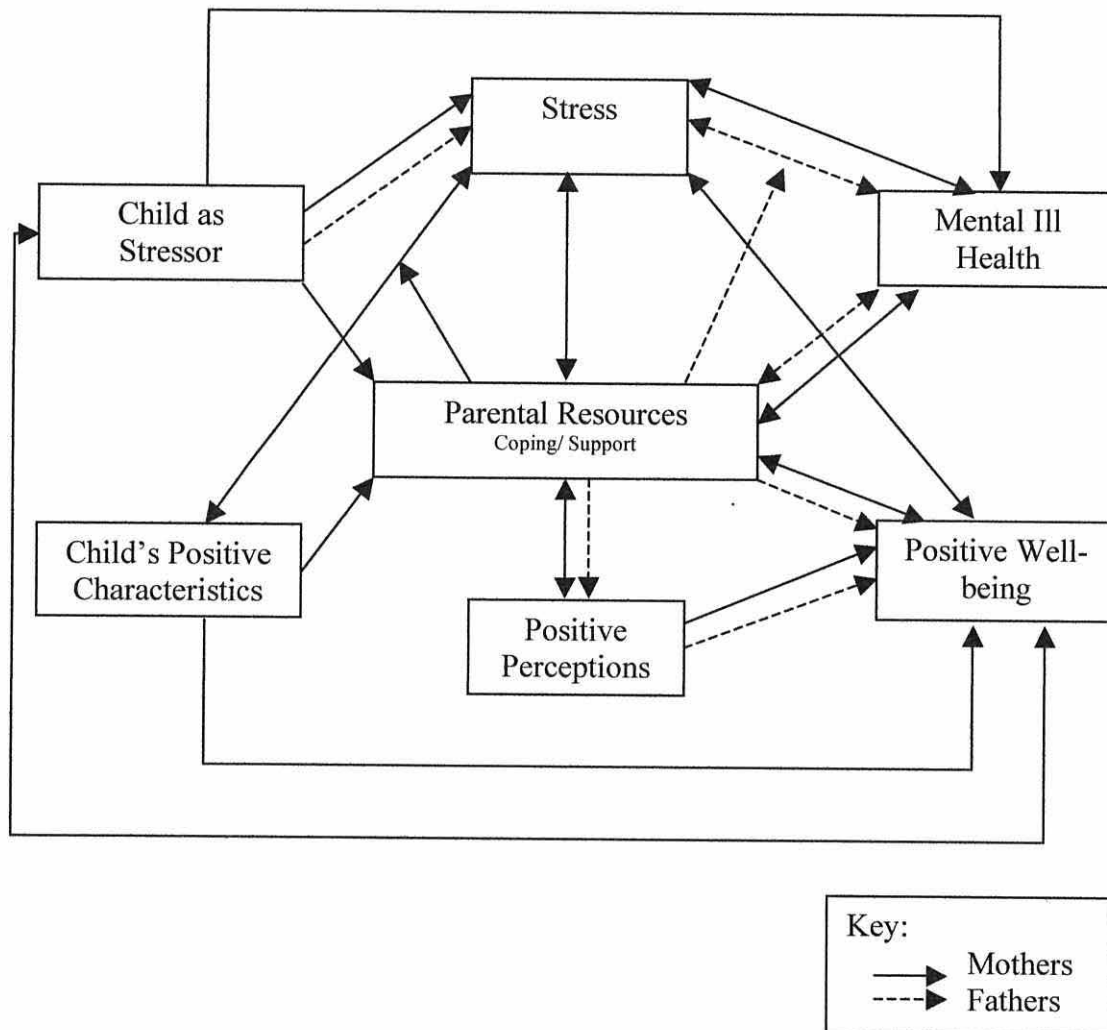


Figure 9.10 An Updated Model of Stress and Coping in Parents of Children with Intellectual Disability with A Summary of Relationships Supported in the Current Research

In the proposed model, it was hypothesised that negative child variables (i.e., child as a stressor) would be related to negative outcomes such as stress and parental ill being, and that positive child characteristics would be related to positive outcomes such as well-being and life satisfaction. However, the updated model indicates that negative child variables also have maladaptive consequences for positive parental outcomes and that child positive characteristics have adaptive consequences for maternal stress. Finally, an

important aspect of the updated model is the distinction between mothers and fathers. The proposed model did not detail differential relationships among the variables for mothers and fathers, but the findings from this thesis suggest that child behaviour, stress and coping clearly have a greater impact on maternal ill health and well-being. Nonetheless, significant findings were also identified for fathers, highlighting the importance of examining stress and coping in both parents of children with intellectual disabilities.

#### 9.10 Limitations and Strengths of the Research

There are a number of additional points that should be noted about the present analyses and limiting factors regarding the research as a whole. First, we address issues concerning the participating families. The sample may suffer from 'self-selecting bias', in that families were able to opt into the research, thus the sample was not representative of any particular population. Certain families might participate while other might not and the reasons for doing so are unclear. For example, a payment was offered and this may have had an impact on the families offering to participate. Another problem we encountered was poor response rates. Initially, it had been hoped to take the entire sample from North Wales. However, we had to begin sampling from the North West of England as well to ensure sufficient numbers were recruited. The overall response rate to advertisements was approximately 8% (although is it difficult to be exact), despite payment being offered. Potentially, using another research method, for example, face-to-face interviewing and home visiting to collect the questionnaire data may increase this response. However, this approach naturally has significant disadvantages of its own, including the length of time that data collection would take and the impact of answering questions in front of the researchers (socially desirable responding).

The research also relied on rating scales to assess the various constructs included in the model. The parents who agreed to participate provided data on their own mental health and stress and their child's behaviour problems. Thus, there is the enduring problem of potentially increased covariance between constructs that may bias finding associations between the measures, both cross-sectionally and over time. Potentially, very stressed parents might misperceive and misreport their child as having more behaviour problems, and so create an apparent relationship between the constructs. Of course, the current research attempted to address this problem by using the observation study to provide an independent measure of child behaviour and begin to explore some of these issues more

objectively. However, no associations were found. As described in Chapter 8, this could have been due to the small sample size recruited for the study, or may have been due to the artificial tasks used to standardise all the observation visits. In future, observations could be used in both structured and non-structured settings, over a number of days and times. Clearly, an approach such as this is beyond the scope of the current research.

Another way of gaining a relatively independent measure of child behaviour would be to collect teacher reports. Hastings et al. (2003) found associations between parent stress and total Developmental Behaviour Checklist scores based on teacher ratings, suggesting this avenue may benefit from further work. A teacher would still know the child, but one might expect their responses to be less affected by emotion or external reasons than the reports of a parent. Whilst there are merits to this approach, we may also experience similar problems to those in observational designs. Teacher reports would naturally only be based on the behaviour of the child at school. This would provide no data on the behaviour of the child at home and thus skew the data.

As mentioned, the number of participants limited the scope of the observation study. Response rates were also very poor for this study, which might be expected, given the degree of intrusion necessary. Another problem was that visits only occurred in school holidays, as this was one of the few times that families could be sure they would be at home together with their child. This limited data collection considerably and given the time constraints of a Ph.D., there was little opportunity to collect data from more families. Another element of the observation study was the inclusion of the construct of EE. Given the limited research between parent behaviour and child behaviour, the inclusion of EE as a 'proxy' measure of behaviour was hoped to provide more data with which to understand this link. However, EE did not significantly relate to any other construct. Again, this may be due to the small *N* of the observational study. A larger sample size, perhaps taking five-minute speech samples over the telephone from all the participants in the main study may have yielded more significant results.

A further variable not measured in this thesis, but highlighted in Chapter 1 was socio-economic status/poverty. As the discussion in Chapter 1 indicated, this dimension is coming under increased scrutiny from researchers within the field of intellectual disabilities. Research suggests that socio-economic status is generally a good predictor of

satisfaction and well-being (Floyd & Saizyk, 1992). Recently, researchers have been using a database, which enables one to search for the economic deprivation of an area, based on its postcode. The current research was conducted across North Wales and into the North-West of England. Unfortunately, socio-economic status was unable to be included in the current research because, as yet, the postcode databases for England and Wales do not use the same method. However, one might also assess socio-economic status by assessing the level of parent education for example. A measure of this was taken in the current research but was not found to significantly predict any of the study variables. Future research might take socio-economic status into consideration when looking at the mutual impact a child with intellectual disabilities and their parents have on one another.

The second area where limitations may have impacted upon the results of the research involved the measures. The choice of stress measure could be viewed as a strength or a weakness, dependent on how one conceptualises stress. The measure of stress used in the present study was the Parent and Family Problem subscale of the QRS-SF, which assesses stress by way of the impact of the child with the intellectual disability on the family. Baker, Blacher, Crnic and Edelbrock (2002) discussed how many researchers have found increased stress in families of children with disabilities, but that the measures used in previous studies contain items that tap into the child's limitations. These items are used to generate the score that purports to measure parental stress. Thus, the more disabled the child, the more stress is reported. In an attempt to address this concern, they used the Family Impact Questionnaire as their measure of stress. The research presented in this thesis used the parent and family problems subscale of the QRS-SF as the measure of stress. Because the parent and family problems subscale of the QRS-SF assesses stress in a similar way to the Family Impact Questionnaire (i.e. by looking at the problems it causes for the family), we may have also alleviated some of the problems that Baker and colleagues (2002) highlighted. Other measures of stress, such as the Parenting Stress Index, evaluate the stress felt towards a specific child. Whilst this issue is largely theoretical in nature, the use of a different stress measure may increase the likelihood of observing the bi-directionality that was not present in this thesis.

The majority of measures employed in the thesis also showed a high degree of stability over time. In controlling for Time 1 scores, there is much less unique variance left to

explain with the other predictor variables. We also had no data available on whether any of the families had received intervention services between the first and second data collection. Being in receipt of services may well have changed the nature of the dyadic system.

With regard to more conceptual weaknesses within the research, one issue may be whether two time points, one year apart constitute a longitudinal design. Many researchers would not regard such a design as legitimately longitudinal (see Cohen, Cohen, West & Aitkin, 2003). However, there is research within the field of intellectual disabilities that has set a precedent for using this sample time frame (Baker et al., 2003; Lecavalier et al., 2006). Another criticism of the design might include the observation study presented in Chapter 8. This aimed to add another, independent measurement of interactions between mother and child though few significant associations were found. This might be due to a small sample size which could limit assessments of how highly stressed parents interact with their child. Future designs might increase the sample size and gather observational data in a variety of settings, thereby increasing the ecological validity of the work.

Despite the limitations of the studies in this thesis, the research also demonstrated a number of strengths. These included the variety of diagnostic groups recruited by the research. There the sample included children with autism, Down syndrome and cerebral palsy, which enabled group differences to be assessed. This also serves to improve the ecological validity of the study in that the sample included children with a range of intellectual abilities and a range of specific syndromes, rather than, say, a sample drawn entirely from schools for child with autistic spectrum disorders. As presented in Chapter Three, fathers have often been somewhat neglected in terms of research into the experiences of parents of children with intellectual disabilities. This thesis sought to include both mothers and fathers, thereby providing a more systemic coverage of the challenges faced by families of children with intellectual disabilities. Whilst the inclusion of fathers in research designs is becoming more commonplace, future studies need to ensure they continue to recruit fathers where possible, given the differences found between mothers and fathers in this research and the finding in previous research that fathers report stress differently to mothers (e.g. see Hastings, 2003).



The design also took heed of the recommendations of previous published research in designing the studies. Lecavalier et al. (2006) highlighted the importance of including a measure of adaptive behaviour in such research. These measures provide an estimate of the behaviours a person engages in, rather than an estimate of their intellectual ability. Given that many children with intellectual disabilities exhibit adaptive skills below their intellectual ability (Zigler & Bennett-Gates, 1999), the use of a measure of adaptive behaviour might provide a better approximation of the level of the child's functioning in relation to the burdens experienced by parents. A second recommendation included from previous research was that by Hastings et al. (2003), who concluded that future research should endeavour to include measures of positive adaptation. Within this thesis, the proposal and application of the two-factor model has gone some way to address this. The current research included measures of positive adaptation within the family, operationalised as the positive affect of both the mothers and fathers, and their perceptions of the positive contributions made by their child to the family. To complete this positive aspect of the model, child pro-social behaviour was investigated.

Bernier (1990) notes that a system has synergistic qualities in that it is more than the sum of its parts, and a family system is not simply a collection of individuals, but an entity in its own right which maintains a bi-directional relationship with its members, with each having influence on the other. The systems approach would embrace the inclusion of the entire family in research studies including fathers, siblings and grandparents. However, previous research has generally relied on the opinion of the mother, typically through the medium of questionnaire measures and checklists. Mothers have presumably been targeted for reasons including ease of collection (mothers typically spend more time than fathers at home with the children) and higher levels of stress and depression expressed by mothers than fathers (e.g. Goldberg et al., 1986). In contrast to much of the literature, the present work examined, wherever possible, both mother and father variables and the parent's individual perception of the child variables, such as the child's behaviour problems. This aspect of the design strengthens the applicability of the research within the family context.

Whilst the main study included both mothers and fathers, the observational study only included a sample of mothers. The nature of the data collection meant that home visits took place in the daytime, and given that 75% of the fathers worked full-time, it was



decided that sufficient recruitment of fathers would be too difficult. However, because of the difference in the experiences of mothers and fathers in the main study, it would be interesting to take a sample of fathers for future observation studies. This inclusion, plus the importance of collecting a larger sample size, would require considerable investment of time from both researchers and families. In addition to fathers, increasingly researchers are interested in the impact of having a child with an intellectual disability has on other family members, such as siblings and grandparents. Whilst this thesis has focused on the parent-child relationship, increasing research is demonstrating the value of exploring adaptation in the context of the parent-child triad (e.g., Hastings, 2003) and considers how siblings and other family members may reciprocally influence one another. A future observation study might employ a design that enabled other members of the family to interact with the main mother-child dyad, and begin to unpick the complexities of how a family with a child with an intellectual disability relate to one another and manage the stresses of such a situation.

A further strength of the work is the number of variables that the sample size and model has allowed us to conceptualise together. Previous work has generally focused attention on a more limited number of constructs, thus inhibiting complex interrelationships between variables to be investigated. Whilst acknowledging that the model has its limitations, the inclusion of a broad range of variables is a strength of this design. In terms of child variables, it has included both traditional, maladaptive measures of the child alongside more recent developments of child psychopathology and the pro-social behaviour of the child. In terms of parental variables, the research contains measures of the impact of mental health and well-being alongside measures of positive perceptions and positive affect. These measures have been conceptualised in a working model. It is important at this juncture to stress that the model that has evolved throughout this thesis is not proposed as a theoretical model that accounts for all the interrelationships between child and parent variables within families with a child with intellectual disabilities. The model was designed to simply act as a guide for the thesis and allow a number of questions to be posed in the context of a model based on previous research findings. As mentioned, it has provided structure to guide the analyses and kept the investigation directed. However, the model could be improved. The variables included in the model are not exhaustive and a number of other possible constructs would be interesting to look at. Also, the placement of variables within the model would alter the way that the

relationships were investigated. For example, a number of variables may be construed as outcome variables but also as coping and support variables. An argument could be made for included marital satisfaction as a support variable, assuming that a healthy relationship functions as a means of social support for most people.

The final, and perhaps most significant strength of the current research lies in the fact that it has drawn together a number of different elements of research that have not been considered together in one work previously. These elements are the inclusion of both mother and father perspectives, the application of a longitudinal methodology, the investigation of potential mediating and moderating variables, and the use of a number of novel measures including child pro-social behaviour and child psychopathology and positive adaptation. Drawing these diverse concepts together places this thesis in a unique position amongst current research.

### 9.11 Clinical Implications

A number of clinical implications may now be drawn from the results gathered in this thesis. The finding that parenting stress is related to child behaviour rather than adaptive behaviour is encouraging for parents and professionals given the success that can be had in reducing behaviour problems. Furthermore, bi-directional effects have been found between parental stress and parental mental health outcomes. Therefore, service providers must consider the potential ineffectiveness of stress reduction programs for parents that do not acknowledge, investigate or treat any underlying mental health problems. Conversely, given the bi-directional nature of the relationship, parents being treated for depression and such like may find that the success of the intervention depends on a concomitant intervention targeting stress.

The finding that child psychopathology accounted for much of the unique variance in parental stress has important implications of clinical practice. Thus, while services for 'challenging behaviour' are well established in services for people with intellectual disabilities, the current research found that a considerable percentage (35.5%) of the present sample also reached the Reiss Scales for Children's Dual Diagnosis clinical cut-off. Thus services may need to understand and explore the unique problems that a dual diagnosis poses and not be tempted to use a 'one size fits all' approach to the management of behaviours exhibited by children with intellectual disabilities. The stress

experienced by parents might be alleviated by a more effective respite service, allowing them a break from the rigours of caring for a child with intellectual disability and co-morbid psychiatric or behaviour problems. The finding that over a third of our sample had a score that reaches or crosses the clinical cut-off for child psychopathology has other implications. Co-morbid psychiatric problems in children with intellectual disability may respond to a pharmacological intervention or psychological therapy specifically targeting their difficulties, for example, depression or anxiety. In addition, child services for children with intellectual disability should ensure that social skill development and behaviour management are priorities for their programmes.

The direct relationships between child variables and parent outcomes might suggest that clinicians focus on addressing child psychopathology in order to reduce parental ill health and improve well-being. However, the success of such interventions may be limited if the clinician fails to acknowledge the impact of mediating variables upon these relationships. Both maternal stress and maternal use of a wishful thinking coping strategy play a part in mothers' experience of a range of adaptive and maladaptive outcomes. On the other hand, practical coping only mediated one relationship, between maternal perceptions of the child's positive contributions and maternal positive affect. Both stress and wishful thinking are maladaptive constructs, while the practical coping is an adaptive resource. Thus, the findings suggest that interventions which focus on the reduction of the maladaptive mediators would be most beneficial for improving parent outcomes. The lack of findings for positive forms of resources, and for perceptions of child positive contributions, as mediators of the relationships between child variables and parent outcomes indicate that it may be the reduction of maladaptive processes, rather than the encouragement of more adaptive processes, that has the most important impact upon parental well-being.

Our finding of the importance of coping strategies as both predictors of parental outcomes and as mediators between child variables and parental outcomes suggests that an effective intervention may focus on the parental cognitions around their coping. Therapeutic approaches such as Cognitive-Behaviour Therapy may enable parents to question and modify less helpful coping strategies such as wishful thinking and to begin to use more effective strategies including practical coping. If, as was hypothesised previously, that coping and support interact with one another, then clinical interventions would be most

effective if they targeted both constructs simultaneously. That is, if services were providing CBT for cognitions attached to the use of coping strategies, they would be ideally also be ensuring that the parent's had access to support, such as family, professionals or support groups. It may also indicate that organised support groups may enable families to provide mutual support to one another.

Finally, mothers displayed higher levels of anxiety and depression, and lower levels of life satisfaction and positive affect than fathers. This finding is unsurprising given that most mothers are the child's primary carer and consequently spend more time with the child. In addition, more significant relationships were identified between variables for mothers. Fewer relationships were found for fathers, particularly those concerning child variables. This suggests that mothers should be the primary target for interventions.

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Appendix A  
Behaviour Problems Inventory

**On the following pages you will find generic definitions followed by specific descriptions of three types of behaviour problems: self-injurious behaviours (items 1-15), stereotyped behaviours (items 16-40), and aggressive/destructive behaviours (items 41-52).**

**Please indicate which behaviours you have observed in your child with special needs during the past two months by circling the number in the appropriate boxes to indicate (a) how often the described behaviour typically occurs (frequency) and (b) how much of a problem the behaviour represents. If the behaviour has never been observed during the last two months, circle the number "0".**

### SELF-INJURIOUS BEHAVIOR

**Generic definition: *Self-injurious behaviour (SIB) causes damage to the person's own body; i.e., damage has either already occurred, or it must be expected if the behaviour remained untreated. SIBs occur repeatedly in the same way over and over again, and they are characteristic for that person.***

|   | Frequency |         |        |       |        | Degree of Problem |          |        |
|---|-----------|---------|--------|-------|--------|-------------------|----------|--------|
|   | Never     | monthly | weekly | daily | hourly | slight            | moderate | severe |
| 1. Self-biting (so hard that a tooth print can be seen for some time; bloodshot or breaking of skin may occur)  | 0         | 1       | 2      | 3     | 4      | 1                 | 2        | 3      |
| 2. Hitting head with hand or other body part (e.g., face slapping, knee against forehead) or with/against objects (e.g., slamming against a wall, knocking head with a toy)                               | 0         | 1       | 2      | 3     | 4      | 1                 | 2        | 3      |
| 3. Hitting body (except for the head) with own hand or with any other body part (e.g., kicking self, slapping arms or thighs), or with/against objects (e.g., hitting legs with a stick, boxing the wall) | 0         | 1       | 2      | 3     | 4      | 1                 | 2        | 3      |
| 4. Self-scratching (so hard that reddening of the skin becomes visible; breaking of the skin may also occur)  | 0         | 1       | 2      | 3     | 4      | 1                 | 2        | 3      |



|   |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|---|
| 5. Vomiting and rumination<br>(deliberate regurgitation of<br>swallowed food with<br>rumination)  | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 6. Self-pinching (so hard that<br>reddening of the skin<br>becomes visible; breaking<br>of the skin may occur)  | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 7. Pica: Mouthing or<br>swallowing of objects<br>which should not be<br>mouthed or swallowed for<br>health or hygiene reasons<br>(non-food items such as<br>faeces, grass, paper,<br>garbage, hair) | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 8. Stuffing objects in body<br>openings (in nose, ears, or<br>anus, etc.)   | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 9. Pulling finger or toe nails  | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 10. Stuffing fingers in body<br>openings (e.g., eye<br>poking, finger in anus)  | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 11. Air swallowing resulting<br>in extended abdomen   | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 12. Hair pulling (tearing out<br>patches of hair)   | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 13. Extreme drinking (e.g.,<br>more than 3 litres per<br>day)   | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 14. Teeth grinding (evidence<br>of ground teeth)  | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |
| 15. Other:<br>.....<br>.....  | 0 | 1 | 2 | 3 | 4 | 1 | 2 | 3 |

# STEREOTYPED BEHAVIOR

**Generic definition:** *Stereotyped behaviors look unusual, strange, or inappropriate to the average person. They are voluntary acts that occur repeatedly in the same way over and over again, and they are characteristic for that person. However, they do NOT cause physical damage.*

|   | Never | Frequency |        |       |        | Degree of Problem |          |        |
|---|-------|-----------|--------|-------|--------|-------------------|----------|--------|
|   |       | monthly   | weekly | daily | hourly | slight            | moderate | severe |
| 16. Rocking back and forth                        | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 17. Sniffing objects                              | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 18. Spinning own body                             | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 19. Waving or shaking arms                        | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 20. Rolling head                                  | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 21. Whirling, turning around on spot              | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 22. Engaging in repetitive body movements         | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 23. Pacing  | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 24. Twirling things                               | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 25. Having repetitive hand movements              | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 26. Yelling and screaming                         | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 27. Sniffing own body                             | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 28. Bouncing around                               | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 29. Spinning objects                              | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 30. Having bursts of running around               | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 31. Engaging in complex hand and finger movements | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 32. Manipulating objects repeatedly               | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 33. Exhibiting sustained finger movements         | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 34. Rubbing self                                  | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 35. Gazing at hands or objects                    | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 36. Maintaining bizarre body postures             | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 37. Clapping hands                                | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 38. Grimacing                                     | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 39. Waving hands                                  | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| 40. Other   | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| .....   | 0     | 1         | 2      | 3     | 4      | 1                 | 2        | 3      |
| .....   |       |           |        |       |        |                   |          |        |

## AGGRESSIVE/DESTRUCTIVE BEHAVIOR

**Generic definition:** *Aggressive or destructive behaviours are offensive actions or deliberate overt attacks directed towards other individuals or objects. They occur repeatedly in the same way over and over again, and they are characteristic for that person.*

|  | Never | monthly | Frequency |       |        | Degree of Problem |          |        |
|--|-------|---------|-----------|-------|--------|-------------------|----------|--------|
|  |       |         | weekly    | daily | hourly | slight            | moderate | severe |
| 41. Hitting others   | 0     | 1       | 2         | 3     | 4      | 1                 | 2        | 3      |
| 42. Kicking others   | 0     | 1       | 2         | 3     | 4      | 1                 | 2        | 3      |
| 43. Pushing others   | 0     | 1       | 2         | 3     | 4      | 1                 | 2        | 3      |
| 44. Biting others  | 0     | 1       | 2         | 3     | 4      | 1                 | 2        | 3      |
| 45. Grabbing and pulling others  | 0     | 1       | 2         | 3     | 4      | 1                 | 2        | 3      |
| 46. Scratching others  | 0     | 1       | 2         | 3     | 4      | 1                 | 2        | 3      |
| 47. Pinching others  | 0     | 1       | 2         | 3     | 4      | 1                 | 2        | 3      |
| 48. Spitting on others   | 0     | 1       | 2         | 3     | 4      | 1                 | 2        | 3      |
| 49. Being verbally abusive with others   | 0     | 1       | 2         | 3     | 4      | 1                 | 2        | 3      |
| 50. Destroying things (e.g., rips clothes, throws chairs, smashes tables)          | 0     | 1       | 2         | 3     | 4      | 1                 | 2        | 3      |
| 51. Being mean or cruel (e.g., grabbing toys or food from others, bullying others) | 0     | 1       | 2         | 3     | 4      | 1                 | 2        | 3      |
| 52. Other:<br>.....  | 0     | 1       | 2         | 3     | 4      | 1                 | 2        | 3      |

Appendix B  
Reiss Scales for Children's Dual Diagnosis

**This test presents a list of maladaptive behaviours that could create problems in the lives of children with special needs. Each item on the list is defined. A few examples are given to help you understand the meaning of the definition. Your task is to read each item and tell us if you think that the item is currently NO PROBLEM, a PROBLEM, or a MAJOR PROBLEM in the child's life. Please keep in mind that we do not want to know simply if the behaviour occurs; what we would like is your opinion if the problem occurs with sufficient frequency, with sufficient intensity, or under sufficiently strange or inappropriate circumstances, so that the behaviour category is a problem or a major problem in the child's life.**

**How to use the Rating Scale:**

**NO PROBLEM.** Use this rating if any of the following are true:

1. The behaviour category does not apply to the child you are rating. For example, the category of "lying" does not apply to a child who is non-verbal.
2. The child you are evaluating does not engage in the behaviour.
3. The behaviour does not occur with sufficient frequency, intensity, or severity to be considered a current problem in the life of the child you are evaluating.

**PROBLEM.** Use this rating if one or more of the following are true:

1. The behaviour causes a significant degree of discomfort and/or suffering for the child being evaluated.
2. The behaviour interferes with the child's social functioning.
3. The behaviour interferes with the child's school functioning.
4. The behaviour occurs often or with unusual degree of severity.

**MAJOR PROBLEM.** Use this rating if one or more of the following are true:

1. The behaviour causes a great deal of discomfort and/or suffering for the child you are evaluating.
2. The behaviour occurs with very high frequency or intensity.
3. The behaviour significantly interferes with the child's social adjustment.
4. The behaviour causes placement in a restrictive environment or increases the need for supervision.

**Now please answer the following questions:**

|   |            |         |               |
|---|------------|---------|---------------|
| <b>1. Afraid of strangers.</b> Becomes fearful in the presence of adult strangers. e.g. resists going near an unfamiliar adult even when encouraged to do so under appropriate circumstances, cries when meeting an adult for the first time, cries in a crowd. | No Problem | Problem | Major Problem |
| <b>1. Angry.</b> Frequently feels hostile or mad. Example: gets mad easily, argues a lot, interrupts others when ignored, expresses anger in inappropriate ways.  | No Problem | Problem | Major Problem |
| <b>3. Anxious.</b> Appears nervous or tense. e.g. nervous, overreacts to unexpected sounds or events, vigilant, worried.  | No Problem | Problem | Major Problem |
| <b>4. Avoids by Illness.</b> False sickness, disability, or pain in order to avoid something he/she does not want to do. e.g. says he/she has a stomach-ache in order to avoid going to school, says he/she has a headache in order to avoid cleaning up room.  | No Problem | Problem | Major Problem |
| <b>5. Avoids Peers.</b> Dislikes interacting with other children.   | No Problem | Problem | Major Problem |

e.g. prefers to play alone, avoids groups, parallel play only, pushes/hits others when approached.

|  |            |         |               |
|--|------------|---------|---------------|
| <b>6. Bizarre Ideas.</b> Expressed strange ideas. e.g. says that he/she is a sailor, says that he/she should collect as many rocks as possible.  | No Problem | Problem | Major Problem |
| <b>7. Blank Stares.</b> Appears expressionless and emotionless. e.g. sometimes appears to be in a trance, gazes off into space.  | No Problem | Problem | Major Problem |
| <b>8. Bodily Complaints.</b> Complains about aches and pains. e.g. headaches, stomach-aches, dizziness, constipation, diarrhoea, unexplained recurrent pains.  | No Problem | Problem | Major Problem |
| <b>9. Bonding Problem.</b> Child or infant has not formed normal emotional attachments with parents/caregivers. e.g. does not seek closeness if caretakers enters room, does not calm when held by parents, does not respond to affection from parents/caretakers.   | No Problem | Problem | Major Problem |
| <b>10. Bullies Others.</b> Controls others with threats, verbal abuse, or actual physical attack. e.g. intimidates smaller or weaker children, bosses around smaller or weaker children.   | No Problem | Problem | Major Problem |
| <b>11. Changes In Sleep Behaviour.</b> A change in usual sleep habits. e.g. recent trouble falling asleep, wakes up in the middle of the night, has trouble waking in mornings.  | No Problem | Problem | Major Problem |
| <b>12. Communication Problem.</b> Marked difficulty in communicating with others. E.g. makes up and uses own words for things, no mode of communication, abnormal gestures, marked speech problem, echolalia, stuttering.  | No Problem | Problem | Major Problem |
| <b>13. Confusing Speech.</b> Poorly related or bizarre ideas or thoughts. e.g. speech makes no sense, thinking is hard to follow, expresses strange ideas, thoughts jump from one topic to another.  | No Problem | Problem | Major Problem |
| <b>14. Crying Spells.</b> Periodic bouts of sobbing. E.g. easily moved to tears, cries more often than most children, cries for no apparent reason.  | No Problem | Problem | Major Problem |
| <b>15. Destructive.</b> Deliberately damages property. E.g. breaks windows, deliberately destroys furniture, throws objects, turns over furniture.   | No Problem | Problem | Major Problem |
| <b>16. Disobedient.</b> Does not follow rules or directions given by people in authority. E.g. does not listen to teacher, does not follow rules of group home/residence, does not follow simple requests.   | No Problem | Problem | Major Problem |
| <b>17. Distracted.</b> Attention to a task is easily interrupted by extraneous or irrelevant stimuli. Example: short attention span, has trouble concentrating   | No Problem | Problem | Major Problem |
| <b>18. Enuresis/Encopresis.</b> A child beyond the age of toilet training with inadequate bladder or bowel control. e.g. bed wetting, urinating on the floor, defecating in pyjamas or pants.  | No Problem | Problem | Major Problem |
| <b>19. Excessive Need For Reassurance.</b> Frequently needs to be told that things are okay. E.g. excessive need to be told that he/she is loved or liked, excessive need to be told that he/she is doing a good job, repeatedly needs to be told that time of a schedule event or reassured that it will occur. | No Problem | Problem | Major Problem |
| <b>20. Excessive Sensitivity To Criticism.</b> Excessive or inappropriate reactions to criticism. E.g. reacts to failure by crying, quits easily, become angry.  | No Problem | Problem | Major Problem |

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|   |            |         |               |
|---|------------|---------|---------------|
| <b>21. Fearful.</b> Afraid of many objects or situations. E.g. afraid to go places, afraid to try new activities, afraid of many different things.  | No Problem | Problem | Major Problem |
| <b>22. Feels Unloved.</b> Has perceptions that parents or significant others do not love or care about him/her. E.g. says that parents/caretakers do not love him/her, says that nobody cares about him/her, says that parents/caretakers love others (e.g. brother or sisters) more. | No Problem | Problem | Major Problem |
| <b>23. Gaze Avoidance.</b> Actively avoids eye contact. E.g. infrequent eye contact with others, becomes upset when face-to face contact is forced.   | No Problem | Problem | Major Problem |
| <b>24. Hallucinations.</b> Experiences things that are not there. E.g. hears voices. Hears sounds, has visions, feels strange bodily sensations.  | No Problem | Problem | Major Problem |
| <b>25. Headaches.</b> Complains about aches and pains in the head. E.g. says head hurts, has migraine headaches, has tension headaches.   | No Problem | Problem | Major Problem |
| <b>26. Impatient.</b> Needs/demands must be met immediately. E.g. demanding, can't wait his/her turn, easily frustrated.  | No Problem | Problem | Major Problem |
| <b>27. Impulsive.</b> Reacts quickly without first thinking about the likely consequences. E.g. makes decisions quickly, quick-tempered.  | No Problem | Problem | Major Problem |
| <b>28. Inattentive.</b> Pays little attention to people or to events around him/her. E.g. pays little attention when spoken to, seems "spaced out".   | No Problem | Problem | Major Problem |
| <b>29. Involuntary Motor movements.</b> Repetitive movements beyond the control of the person. E.g. excessive blinking, strange motor movements, frequent shrugs, hand flapping.  | No Problem | Problem | Major Problem |
| <b>30. Irritable.</b> Easily annoyed or provoked. E.g. easily frustrated, becomes angry over minor annoyances, easily offended, feelings are hurt easily.   | No Problem | Problem | Major Problem |
| <b>31. Isolated.</b> Spends a lot of time alone. E.g. has no friends, plays alone, is ignored or avoided by other children.   | No Problem | Problem | Major Problem |
| <b>32. Lacks Enjoyment.</b> Does not seem to enjoy things anymore. E.g. has no fun, does not want to play anymore, does not want to do much of anything.  | No Problem | Problem | Major Problem |
| <b>33. Lies.</b> Habitually says things that he/she knows are false or misleading. E.g. lies about getting into fights, fabricates incredible tales, lies about being late.   | No Problem | Problem | Major Problem |
| <b>34. Negative Self-Image.</b> Dislikes self. E.g. he/she is stupid, says he/she is a bad person, says he/she is ugly.   | No Problem | Problem | Major Problem |
| <b>35. Obese.</b> Excessively overweight. Example: perceived by others as being fat, eats too much.   | No Problem | Problem | Major Problem |
| <b>36. Object Attachment.</b> Strong and persistent attachments to a particular object. E.g. Often wants to hold a particular ball, searches for missing objects, likes to carry a key chain and gets upset when the key chain cannot be found.                                       | No Problem | Problem | Major Problem |
| <b>37. Overactive.</b> Excessive movement to the point where the person has difficulty staying still. E.g. appears to be in constant motion, excessive physical movement, pacing, constantly changing activity.   | No Problem | Problem | Major Problem |
| <b>38. Pessimistic.</b> Has a negative view of the future. E.g. negative outlook, lacks hope, expects the worst, negative thinking.   | No Problem | Problem | Major Problem |



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|   |            |         |               |
|---|------------|---------|---------------|
| <b>39. Physically Aggressive.</b> Physically attacks others. E.g. fights, spits on others, hits others.   | No Problem | Problem | Major Problem |
| <b>40. Pica.</b> Tendency to eat non-edible objects. E.g. eats dirt, eats paint chips, eats paper, drinks cleaner solution.   | No Problem | Problem | Major Problem |
| <b>41. Rebellious.</b> Defies authority and/or resists control from adults. e.g. defiant, refuses to co-operate with adults, hostile toward authority figures.  | No Problem | Problem | Major Problem |
| <b>42. Runs Away.</b> Leaves without permission and without informing other people. E.g. runs away from home, residential facility, runs away from school.  | No Problem | Problem | Major Problem |
| <b>43. Sad.</b> Displays frequent or excessive feelings of unhappiness. e.g. often gives appearance of unhappy child, has bouts of crying, rarely smiles.   | No Problem | Problem | Major Problem |
| <b>44. Seeks Medical Care.</b> Frequently asks for or seeks out medical attention. E.g. asks for medicine, often needs medical care for one thing after another.  | No Problem | Problem | Major Problem |
| <b>45. Self-Injury.</b> Repeatedly injures body on purpose. E.g. bites arm, hits self repeatedly, bangs head repeatedly.  | No Problem | Problem | Major Problem |
| <b>46. Self-Stimulatory Behaviour.</b> Repetitive movements that are performed frequently and appear to be non-functional. E.g. body-rocking, object twirling, head rocking.  | No Problem | Problem | Major Problem |
| <b>47. Separation Anxiety.</b> Afraid of being away from parent/caretaker. e.g. body-rocking, object-twirling, head-rocking.  | No Problem | Problem | Major Problem |
| <b>48. Sets Fire.</b> Deliberately starts fires. Example: sets fire to room, sets fires in schools  | No Problem | Problem | Major Problem |
| <b>49. Sexual Problem.</b> Repeatedly performs sexual behaviours that are socially disapproved. e.g. sexual expression at in appropriate times or places, masturbates in public.  | No Problem | Problem | Major Problem |
| <b>50. Shy.</b> Uncomfortable in the presence of other people. e.g. dislikes being the centre of attention, bashful, ill at ease in groups, dislikes meeting new people.  | No Problem | Problem | Major Problem |
| <b>51. Social Inadequacies.</b> Has difficulty relating to peers in appropriate or satisfying ways. e.g. has no friends, tends to be disliked, insensitive to the feelings of other people.   | No Problem | Problem | Major Problem |
| <b>52. Steals.</b> Takes property that belongs to others. e.g. takes classmate's possessions, takes money for others.   | No Problem | Problem | Major Problem |
| <b>53. Stomach aches.</b> Complains about stomach aches. e.g. says stomach is upset, feels nauseous, complains of gassy stomach.  | No Problem | Problem | Major Problem |
| <b>54. Strange Behaviour.</b> Engages in behaviour that impresses many observers as unusual, peculiar, strange, or bizarre. e.g. hoards food in pockets or under bed, unusually wears several layers of clothes regardless of weather, always mutters things to self. | No Problem | Problem | Major Problem |
| <b>55. Suicidal Statements.</b> Thinks about, attempts, or threatens to kill himself/herself. e.g. says that he/she would like to die, intentionally cuts or hurts self, tries to get run over by cars.   | No Problem | Problem | Major Problem |
| <b>56. Temper Tantrums.</b> Angry outbursts when frustrated or disappointed. e.g. shouts and yells when not given in to, has  | No Problem | Problem | Major Problem |

outburst when asks to do something he/she does not want to do.

**57. Uncompleted Activities.** Marked tendency not to finish things. e.g. usually does not finish, goes from one uncompleted activity to another.

No Problem

Problem

Major Problem

**58. Unusual Vocalisations.** Makes strange or unusual sounds. e.g. grunts, barking noises, whispers words, sudden anger or swear words when not obviously angry.

No Problem

Problem

Major Problem

**59. Verbally Abusive.** Threatens or insults other people e.g. taunts, insults, threatens others, makes fun of other people, yells or shouts at others.

No Problem

Problem

Major Problem

**60. Withdrawn.** Avoids personal contact with other people. e.g. excessively shy, doesn't participate in group activities, prefers to be alone, socially isolated.

No Problem

Problem

Major Problem

Appendix C

Nisonger Child Behaviour Rating Form

The following questionnaires are about your child's behaviour. Please answer the questions as honestly as possible.

**Please describe you child's behaviour as it was at home over the last month.  
Please circle the number for each question that best describes your child.**

**In the last month, your child has:**

|                                       | Not<br>True<br>0 | Somewhat or<br>Sometimes True<br>1 | Very or<br>Often True<br>2 | Completely<br>Always true<br>3 |
|---------------------------------------|------------------|------------------------------------|----------------------------|--------------------------------|
| 2. Accepted redirection               | 0                | 1                                  | 2                          | 3                              |
| 2. Expressed ideas clearly            | 0                | 1                                  | 2                          | 3                              |
| 3. Followed rules                     | 0                | 1                                  | 2                          | 3                              |
| 4. Initiated positive interactions    | 0                | 1                                  | 2                          | 3                              |
| 5. Participated in group activities   | 0                | 1                                  | 2                          | 3                              |
| 6. Resisted provocation, was tolerant | 0                | 1                                  | 2                          | 3                              |
| 7. Shared with or helped others       | 0                | 1                                  | 2                          | 3                              |
| 8. Stayed on task                     | 0                | 1                                  | 2                          | 3                              |
| 9. Was cheerful or happy              | 0                | 1                                  | 2                          | 3                              |
| 10. Was patient, able to delay        | 0                | 1                                  | 2                          | 3                              |

Appendix D

Questionnaire on Resources and Stress – Short Form

### The Impact of Your Child on You and Your Family

The following statements deal with your feelings about your child with special needs. There are many blank spaces on the questionnaire (\_\_\_\_\_). **Imagine** the name of your child with special needs in each of these blank spaces. Please give your honest feelings and opinions. Respond to all of the statements, even if they do not seem to apply. If it is difficult to decide “true” or “false”, answer in terms of what you or your family feel or do *most* of the time. Sometimes, the statements will refer to difficulties that are not applicable to your family. These statements can still be responded to with a “true” or “false”. Please respond to all of the statements by circling either TRUE or FALSE.

1. \_\_\_\_\_ doesn't communicate with others of his/her age group. TRUE FALSE
2. Other members of the family have to do without things because of \_\_\_\_\_ TRUE FALSE
3. Our family agrees on important matters. TRUE FALSE
4. I worry about what will happen to \_\_\_\_\_ when I can no longer take care of him/her TRUE FALSE
5. The constant demands for care for \_\_\_\_\_ limit growth and development of someone else in our family. TRUE FALSE
6. \_\_\_\_\_ is limited in the kind of work he/she can do to make a living TRUE FALSE
7. I have accepted the fact that \_\_\_\_\_ might have to live out his/her life in some special setting (e.g., group home, institution) TRUE FALSE
8. \_\_\_\_\_ can feed himself/herself. TRUE FALSE
9. I have given up things I have really wanted to do in order to care for \_\_\_\_\_ TRUE FALSE
10. \_\_\_\_\_ is able to fit into the family social group. TRUE FALSE
11. Sometimes I avoid taking \_\_\_\_\_ out in public. TRUE FALSE
12. In the future, our family's social life will suffer because of increased responsibilities and financial stress. TRUE FALSE
13. It bothers me that \_\_\_\_\_ will always be this way. TRUE FALSE
14. I feel tense whenever I take \_\_\_\_\_ out in public. TRUE FALSE
15. I can go to visit friends whenever I want. TRUE FALSE
16. Taking \_\_\_\_\_ on a holiday spoils the pleasure for the whole family. TRUE FALSE
17. \_\_\_\_\_ knows his/her own address. TRUE FALSE
18. The family does as many things together now as we ever did. TRUE FALSE
19. \_\_\_\_\_ is aware of who he/she is. TRUE FALSE
20. I get upset with the way my life is going. TRUE FALSE
21. Sometimes I feel very embarrassed because of \_\_\_\_\_. TRUE FALSE

|  |      |       |
|--|------|-------|
| 22. _____ doesn't do as much as he/she should be able to do.   | TRUE | FALSE |
| 23. It is difficult to communicate with _____ because he/she has difficulty understanding what is being said to him/her. | TRUE | FALSE |
| 24. There are many places where we can enjoy ourselves as a family when _____ comes along.                               | TRUE | FALSE |
| 25. _____ is over-protected.   | TRUE | FALSE |
| 26. _____ is able to take part in games or sports.   | TRUE | FALSE |
| 27. _____ has too much time on his/her hands.  | TRUE | FALSE |
| 28. I am disappointed that _____ does not lead a normal life.  | TRUE | FALSE |
| 29. Time drags for _____, especially free time.  | TRUE | FALSE |
| 30. _____ can't pay attention very long.   | TRUE | FALSE |
| 31. It is easy for me to relax.  | TRUE | FALSE |
| 32. I worry about what will be done with _____ when he/she gets older.   | TRUE | FALSE |
| 33. I get almost too tired to enjoy myself.  | TRUE | FALSE |
| 34. One of the things I appreciate about _____ is his/her confidence.  | TRUE | FALSE |
| 35. There is a lot of anger and resentment in our family.  | TRUE | FALSE |
| 36. _____ is able to go to the bathroom alone.   | TRUE | FALSE |
| 37. _____ cannot remember what he/she says from one moment to the next.  | TRUE | FALSE |
| 38. _____ can ride on a bus.   | TRUE | FALSE |
| 39. It is easy to communicate with _____.  | TRUE | FALSE |
| 40. The constant demands to care for _____ limit my growth and development.  | TRUE | FALSE |
| 41. _____ accepts himself/herself as a person.   | TRUE | FALSE |
| 42. I feel sad when I think of _____.  | TRUE | FALSE |
| 43. I often worry about what will happen to _____ when I can no longer take care of him/her.                             | TRUE | FALSE |
| 44. People can't understand what _____ tries to say.   | TRUE | FALSE |
| 45. Caring for _____ puts a strain on me.  | TRUE | FALSE |
| 46. Members of our family get to do the same kinds of things other families do.  | TRUE | FALSE |
| 47. _____ will always be a problem to us.  | TRUE | FALSE |
| 48. _____ is able to express his/her feelings to others.   | TRUE | FALSE |
| 49. _____ has to use a bedpan or a nappy.  | TRUE | FALSE |



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- |                                    |      |       |
|------------------------------------|------|-------|
| 50. I rarely feel blue.            | TRUE | FALSE |
| 51. I am worried much of the time. | TRUE | FALSE |
| 52. _____ can walk without help.   | TRUE | FALSE |

Appendix E

Positive Contributions Scale (Kansas Inventory of Positive Perceptions)

The statements in this section are divided into four sub-parts: A, B, C and D. Each part begins with a different sentence. The statements complete the sentence at the top of each section. For example, the sentence at the top of Part A is:

**MY CHILD \_\_\_\_\_ IS:**

**All the statements in Part A complete this sentence. The blank space after the word “child” is there to remind you to think only of your child with special needs when you answer each statement.**

**Read each statement and circle the one response that best describes how much you agree or disagree with each statement. The answers and their meanings are:**

### Part A

**MY CHILD \_\_\_\_\_ IS:**

|   | Strongly<br>Disagree | Disagree | Agree | Strongly<br>Agree |
|---|----------------------|----------|-------|-------------------|
| 1. the reason I attend religious services more frequently.                          | 1                    | 2        | 3     | 4                 |
| 2. why I met some of my best friends.   | 1                    | 2        | 3     | 4                 |
| 3. the reason my life has better structure.   | 1                    | 2        | 3     | 4                 |
| 4. why I am a more responsible person.  | 1                    | 2        | 3     | 4                 |
| 5. the reason I've learned to control my temper.                                    | 1                    | 2        | 3     | 4                 |
| 6. responsible for my learning patience.  | 1                    | 2        | 3     | 4                 |
| 7. responsible for my increased awareness of people<br>with special needs.          | 1                    | 2        | 3     | 4                 |
| 8. fun to be around.  | 1                    | 2        | 3     | 4                 |
| 9. the reason I am more realistic about my job.                                     | 1                    | 2        | 3     | 4                 |
| 10. responsible for my being more aware and concerned<br>for the future of mankind. | 1                    | 2        | 3     | 4                 |
| 11. kind and loving.  | 1                    | 2        | 3     | 4                 |
| 12. helpful to other family members, which saves time<br>and energy for me.         | 1                    | 2        | 3     | 4                 |
| 13. a source of pride because of his/her artistic<br>accomplishments.               | 1                    | 2        | 3     | 4                 |

**Part B**

**I CONSIDER MY CHILD \_\_\_\_\_ TO BE:**

|  | Strongly<br>Disagree | Disagree | Agree | Strongly<br>Agree |
|--|----------------------|----------|-------|-------------------|
| 14. what gives me common ground with other parents.                          | 1                    | 2        | 3     | 4                 |
| 15. helpful without having to be asked.                                      | 1                    | 2        | 3     | 4                 |
| 16. responsible for my increased sensitivity to people.                      | 1                    | 2        | 3     | 4                 |
| 17. what gives our family a sense of continuity – a sense of history.        | 1                    | 2        | 3     | 4                 |
| 18. the reason I am more productive.   | 1                    | 2        | 3     | 4                 |
| 19. an advantage to my career.   | 1                    | 2        | 3     | 4                 |
| 20. the reason I budget my time better.                                      | 1                    | 2        | 3     | 4                 |
| 21. the reason I am able to cope better with stress and problems.            | 1                    | 2        | 3     | 4                 |
| 22. very affectionate.   | 1                    | 2        | 3     | 4                 |
| 23. what makes me realise the importance of planning for my family's future. | 1                    | 2        | 3     | 4                 |
| 24. able to use good judgement.  | 1                    | 2        | 3     | 4                 |
| 25. a great help around the house.   | 1                    | 2        | 3     | 4                 |

**Part C**

**THE PRESENCE OF MY CHILD \_\_\_\_\_:**

|  | Strongly<br>Disagree | Disagree | Agree | Strongly<br>Agree |
|--|----------------------|----------|-------|-------------------|
| 26. is an inspiration to improve my job skills.  | 1                    | 2        | 3     | 4                 |
| 27. helps me understand people who are different.  | 1                    | 2        | 3     | 4                 |
| 28. is a source of pride because of his/her athletic achievements.                         | 1                    | 2        | 3     | 4                 |
| 29. cheers me up.  | 1                    | 2        | 3     | 4                 |
| 30. confirms my faith in God.  | 1                    | 2        | 3     | 4                 |
| 31. gives a new perspective to my job.   | 1                    | 2        | 3     | 4                 |
| 32. renews my interest in participating in different activities.                           | 1                    | 2        | 3     | 4                 |
| 33. is very uplifting.   | 1                    | 2        | 3     | 4                 |
| 34. is a reminder that all children, including those with special needs, need to be loved. | 1                    | 2        | 3     | 4                 |
| 35. is a reminder that everyone has a purpose in life.                                     | 1                    | 2        | 3     | 4                 |
| 36. makes us more in charge of ourselves as a family.                                      | 1                    | 2        | 3     | 4                 |
| 37. helps me take things as they come.   | 1                    | 2        | 3     | 4                 |

**Part D**

**BECAUSE OF MY CHILD\_\_\_\_\_:**

|  | Strongly<br>Disagree | Disagree | Agree | Strongly<br>Agree |
|--|----------------------|----------|-------|-------------------|
| 38. my circle of friends has grown larger.   | 1                    | 2        | 3     | 4                 |
| 39. I have someone who shares responsibility for doing several tasks around the house. | 1                    | 2        | 3     | 4                 |
| 40. my social life has expanded by bringing me into contact with other parents.        | 1                    | 2        | 3     | 4                 |
| 41. I am more compassionate.   | 1                    | 2        | 3     | 4                 |
| 42. I learned about special needs.   | 1                    | 2        | 3     | 4                 |
| 43. my family is more understanding about special problems.                            | 1                    | 2        | 3     | 4                 |
| 44. I am grateful for each day.  | 1                    | 2        | 3     | 4                 |
| 45. our family has become closer.  | 1                    | 2        | 3     | 4                 |
| 46. I am more sensitive to family issues.  | 1                    | 2        | 3     | 4                 |
| 47. I have learned to adjust to things I cannot change.                                | 1                    | 2        | 3     | 4                 |
| 48. my other children have learned to be aware of peoples needs and their feelings.    | 1                    | 2        | 3     | 4                 |
| 49. I have many unexpected pleasures.  | 1                    | 2        | 3     | 4                 |
| 50. I am more accepting of things.   | 1                    | 2        | 3     | 4                 |

Appendix F  
The Hospital Anxiety and Depression Scale

## Your Day to Day Feelings

**This questionnaire focuses on how you feel about things. Please read each item and circle the reply underneath the item that comes closest to how you have been feeling in the past week. Do not take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.**

**1. I feel tense or "wound up"**

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

**2. I still enjoy the things I used to enjoy**

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

**3. 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.

**4. 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.

**5. 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.

**6. I feel cheerful**

Not at all.      Not often.      Sometimes.      Most of the time.

**7. I can sit at ease and feel relaxed**

Definitely.      Usually.      Not often.      Not at all.

**8. I feel as if I am slowed down**

Nearly all the time.      Very often.      Sometimes.      Not at all.



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

Not at all.                      Occasionally.                      Quite often.                      Very often.

**10. 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

**11. I feel restless as if I have to be on the move**

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

**12. 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.

**13. I get sudden feelings of panic**

Very often indeed.                      Quite often.                      Not very often.                      Not at all.

**14. I can enjoy a good book, radio or TV programme**

Often.                      Sometimes.                      Not often.                      Very seldom.

Appendix G  
Satisfaction With Life Scale

**Satisfaction with Your Life**

**Below are five statements that you may agree or disagree with. Read each one and circle the response that best describes how strongly you agree or disagree.**

|  | Strongly<br>Disagree | Disagree | Slightly<br>Disagree | Neither<br>or Disagree | Agree<br>Slightly | Agree | Strongly<br>Agree |
|--|----------------------|----------|----------------------|------------------------|-------------------|-------|-------------------|
| 1. In most ways, my life is close to my ideal.                 | 1                    | 2        | 3                    | 4                      | 5                 | 6     | 7                 |
| 2. The conditions of my life are excellent.                    | 1                    | 2        | 3                    | 4                      | 5                 | 6     | 7                 |
| 3. I am completely satisfied with my life.                     | 1                    | 2        | 3                    | 4                      | 5                 | 6     | 7                 |
| 4. So far I have got the most important things I want in life. | 1                    | 2        | 3                    | 4                      | 5                 | 6     | 7                 |
| 5. If I could live my life over again, I would change nothing. | 1                    | 2        | 3                    | 4                      | 5                 | 6     | 7                 |

Appendix H

Golombok Rust Inventory of Marital State

**You and Your Partner**

**Please read each statement and decide which response best describes how you feel about your partner. Please do not discuss any of the responses with your partner.**

|   | Strongly<br>Disagree<br>1 | Disagree<br>2 | Agree<br>3 | Strongly<br>Agree<br>4 |
|---|---------------------------|---------------|------------|------------------------|
| 1. My partner is usually sensitive to and aware of my needs                       |                           |               |            |                        |
| 2. I really appreciate my partner's sense of humour                               | 1                         | 2             | 3          | 4                      |
| 3. My partner doesn't seem to listen to me any more                               | 1                         | 2             | 3          | 4                      |
| 4. My partner has never been disloyal to me                                       | 1                         | 2             | 3          | 4                      |
| 5. I would be willing to give up my friends if it meant saving our relationship   | 1                         | 2             | 3          | 4                      |
| 6. I am dissatisfied with our relationship  | 1                         | 2             | 3          | 4                      |
| 7. I wish my partner was not so lazy and didn't keep putting things off           | 1                         | 2             | 3          | 4                      |
| 8. I sometimes feel lonely even when I am with my partner                         | 1                         | 2             | 3          | 4                      |
| 9. I am with my partner if my partner left me life would not be worth living      | 1                         | 2             | 3          | 4                      |
| 10. We can "agree to disagree" with each other                                    | 1                         | 2             | 3          | 4                      |
| 11. It is useless carrying on with a marriage beyond a certain point              | 1                         | 2             | 3          | 4                      |
| 12. We both seem to like the same things  | 1                         | 2             | 3          | 4                      |
| 13. I find it difficult to show my partner that I am feeling affectionate         | 1                         | 2             | 3          | 4                      |
| 14. I never have second thoughts about our relationship                           | 1                         | 2             | 3          | 4                      |
| 15. I enjoy just sitting and talking with my partner                              | 1                         | 2             | 3          | 4                      |
| 16. I find the idea of spending the rest of my life with my partner rather boring | 1                         | 2             | 3          | 4                      |
| 17. There is always plenty of "give and take" in our relationship                 | 1                         | 2             | 3          | 4                      |
| 18. We become competitive when we have to make decisions                          | 1                         | 2             | 3          | 4                      |
| 19. I no longer feel I can really trust my partner                                | 1                         | 2             | 3          | 4                      |
| 20. Our relationship is still full of joy and excitement                          | 1                         | 2             | 3          | 4                      |
| 21. One of us is continually talking and the other is usually silent              | 1                         | 2             | 3          | 4                      |
| 22. Our relationship is continuously evolving                                     | 1                         | 2             | 3          | 4                      |

## Appendices

|   |   |   |   |   |
|---|---|---|---|---|
| 23. Marriage is really more about security and money than about love                  | 1 | 2 | 3 | 4 |
| 24. I wish there was more warmth and affection between us                             | 1 | 2 | 3 | 4 |
| 25. I am totally committed to my relationship with my partner                         | 1 | 2 | 3 | 4 |
| 26. Our relationship is sometimes strained because my partner is always correcting me | 1 | 2 | 3 | 4 |
| 27. I suspect we may be on the brink of separation                                    | 1 | 2 | 3 | 4 |
| 28. We can always make up quickly after an argument                                   | 1 | 2 | 3 | 4 |

Appendix I  
Positive Affect Scale



### Your Positive Feelings

**This scale consists of a number of words that describe different feelings and emotions. Read each item and circle the number which corresponds to what extent you feel this way right now, that is, at the present moment.**

|                | Very slight<br>or not at all | A Little | Moderate | Quite a bit | Extremely |
|----------------|------------------------------|----------|----------|-------------|-----------|
| 1.INTERESTED   | 1                            | 2        | 3        | 4           | 5         |
| 2.EXCITED      | 1                            | 2        | 3        | 4           | 5         |
| 3.STRONG       | 1                            | 2        | 3        | 4           | 5         |
| 4.ENTHUSIASTIC | 1                            | 2        | 3        | 4           | 5         |
| 5.PROUD        | 1                            | 2        | 3        | 4           | 5         |
| 6.ALERT        | 1                            | 2        | 3        | 4           | 5         |
| 7.INSPIRED     | 1                            | 2        | 3        | 4           | 5         |
| 8.DETERMINED   | 1                            | 2        | 3        | 4           | 5         |
| 9.ATTENTIVE    | 1                            | 2        | 3        | 4           | 5         |
| 10.ACTIVE      | 1                            | 2        | 3        | 4           | 5         |

Appendix J  
Shortened Ways of Coping - Revised

Coping with Your Child

We would like to know how you cope with everyday experiences. Obviously there are many different ways of coping but we are interested in the way that you have been dealing with your child with special needs. Each item below says something about a particular way of coping and we are interested in to what extent you have been doing this to cope with stressful situations. Do not answer on the basis of whether it seems to be working or not, just whether you are doing it or not.

|   | Not Used | Used Somewhat | Used Quite a Bit | Used a Great Deal |
|---|----------|---------------|------------------|-------------------|
| 1. I daydream or imagine a better time or place than the one I am in                | 1        | 2             | 3                | 4                 |
| 2. I draw on my past experiences.   | 1        | 2             | 3                | 4                 |
| 3. I think up a couple of different solutions to problems.                          | 1        | 2             | 3                | 4                 |
| 4. I wish that I could change how I feel.   | 1        | 2             | 3                | 4                 |
| 5. I try to come out of experiences better than when I went in.                     | 1        | 2             | 3                | 4                 |
| 6. I wish that I could change what has happened.                                    | 1        | 2             | 3                | 4                 |
| 7. I try to analyse the situation in order to understand it better.                 | 1        | 2             | 3                | 4                 |
| 8. I usually know what has to be done, so I keep up my efforts to make things work. | 1        | 2             | 3                | 4                 |
| 9. I take it out on other people.   | 1        | 2             | 3                | 4                 |
| 10. I avoid being with people in general.   | 1        | 2             | 3                | 4                 |
| 11. I have fantasies or wishes about how things might turn out.                     | 1        | 2             | 3                | 4                 |
| 12. I stand my ground and fight for what I want.                                    | 1        | 2             | 3                | 4                 |
| 13. I wish that the situation would go away or somehow be over with.                | 1        | 2             | 3                | 4                 |
| 14. I make a plan of action and follow it.  | 1        | 2             | 3                | 4                 |

Appendix K  
Support Functions Scale

### Support You Receive

**Listed below are 12 different types of assistance which people sometimes find helpful. This questionnaire asks you to indicate how much you need help in these areas. To what extent do you have or feel a need for any of the following types of help or assistance:**

|  | Never | Once in<br>a While | Sometimes | Often | Quite Often |
|--|-------|--------------------|-----------|-------|-------------|
| 1. Someone to talk to about things that worry you                      | 1     | 2                  | 3         | 4     | 5           |
| 2. Someone to help take care of your child                             | 1     | 2                  | 3         | 4     | 5           |
| 3. Someone to talk to when you have questions about raising your child | 1     | 2                  | 3         | 4     | 5           |
| 4. Someone who loans you money when you need it                        | 1     | 2                  | 3         | 4     | 5           |
| 5. Someone to encourage you to keep going when things seem hard        | 1     | 2                  | 3         | 4     | 5           |
| 6. Someone who accepts your child regardless of how (s)he acts         | 1     | 2                  | 3         | 4     | 5           |
| 7. Someone to help with the household chores                           | 1     | 2                  | 3         | 4     | 5           |
| 8. Someone to relax or joke with                                       | 1     | 2                  | 3         | 4     | 5           |
| 9. Someone to do things with your child                                | 1     | 2                  | 3         | 4     | 5           |
| 10. Someone to provide you or your child transportation                | 1     | 2                  | 3         | 4     | 5           |
| 11. Someone to hassle with agencies or individuals when you can't      | 1     | 2                  | 3         | 4     | 5           |
| 12. Someone who tells you about services for your child or family.     | 1     | 2                  | 3         | 4     | 5           |

Appendix L  
Social Readjustment Rating Scale

### Life Events

This questionnaire focuses on life changes. Place a tick beside any of the following events that **YOU** have experienced in your life over the **past 12 months.**

|   |  |
|---|--|
| Death of spouse or child  |  |
| Divorce   |  |
| Marital Separation  |  |
| Death of a close family member (eg parent or sibling)                         |  |
| Major personal injury or illness  |  |
| Marriage  |  |
| Marital reconciliation  |  |
| Retirement  |  |
| Major change in health or behaviour of family member                          |  |
| Pregnancy of spouse/partner   |  |
| Gaining a new family member (e.g. through birth, adoption etc)                |  |
| Major business readjustment (e.g. merger, re-organization, etc)               |  |
| Major change in financial state (e.g. a lot worse off or a lot better off)    |  |
| Death of a close friend   |  |
| Changing to a different type of work  |  |
| Major change in the number of arguments with spouse (e.g. a lot more or less) |  |
| Taking on a significant (to you) mortgage                                     |  |
| Foreclosure on a mortgage or loan   |  |
| Major change in responsibility at work (e.g. promotion, transfer, demotion)   |  |
| Son or daughter leaving home (marriage, college etc)                          |  |
| Trouble with in laws  |  |
| Outstanding personal achievement  |  |
| Partner beginning or ceasing work outside of the home                         |  |
| Major change in living conditions (e.g. new house, renovating)                |  |
| Revision of personal habits (dress, manners, association etc)                 |  |
| Troubles at work with colleagues  |  |
| Change in residence   |  |
| Major change in usual type and/or amount of social activities                 |  |
| Major change in sleeping habits (e.g. a lot more or less)                     |  |
| Major change in number of family get-togethers (e.g. a lot more or less)      |  |
| Major change in eating habits (e.g. a lot more or less food intake)           |  |
| Holiday or vacation   |  |



Appendix M  
Initial Contact Form

## Initial Contact Form

### Special Needs and Families Research Project

Please read the following, place a tick in the appropriate boxes, then return the form in the stamped addressed envelope provided.

☐ I would like more information before I decide to take part in the study. *Please give us a contact number below.*

☐ I would like to take part in the study. *Please complete the information below.*

Please tell us if you are the child's primary or secondary parental caregiver:

☐ I am the **primary parental caregiver** (parent, foster parent, adoptive parent etc., primarily responsible for the day-to-day care) of a child with special needs (age 4-17 years only)

☐ I am the **secondary parental caregiver** (parent, foster parent, adoptive parent etc., involved in the child's care but not primarily responsible) of a child with special needs (age 4-17 years only)

Please tell us whether your child with special needs has another parental caregiver, and whether they would also be willing to participate in the research:

My child with special needs has another parental caregiver.

☐ Yes ☐ No

If yes, is this person willing to participate in the research?

☐ Yes ☐ No *If yes, please include their contact details below.*

**Your Name** (please print):

\_\_\_\_\_

Your contact  
address:

\_\_\_\_\_

\_\_\_\_\_

—

\_\_\_\_\_ Postcode \_\_\_\_\_

—

**Your** telephone number:

\_\_\_\_\_

Best days to contact you are

\_\_\_\_\_

Best time of day to contact you is ☐ Morning ☐ Afternoon ☐ Evening

specific times \_\_\_\_\_

-----

---

**Name of other parental caregiver** (please  
print):

\_\_\_\_\_

**Their address** and telephone details (if different from above):

\_\_\_\_\_

\_\_\_\_\_

—

\_\_\_\_\_

—

\_\_\_\_\_ Postcode \_\_\_\_\_

—

Telephone Number (if different from  
above):

\_\_\_\_\_

Best days to contact this person are

\_\_\_\_\_

Best time of day to contact this person is ☐ Morning ☐ Afternoon ☐  
Evening

specific times \_\_\_\_\_

Appendix N  
Participant Information Sheet

## Information for Families

### 1. Study Title

Special Needs and Families Research Project.

### 2. Research Team

Dr Alexandra Beck (Research Officer)  
 Christopher Hill (Doctoral Researcher)  
 Dr Richard Hastings (Project Leader)

### 3. What is the purpose of the study?

We are interested in how family members, especially parents/parental caregivers, adapt to the care of children with special needs (specifically, learning disabilities). There is already research on this topic, but we are aiming to explore two issues that have received little attention by researchers and others to date:

- What kinds of positive experiences are there associated with the care of children with special needs, and how might these experiences help parents to adapt successfully?
- How do changes over time affect the adaptation of parental caregivers, and do various positive experiences help parents to maintain a sense of satisfaction in their caring role?

### 4. Invitation to participate

We are looking for 150 families of children with special needs in the Wales and adjacent areas to participate in our research project. Ideally, families will be willing to participate in our research now and also agree to be involved in a follow-up data gathering phase in approximately 12 months time. Please read the remainder of this information sheet carefully and complete the form enclosed if you are interested in helping us with this research. If there is anything that is not clear, or you would just like more information before you decide, please contact us by mail, telephone or email (including your telephone contact number) and we will telephone you to discuss the project further and answer any questions that you may have.

As several organisations have agreed to help us distribute information about this research, you may receive a duplicate of this information sheet and invitation to participate in the study. *If so, you only need to respond once.*

## 5. What are the benefits of taking part in the research?

The main benefits of this research relate to improving the knowledge that we have about families and how they adapt to caring for children with special needs. In particular, almost nothing is known about parents' positive experiences and how these might help families to cope effectively. We hope to use the information from this research in the future to develop support interventions for families that focus on recognition of positive experiences of caring for children with special needs. We think that existing support services sometimes focus too much on stressful aspects of life and that new interventions and services might prove helpful. Your participation in the research will contribute to these overall aims.

There are three more concrete benefits to participation in the research. First, the measures to be used in the research include an assessment of children's adaptive skills (i.e., daily living skills, communication, and socialization skills). If you would like to receive one, we will provide you with a summary report of the findings from this assessment which you may wish to use to help identify appropriate service provision for your child.

Second, we appreciate that participation in research takes up valuable time and that it can be difficult to cover the costs of alternative care arrangements for your child. Therefore, we hope that you will feel able to accept a payment for participating in the research as outlined below. This payment would be made to you after your initial participation and then again if you agree to take part in our follow-up data collection in around 12 months time.

| Receipt of data from Parent/Carer 1 | Receipt of data from Parent/Carer 2 | Receipt of follow-up data from Parent/Carer 1 | Receipt of follow-up data from Parent/Carer 2 | Maximum payment possible for family |
|-------------------------------------|-------------------------------------|---|---|-------------------------------------|
| £25                                 | £10                                 | £15   | £10   | £60                                 |

Finally, we plan several ways to keep all families up-to-date with the project's progress and its findings, including:

- A regular newsletter.
- Access to a dedicated website about the project, including links to organizations offering advice and assistance to families of children with special needs.
- Facility to request full copies of research publications on families of children with special needs produced by members of the project team.



## **6. What are the risks of taking part?**

We do not believe that you are at risk of any harm from taking part in this study. Whether or not you take part, we are not involved in providing services to families of children with special needs and so your decisions will not affect any services you might receive.

## **7. Do we have to take part?**

It is up to you to decide whether you want to take part. If you do decide to take part, or want further information, please sign the Initial Contact Form and return it in the envelope provided. You can keep this information sheet for your records. You are still free to withdraw from the research at any time, and without giving a reason.

## **8. What will happen to us if we take part?**

After you have returned the Initial Contact Form, we will go through the following contact process:

1. Telephone you to answer any questions (if you have requested this).
2. Send you a questionnaire pack in the mail to complete and return to us. This will include questions about your child and their special needs, yourself, and your family. Specifically, we will ask about your positive feelings and feelings of stress, the strategies you use to cope with problems, the support available to you, and your child's behaviour problems (if any). This pack will also include another copy of this information sheet and a Consent Form to sign to say that you are willing to participate in the research. The questionnaires take between 60 and 75 minutes to complete.
3. Either telephone you to complete a short interview (our preferred option), or make a visit to your home or another place to carry out this interview (if you would rather). This interview for Parent/Carer 1 (approximately 25 minutes) will focus on how you see your relationship with your child with special needs and also completion of the adaptive behaviour assessment. For Parent/Carer 2, only the first part of the interview will be conducted (10 minutes).
4. If you are happy to let us make contact with them, we will also write to your child's school or nursery teacher and ask them to complete questionnaires about your child's pro-social behaviour and any behaviour problems your child may have in the school setting.
5. Send you a payment for helping us with the research.
6. Send you information about the initial results of the study.
7. 12 months later, we will write to ask you if you would be willing to help us with the follow-up data collection. This letter will include a fresh consent form for you to confirm that you are still willing to help. You will also be able to tell us at this point that you do not want to be included in this stage of the research.
8. Questionnaire and telephone contact, and payment will be made as before. However, the questionnaires (50-60 minutes) and interview (10 minutes only) will be shorter.

9. Send you final results of the study and let you know how you can access more detailed information.

## **9. What do we have to do now?**

If having discussed this information with you partner, friends and/or family you would like to discuss the study further, or you would like to take part, then please return the Initial Contact Form. If you decide not to take part, please discard this letter. You do not need to make contact with us. We apologise if you receive any more copies of this invitation. Just ignore these as we have no way of contacting you directly unless you return the Initial Contact Form to us.

All the information that you give us will be treated as strictly confidential, and will be kept securely locked in a filing cabinet without your names attached. None of the information that you provide will be used in any way that would identify you as a family. Results of the study will describe overall findings and not information about individual families.

If your preferred language is Welsh, we would like to apologise for the fact that the questionnaires and interview can be conducted in English only. It is not possible to translate them into Welsh without extensive testing of the measures due to potential problems in losing important aspects of their meaning through translation. We hope that you will be willing to participate in this research using English but understand that you may wish not to do so.

## **10. Further details**

If you want to contact the research team, our details are below:

Alex Beck or Chris Hill: Special Needs and Families Research Project  
Mail - School of Psychology, Brigantia Building, University of Wales Bangor,  
Bangor, LL592AS. Telephone - 01248 388436. E-Mail  
[specialfamilies@bangor.ac.uk](mailto:specialfamilies@bangor.ac.uk)

If you have any complaints about the way that this research is being conducted you are welcome to address unresolved concerns to:

Professor Fergus Lowe  
Head of the School of Psychology  
University of Wales Bangor  
Bangor  
Gwynedd  
LL57 2AS

This research project is funded by a grant from the PPP Foundation who fund various health and social care research projects.

Appendix O

Consent Form for Phase 1 Data Collection

## Research Consent Form Phase 1

### Special Needs and Families Research Project

*Please complete the following and delete as necessary:*

- |   |        |
|---|--------|
| 1) Have you read the Information for Families leaflet?                  | YES/NO |
| 2) Have you had an opportunity to ask questions and discuss this study? | YES/NO |
| 3) Have you received satisfactory answers to all of your questions?     | YES/NO |
| 4) Have you received enough information about this study?               | YES/NO |
| 5) Do you understand that you are free to withdraw from this study:     |        |

..at any time

..without giving a reason for withdrawing

..without affecting any treatment you receive YES/NO

I am willing to participate in this study. YES/NO

Signature\_\_\_\_\_

Date\_\_\_\_\_

Name in block letters\_\_\_\_\_

Address

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_ Postcode \_\_\_\_\_

Please answer the following two questions:

1. If you are a member of staff of the University of Wales Bangor please tick this box ☐

2. We would like to contact your child's teacher to ask them to complete a questionnaire about your child's behaviour in the school or nursery context. If you are happy for us to do this, please complete the information below.

Name of Teacher\_\_\_\_\_

Name and Address of School\_\_\_\_\_

Appendix P  
Consent Form for Phase 2 Data Collection

## Research Consent Form Phase 2

### Special Needs and Families Research Project

*Please complete the following and delete as necessary:*

1. Have you read the Information for Families leaflet?  
YES/NO
2. Have you had an opportunity to ask questions and discuss this study? YES/NO
3. Have you received satisfactory answers to all of your questions?  
YES/NO
4. Have you received enough information about this study?  
YES/NO
5. Do you understand that you are free to withdraw from this study:

..at any time

..without giving a reason for withdrawing

..without affecting any treatment you receive YES/NO

I am willing to participate in the follow-up data collection for this study. YES/NO

Signed \_\_\_\_\_

Date \_\_\_\_\_

Name in block letters \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_ Postcode \_\_\_\_\_

\_\_\_\_\_

Please answer the following two questions:

1. If you are a member of staff of the University of Wales Bangor please tick this box ☐

2. We would like to contact your child's teacher to ask them to complete a questionnaire about your child's behaviour in the school or nursery context. If you are happy for us to do this, please complete the information below.

Name of Teacher \_\_\_\_\_

Name and Address of School \_\_\_\_\_

Appendix Q

Observational Study Letter to Parents



Dear \_\_\_\_\_

Firstly, I would like to thank you once again for participating in the Special Needs and Families Research Project.

## **An Additional Study...**

I am writing to you now as you have recently received questionnaires to fill out for the second phase of our data collection. We are carrying out an additional small study, starting with families in the main project that live closest to the University. In this study, we are interested in looking at how you and your child with special needs interact with each other. We want to do this by carrying out some simple observations at your home.

What is the relationship between the main Special Needs and Families Research Project and this study?

This is a separate study. You do not have to participate in an additional observation study, we just hope that you will be willing to help us. You can still participate in the main research even if you do not want to participate in the observational study. We have included a separate consent form with this letter and will not enrol you in the observational study unless you are happy to sign this and return it to us.

## **What would the observations involve?**

Two researchers would be visiting, Chris Hill, a doctoral researcher and Tracey Lloyd, a Masters student. We would envisage being at your home for an hour and a half at the most. In that hour and a half we would set up a video camera, talk you through exactly what was going to happen and record you and your child for approximately 20 minutes. We would be asking you to firstly follow your child's lead and play with whatever toys they want. The second task would involve you choosing a number of toys for your child to play with, but you make up the rules. A third task involves lego, and the fourth and final task is to have your child clear up all the toys. We will provide the toys and items for all the tasks. You would then have the opportunity to ask any questions regarding the study before we left.

## **What are the benefits of taking part?**

This observational research would enable us to get an additional view of parents' relationships with their child with special needs. As with the main project, we are especially interested in the positive dimensions of interaction between parents and children.

In recognition of the disruption we would be causing we will offer to make an extra payment of £20 if you want to help us with this additional study. When the observations with all the families are complete, we propose to write to you to let you know the findings of the research and how they might benefit families of children with special needs.

## **Are there any risks to myself or my child?**

We do not believe that either you or your child is at any risk from the observational research. Should you feel unhappy at any point during the observations, you may ask us to stop recording. In the event of this, the researchers will simply pack their equipment away and leave the house.

You also have the right to withdraw from this additional study at any time.

We should also stress that we are not involved in providing services to families of children with special needs, so your decisions will not affect any services you receive.

## **How can I take part in this research?**

If you are happy to be a part of the observational research, we would ask you to tick the YES box on the Consent Form, answer the rest of the questions, and return it in the envelope provided. If you decide to that you do not wish to take part, we would appreciate it if you could tick the NO box on the Consent Form and return this to us. If you do not want to participate in the research, you do not need to answer the rest of the questions on the consent form.

All information you provide to us will be treated in the strictest confidence, and will be kept in a locked filing cabinet without your names attached. All the results we gather will describe overall findings and not information about individual families. No video material will be shown to anyone outside of the project team, and will only be used for the purposes of our research. In the event of us wishing to show any video footage to anyone else (e.g., for teaching or training), we will ask for your consent in writing.

## **I have some further questions...**

If you wish to ask any further questions about any this additional study, please do not hesitate to contact us:

Chris Hill  
Special Needs and Families Research Project  
School of Psychology  
Brigantia Building  
University of Wales Bangor  
Bangor

Gwynedd  
LL59 2AS

Tel: 01248 388436  
Email: [pspc2b@bangor.ac.uk](mailto:pspc2b@bangor.ac.uk)

If you feel unhappy about the way this research is being conducted you are welcome to address unresolved complaints to:

Professor Fergus Lowe  
Head of School  
University of Wales Bangor  
Bangor  
Gwynedd  
LL59 2AS

Thank you for your time.

Yours sincerely

Chris Hill  
On behalf of the Special Needs and Families Research Project team

Appendix R  
Observation Study Consent Form

## CONSENT FORM

Code number (office use only):

### SPECIAL NEEDS AND FAMILIES RESEARCH PROJECT – OBSERVATION STUDY

**Name** (name of parent will already be printed here)

I would like to participate in the observation study YES/NO

If you want to participate, please complete the following and circle your answer:

I have read the letter that explains this observational research YES/NO

I have had the opportunity to ask questions and discuss this study YES/NO

I have received enough information about this study YES/NO

I understand that I am free to withdraw from this study:

...at any time

...without giving a reason for withdrawing

...without affecting any treatment I receive YES/NO

I am happy for interactions with my child to be videotaped YES/NO  
and understand that these recordings will be used for research  
purposes only and will not be shown to anyone outside of the  
research team unless my permission has been given in writing.

If you are to take part in the research, we will contact you to organise a visit. Please  
let us know if your address/telephone number change.

Thank you.

Please return this form in the envelope provided.

Appendix S  
Parent Instructions for Observations

## PARENT-CHILD GAMES

### 1) **Child's Game.**

Your child can play with whatever toy he/she chooses.  
You follow your child's lead.

### 2) **Parent's Game.**

You choose which toys your child plays with.  
Have your child play with several sets of toys.  
Have your child play according to **your** rules.

### 3) **Lego Task.**

We will explain this when it is time.

### 4) **Tidy-Up.**

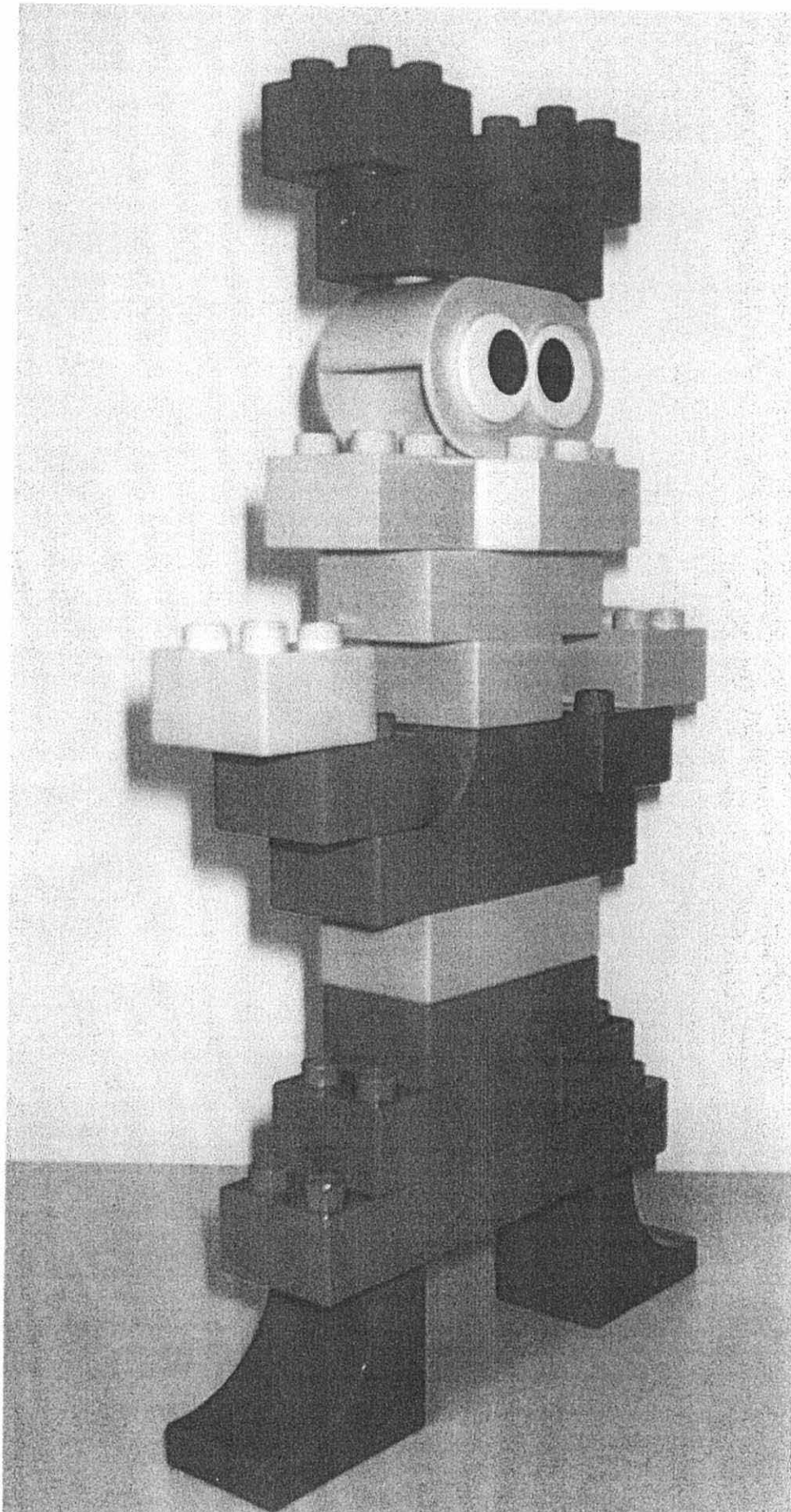
Have your child pick up **all** of the toys.

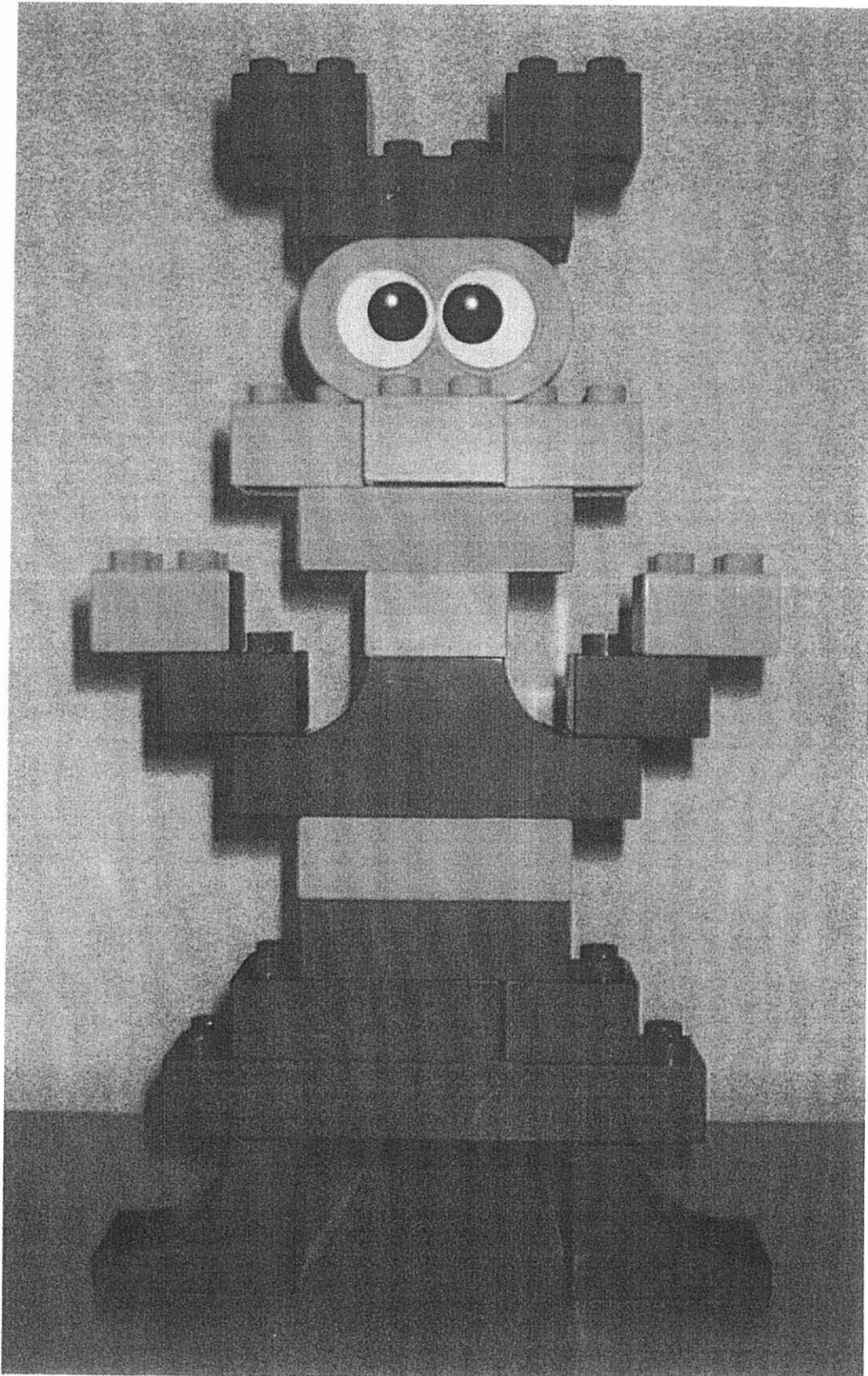
- Legos in the box.
- Crayons in the crayon box.
- Cars/trucks in the Lego box.
- Animals in the bag.

\*\*\*\*\*



Appendix T  
Photographs of Lego Task





Appendix U  
Behaviour Coding System Rating Form

FAST Track  
March, 1992  
(Revised January, 1993)

PCIT SCORE SHEET

Page \_\_\_\_

Task: CG  
PG  
LEGO  
CU

Child's ID: \_\_\_\_\_  
Interviewer ID: \_\_\_\_\_  
Date: \_\_\_\_/\_\_\_\_/\_\_\_\_  
Cohort Number: \_\_\_\_\_  
Site No: \_\_\_\_\_

|   |   |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |    |   |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
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ROW 1

C Command  
P Positive attention  
N Negative attention

ROW 2

C Compliance  
N Noncompliance

CIRCLE

✓ Disruptive child behavior  
○ Nondisruptive child behavior

Appendix V  
Interaction Rating Scale Rating Form

9  
FAST Track  
3/92

**PCIT  
INTERACTION RATING SCALES**

TCID: \_\_\_\_\_  
RATER: \_\_\_\_\_  
DATE: \_\_\_\_\_  
Site: \_\_\_\_\_  
Cohort: \_\_\_\_\_

**GRATIFICATION (M) & (C)**

| 1  | 2 | 3                                      | 4 | 5                               |
|--|---|--|---|---------------------------------|
| None,<br>negativity,<br>no positive<br>enjoyment |   | Some positive<br>enjoyment --<br>brief |   | Long<br>periods of<br>enjoyment |

**SENSITIVITY (M)**

| 1                         | 2 | 3                          | 4 | 5  |
|---------------------------|---|----------------------------|---|--|
| Intrusive,<br>out of sync |   | Okay, mixed<br>or variable |   | No intrusions,<br>tuned in to<br>child, good<br>rhythm |

**INVOLVEMENT (M)**

| 1   | 2 | 3   | 4 | 5   |
|---|---|---|---|---|
| Little interest in<br>child or his/her<br>activity. Self-occupied |   | Some joint<br>activity, some<br>self-occupation |   | Predominantly<br>engaged in<br>interactive<br>play/activity |

**INVOLVEMENT (C)**

| 1   | 2 | 3   | 4 | 5  |
|---|---|---|---|--|
| Little interest in<br>mother -<br>self-occupied |   | Some joint<br>activity, some<br>self-occupation |   | Actively seeks<br>maternal<br>attention,<br>predominately<br>engaged |

**CHILD'S GAME**

1. Gratification (M) \_\_\_\_\_
2. Gratification (C) \_\_\_\_\_
3. Sensitivity (M) \_\_\_\_\_
4. Involvement (M) \_\_\_\_\_
5. Involvement (C) \_\_\_\_\_

**PARENT'S GAME**

6. Gratification (M) \_\_\_\_\_
7. Gratification (C) \_\_\_\_\_
8. Involvement (M) \_\_\_\_\_
9. Involvement (C) \_\_\_\_\_

**LEGO TASK**

10. Gratification (M) \_\_\_\_\_
11. Gratification (C) \_\_\_\_\_
12. Sensitivity (M) \_\_\_\_\_
13. Involvement (M) \_\_\_\_\_
14. Involvement (C) \_\_\_\_\_

**CLEAN-UP**

15. Involvement (M) \_\_\_\_\_
16. Involvement (C) \_\_\_\_\_