

UNIVERSITY OF SOUTHAMPTON

Family Adjustment to Disability and Chronic Illness in Children

Ineke Martha Pit-ten Cate

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Department of Psychology

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**In loving memory of my parents**

**To Jeroen and Sophie (it's finished, let's go feed the ducks!)**

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF SOCIAL SCIENCE

PSYCHOLOGY

Doctor of Philosophy

**Family Adjustment to Disability and Chronic Illness in Children**

**By Ineke M. Pit-ten Cate**

The aims of this thesis were threefold. First a measure of perceived positive gain was developed. Second it tested a model of adjustment to disability on cross-sectional questionnaire data from samples of mothers of children with spina bifida and hydrocephalus (N=290) and mothers of children with asthma (N=73). The third aim was to investigate the effect of perceived positive gain on the disability-outcome relationship. The first set of studies focused on the development of a measure of perceived positive gain. The reliability and validity of the 7-item measure were acceptable. Interspersing these items with items of the Parenting Stress Index-Short Form (PSI-SF36) did not jeopardize the psychometric properties of this measure but rather added to its predictive and construct validity. The second set of studies focused on testing the transactional stress and coping model of adjustment to disability. Structural equation modelling procedures permitted the identification of indirect and direct effects. Results provided general support for the proposed model. As expected, the effect of illness parameters on parent adjustment, i.e. parenting stress, was mediated by parental adaptation processes, i.e. coping, caregiving efficacy and family satisfaction, and child adjustment, i.e. child behavioural problems. The model applied to both conditions, providing support for the non-categorical approach. The third set of studies focused on the effect of positive gain on the illness-outcome relationship. Multigroup analyses in structural equation modelling were used to detect differences between high and low gain groups. Results showed that perceived positive gain moderates the illness-outcome relationship such that the effect of illness on parental adjustment is less in mothers with higher positive gain scores. Limitations of the studies and implications for future research were discussed.

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## CHAPTER 1

### Stress, coping, and adjustment to disability

#### 1.1 Introduction

A crucial issue affecting the life of families with children with disabilities is the ability of these families to cope with stress. Caring for a child with a disability is a challenging task. Parents are at risk of experiencing stress as a result of physically and emotionally taxing situations associated with the child's disability, e.g. hospitalisations and daily hassles such as transportation problems. Research indicates that the prevalence of distress in these parents is significantly greater than that experienced by parents of non-disabled children (Carr, 1991; Kronenberger & Thompson, 1992b; Miller, Gordon, Daniele, & Diller, 1992; Singer & Irvin, 1989; Wallander et al., 1989b; Wallander, Pitt, & Mellins, 1990). Furthermore, the child with a disability is also at risk for elevated stress. The children may face stressful events not typically experienced by their healthy peers such as undergoing invasive medical treatments or not being able to go out because of incontinence problems or problems associated with wheelchair accessibility. Research shows that a significant number of children with disabilities experience secondary educational, psychiatric, family and social problems (Goodman & Graham, 1996; Rutter, Tizard, & Whitmore, 1970). In a review Lavigne and Faier-Routman (1992) concluded that children with physical disorders, especially children with sensory or neurological disorders, show an increased risk for psychological adjustment problems as well as decreased levels of self-esteem.

To provide professional help to these families in dealing with stressful situations and to prevent secondary psychosocial problems, it is necessary to obtain a better understanding of the processes that influence stress and its outcome. Coping is understood to be an important factor affecting the relationship between the occurrence of a stressful event and the outcome (Beresford, 1994; Lazarus & Folkman, 1984). Coping responses may also influence the person's future physical and psychological state and adaptation. The next few paragraphs will describe different models of stress and then apply

these to families with a child with a disability/chronic illness. Of special interest are the differences between families in coping with life stressors. Studying these differences can give insight in processes underlying (mal)adjustment. This is not only of interest for purposes of a theoretical nature, but for clinical purposes as well as it may facilitate support to these families and promote positive outcomes. Before moving on to the description of the models, it is important to define adaptation and adjustment. Both terms are frequently used in the stress and coping literature, sometimes interchangeably. In this thesis *adaptation* is defined as “the extent to which an individual can accommodate the demands of the stressful situation (e.g. find resources, change lifestyle)” and *adjustment* is defined as “psychological balance or freedom from abnormality in face of pathological circumstances” (Pless & Pinkerton, 1975, p6).

## 1.2 Models of stress

Stress can be conceptualised in different ways, based on different theoretical frameworks. Historically, two frameworks have been used to define stress: the life-events model and the response-oriented model (Lazarus, 1999). The life-events model focused on the stress-provoking event, i.e. the stressor, whilst 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 model assumed that there were easily identifiable events that were likely to cause stress, e.g. the death of a spouse or undergoing surgery. 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) illustrates how the model was applied in research. The scale was developed to evaluate the type and magnitude of life events associated with the onset of disease and illness. Subjects were asked to rate a series of 43 common life events as to their relative degrees of necessary adaptations. The 43 items were then ranked and given a mean value according to the amount of effort needed to deal with them. For example, the death of a close family member had a mean value of 63 and was ranked at the top end, whilst a vacation had a mean value of 13 and was ranked at the lower end of the scale. It is interesting to note that both negatively

and positively natured life events can make adaptation demands. The Social Readjustment Rating Scale has been used in several studies and continues to be used (e.g. Naldi, Peli, Parazzini, & Carrel, 2001). Subjects were typically asked to indicate which life events on the list have occurred over the last year. The amount of stress was computed by adding the mean values of the events. Data suggested that high stress scores predispose people to illness roughly 6 months later, although correlations are typically low (.3 or less) and may therefore be of limited practical value (Lazarus, 1999).

The response-oriented model defined stress based on the nature of a person's response to a situation. A situation was valued stressful when certain physiological or psychological reactions are noticed, e.g. sweating or if a person is tense or anxious. The work of Selye (1976) demonstrated this response approach. He described how the body responds when faced with a stressful encounter, which can be either physiological or psychological. The response process, which he referred to as the General Adaptation Syndrome (GAS), develops in three phases. Firstly, there is an alarm reaction. This is followed by a second phase, resistance, when the stress continues and the body is mobilised to defend itself. The nervous and endocrine systems play an important part in maintaining resistance during stress. They help to keep the structure and function of the body steady despite exposure to stress producing factors, i.e. help to maintain the homeostatic balance of the body. The third phase, exhaustion, occurs when the stress is so severe that bodily resources begin to fail. Mostly the body will successfully defend itself against the threat and the third phase is not reached. However when the stress is very severe and continues long enough, the struggle can weaken the organism to an extent that it cannot longer sustain itself and dies. Similar to the life-events model, the response model also acknowledges that both positive (eustress) and negative (distress) events can trigger the GAS response. This physiological-based approach is still recognised in studies of stress and coping, for example when measures of hormones (i.e. cortisol) or cardiovascular reactivity are used as indicators of stress (e.g. Matthews, Woodall, & Stoney, 1990).

Both models had shortcomings. A first limitation of the life-events model was that it has proven difficult to design a list including all possible life events. A limitation of the response-oriented model was that it was difficult to determine

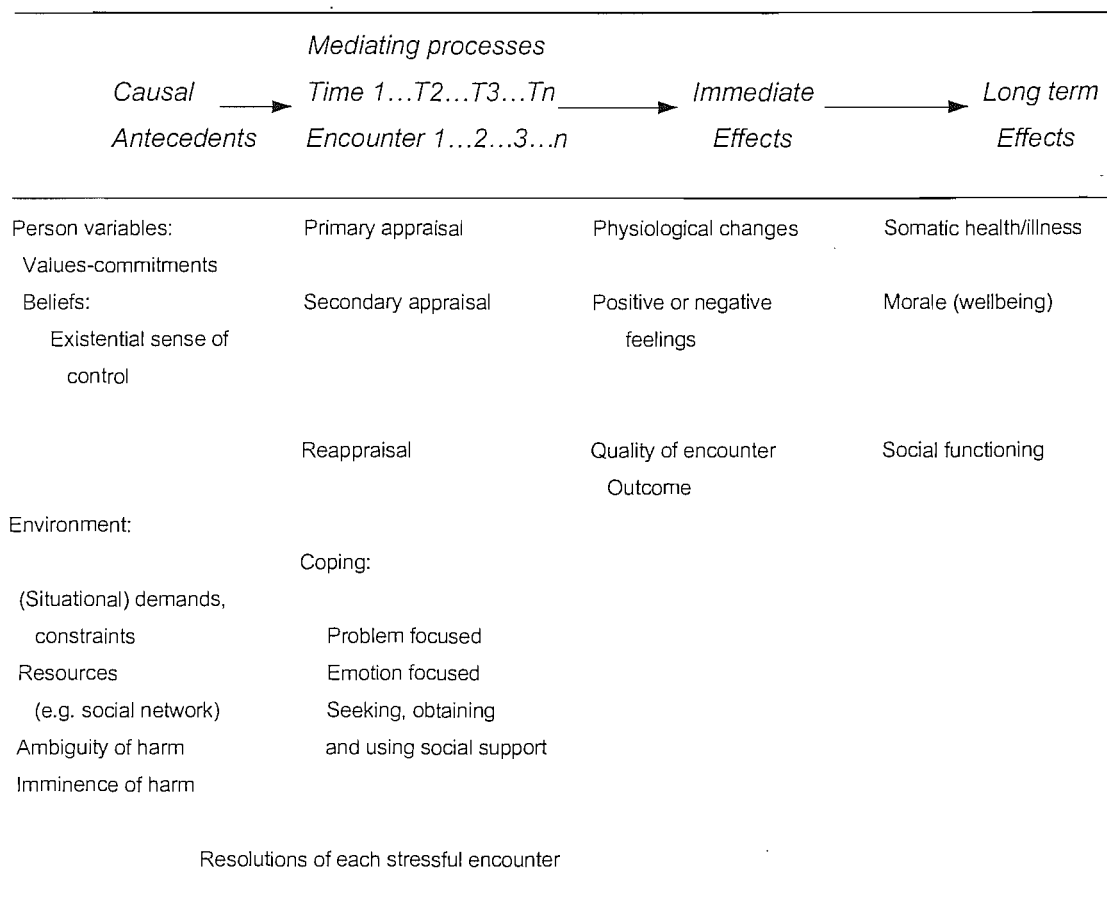
the relationship between stressors and responses. Neither model accounted for individual differences, i.e. what one person may perceive as stressful, another may not consider stressful at all. Furthermore, the models did not consider that the relationship between stressors and responses could be mediated / moderated by other variables such as cognitive appraisal. Finally, both models focused on negative outcome of stress only. They did not take into account that some people see stressors as challenges, which ultimately can result in positive outcomes, e.g. personal growth.

In response to the shortcomings of above described models, Lazarus and Folkman (1984) proposed a transactional model. This model emphasises the relationship between the person and the environment, i.e. 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 functional and dysfunctional ways of dealing with stress.

The cognitive behavioural model of stress (Lazarus & Folkman, 1984) is based on the transactional perspective. This stress and coping model suggests that distress is the result of the interaction of a stressful event (stressor), personal resources, cognitive appraisal of the event, and coping responses (see Figure 1), thereby emphasising the active role of an individual in dealing with a stressor. Cognitive appraisal is understood as the process through which an event is evaluated. 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). Specific coping strategies serve to manage or alter the source of stress (problem focused coping) or to regulate stressful emotions (emotion focused coping). According to this process model of stress and coping, appraisal is mediated by situational and personal factors. In addition coping mediates the effects of stress on an individual's well-being (Beresford, 1994; Lazarus & Folkman, 1984). Successful coping, i.e. coping resulting in

adjustment, is a result of a match between appraisal and coping strategy rather than of the relative efficacy of one strategy over another (Folkman, Lazarus, Dunkelshetter, DeLongis, & Gruen, 1986).

Figure 1: A theoretical schematisation of stress, coping and adjustment (From (Lazarus & Folkman, 1984, p305).



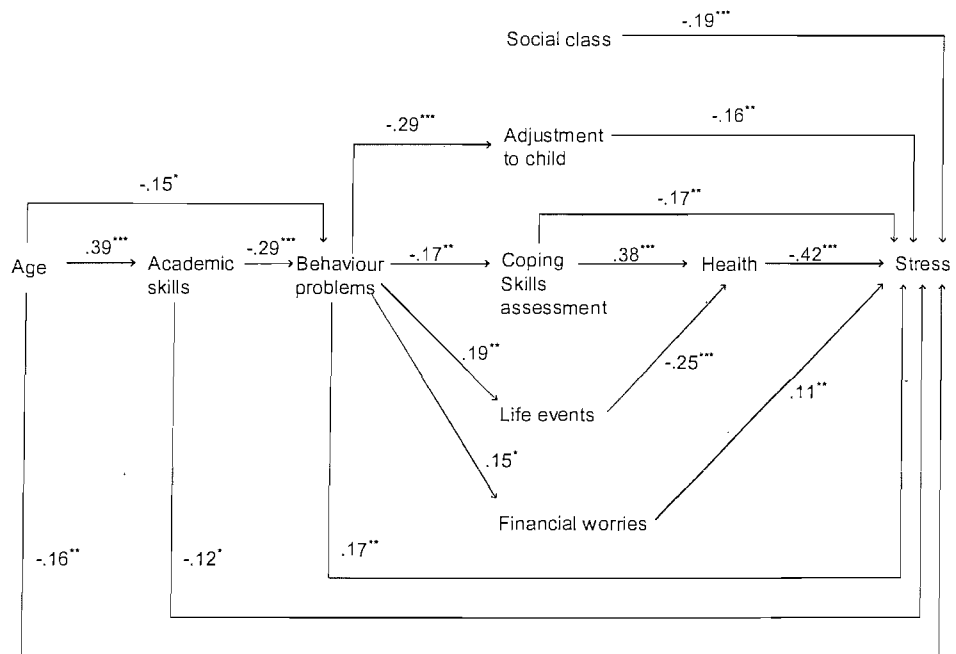
Although Figure 1 does not account for the study of *processes* as proposed in the cognitive behavioural model of stress, Lazarus has emphasised repeatedly that coping should be considered a process, the study of which should be carried out at different stages of a stressful encounter or in different encounters to detect patterns for individuals (intra-individual) or groups of individuals (inter-individual) (Lazarus, 1999; Lazarus & Folkman, 1984).

The way in which coping has been defined in the cognitive behavioural model of stress may lead to some confusion over the effect it has on the relationship between the stressful encounter and adjustment outcome, i.e. is

coping a mediator or a moderator? Lazarus defines coping in the model as a mediator '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 the above 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 (1986) this 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).

Quine and Pahl (1991) tested the model in a sample of mothers of children with severe learning disabilities, e.g. 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 mother' distress could be explained by child variables and coping resources. Results provided support for the transactional stress and coping model as coping 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) further used path analyses to plot the effects of child characteristics and coping resources on maternal stress. The beta coefficients reflect the strength of the associations between variables (Figure 2). The diagram illustrates direct effects of most variables on maternal stress as well as mediating effects of academic skills, behaviour problems, adjustment to child, coping, health, financial worries and life events.

Figure 2: A path model of stress scores (From Quine & Pahl, 1991, p 66)



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 earlier stress models. However the model has received some criticism as well. For example, Hobfall (as cited in Aldwin, 2000) criticised the emphasis the model puts on the role of subjective appraisals. Although the personal cognitive processes may be very important in stress experiences, other more objective factors may contribute as well. 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, e.g. if a person is still dealing with an actual event it is hard to estimate what the outcome will be. For example, 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, not least in the area of adjustment to disability and chronic illness (see paragraph 2.3).

It is important to note that the models discussed so far operate on the level of the individual. This is in contrast to the more family based models. For example, the double ABCX model (McCubbin & Patterson, 1983) accommodates the notion of family coping. In the ABCX model, family resources (B) and the family's appraisal of the situation (C) determine the family response (X) to a stressful situation (A). In the double ABCX model, the stressful situation (A) reflects an accumulation of experiences, e.g. the chronicity of the child's disability or illness has an accumulative effect on the stressor (A), to which the family repeatedly needs to adapt (Cherry, 1989). Evaluation of the double ABCX model using path analyses revealed a linear chain following the ACBX path in families of children with mental retardation (Orr, Cameron, & Day, 1991). This finding is in line with the cognitive behavioural model of stress (Lazarus & Folkman, 1984), that is, the effectiveness of resources (B) in reducing stress (X) is dependent on the family's appraisal of the child's needs (C). Other examples of family models include the Circumplex model of marital and family systems (Olson, Russell, & Sprenkle, 1983) and models of stress, coping and family ecology (Crnic, Friedrich, & Greenberg, 1983). Although these family models are helpful in gaining a better understanding of the dynamics of family life and the ways in which families react in times of stress, they are limited in that they do not take into account intrapersonal variables or socio-ecological factors external to the family that may mediate the stress-adjustment relationship.

### 1.3 Models of stress and adjustment to disability

Several models have emerged to conceptualise adjustment to disability and chronic illness. Initially the models focused mainly on parental (maternal)

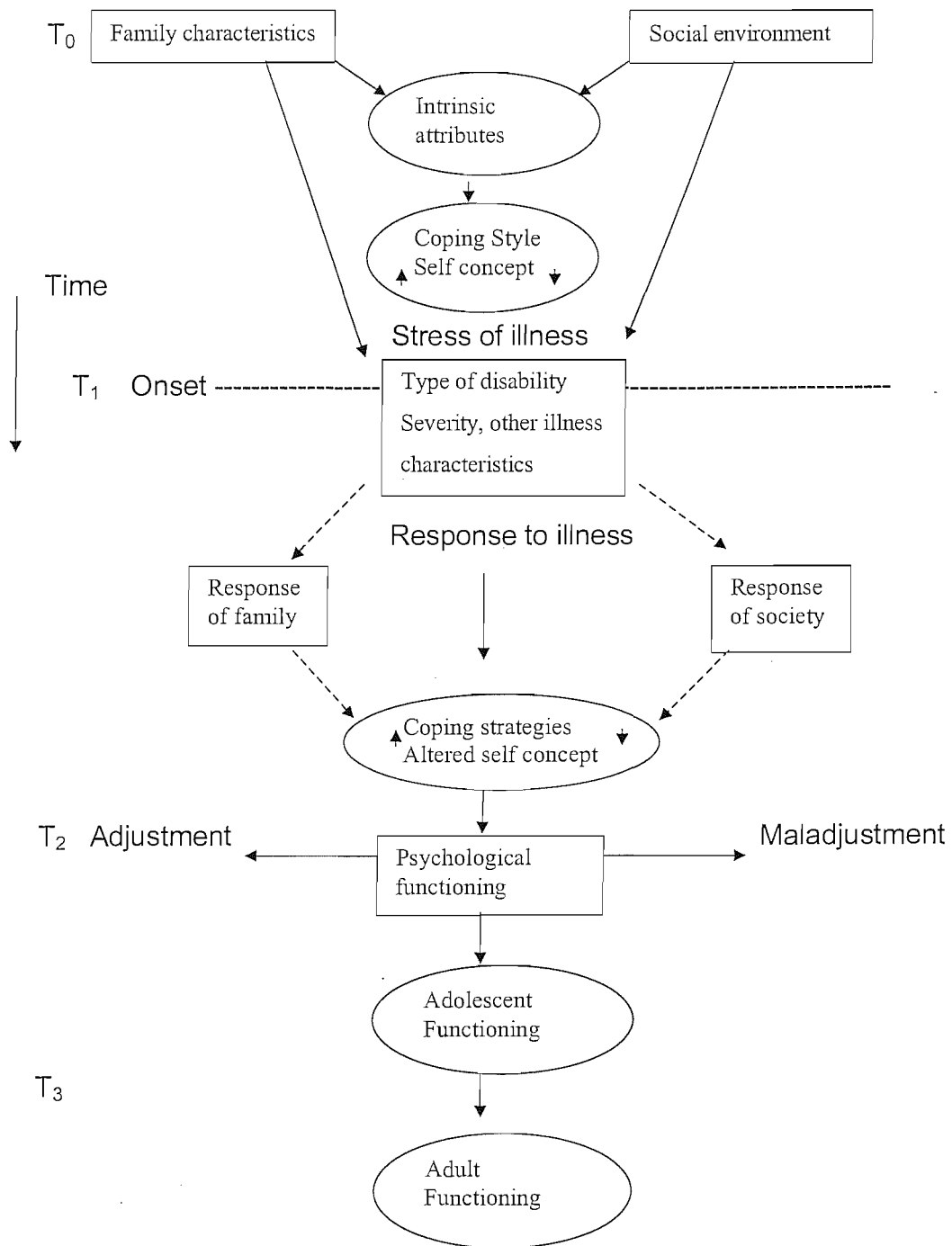


adjustment but more recently the models have incorporated the adjustment of the child with a disability itself. The models have a few conceptual components in common. First, they all recognise an illness or disability as a potential stressor. Second, they emphasise the role of psychological processes in adjustment outcome. And third, adjustment is viewed as a result of transactions between a person and his/her environment.

### 1.3.1 An integrated model of adjustment

Pless and Pinkerton (1975) developed one of the first models incorporating the role of psychological processes in adjustment to illness and disability (Figure 3). In this model adjustment is considered both a continuous and reciprocal process. The process is continuous as it assumes that earlier transactions have a cumulative effect on current psychological functioning, i.e. functioning in early childhood can, at least to a certain extent, predict functioning later on in life. Reciprocity is reflected by 'feedback loops', whereby the way a person functions influences other people's responses, which in turn influences future functioning. An example of a feedback loop, indicated by dotted arrow lines, is illustrated in Figure 3. The model emphasises the importance of coping style and self-concept in the process of adaptation. Both coping and self-concept are influenced by intrinsic attributes, e.g. temperament, as well as family and environmental characteristics. A person's response to stress associated with illness or disability is to a great extent determined by a person's coping style and self-concept. However, the nature of the disability, reactions of significant others and the person's own reaction to the disability are considered as mediating factors (Pless & Pinkerton, 1975).

Figure 3: An integrated model of adjustment (From Pless & Pinkerton, 1975, p31)



Pless and Pinkerton illustrated the application of the model by describing three large populations surveys: The National Survey of Child Health and Development, a longitudinal study of a representative national sample of all children born in England, Wales and Scotland in a particular week in March 1946 (Pless and Douglas, 1971 as cited in Pless & Pinkerton, 1975); The Isle of

Wight Survey, an extensive epidemiological survey including both physically and learning disabled children (Rutter et al., 1970) ; and the Rochester Child Health Studies, a study involving a 1% random sample of all families with children under 18 years residing in Monroe county, New York State (Pless & Roughman, 1971 as cited in Pless & Pinkerton, 1975).

The data from these 3 large survey studies provided support for the model to the extent that the frequency of secondary psychosocial consequences was predicted by the illness/disability of the children. For example in the Isle of Wight study 17% of the children with chronic illness had psychiatric disturbance compared to only 7% of the children in the control group. In addition, analyses of the data from the Rochester Child Health studies showed that family function and family structure predict an additional amount of the variance in child adjustment over and above chronic illness, supporting the notion that the family plays an important role in child adjustment to disability.

It should be noted that these studies only partially support the model. Results of the studies confirm the relationship between disability and secondary psychosocial consequences and provide support for the importance of family functioning and family structure in predicting adjustment outcome. However, more research is needed to establish the role of self-concept and coping strategies in the process of adaptation. Also the extent to which reciprocal processes account for variation in adjustment outcomes needs to be investigated further.

### 1.3.2 The life crisis model

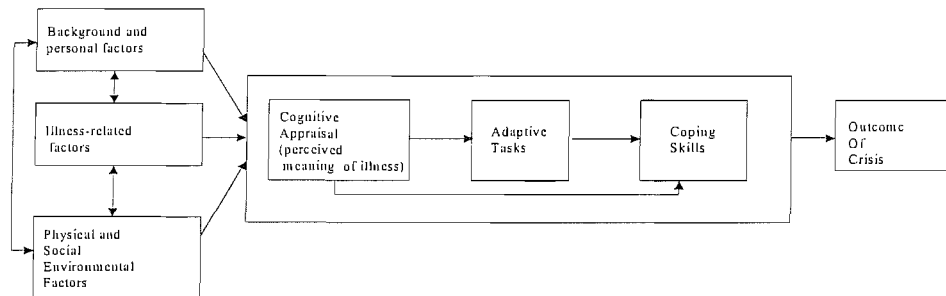
The life crisis model (Moos & Schaefer, 1984) perceives chronic illness as a life crisis. According to the life crisis model, illness factors, background and personal characteristics, physical and social environmental factors determine the response to an illness or disability. The model follows from the cognitive behavioural model of stress (Lazarus & Folkman, 1984), in that the relationship between crisis and adjustment is mediated by appraisal and coping. In other words, the effect of illness factors, background and personal characteristics, physical and social environmental factors ('risk factors') is mediated by the 'appraisal - tasks setting - coping' process ('resistance factors'). A person's

cognitive appraisal of the crisis, i.e. illness, results in a set of 'adaptive tasks' to which coping strategies can be applied (see Figure 4).

Moos and Schaefer (1984) define seven categories of adaptive tasks, three of which are illness related and four are more general and apply to all types of life crisis. The three illness related adaptive tasks include: 1) dealing with pain, incapacitation and other symptoms, 2) dealing with the hospital environment and special treatment procedures, and 3) developing and maintaining adequate relationships with health care staff. The general adaptive tasks include: 1) preserving a reasonable emotional state, 2) preserving a satisfactory self-image and maintaining a sense of competence and mastery, 3) sustaining relationships with family and friends, and 4) preparing for an uncertain future. Coping strategies are defined as the ways in which these adaptation tasks are addressed. Coping strategies are organized in three domains: 1) appraisal focused coping, 2) problem focused coping, and 3) emotion focused coping. Appraisal focused coping refers to attempts to understand and find meaning in a crisis, such as logical analysis and cognitive redefinition. Problem focused coping refers to attempts to confront the reality of a crisis by dealing with its consequences, e.g. seeking information and support and taking problem solving action. Finally emotion focused coping refers to attempts to manage the emotions associated with a crisis such as emotional discharge and affective regulation.

The model has been applied in several studies (e.g. Daniels, Moos, Billings, & Miller, 1987; Timko, Stovel, & Moos, 1992). For example, Timko, et al. (1992) in a longitudinal design examined parental adaptation to their child's juvenile rheumatic disease. Results showed that parental adjustment was partly explained by illness-related factors including functional disability, pain and psychosocial functioning, as well as by poor adjustment of the spouse. In addition, parental coping mediated between illness and adjustment outcome as measured by depressed mood, social activities, personal strain and mastery. For both parents more use of problem focused coping was associated with better adjustment outcome (more social activity) whereas more use of emotion focused coping was associated with poorer outcome (more depression and personal strain).

Figure 4: A conceptual model for understanding the crisis of physical illness  
 (From Moos & Schaefer, 1984, p19)



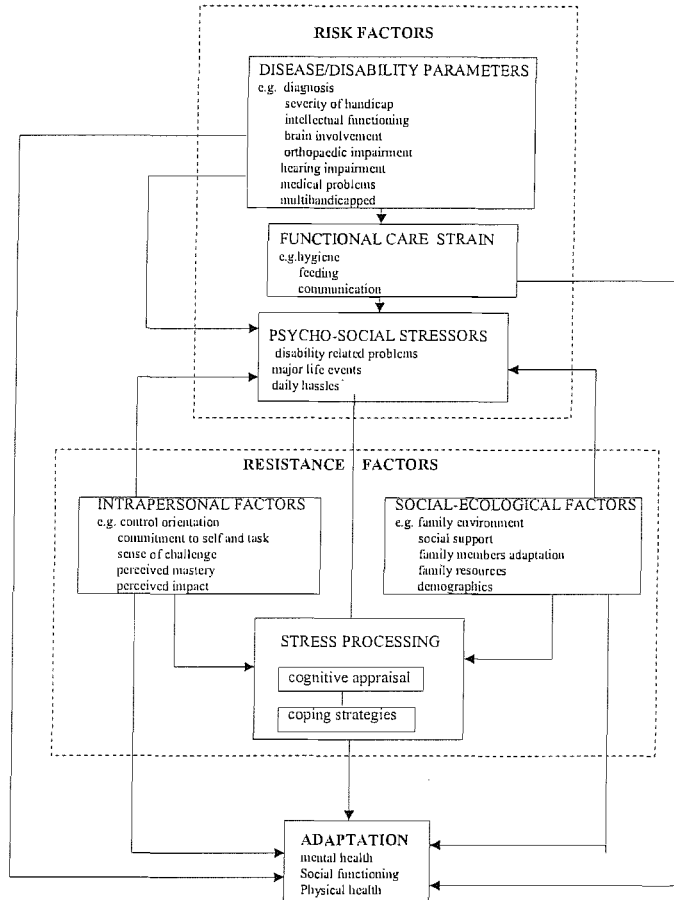
### 1.3.3 The disability-stress-coping model

The disability-stress-coping model (Wallander et al., 1989b; Wallander & Varni, 1992) incorporates notions put forward by Pless and Pinkerton (1975), Moos and Schaefer (1984) and Lazarus & Folkman (1984) and defines parental adjustment to their child's disability in terms of the balance between risk and resistance factors. Risk factors, i.e. sources of stress, include disability parameters, associated functional limitations and psychosocial problems. Resistance factors, i.e. resources, include intra-personal factors, stress processing (appraisal and coping) and social-ecological factors. In the model, resistance factors moderate the impact of the risk factors on adjustment, i.e. mental health, social functioning and physical health. Both risk and resistance factors have direct and indirect effects on adjustment. Disability parameters directly effect adjustment, but there is also an indirect effect via increased levels of functional care strain and psychosocial stress. For example, if the child's inability to walk is caused by a condition that affects the brain, e.g. hydrocephalus, it is possible that this brain involvement also affects behaviour and emotion. Alternatively, a condition that causes incontinence, such as spina bifida, may cause social stressors, which in turn may affect adjustment. Similarly, intra-personal factors and social-ecological factors have direct effects on adjustment as well as indirect effects via both psychosocial stressors and

stress processing. The direct and indirect pathways reflect the ongoing interaction between individual and family variables and their environmental context (see Figure 5).

Wallander and Varni (1992) have applied the model to a variety of conditions, including cerebral palsy, spina bifida, limb deficiency, and general physical and sensory disabilities. The model has also been used in studies involving children with cancer, emotional disturbance and mental retardation. In a review of this research Wallander and Varni (1992) conclude that the model is applicable and useful to study adjustment to a variety of chronic physical disorders. They further conclude that not the medical or physical status itself but rather the psychosocial processes are helpful in explaining adjustment. The most important resistance factors identified include family resources and social support. They state that more research is needed especially research involving larger sample sizes, follow longitudinal designs and use independent and objective measurement. Also, alternative conceptual models should be entertained (Wallander & Varni, 1992, p295).

Figure 5: Conceptual model for research on mothers of physically handicapped children (From Wallander et al., 1989b).



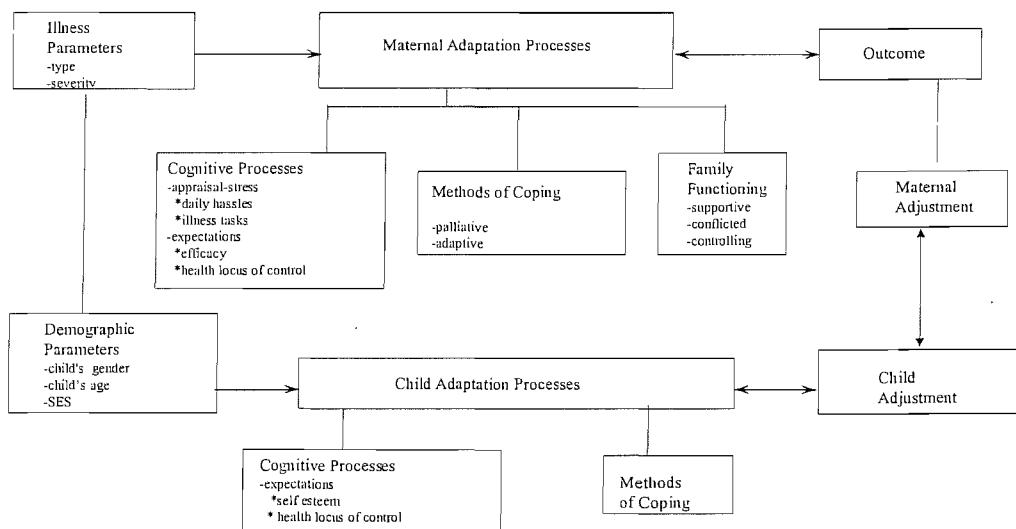
### 1.3.4 The transactional stress and coping model of adjustment to disability

Finally, the transactional stress and coping model of adjustment to disability (Thompson et al., 1993a; Thompson, Gil, Burbach, & Keith, 1993b; Thompson, Gustafson, George, & Spock, 1994) also views the disability as a potential stressor, i.e. risk factor, to which individuals and the family as a whole adapt as a function of their resources. However, the model differs from the disability-stress-coping model in that it attempts to incorporate the ecological-systems theory (Bronfenbrenner, 1977) by emphasising that the levels of stress and adjustment experienced by other family members mediate the psychological adjustment of an individual. Adjustment is therefore defined as a

function of the adjustment of individual family members and their interrelationships (Figure 6).

As illustrated in Figure 6, disability/chronic illness is perceived as a potential stressor to which both the child and the family need to adjust. Adaptation processes mediate the relationship between illness parameters and adjustment. The processes of adaptation include the cognitive processes of appraisal of stress, expectations of locus of control and efficacy, coping and family functioning. Furthermore, the model incorporates the notion of family adaptation as parent- and child adjustment mutually affect each other.

Figure 6: Conceptual transactional stress and coping model for chronic childhood illness (From Thompson et al., 1994)



Thompson and his research group have applied this model to a variety of studies involving children with cystic fibrosis, sickle-cell disease, spina bifida and muscular dystrophy (e.g. Thompson, Gil, Abrams, & Phillips, 1992a; Thompson et al., 1993a; Thompson, Gustafson, Gil, Kinney, & Spock, 1999; Thompson, Gustafson, Hamlett, & Spock, 1992b; Thompson, Zeman, Fanurik, & Sirotkin, 1992c). Results of these studies typically indicate that illness parameters, coping and family functioning explain a significant proportion of variance in both mother's and children's adjustment outcomes. Although support



for the associations between the variables is provided by these studies, they fail to establish causal links between the variables.

The described models are comprehensive and sophisticated, however, they are mostly descriptive of the factors and processes found to impact adjustment, rather than explanatory. It may be helpful to review the extent to which these models have been empirically tested such that causality could be inferred as such evaluation may help decide the relative standing of these models. Three criteria need to be fulfilled to infer causality (Mitchell & Jolley, 2004):

- 1) Co-variation: changes in the independent variable result in changes in the dependent variable, e.g. parent's using more problem focused coping strategies have fewer adjustment problems. Co-variation can be established by estimating the level of correspondence between variations in the dependent and independent variable, e.g. problems focused coping and adjustment.
- 2) Temporal precedence: the change in the independent variable occurs before the change in the dependent variable, e.g. parent adjustment problems only arise after child with disability is born. Temporal precedence can be established in a longitudinal design or randomized experiment. 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, for example variance in parent adjustment at time 2 can be explained by illness characteristics at time 1. 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. For example, adjustment problems decrease after parents receive training in coping skills.
- 3) 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, e.g. parent adjustment problems are a result of the child's disability and not due to other factors, such as housing problems. Spuriousness is established by ensuring other factors

remain constant whilst studying the effect of the independent variable on the dependent variable. Although this may seem an impossible 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. In the data analysis the effect of the irrelevant factors can then be estimated (type 1 error).

The longitudinal studies to test the integrated model of adjustment (Pless & Pinkerton, 1975), revealed not only co-variation of independent (e.g. chronic illness) and dependent (e.g. psychiatric disturbance) variables, but also temporal precedence. In addition the effect of independent variables (e.g. family functioning) on the dependent variable (child adjustment) was estimated controlling for other variables (e.g. illness), battling spuriousness. Therefore causal inferences could be made regarding the relationship between illness and adjustment outcome, i.e. illness parameters can cause adjustment problems in children. Similarly, the life crisis model (Moos & Schaefer, 1997) was tested in a longitudinal study, establishing causal links between illness parameters and parent adaptation. Unfortunately neither the disability-stress-coping model (Wallander et al, 1986) nor the transactional stress and coping model of adjustment to disability (Thompson et al 1993a) have been tested using longitudinal design or randomized experiments, i.e. all research has been cross-sectional. Therefore, the criterion of temporal precedence cannot be fulfilled and causality not be inferred.

The described models all recognise that childhood illness can act as a stressor to which family members have to adapt. They all distinguish factors that may affect this adaptation process, such as resources and coping. The level of adjustment outcomes typically indicates the success of the adaptation process. The models differ however in the factors they specify as mediating the relationship between illness and adjustment outcome. For example the disability-stress-coping model (Wallander et al., 1989b; Wallander & Varni, 1992) specifies stress-processing factors, i.e. cognitive appraisal and coping strategies as mediators whereas the transactional stress and coping model defines cognitive processes, methods of coping and family functioning. Although

family functioning is acknowledged in the disability stress as affecting stress processing it is not represented to mediate the illness-adjustment relationship. Another issue that needs to be clarified in order to decide which model may be best is the difference between mediation and moderation. A mediator specifies how a given effects occurs, whilst a moderator specifies the conditions under which the effect occurs and the conditions under which the direction of the effect vary (Baron & Kenny, 1986). In the description of the models the distinction between mediation and moderation is not always clear. For example, the transactional stress and coping model uses the term mediator to describe the impact of coping, whilst it is hypothesised that coping acts as a buffer between illness and adjustment outcome, i.e. acts as a moderator. Similarly in the disability-stress-coping model stress processing factors are portrayed as mediators whilst Wallander, Feldman and Varni (1989a) describe that the impact of the effect of the child's physical disorder on individual adjustment is moderated by a variety of resistance factors including social ecological, intrapersonal and stress processing factors.

Research is needed to test the different models of mediation to ultimately decide which model best represents the data. Although current literature supports the existence of associations between illness variables, adaptive factors and adjustment outcomes, specific tests of mediation or moderation (Baron & Kenny, 1986) are not discussed. Nevertheless these models have contributed significantly to the field by stimulating research identifying the processes associated with psychological adjustment to disability.

#### 1.4 Adjustment to disability / chronic illness - Research findings

There is considerable literature on family adjustment after the birth of a child with a disability. The initial response process to the birth of a child with a disability evolves in 5 stages: shock, denial, sadness/anger/anxiety, adaptation and reorganisation (Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975). Research on family adjustment during school age years is less extensive and most research has focused on parental outcome rather than family outcome. The next sections will describe research involving children with physical disabilities or chronic illnesses and their parents. Chronic illness refers to a physical condition

that may impair health status or psychological functioning, e.g. diabetes, asthma and juvenile arthritis. Physical disability refers to reductions in a person's ability to perform basic tasks resulting from physical impairments, i.e. abnormalities in body or organ structures and functions, e.g. spina bifida, cerebral palsy, and muscular dystrophy.

#### 1.4.1 Parent research:

Results of several studies support the notion that parents of children with disabilities experience higher level of stress compared to parents caring for non-disabled children. (e.g. Miller et al., 1992; Singer & Irvin, 1989). Most studies in this area reveal associations between stressors, psychological processes and adjustment outcome. For example, in a study involving 116 mothers of a child with spina bifida or cerebral palsy a strong association was found between a mother's appraisal of stress related to disability and maternal maladjustment. Perceptions of competence in problem solving were associated with better adjustment (Noojin & Wallander, 1997). Similarly, Wanamaker and Glenwick (1998) found that stress in mothers of pre-schoolers with cerebral palsy was associated with social support and perceptions of parenting satisfaction and efficacy. More specifically, higher levels of social support and parenting competence were associated with decreased levels of parenting stress. In a longitudinal study involving mothers of children with various disabilities results showed no significant differences between disability groups over time. However, analyses for each of the 3 assessments separately, revealed that mothers of children with neurological impairments, i.e. spina bifida, hydrocephalus, cerebral palsy, and developmental delays, consistently reported higher levels of parenting stress than mothers of children with Down's syndrome and hearing impairments. Increased levels of parenting stress in all three groups were associated with lower levels of parenting satisfaction and social support (Hanson & Hanline, 1990).

Thompson and his group conducted several studies involving parents of children with chronic physical illness, i.e. cystic fibrosis, sickle cell disease and muscular dystrophy (Thompson & Gustafson, 1996a; Thompson et al., 1992a; Thompson, Gil, Gustafson, & George, 1994; Thompson et al., 1992b; Thompson et al., 1992c). Results of these studies typically reveal that illness

parameters and demographic variables account for only a small portion of the variance in maternal distress (approximately 10-20%). Psychosocial/mediation variables, such as appraisal of illness related hassles, use of palliative coping and levels of family supportiveness, made significant independent contributions to maternal adjustment, i.e. these variables accounted for up to 60% of the variance in maternal distress. Findings consistently reveal that higher levels of illness-related stress, lower levels of family supportiveness and greater use of palliative coping were associated with higher levels of maternal distress.

Several studies have focused on coping as an important factor affecting the illness-outcome relationship (e.g. Barakat & Linney, 1995; Blankfeld & Holahan, 1996; Boyer & Barakat, 1996; Davis, Brown, Bakeman, & Campbell, 1998). Although Folkman et al (1986) suggested that successful coping is a result of a match between appraisal and coping strategy rather than of the relative efficacy of one strategy over another, the use of problem focused coping has been associated with better adjustment outcomes whilst the use of emotion focused coping has been linked to poorer outcomes. In a review Beresford (1994) outlines research related to coping resources and coping strategies adopted by parents to manage the daily stresses and chronic strains associated with raising a child with a disability. She concludes that problem focused coping strategies, such as planning, problem solving and information seeking, are consistently associated with better adjustment outcomes. Findings regarding the use of emotion focused coping are more unequivocal, however in most studies using quantitative measures of coping, emotion focused coping was found to be maladaptive. One problem focused coping strategy, seeking information, was further investigated by Pain (1999). In a study involving parents of children with learning and physical disabilities, results revealed that information about the child's condition enabled parents to access services, helped parents in managing the child's behaviour and facilitated emotional adjustment to disability (Pain, 1999).

Most studies in this area have focused on disability parameters in predicting parent adjustment outcomes. However, the transactional stress and coping model of adjustment to disability proposes that child adjustment also affects parent adjustment. The importance of this notion is illustrated by findings of Floyd and Gallagher (1997). They conducted a study to evaluate the effects

of child disability status (mental retardation, chronic illness, no disability) and child behaviour problems on parental stress and care demands associated with disabilities. Results showed not only high prevalence rates of behaviour problems in children with disabilities, but also that the presence of significant behaviour problems was more important than disability type in determining parental stress (Floyd & Gallagher, 1997).

#### 1.4.2 Research involving the child with a disability /chronic illness

In a meta analytic review, Lavigne and Faier-Routman (1992) concluded that children with physical disorders, especially children with sensory or neurological disorders, show increased risk for psychological adjustment problems as well as decreased levels of self-esteem. In contrast, Boekaerts and Roder (1999) concluded that the incidence of maladjustment in children with a chronic disease varies across studies and illness, and that children with a chronic illness generally do not show lower school performance and have similar self-esteem compared to healthy children. Differences in research findings may in part be explained by differences in emphasis on commonalities across illnesses (non-categorical approach) or differences between illness categories (categorical approach). Therefore, it has been suggested that research evaluating the effects of chronic illness on children and families should control for the common factors when attributing effects to individual disease states (Holden, Chmielewski, Nelson, Kager, & Foltz, 1997). In addition, methodological differences, such as the use of different informants across studies may also affect research findings.

Several studies support the notion that children with chronic illness show more psychosocial problems (e.g. Cadman, Boyle, Szatmari, & Offord, 1987; Floyd & Gallagher, 1997; Rutter et al., 1970; Wallander et al., 1989a; Wallander & Vami, 1989). Wallander et al. (1989a) estimated that the incidence of clinical maladjustment among children with chronic illness or disabilities is at least twice that expected for children in general. Rutter et al. (1970) found that 30% of the children with disabilities in their study had educational, psychiatric, family and social problems despite the fact that they had received adequate medical care. In a study involving a large sample of children with hemiplegia, psychiatric disorders were quite common, even among the mildly affected children

(Goodman & Graham, 1996). In a follow up survey, these psychiatric problems proved not only common but also persistent (Goodman, 1998), stressing the vulnerability of these children in developing secondary problems.

Contradictory findings have been reported regarding the relationship between severity of condition and adjustment outcome. For example Cadman et al. (1987) reported that severity of condition affected psychosocial adjustment in children with chronic illness and physical disability, whilst Tew and Laurence (1985) reported that elevated levels of adjustment problems in children with spina bifida were not related to severity. Similarly mothers of children with spina bifida reported significantly more behavioural and social competence problems than expected for children in the general population irrespective of the severity of the condition (Wallander et al., 1989a). Stein & Jessop (1984) reported that in children with chronic illness including respiratory conditions, conditions involving the central nervous system, renal problems, endocrine/metabolic disorders, haematological conditions and musculoskeletal disorders, psychological adjustment outcome was related to some but not all measures of health status. Children who had missed more days in school and had more problems performing age-appropriate roles and tasks had poorer psychological adjustment outcomes. The number of days the child spent in bed or in hospital was not related with adjustment outcomes.

Several studies have explored the relationship between parental adaptation and adjustment and the well-being of other family members, i.e. the child with a disability or siblings. However, this research has either been restricted to specific illness groups, or to certain events (e.g. hospitalisation, surgery) (see Beresford, 1994; Drotar, 1997 for a review). For example, in a study involving 100 children with physical disabilities admitted for orthopaedic procedures, children of parents who had more difficulty in accepting and adjusting to their children's disability exhibited more difficulty accepting their own condition, as manifested by loss of interest, self-reproach, suicidal ideation and depression (Kashani, Venzke, & Millar, 1981). Similarly, children with juvenile rheumatic diseases and their siblings experienced more psychological and physical problems when their parents suffered from depression or other medical conditions. Yet, adjustment of both the child with the disease and the sibling was facilitated by family cohesion and open communication (Daniels et al., 1987).

Research investigating family functioning and child adaptation is sparse. However, in a longitudinal study involving children with spina bifida and a healthy comparison group a relationship between parenting behaviours and children's use of problem focused coping strategies was reported. Specifically, higher levels of parental responsiveness and family cohesiveness were associated with the use of more problem focused coping strategies in children with and without health problems (McKernon et al., 2001).

Results of a study involving families of children with various chronic health conditions showed that family composition moderated the relationship between health status and adjustment outcome, i.e. the impact of health status on adjustment outcome was weaker for children living with both biological parents than for children living with their mothers and another adult, e.g. new partner (Stein & Jessop, 1984). Similar results were reported for a sample including children with asthma, sickle cell anaemia, epilepsy, congenital heart disease, cleft lip or palate, endocrine disorders and cancer (Silver, Stein, & Dadds, 1996). More specifically, the relationship between the severity of the chronic illness and children's psychological adjustment was stronger in children living with their mother and an unrelated adult partner than in children living with both biological parents or the mother and a related adult (e.g. grandmother).

Although research findings have consistently linked more adaptive family relationships and parental psychological adjustment with positive child psychological adjustment in children with chronic illness, research progress would be enhanced by prospective analyses that clarify specific causal pathways between family functioning and children's adjustment (Drotar, 1997).

## 1.5 Conclusion

Based on the described conceptual models of stress and research findings, the impact of a child's disability on the family may be best conceptualised as a risk factor, the significance of which is mediated/moderated by socio-demographic features, individual and family adaptive and functional patterns, and disability characteristics. Research is needed to identify those families most at risk for developing adjustment



problems. Both risk and protective factors must be identified. Conceptual models of stress can facilitate the design of the research studies.

So far, research in this area has mainly focused on maladjustment. Different models have been used to determine the variables that can account for variance in psychosocial adjustment problems, e.g. illness variables, family functioning and coping. Most studies have failed to look at the mechanism of action of the intervening variables. For example does coping mediate or moderate the relationship between disability and adjustment? Furthermore attempts should be made to include all aspects of a model instead of just parts, in order to do justice to the complexity of existing interrelationships.

Although these studies have been helpful in identifying people most at risk for maladjustment, they do not give much direction for prevention or intervention. For a better understanding of the processes that lead to adjustment and psychological well-being, it may be more helpful to focus on positive outcome, i.e. resilience, stress related growth or thriving. This area of study has traditionally been neglected. In response to consistent findings of the co-occurrence of positive and negative affect states and adjustment outcomes, some attempts have been made to include positive outcome in stress models. These modified models will be discussed in the next chapter as well as some research into the positive experiences of parents of children with disabilities / chronic illnesses.

## CHAPTER 2

### Positive Outcome

As described in Chapter 1 most studies involving children with disabilities have focused on the negative effects of disability on individual family members, mostly the parents or child itself, and family functioning. Individual differences in people's response to adverse situations have long been acknowledged. The notion of resilience, however, has received relative little attention in research. Resilience refers to the fact that some people are able to maintain adaptive functioning in spite of a serious risk situation (stressor). This is rather unfortunate as understanding the processes that lead to resilience may provide us with directions for prevention and intervention (Rutter, 1990). According to Rutter (1990) the defining feature of resilience is a modification of the person's response to the risk situation. In other words, there may be some form of intensification (vulnerability) or amelioration (protection or resilience) of the reaction to adversity that in ordinary circumstances would lead to a maladaptive outcome. The existing literature mainly focuses on vulnerability of people facing stressful situations, e.g. parents of children with disabilities, especially disabilities that involve neurological impairments, are at increased risk to experience parenting stress. In contrast, protection may result from successful engagement with the stressor, i.e. successful coping may lead adaptable changes, which protect against the detrimental affects of an adverse event (Rutter, 1990).

It is important to include the notion of resilience and positive adjustment outcomes into theoretical frameworks of adjustment to disability. It should be noted that resilience and positive gain are two different constructs. Resilience refers to the situation in which a person is at risk for adverse outcomes, e.g. depression, but does not develop this outcome whilst positive gain refers to the situation in which a person experiences benefits from their reaction to threat. Thus far, factors promoting resilience or positive gain remain poorly understood. Theoretical frameworks may guide research to gain further insights on how facing up to challenges may lead to positive mental, physical or social outcomes. A focus on positive outcomes would be

in line with a new movement within the psychology discipline: Positive Psychology. Positive psychology was first introduced by Seligman and Csikszentmihalyi (2000) and concerns 'happiness', i.e. "happiness and well-being are the desired outcomes of positive psychology" (Seligman, 2003, p127). Seligman states that a sole focus on pathology, which has dominated the psychology discipline, has overshadowed positive human features and the potential of positive actions or feelings (Seligman, 2003; Seligman & Csikszentmihalyi, 2000). With respect to adverse events positive psychology focuses on the search for and finding of meaning. This theme is very much apparent in the potentially helpful theoretical frameworks, which will be described in the next few paragraphs.

## 2.1 Theoretical frameworks

### 2.1.1 Cognitive adaptation to threat

The theory of cognitive adaptation to threat (Taylor, 1983) was formulated in response to the observation that most people faced with personal tragedy, e.g. illness, ultimately achieve states of psychological well-being equivalent or exceeding their prior level of satisfaction. The theory holds that a person's adaptation process in response to threat focuses around three themes: meaning, mastery and self-enhancement. The search for meaning refers to the need to know why things have happened (causal attribution) and to establish its impact (reappraisal, reflection, and restructuring one's life). The capability of people to construe positive meaning from the threatening experience leads to better adjustment outcomes. The second theme, mastery, refers to one's ability to gain a feeling of control over the threatening situation so as to manage it or to prevent it from reoccurring. A sense of mastery can be achieved by perceptions that one can actively take control over the threat (e.g. illness) or over related aspects (e.g. treatment). Feelings of control are strongly associated with positive adjustment outcomes. The third theme, self-enhancement, refers to the need to rebuild self-esteem after threatening events. Social comparisons are one way to build up self-esteem. Especially downward comparisons, i.e. comparing oneself with someone coping less well or someone less fortunate, are a powerful manner to reinforce self-esteem. To

this extent both the comparison target as the comparison dimensions are of importance.

Although the three themes (meaning, mastery, and self-enhancement) may be observed in all people facing threat, there are many individual differences in the form through which the themes are expressed. This implies that it is not so much the form of cognitions that people hold about the threat, but rather their function that are important in the adaptation process. In addition cognitions may serve more than one need, e.g. a causal attribution can provide meaning as well as a sense of mastery. Taylor (1983) further suggests that a person's efforts to resolve these three themes depend on the ability to form and maintain a set of illusions or beliefs. Beliefs or illusions refer to a characteristic manner in which people view themselves and their ability to act on the environment. Although traditionally it is assumed that illusions were associated with psychological dysfunction, Taylor (1983) suggests that these beliefs could be beneficial in the adaptation process and may lead to positive adjustment outcomes. Beliefs may not be in contrast with known facts; rather the maintenance of the illusions depends on specific *interpretations* of these facts (selective valuation). The way in which illusions could operate is illustrated by H. Shrand (as cited in Shapiro, 1983): "If the family interprets the disability / illness as a threat it may produce anxiety; if it is interpreted as a loss, it may cause depression; if it is interpreted as a challenge both anxiety and hope will create problem solving energy and promote motivation and growth within the family."

Illusions or beliefs have a dynamic force as they can protect as well as prompt constructive thought and action (Taylor, 1983). The cognitive adaptation theory also implies that cognitions are strategic changing elements that serve value-laden themes rather than static with cross-situational meaning. Cognitions may vary their meaning depending on the situation, may serve different functions at different times or simultaneously. This flexibility of the relationship between cognitions and themes may facilitate adaptation when faced with a disconfirmation of a specific cognition (e.g. recurrence of cancer) as it may help a person to find alternative responses.

This theoretical framework ties in with stress and coping models. Beliefs can play an important role in both the appraisal process and coping

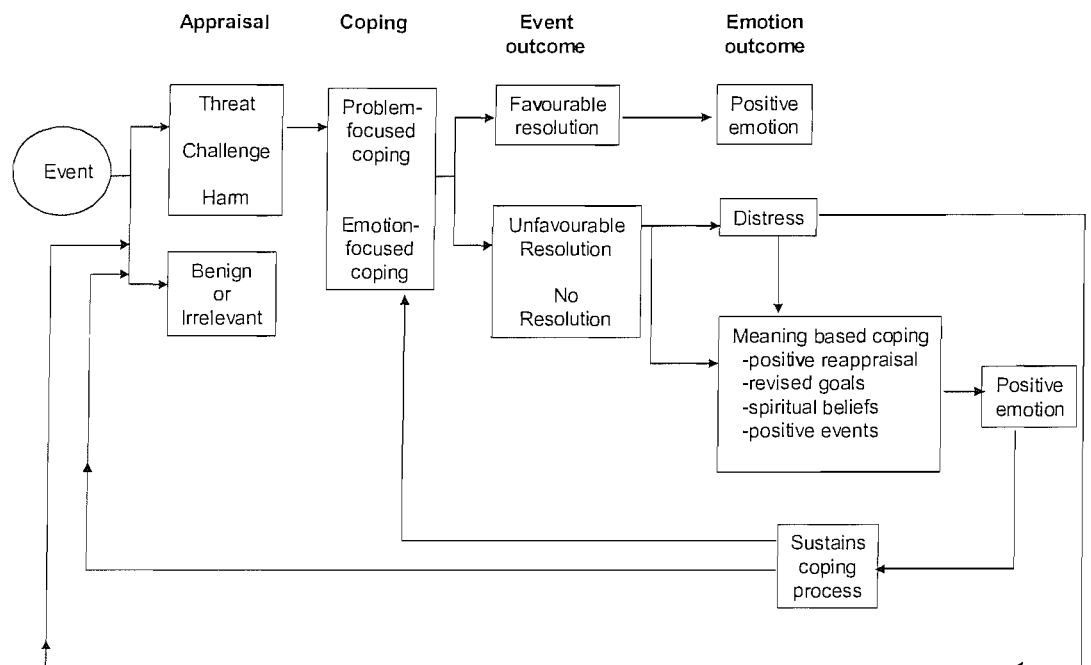
(Brown, 1993). For example, illusions of control may affect the appraisal of adverse events such that they are perceived as challenge rather than as threats. This in turn reduces stress reactions, leading to better adjustment outcomes. Similarly, illusions may foster effective coping strategies. For example, self-enhancing illusions, such as exaggerating one's capabilities, may result in the sustained use of active coping behaviour to alter the source or implications of adverse events.

Affleck and Tennen (1993) applied this theory in their research involving parents of prematurely born children. They found that most parents of children in neonatal intensive care units were able to find meaning by discovering a purpose, e.g. test of their faith in God, construing a benefit or gain, e.g. family closeness, or making comforting comparisons, i.e. parents made downward comparisons, such that their child's condition appeared less worrisome. Parents who were able to find some purpose before their baby was discharged were more responsive to their child's needs when caring for the child at home. Mothers who were able to construe some benefit before discharge displayed less psychological distress in the months after discharge independently of their emotional well-being at time of discharge or the severity of the child's medical problems. Most parents were also able to regain a sense of control, though sometimes only after the baby was discharged from the hospital. As predicted by theory, personal control was associated with emotional well-being in these parents. However, mothers convinced that their child's future health and development depended on their on personal actions displayed more emotional distress, because they tended to make many burdensome accommodations or because they realised some appropriate actions were beyond their scope. Affleck and Tennen (1993) reported that some parents were willing, at least partially, to give control to health care providers as they believed the health care providers were better equipped to make care or treatment decisions. Some parents benefited from 'participatory control', whereby parents and health care providers form a cooperative partnership. Others were comforted by a sense of vicarious control, whereby the parents were willing to cede control over their child's treatment to the staff in the intensive care units.

### 2.1.2 Coping and positive psychological states

In response to her findings that positive and negative states co-occurred throughout stressful circumstances, i.e. throughout caregiving and during bereavement in partners of men with AIDS, Folkman (1997) modified her stress and coping model (Lazarus and Folkman, 1984) to accommodate positive psychological states (see Figure 7).

Figure 7: Modified theoretical model of the coping process (Folkman, 1997, p 1217)



In the original model, (Lazarus and Folkman, 1984) it was proposed that a person is constantly appraising his/her transactions with the environment. In response to threatening or harmful transactions (stressors) a person will use coping strategies to either regulate distress (emotion focused coping) or to manage the problem (problem focused coping). Successful coping leads to favourable event outcomes and positive emotions. If coping is not successful the event may not be resolved or the event outcome may be

unfavourable, leading to distress and additional coping. In the revised model (Folkman, 1997), it is proposed that a person will use meaning-based coping, e.g. positive reappraisal, to deal with the distress resulting from unfavourable or non-resolved events, which in turn will lead to positive emotions. These positive emotions therefore derive from coping with the distress rather than with the events that caused the distress, hence the co-occurrence of positive and negative emotions. In the revised model it is further suggested that positive psychological states help sustain renewed coping efforts to deal with the chronic stressor (see Figure 7). This suggestion underlines the adaptational significance of positive states in the stressor-adjustment outcome.

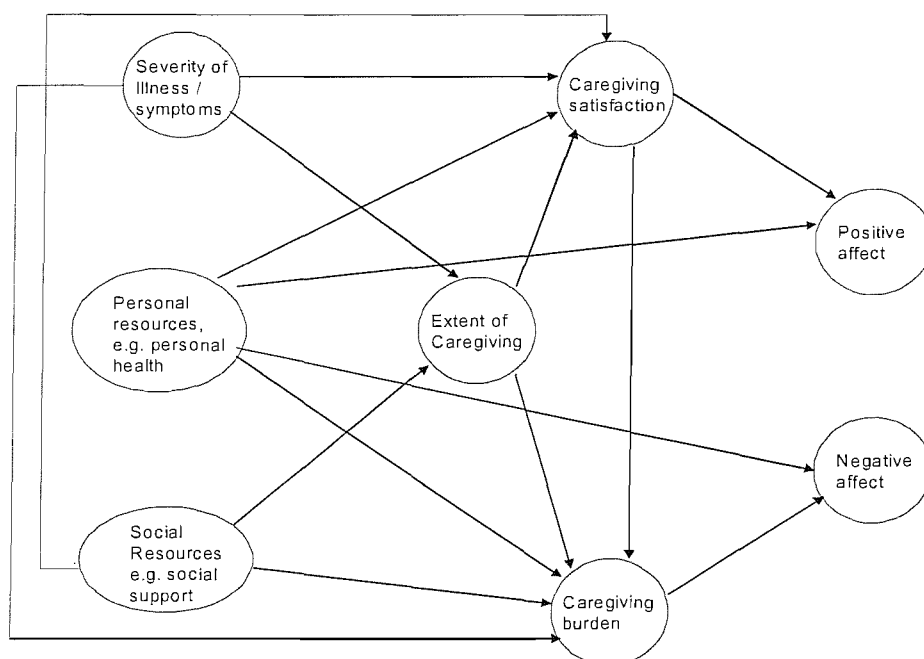
Folkman (1997) concludes that further research is necessary into the role of positive psychological states in the coping process. It is yet unclear which coping processes lead to positive emotions in the context of enduring stress. Also it is not known if positive psychological states need to have a certain affective intensity to help sustain coping efforts in dealing with the stressful context.

### 2.1.3 A two-factor model of caregiving appraisal and psychological well-being

Lawton and colleagues proposed a two-factor model of caregiving (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991). In this model the objective stressor, caregiver resources, and subjective appraisal affect both positive and negative affect. The model is based on the stress and coping model of Lazarus and Folkman (1984) and a two-factor view of psychological well-being (Bradburn, 1969; Diener & Emmons, 2003). As in the stress and coping model a person's evaluation of caregiving (appraisal) determines the use of coping strategies, which are believed to mediate the relationship between caregiving demand (stressor) and adjustment outcome (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 or emotional states 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. This notion is reflected in the two-factor model, i.e. proposed links between positive appraisals (e.g. caregiving satisfaction) and positive affect and negative appraisal (e.g. caregiving burden) and negative affect, respectively, are incorporated (see Figure 8).

Figure 8: Two-factor model of caregiving appraisal and psychological well-being (From Lawton et al., 1991, p 183).

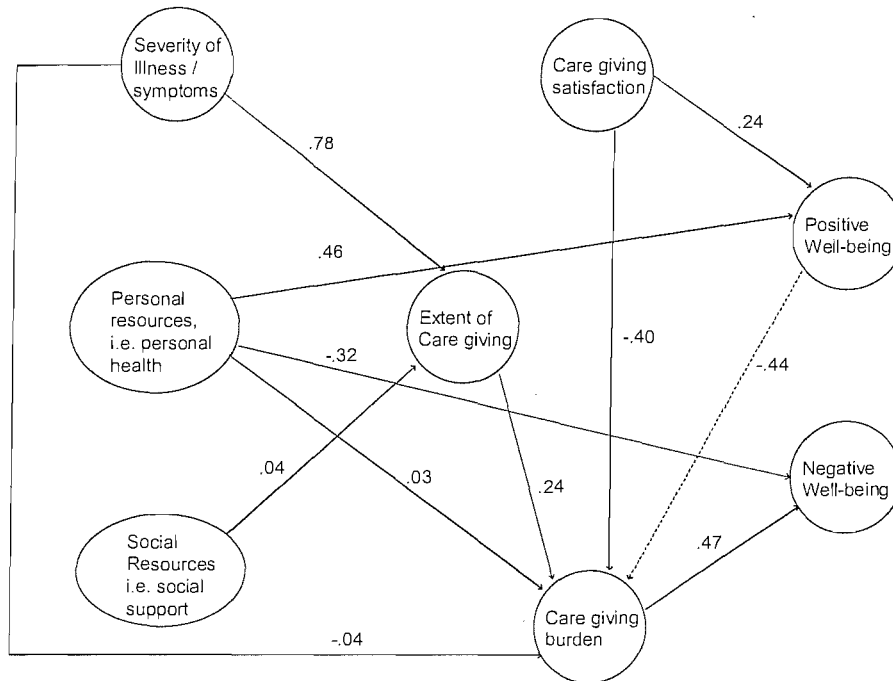


The model has been tested in different samples, for example in groups of spouse and adult child caregivers of elderly patients with Alzheimer’s disease (Lawton et al., 1991), in caregivers of elderly relatives (Pruchno, Peters, & Burant, 1995), in aging mothers of children with chronic disabilities (Pruchno, Patrick, & Burant, 1996) and in aging mothers of adults with learning disabilities (Smith, 1996). Results typically support the model, i.e. caregiving appraisals mediate the relationship between caregiving demands and psychological adjustment outcomes. Not all paths in the model are significant for all samples, i.e. more parsimonious models apply to different groups of caregivers. However, in all groups there is clear evidence that reactions to



stressors can lead to both positive and negative psychological adjustment outcomes. For illustration purposes, results of Smith (1996) are shown in Figure 9.

Figure 9: Caregiving model for older mothers of adults with mental retardation (From Smith, 1996, p355)



Interestingly, Smith (1996) found that higher levels of positive psychological well-being were associated with decreased levels of subjective burden in mothers of children with learning disabilities. More research is needed to explore the affect of positive adjustment outcome on the relationships within the model.

#### 2.1.4 Positive meaning and coping

Like Taylor (1983), S.C.Thompson (1981; 1985) also stresses the importance of finding meaning in adverse events. With reference to consistent findings that a person's ability to find meaning in adverse events determines their reaction and ability to cope, she states that finding positive meaning in traumatic events may enable people to cope better with the

stresses of the experience (Thompson S.C., 1985). She distinguishes five ways in which stressful experiences can be reevaluated as positive: 1) finding side benefits e.g. increased family closeness; 2) making favourable – downward - social comparisons; 3) imagining worse situations; 4) forgetting the negative; and 5) redefining. She reports on a study involving 32 people whose homes were destroyed or damaged by a fire (Thompson S.C., 1985). Results indicated strong inter-correlations between the five ways of focusing on the positive aspects (Cronbach's alpha .71-.75). People tend to use all techniques rather than just one, indicating that the process of focusing on the positive reflects a comprehensive cognitive orientation toward the event. Focusing on positive aspects was associated with better coping, both immediately after the event and 1 year later. Focusing on the positive as also associated with better adjustment outcomes, i.e. these people experienced more positive emotions, reported fewer physical symptoms and derived more pleasure from everyday events. These relations remained significant even after controlling for the amount of (non-reimbursed) loss.

#### 2.1.5 Value added models and stress related growth

In 1998, an issue of the Journal of Social Issues aimed to go beyond the vulnerability/deficit approach to disability to focus on thriving. Thriving was defined as “the effective mobilisation of individual and social resources in response to risk or threat, leading to positive mental or physical outcomes and/or positive social outcomes” (Ickovics & Park, 1998). A value-added model was proposed, in which it was suggested people might go beyond survival and recovery from an adverse situation (e.g. illness) to thrive. This notion suggests that challenge can provide impetus for growth and greater well-being. In this model, adjustment following the experience of adversity entails not just resilience but more importantly personal development (stress-related growth).

As discussed in Chapter 1 transactional models of stress and coping focus on the interaction of a person and his/her environment and emphasise the importance of personal appraisals of adverse situations for adjustment outcomes. The models posit that a person's interpretation (appraisal) of an event, based on personal and social resources, determines how they respond

in terms of emotional reaction and coping efforts. Without arguing against these conceptual models, Park (1998) explored the kinds of personal characteristics, resources, appraisal and coping efforts that are associated with stress related growth and thriving. Personality characteristics associated with stress related growth included optimism, hope, spirituality, religiousness and extroversion. People who possess higher levels of these personality characteristics were more likely to experience stress related growth. Similarly, social resources affected stress related growth, i.e. people with stronger social support networks and more positive life events during the 6 months surrounding the adverse event reported more stress related growth. Personality characteristics and resources may have a direct effect on stress outcome, however, it is more likely that these effects are mediated by appraisals and coping efforts (Park, 1998). Although it has been assumed that the appraisals such as controllability of the event and resources to deal with consequences will affect the extent of stress related growth, research into this area is sparse. Similarly, cognitive coping is believed to facilitate growth. In essence, cognitive coping entails that a person finds meaning in the situation. Although cognitive coping repeatedly has been theorised to facilitate positive outcome (see previous paragraphs) research addressing this notion is sparse.

Park, Cohen and Murch (1996) found some support for a positive relationship between controllability and stress related growth in a sample of college students, however they were not able to replicate this finding in subsequent studies. In the same study Park et al. (1996) suggested that stress related growth was positively associated with appraisals of stressfulness, i.e. increased stress is associated with more growth. Such a relationship suggests that growth is more likely from adverse events for which resolution is more difficult (Park et al., 1996). Interestingly their findings further suggested that situations do not have to be resolved before resolution has occurred, i.e. growth can occur whilst dealing with the situation (Park et al., 1996). Coping strategies associated with stress related growth included positive reappraisal, acceptance, religious coping, and emotional social support (Park et al., 1996). Positive reappraisal helps the person to see the stressor in a more positive light, e.g. as a learning experience, and the

association with positive outcome is therefore not surprising. Acceptance coping may allow the person to integrate the adverse situation into his/her life, opening the path for enhanced functioning and growth. The positive associations between growth and religious coping and social support are consistent with findings that personality characteristics such as religious beliefs and social support affect stress related growth and merely point to possible mediation effects of coping. Park (1998) concludes that more research is needed to address the role of personality characteristics, resources and coping on stress related growth to develop models. Gained insights may lead to better provision of adequate resources and interventions by helping professionals.

## 2.2 Research involving families of children with a disability / chronic illness

Few studies have included the notion of positive outcome associated with raising a child with a disability. For example, in a review of existing published research on the positive perceptions and experiences of families of children with disabilities Hastings and Taunt (2002) identified just five descriptive studies on positive impact. However, as described in the previous paragraphs it is plausible that families might derive some positive effects from a stressful event.

Studies merely describe positive contributions, e.g. source of happiness, source of family closeness. For example, parents reported positive changes in their lives associated with raising their child with learning disabilities, sensory impairment or ADHD (Scorgie & Sobsey, 2000). These changes were clustered in three themes: personal transformations, relational transformations and 'perspectival' transformations. Personal transformations refer to changes parents observe in themselves, i.e. personal growth. They include acquired roles, e.g. conference speaker or vocational changes, and acquired traits, e.g. ability to speak out on behalf of their children. Relational transformations refer to changes in the manner in which parents relate to other people. They include changes in family relationships, e.g. strengthening of marriage, changes in friendship networks, e.g. acquiring new friends because of child with disability, changes in advocacy relationship, and changes in attitudes toward people in general. 'Perspectival' transformations

refer to changes in the way that people view life and include changes in philosophical or spiritual values (Scorgie & Sobsey, 2000).

Few studies try to incorporate the notion of positive contributions into theoretical frameworks of adjustment to disability. Summers, Behr and Turnbull (1989) attempted to provide a theoretical rationale for positive contributions of children with disabilities on their families. They referred to the ABCX model of stress (McCubbin & Patterson, 1983) and suggested that the ongoing process of reacting to stressful situations may not only lead to a downward spiral of dysfunction and crisis (mal-adaptation) but also to a progressively upward spiral of growth (bon-adaptation). Bon-adaptation is characterized by a process which leads to the maintenance or strengthening of family integrity, the continued promotion of development of both individual family members and the family as a whole, and the maintenance of family independence and its sense of control over environmental influences (McCubbin & Patterson, 1983; Summers et al., 1989). Drawing from Taylor's theory of cognitive adaptation to threat (Taylor, 1983), Summers et al. (1989) concluded that a better understanding of the adaptation processes, specifically appraisal and coping, will be the key to understanding why some families adjust well to a child's disability whilst others do not.

Turnbull, Guess and Turnbull (1988) analysed letters written by people with disabilities or close relatives in response to proposed federal regulations to prohibit discrimination in non-treatment decisions of newborns with disabilities in the US. Content analysis revealed several themes to support these regulations. Ten different subcategories of positive attributes were identified, including experiencing happiness, experiencing love, having personal interests, maintaining meaningful family relationships, attaining success in a job/career, making progress in developmental accomplishments, achieving academically, having positive personal qualities, having commendable moral characters, and providing help to others. In addition comments on positive contributions, reflecting perceptions that the life of a person with a disability has enriched and enhanced the quality of life for family and friends, revealed six subcategories. These included: source of joy, source of love, source of learning life's lessons, source of blessing and fulfilment, source of pride and source of family strengths.

Chernoff and her colleagues asked mothers to identify the positive impact and potential benefits associated with raising a child with a chronic illness (Chernoff, List, DeVet, & Ireys, 2001). Almost 90% of the mothers reported feeling better about themselves by learning to manage their child's condition, 70% reported increased family strength and 80% reported that their family in some way had benefited from the experience. For example, mothers reported increased family cohesion, increased awareness, sensitivity and tolerance, and enhanced self-esteem. These maternal reports reflected a broad capacity to give positive meaning to the impact of a child's chronic illness on the family.

In an exploratory study involving mothers of children with intellectual disabilities, psychological factors, i.e. active coping and social support, but not demographic characteristics nor caregiving demands were associated with parent's perceptions of positive contributions of their child on the family (Hastings, Allen, McDermott, & Still, 2002). Specifically, parents' perceptions of the child as a source of happiness/fulfilment and source of family strength and closeness were associated with the coping strategy 'positive reframing', whilst parents' perceptions of the child as a source of personal growth and maturity were positively associated with the coping strategy 'seeking social support', but negatively associated with the coping strategy 'mobilising the family', i.e. mobilising the family to acquire and accept help from community resources. Although some methodological problems with the study are discussed, the results clearly support the link between family adaptation processes, i.e. coping and social support, and positive perceptions.

### 2.3 Conclusion

Traditional stress and coping models have stimulated research into the area of adjustment to adverse events. Many studies have focused on various components or subsystems of these models (Aldwin, 2000) and results support the models in explaining (mal)adjustment to adverse events. Individual differences have long been acknowledged, i.e. some people show resilience whilst others display psychological problems. Positive outcomes, e.g. positive emotional affect or stress related growth, have received little

attention. Reports of positive outcomes were often regarded as denial and an inability to face up to reality. More recently, in response to consistent findings of positive outcomes, attempts have been made to include positive outcomes in theoretical frameworks. Theories of psychological reorganisation in the aftermath of traumatic events, the value added model and the revised model of stress and coping provide some insight on how overcoming stressful situations may result in positive psychological outcome and positive emotions. These theories share their focus on the role of adaptation processes, specifically cognitive coping, in facilitation positive adjustment outcomes. It should be noted that these theoretical frameworks are merely reinterpretations of existing stress and coping models. In other words relationships between stress, adaptation and adjustment outcomes are re-examined to determine which personality characteristics, resources, appraisals, and coping strategies can facilitate not just resilience but growth. Although models have been drawn up, research addressing positive outcomes has been sparse. However associations between appraisals, cognitive coping and positive outcomes have been confirmed, i.e. people who appraise adverse events as controllable or as challenges, people who believe they have the resources to deal with the consequences of adverse situations, people who adopt coping strategies aimed at the reinterpretation or acceptance of the events, and people who try to find meaning in the adverse situation or its consequences are more likely to report stress related growth. Another important notion that has appeared in the literature is that negative and positive outcomes can co-occur. Negative and positive outcomes therefore are believed to function as two partially independent constructs rather than two endpoints of one dimension.

Positive outcome research involving families of children with disabilities or chronic illnesses has relied mostly on anecdotal reports or qualitative data, using open-ended questions or general questions regarding perceptions of positive outcome. These studies generally confirm relationships between positive outcome and social resources and coping efforts. In addition, parents of children with disabilities are able to identify positive outcomes associated with raising a child with special needs, e.g. increased family cohesion and personal growth.

## CHAPTER 3

### Outline of thesis

As has become clear from the previous two chapters, traditionally research has focused on the detrimental effects of physical disabilities and chronic illness on the affected child and his/her family. Models have been developed to describe the illness - adjustment outcome relationship, emphasizing the importance of adaptation processes such as coping. Studies have supported the notion that parents, especially mothers, of children with disabilities / chronic illnesses are at risk for developing psychosocial adjustment problems. However, many parents of children with disabilities are able to focus on the positive aspects of their experience rather than the negative. This is quite an achievement given the challenges these parents are faced with. Most children with physical disabilities or chronic illnesses need special medical and/or educational care and the long-term quality of life of both child and family are threatened. Anecdotal reports of positive contributions of children with disabilities to their families typically mention increased family coherence, personal growth and increased awareness of disability in society. Although stress and coping models have been modified to allow for positive outcome, little is known about the affect of positive contributions on parental adjustment to their child's disability.

This thesis investigates the relationships between illness, adaptation processes and adjustment outcomes in families of children with physical disability or chronic illness. The thesis focuses on the application of the transactional stress and coping model of adjustment to disability (Thompson, Gil, Burbach, & Keith, 1993a) to families of children with physical disabilities, i.e. spina bifida and hydrocephalus, and chronic illness, i.e. asthma (Study 4 and 5). In addition, the effect of perceived positive gain on the relationships within the model was investigated (Study 7). The thesis describes the development of a measure of perceived positive gain and the testing of its psychometric properties (Study 1 and 2). Study 3 was conducted to investigate the effect of coping on the illness / outcome relationship



(mediation versus moderation), whilst Study 6 investigates the effect of age and gender on the illness-outcome relationship.

The thesis is organised in 13 chapters. Chapter 1 and 2 provided the theoretical basis of the studies. In Chapter 1 stress and coping models of adjustment to disability were reviewed. Chapter 2 focused on theoretical frameworks that have been used to explain positive outcomes associated with adverse events. Since most studies in this thesis involve families of children with spina bifida and hydrocephalus Chapter 4 describes these conditions and their implications for the child and its family. A widely used instrument of parenting stress was modified to include items reflecting positive experiences associated with raising a child with a disability. This modified measure was administered to a large sample of mothers of children with spina bifida and hydrocephalus. This data was used to test the psychometric properties of this measure of perceived positive gain and the effect of the additional items on the psychometric properties of the original scale (Chapter 5). Levels of parenting stress and perceived positive gain were also assessed in a general population sample to allow for comparisons (Chapter 7). Before testing the transactional stress and coping model of adjustment to disability, analyses were conducted to test the role of coping in affecting the relationship between disability and adjustment, i.e. mediation or moderation (Chapter 8). The transactional stress and coping model of adjustment to disability was tested using structural equation modelling in a sample of mothers of children with spina bifida and hydrocephalus (Chapter 9) and in a sample of mothers of children with asthma (Chapter 10). This statistical method allows for the simultaneous effects of all relationships within the model. It further allows for testing of mediating effects. The effect of age and gender on the illness-outcome relationship is investigated in Chapter 11. Finally, the moderating role of positive experiences on the relationship between disability/illness, adaptation processes, and adjustment outcome is investigated (Chapter 12). In Chapter 13 findings are reviewed in light of existing literature. The significance of these findings and their relevance for developing a better understanding of the underlying processes of adjustment to disability will be demonstrated. Finally, methodological limitations and directions for future research are discussed.

## CHAPTER 4

### Spina bifida and hydrocephalus

The first set of studies to be discussed involves families of children with spina bifida and/or hydrocephalus. The next sections will describe the nature of these conditions to better understand the challenges they present to these children and their parents. Descriptions not only include prevalence and symptomatology of the conditions but also discuss potential psychological affects.

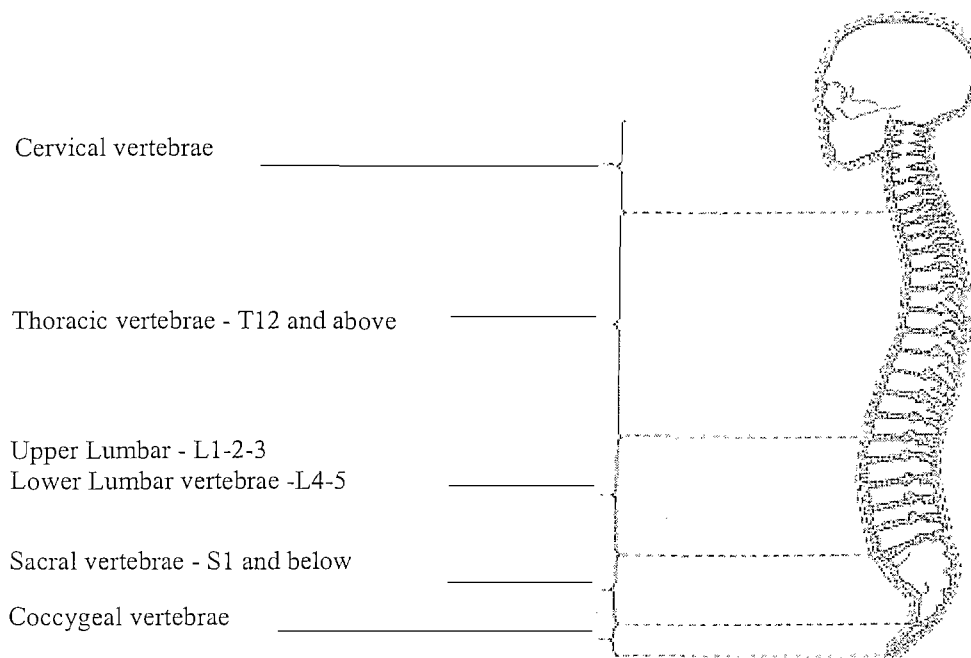
#### 4.1 Spina bifida

Spina bifida is a congenital neural tube defect, arising from a failure of neurulation or canalisation of the primitive neural tube. Spina bifida is characterised by a fault in the spinal column in which one or more vertebrae fail to form properly leaving a gap or split. This defect may occur anywhere along the spinal column but is usually found in the mid-back (thoracic), in the lower back (lumbar) or at the base of the spine (sacral) (see Figure 10).

The spina bifida may be closed (spina bifida occulta) or open (spina bifida aperta or cystica) (see Figure 11). Spina bifida occulta is a common condition, in which the bones of the spine may be incomplete, but the defect is covered by skin and the spinal cord is usually unaffected. Most people with spina bifida occulta do not have any symptoms or clinical problems. As symptoms and problems associated with spina bifida occulta are minimal, this form of spina bifida will not be discussed further. Spina bifida aperta refers to an open defect of the spine in which the spinal cord does not form properly and is exposed. The visible signs are a sac or cyst on the back, covered by a thin layer of skin. There are two forms of spina bifida aperta: meningocele and myelomeningocele (see Figure 11). In the meningocele form the lump or cyst on the back contains cerebrospinal fluid (CSF) and the meninges, which are the covering membranes of the spinal cord, but no nerve tissue. In the more common and serious myelomeningocele form, the cyst contains both the nerve tissue and its coverings. As nerve tissue is involved, there is always

some degree of paralysis and loss of sensation below the affected vertebrae as well as problems with bowel and bladder function.

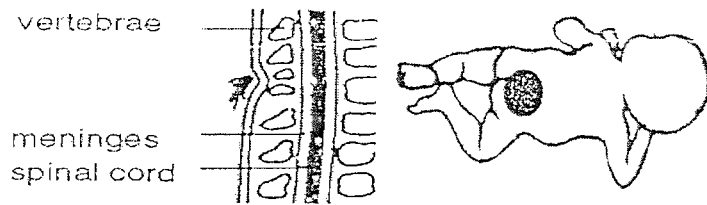
Figure 10: The vertebral column (From Anderson & Spain, 1977, p16)



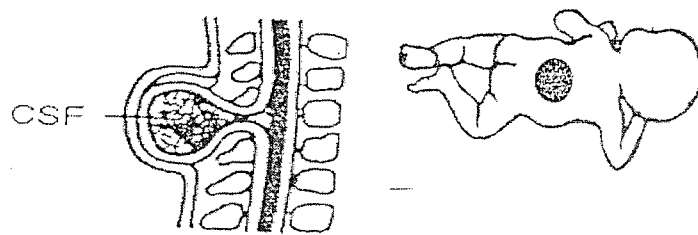
Over 80% of the affected children have their lesion in the lumbo-sacral region (Shonkoff & Marshall, 1990). Most children with a lumbo-sacral lesion (approx. 90%) also have a malformation of the brain stem and cerebellum (Arnold Chiari malformations) and hydrocephalus. If the lesion occurs in the thoracic region, a severe curvature of the spine (kyphoscoliosis) develops as a frequent result of the malfunction of the adjacent (paraspinal) muscle groups (Shonkoff & Marshall, 1990).

Figure 11: Forms of Spina Bifida

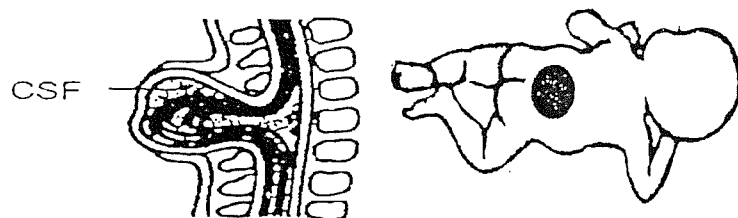
Occulta  
 Outer part of vertebrae not completely joined.  
 Spinal cord and covering meninges undamaged.  
 Hair often at sight of defect.



Aperta - Meningocele  
 Outer part of vertebrae split. Spinal cord normal.  
 Meninges damaged and pushed out through opening.



Aperta - Myelomeningocele  
 Outer part of vertebrae split. Spinal cord and meninges damaged and pushed out through opening. Possible hydrocephalus.



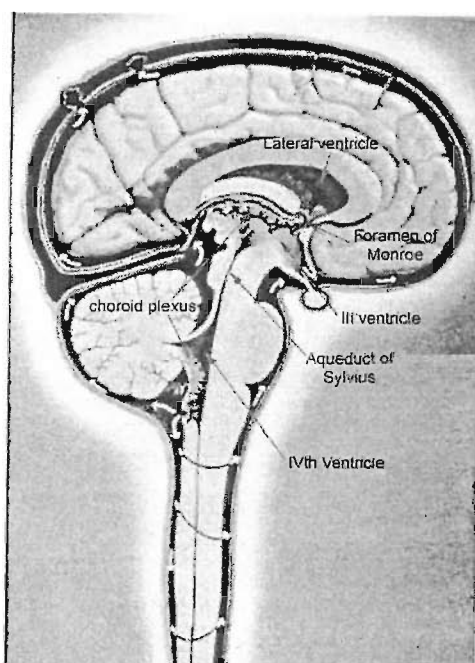
Note: CSF=Cerebrospinal fluid

#### 4.2 Hydrocephalus

Hydrocephalus is a neurological condition which occurs when there is an abnormal accumulation of cerebrospinal fluid (CSF) within the ventricles and/or subarachnoid space of the brain. Hydrocephalus causes raised intracranial pressure, and can be a result from an overproduction of CSF, an

obstruction of the CSF flow, or a failure of the structures of the brain to reabsorb the fluid. CSF is produced by the brain in the choroid plexus. The choroid plexus is a network of blood vessels covered by a tissue membrane that secretes newly formed CSF. The average person produces about 500 ml CSF per day, which is the same amount also absorbed by the body. The CSF flows through the structures of the brain before it is reabsorbed into the bloodstream (see Figure 12).

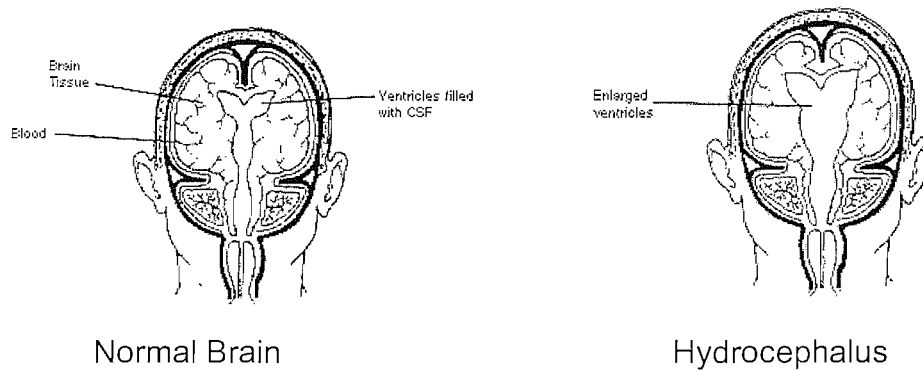
Figure 12: Ventricular system of the brain



CSF flows from the choroids plexus in the lateral ventricles through the foramen of Monro to the third ventricle. From here CSF passes through the cerebral aqueduct (aqueduct of Sylvius) to the fourth ventricle. The most common form of hydrocephalus, aqueduct stenosis, is caused by a blockage in this area. From the fourth ventricle the CSF enters the subarachnoid spaces. CSF flows over the brain to the arachnoid granulations where it is reabsorbed in the superior sagittal sinus. CSF functions to protect the brain from injury and to and clean the structures of the brain by carrying away waste products. If the normal flow of CSF is obstructed (non-communicating hydrocephalus) or CSF is prevented from being reabsorbed (communicating

hydrocephalus), the fluid accumulates in the ventricles, causing them to swell (Figure 13).

Figure 13: Normal brain and Hydrocephalus



Hydrocephalus can be present at birth (congenital hydrocephalus) or acquired after birth from a variety of causes. Hydrocephalus can be caused by spina bifida but is also associated with other conditions such as Chiari malformations, meningitis, premature birth, Dandy Walker cysts or brain tumours. In young infants hydrocephalus is mostly detected by an abnormally large head or by an increased head growth. However with older children and adolescents the head size cannot increase any more because the bones of the skull are now completely joined. Common symptoms of hydrocephalus in children and adolescents include: frequent headaches, gait disturbance, vision problems, concentration or mental difficulties, nausea or vomiting, incontinence, lethargy and neck pain. People may not experience all these symptoms, and some may be more prominent than others in different developmental stages.

Most forms of hydrocephalus require to be treated, although occasionally it will arrest spontaneously. Usually the treatment involves an insertion of a shunting device. Shunting controls the intracranial pressure by draining excess CSF. CSF is either drained into the heart (ventriculo-atrial shunt) or into the abdomen (ventriculo-peritoneal shunt). It is important to note that shunting is not a cure, but rather a controlling device. Unfortunately shunting can have complications, which include under-drainage, over drainage or infections.

## 4.3 Incidence

### 4.3.1 Spina Bifida

Prevalence figures vary depending on the reporting source.

Kronenberger and Thompson (1992b) state that spina bifida is the most frequently occurring central nervous system malformation with an incidence rate of 1.5-4 per 1,000 live births. Gold (1993) reports a much lower incidence of spina bifida in the United States of approximately 4.6 per 10,000 births. Similarly, Chauvel (1991) reports a prevalence rate 0.4-1 per 1,000 births in the United States, however he stresses that the incidence of spina bifida varies across the world. For example, the incidence in Ireland is 8 per 1,000 live births, whilst in South East Asia the condition is rare (Chauvel, 1991). Smithells, Sheppard, Schorah and Wild (1991) also report a wide variation in prevalence across the world, as well as variation among ethnic and social groups within individual countries. Neural tube defects, e.g. spina bifida, are most common in families of unskilled manual workers and less common in better-educated, professional families. In 1999 the reported rate in England and Wales for central nervous system anomalies was 4.2 per 10,000, i.e. 265 children. Rates for spina bifida for England and Wales were 1.0 and 0.9 per 10,000 births, respectively (Office for National Statistics, 2000). It needs to be noted that reporting to the National Congenital Anomaly System is voluntary, and therefore these figures may be conservative due to underreporting. Also there were 117 abortion notifications associated with spina bifida further affecting the incidence rates. There is limited data on gender differences in incidence rates. Girls slightly outnumber boys (1.3:1 ratio) and girls may be more likely to develop hydrocephalus (Anderson & Spain, 1977; Scarff & Fronczak, 1981).

### 4.3.2 Hydrocephalus

It is hard to estimate the incidence and prevalence of hydrocephalus given the differences in aetiology. Data available primarily concerns congenital hydrocephalus, i.e. hydrocephalus present at birth. The United States Centres for Disease Control and Prevention have reported that approximately 1 out of every 1,000 children born each year is affected with

hydrocephalus (Toporek & Robinson, 1999). The prevalence of infantile hydrocephalus is estimated at 6 per 10,000 in neonatal survivors (Fernell, Hagberg, & Hagberg, 1994). In 1999 sixty-one children were born with congenital hydrocephalus in England and Wales, reflecting a rate of 1.0 per 10,000 births (Office for National Statistics, 2000). Like with the rates for spina bifida, it needs to be noted that reporting to the National Congenital Anomaly System is voluntary and also there were 55 abortion notifications, therefore these figures may be conservative. The rates of infantile and acquired hydrocephalus may have increased over the last decennia, as a result of improvements in medical techniques. For example, Fernell et al. (1994) reported a significant increase in infantile hydrocephalus cases associated with survival of babies born prematurely in Sweden between the years 1973 and 1982. The same may be true for hydrocephalus associated with brain tumours or other acquired brain impairments.

#### 4.4 Associated problems

The effect of spina bifida on the child's functioning depends on the level of lesion and the nerve damage involved. Associated problems include varying degrees of lower extremity motor impairment, sensory loss, and bowel and bladder dysfunction. Children with spina bifida and hydrocephalus typically have additional brain abnormalities, e.g. the corpus callosum is often malformed or missing, further affecting neuropsychological functioning (Wills, 1993). Chauvel (1991) uses criteria defined by Lorber (1971) to determine the prognosis of a child with spina bifida: (1) the degree of paralysis (2) the presence of hydrocephalus, (3) the presence of kyphosis/scoliosis and (4) the presence of associated gross congenital anomalies or peri-natal trauma. The prognosis is poorer if the level of lesion is higher, hydrocephalus and pathologic curvature of the spine are present at birth and when the child suffered birth injury or has congenital organ system anomalies. The effects of hydrocephalus on child functioning vary considerably across children and depend on the areas of the brain most affected. The varying neurobehavioral outcomes reflect the influence of not only hydrocephalus, but also other congenital neuropathological processes and environmental, sociocultural and



emotional factors (Fletcher et al., 1996). They can include impaired fine motor skills, executive functioning, learning, attention and behaviour (Tew, 1991).

Research has indicated that spina bifida and hydrocephalus may affect cognitive functioning. In general, children with spina bifida and hydrocephalus function within the low average range of intelligence. The performance of these children on verbal tasks is better than their performance on tasks that require visual and spatial awareness (e.g. Brookshire et al., 1995; Dennis et al., 1981; Donders, Rourke, & Canady, 1991; Fletcher et al., 1992; Wills, 1993). Shaffer, Friedrich, Shurtleff and Wolf (1985) suggested that this may be due to difficulties in eye-hand co-ordination, problems in executive functioning, or both. Data from a longitudinal study by Fletcher's research group suggested that differences between verbal and nonverbal do not seem to reflect motor demands of the nonverbal tasks (Brookshire et al., 1995; Fletcher et al., 1992). However, the differences may be attributable to neuropsychological deficits associated with white matter abnormalities (Donders et al., 1991). A study by Dise and Lohr (1998) provided further evidence that children with spina bifida have deficits in 'higher order' cognitive abilities. They reported that subjects with spina bifida aged 10 to 23 years experienced problems in at least one domain of executive functioning, i.e. mental flexibility, processing efficiency, conceptualisation or problem solving, regardless of their lesion level or IQ.

For children with spina bifida, the level of lesion is associated with cognitive functioning, i.e. higher (thoracic) lesion levels are associated with lower IQ scores, especially in regards to scores on visual-motor tasks. This finding may be due to the fact that hydrocephalus is also more common with higher lesion levels (Wills, 1993). The aetiology of hydrocephalus may also be important in this context. Larger discrepancies between verbal and nonverbal performance are noted in children with hydrocephalus associated with Aqueduct Stenosis than children with hydrocephalus associated with spina bifida or prematurity (Dennis et al., 1981; Fletcher et al., 1992). Early developing obstructive hydrocephalus, e.g. hydrocephalus due to Arnold Chiari malformation, may affect visuospatial and visuomotor performance specifically, with limited affect on language abilities, whereas later developing hydrocephalus, e.g. hydrocephalus associated with intra-ventricular

haemorrhage, yields low scores on both nonverbal and verbal tasks. In general, the more complications associated with the cause of hydrocephalus, the poorer the outcome on cognitive functioning for that diagnostic group (Wills, 1993).

In spite of low average IQ levels, children with spina bifida and hydrocephalus often display academic problems. These problems include arithmetic, spelling and reading comprehension (see Wills, 1993, for a review). These learning problems may arise from impairments in other cognitive functions. For example, children with shunted hydrocephalus of different aetiology were more likely to display cognitive visual problems, e.g. object recognition and orientation than children without cerebral pathology, with most affected children having multiple cognitive visual problems (Houliston, Taguri, Dutton, Hajivassiliou, & Young, 1999). Furthermore, children with hydrocephalus are at risk for discourse and pragmatic impairments. In a study analysing the development of narrative content data suggested that children with hydrocephalus show content-poor language. Compared to matched controls the narratives of children with hydrocephalus were characterised by impaired textual rhetoric, e.g. less cohesive, less clear and less coherent (Dennis, Jacennik, & Barnes, 1994).

There may also be social disadvantages such as decreased opportunity for peer relationships, prolonged dependency on parents and decreased community acceptance (Castree & Walker, 1981; Kirpalani et al., 2000). Repeated findings of psychopathology and low self-esteem have been reported for children and adolescents with spina bifida and hydrocephalus (Ammerman et al., 1998; Appleton et al., 1994; Dornier, 1975; Hayden, Davenport, & Campbell, 1979; Kazak & Clark, 1986; Thompson, Kronenberger, Johnson, & Whiting, 1989; Wallander et al., 1989a; Williams & Lyttle, 1998). Estimates of prevalence of emotional and behavioural disorders among children with hydrocephalus range from 24-44% (Donders, Rourke, & Canady, 1992). Results of a study by Dornier (1975) suggested that impaired mobility is associated with both social isolation and feelings of depression of the adolescent with spina bifida. However, in more recent studies, elevated levels of behaviour and social competence problems were not associated with disability parameters such as level of lesion, ambulatory status, or bladder

function (Ammerman et al., 1998; Wallander et al., 1989a). It should be noted that not all aspects of self-esteem might be affected. Appleton et al (1994) reported that although children with spina bifida scored significantly lower on athletic and scholastic competence and peer acceptance compared to able-bodied peers, their ratings of physical appearance, behavioural conduct and global self worth were similar. Hommeyer, Holmbeck, Wills and Coers (1999) examined the relationship between severity of condition and psychosocial functioning in children with spina bifida, thereby differentiating between proximal functional status and distal adjustment outcomes. Proximal functional status outcomes were defined as functional consequences of specific disability related symptoms, e.g. physical and cognitive outcomes. In contrast, distal adjustment outcomes do not clearly represent functional limitations associated with the disability, e.g. mental health and social functioning. As predicted condition severity was associated with the proximal functional status outcomes, i.e. scholastic competence, athletic competence, attention problems and degree of involvement in activities, but not with distal outcomes, i.e. behavioural problems and social competence (Hommeyer et al., 1999).

#### 4.5 Impact of a child with spina bifida and/or hydrocephalus on the family

Families of children with spina bifida and/or hydrocephalus experience higher levels of parenting stress than families of non-disabled children (Donders et al., 1992; Holmbeck et al., 1997; Kazak & Clark, 1986; Kazak & Marvin, 1984). Estimates of the prevalence of psychological distress in the parents of children with hydrocephalus range from 22 to 42.5% (Donders et al., 1992). Crucial factors in parent's adjustment include not only the degree of physical impairment but also, more importantly, social and emotional factors (Kolin, Scherzer, New, & Garfield, 1971). Major predictors of the impact of spina bifida on the family include the number of activities of daily living affected by spina bifida, and parents' perceptions of child health (Havermans & Eiser, 1991; McCormick, Charney, & Stemmler, 1986). Other important factors include maternal educational status, family income, number of adults in the

family, number of visits to the doctor in the month prior to the interview, and parent employment status (McCormick et al., 1986).

Dorner (1975) reported higher rates of depression in mothers of adolescents with spina bifida. However, no association was found between maternal depression and the adolescents' physical impairments. Similarly, Donders et al (1992) reported that the elevated stress levels in parents of children with hydrocephalus were not related to the hydrocephalus per se. Dorner's explanation for this finding was that the presence of a child with a disability in the family increases the vulnerability of mothers to other stressful life events, i.e. raising a child with spina bifida may reduce the mothers' resources to cope, therefore mothers are more likely to become depressed by other problems in their lives (Dorner, 1975). Holmbeck & Faier-Routman (1995) investigated the relationship between disability parameters, i.e. level of lesion and shunt status, and indicators of family functioning, i.e. affect, control and conflict. Differences in family functioning were found between the lesion level groups but not for the shunt status groups. Mothers of children with higher lesion levels reported a greater willingness to grant autonomy to their child and less parent-adolescent conflict and were more attached to their children. Kronenberger and Thompson (1992a) reported that the psychological symptoms of mothers of children with spina bifida (myelomeningocele) were not associated with medical indices of severity of disability. However, they reported a significant association between mother's appraised stress pertaining to the child's medical condition, to the mother's emotional reaction to the child's medical condition and to other life crises and mothers' psychological adjustment (Kronenberger & Thompson, 1992a). Social relationships may also play an important role in maternal adjustment. For example, Barakat and Linney (1992) reported that social support was related to better maternal psychological adjustment and child adjustment in both families with children with spina bifida and healthy controls. Kazak and Marvin (1984) reported that although parents, especially mothers of children with spina bifida, experienced higher levels of parenting stress than parents of healthy controls, no differences were found for marital satisfaction. In other words, despite the stress experienced in the parent-child dyad, the marital relationship in the spina bifida families remained both strong and central.

Mothers with more supportive families and marriages experienced lower levels of psychological symptoms (Wallander et al., 1989b). Similarly, maternal psychological adjustment was associated with supportive, conflictive and controlling dimensions of family relationships and marital quality (Kronenberger & Thompson, 1992b).

#### 4.6 Summary

This review of the literature clearly indicates that spina bifida and hydrocephalus can have a major impact on the lives of children affected and their families. The conditions may not only result in physical impairments but could also affect cognitive functioning, learning, behaviour and self-esteem. Furthermore the impact on the family can be quite substantial, as reflected by elevated levels of distress and psychopathology in parents. So far this review of the literature reveals mainly aversive reactions to disability by children and their families. However, some researchers have claimed that the presence of a physical disability is not associated with increased levels of psychological problems, i.e. child behaviour problems, parenting stress and family functioning (Spaulding & Morgan, 1986). Some methodological issues may account for these discrepancies in research findings, however, it may be that resilience factors, such as coping and social support, further explain differences between adjusted and maladjusted families. What has become clear from this line of research is that the psychosocial functioning of children with spina bifida and their parents is not so much a function of the level of impairment but rather determined by ecological factors.

## CHAPTER 5

### Rationale and method

This chapter will give an outline of the rationale, design, and method of the studies presented in chapters 6-12. The studies involve three samples: mothers of children with spina bifida and/or hydrocephalus, mothers of children with asthma and a general population sample.

#### 5.1 Rationale

In Chapter 1 different stress and coping models of adjustment to disability have been discussed. The transactional stress and coping model is one of the models frequently applied in studies concerning families with children with chronic illness and physical disability. Although the associations between the variables in the model have been confirmed in many studies using regression analysis (e.g. Kronenberger & Thompson, 1992a; Kronenberger & Thompson, 1992b), the direction of the pathways, i.e. causality, has not been tested. In addition, studies have focused mainly on adjustment problems and do not take into account positive aspects that may be associated with raising a child with a disability. As has become clear from Chapter 3, parents have both negative and positive experiences associated with raising a child with a disability. Furthermore, positive aspects may influence the affect of negative events on adjustment.

The first set of studies (Chapter 6 and 7) concern the reliability and validity of a new measure assessing 'positive gain'. A set of questions was incorporated into the Parenting Stress Index Short Form (PSI-SF36, Abidin, 1995) and administered to a sample of mothers of children with spina bifida and hydrocephalus. The changes were made to measure positive aspects associated with raising a child with a disability. First the psychometric properties of the modified Parenting Stress Index were investigated. More specifically, tests were conducted to determine the extent to which the new items affected the original psychometric properties of the PSI-SF36 and also to investigate if the new items formed a separate scale (Chapter 6). The

modified Parenting Stress Index was then administered to a general population sample (Chapter 7) for comparison purposes. The original PSI-SF36 manual (Abidin, 1995) provides US norms, however UK norms are not available. Also, comparing positive gain levels in the two samples may provide evidence of predictive validity of the positive gain scale.

The second set of studies was conducted to test the transactional stress and coping model of adjustment to disability. The model was tested in two samples: a sample of mothers of children with spina bifida and hydrocephalus (Chapter 9) and a sample of mothers of children with asthma (Chapter 10). The model is tested using structural equation modelling. This analysis differs from regression analysis in that, when it is used to investigate the relationship between independent and dependent variables, it takes into account the interactions between the variables. The main advantage of structural equation modelling is that when it is used to investigate the relationships between latent variables, these relationships are free of measurement error.

The third set of studies will investigate the role of gender, age and perceived positive gain on the illness-outcome relationship (Chapter 11 and 12).

Main research questions:

- 1) How does the addition of positive items affect the psychometric properties of the modified Parenting Stress Index? (Chapter 6 and 7)
- 2) How well does the transactional stress and coping model fit the observed data in samples of mothers of children with spina bifida and/or hydrocephalus and mothers of children asthma? (Chapter 9 and 10)
- 3) How does positive gain affect the adaptation and adjustment in mothers of children with a disability / chronic illness? (Chapter 12)

## 5.2 Method

### 5.2.1 Ethical approval and consent

Ethical approval for the studies was obtained from the Department of Psychology Ethical Committee, University of Southampton (Study 1-4, 6-7) and/or the Southampton and South West Hants Joint Research Ethics Committee (Study 5-7). Verbal or written consent was obtained for all participants.

### 5.2.2 Participants and procedure

#### 5.2.2.1 Sample 1: mothers of children with spina bifida and hydrocephalus

A survey was sent to 399 families with a child with spina bifida and/or hydrocephalus aged 6-12 years. All families had completed a postal questionnaire approximately 6 months previously; as part of a comprehensive study concerning the developmental, behavioural and educational characteristics of children with these conditions (see Pit-ten Cate & Stevenson, 1999). The initial sample was recruited through the register of the Association for Spina Bifida and Hydrocephalus (ASBAH). Families are entered on this register when they contact ASBAH for information and/or support. The current sample included families who indicated they would be interested in taking part in future research. At the end of a 3-month period 325 questionnaires (82%) had been returned and were included for analyses. T-tests and Chi square analyses were conducted to test for differences between respondents and non-respondents survey on demographic and disability characteristics (Appendix A). No significant differences were detected except for mother's age and educational level. Respondent mothers were older than non-respondent mothers (Mean = 38.61, SD = 6.42 and Mean = 36.63, SD = 5.42 for respondent and non-respondent mothers respectively). Non-respondent mothers were less well educated than respondent mothers. It should be noted that data used in the studies were collected at 2 different time points. Time 1 data was collected as part of the original survey conducted in



July - September 1999 and Time 2 data was collected in February – April 2000.

The participating families represent the following groups: spina bifida alone N = 44 (14%), hydrocephalus alone N = 203 (63%) and spina bifida and hydrocephalus N = 78 (24%). The sample included 144 girls (44%) and 181 boys (56%). Most children attended a mainstream school N = 224 (69%), others attended either a special class within a mainstream school N = 21 (7%) or a school for special education N = 76 (23%). The developmental level of 145 (45%) children was average or above, and of 177 (55%) children below average (based on parent rating). The children's ages range from 6 to 14 years (Mean = 9.41, SD = 2.16). The ages of the mother or primary caregiver ranged from 24 to 55 years (Mean = 38.61, SD = 6.42) and the ages of the father or secondary caregiver ranged from 25-62 years (Mean = 41.05, SD = 6.83). Most children lived with their biological parents (N = 222, 68%). The remaining children lived with their mother only (N = 59, 18%), with their father only (N = 3, 1%), with their mother and a new partner (N = 23, 18%), with foster or adoptive parents (N = 11, 3%), or with others (N = 4, 1%). In total 254 children were raised in two-parent families and 65 children in one-parent families. The average total number of children in the family was 2.54 (SD = 1.32).

#### 5.2.2.2 Sample 2: mothers of children with asthma

Families were recruited via the asthma clinic at Southampton General Hospital. Families were identified using in- and outpatient record sheets. Surveys were sent to 250 families with a child with asthma aged 5-13 years. Initially only families of 6-12 year old children were contacted, however, as only a relative small number of questionnaires was returned, the age range was extended to also include families of children aged 5 and 13 years. Ten families responded that their child did not suffer from asthma. At the end of a 4-month period a total of 92 completed questionnaires were returned (38%). Mother's ages ranged from 22 to 54 years (Mean = 36.41, SD = 7.07). The mean age of the children (22 girls and 51 boys) was 8.17 years (SD = 2.59), ranging from 4 to 13 years. Seventy-five children (83%) functioned on an average or above developmental level and 15 (17%) children functioned

below average. Most children lived with their biological parents (N = 68, 74%). The remaining children lived with their mother only (N=13, 14%) or with their mother and a new partner (N=9, 10 %). In total 77 children were raised in two-parent families and 14 children in one-parent families. The total number of children in the family ranged from 1 to 6 with an average of 2.45 (SD = 1.11).

#### 5.2.2.3 Sample 3: general population sample

Families were recruited via 3 mainstream schools in the Southampton area (2 primary schools, 1 junior/infant school). Schools were asked to distribute questionnaires amongst parents of children aged 6-12. As some parents have more than one child attending the same school, the parent was asked to complete the questionnaire for their oldest child at that school. The current sample includes 168 families who returned a completed questionnaire. The sample included mothers of 92 boys and 74 girls. The child's age ranged from 5 to 14 years (Mean = 8.81, SD =1.85). The age of the mothers ranged from 25 to 49 years (Mean = 38.84, SD = 4.88). Most children lived with both biological parents (N = 149, 89%), nine (5%) lived with mother only, six (4%) lived with their mother and a new partner and four (3%) lived in other circumstances. The number of children living at home ranged from 1 to 5, with an average of 2.23 (SD = .74).

#### 5.2.3 Measures

Measures used in the studies were either sent to parents (Sample 1 and 2) or handed out in school (Sample 3). As described above, Sample 1, mothers of children with spina bifida and/or hydrocephalus, received two postal surveys (see Appendix B). Only parts of the initial survey were used, including demographic and disability characteristics, the impact of the disability on the family as a whole, as well as the following standard measures: (1) Family Needs Survey (Bailey, Blasco, & Simeonsson, 1992; Bailey & Simeonsson, 1988), (2) Caregiving Self-Efficacy Scale (Hastings & Brown, 2002), and (3) Strengths and Difficulties Questionnaire (Goodman, 1997). The second survey regarded stress, coping and family functioning and included the following standard measures: (1) Handicap-related Problems for Parents Inventory (Wallander & Marullo, 1997), (2) a modified version of the

Parenting Stress Index-Short Form (Abidin, 1995), (3) Brief COPE (Carver, 1997), (4) Family Satisfaction Scale (Olson & Wilson, 1992).

Sample 2, mothers of children with asthma, received one questionnaire including some questions regarding demographic characteristics and asthma medication as well as the following standardised measures: (1) questionnaire on perceived symptoms and disability in asthma (Usherwood, Scrimgeour, & Barber, 1990), (2) Handicap-related Problems for Parents Inventory (Wallander & Marullo, 1997), (3) Caregiving Self-Efficacy Scale (Hastings & Brown, 2002), (4) Strengths and Difficulties Questionnaire (Goodman, 1997), (5) a modified version of the Parenting Stress Index-Short Form (Abidin, 1995), (6) Brief COPE (Carver, 1997), and (7) Family Satisfaction Scale (Olson & Wilson, 1992) (see Appendix C).

Sample 3, general population sample, received questionnaires via the school of their child (see Appendix D). These questionnaires contained a few questions on demographic characteristics and only the modified version of the Parenting Stress Index-Short Form (Abidin, 1995).

#### 5.2.3.1 Demographic and disability characteristics

For all 3 samples questions on demographic characteristics included the family constellation, age of parents and child, and the educational level and employment status of both parents. For Samples 1 and 2 further questions were asked regarding the number of children in the family and the developmental level of child. For Sample 1, questions on disability characteristics included type of disability, type of spina bifida and level of lesion (spina bifida), shunt status and number of revisions (hydrocephalus), and if the child suffered from epileptic fits or other medical conditions. For Sample 2 questions on chronic illness characteristics included type and frequency of use of medication.

#### 5.2.3.2 Disability parameters

Based on literature several questions were included to determine the type and severity of the disability. For Sample 1 the severity of disability was defined in terms of the child's ability to walk, urinary and bowel function, weight and the occurrence of pressure sores. This measure was adapted from

the scheme used by Dorner (1975). For Sample 2 severity of asthma was assessed using the questionnaire to measure perceived symptoms and disability in asthma (Usherwood et al., 1990). This questionnaire provides a quantitative measure of symptoms and disability parents perceive in their children with asthma aged 5-14 years. The questionnaire contains 17 items comprising three scales: perceived disability, perceived daytime symptoms and perceived nocturnal symptoms. A total score can be computed by adding the subscale scores. Items are scored on a 5-point Likert scale (0 = not at all, 4 = every day). Higher scores indicate greater perceived disability or extent of symptoms. The content validity of the three subscales was supported by a principal component analyses with varimax rotation. Internal reliability was established by computing Coefficient Alpha for each subscale. Coefficient Alpha ranged from .71 to .92 for the three scales in two different samples (Usherwood et al., 1990).

Functional limitations were measured using six questions regarding the child's difficulties with activities of daily life, i.e. washing, dressing, eating, continence, finding way, and walking ordinary distances. The extent to which routine activities are restricted by chronic illness/disability plays a central role in psychological adjustment (Williamson, 1998). The measure was adapted from a measure used by Goodman and Yude (R. Goodman, personal communication, May 1999) in studies involving children with hemiplegia.

#### 5.2.3.3 Impact on Family

To determine the impact on family, nine items on how the child with a disability had affected the family as a whole were included. The items were adapted from Goodman and Yude (R. Goodman, personal communication, May 1999). Items reflect possible affects, e.g. 'less time for other children' or 'we have become more caring'. In addition the parent can indicate 'no effect'. The items are scored 0 or 1. A total 'family impact score' can be computed by adding the item scores (range 0-9). If parents indicate the child has had 'no effect' on the family as a whole, the family impact score is 0.

#### 5.2.3.4 Family Needs Survey (FNS)

The FNS (Bailey et al., 1992; Bailey & Simeonsson, 1988) was developed for the assessment of needs of families of children with disabilities such that findings could be easily translated into early intervention goals and programs. The instrument has also been used in studies on parental adaptation to children with disabilities. The FNS was adapted for use in a European, i.e. Finnish, sample of families of children with special needs (M. Leskinen, personal communication, November 1998). Adaptations included the omission of 2 items: 'paying for therapy, day care or other services my child needs' and 'explaining my child's condition to other children'. In addition 2 items, 'explaining my child's condition to my parents or my spouse's parents' and 'explaining my child's condition to his/her siblings' were combined into one item 'explaining my child's condition to other family members'. This adapted version was used in the current study. The adapted FNS consists of 32 items, yielding six subscales: information (7 items), family and social support (8 items), professional support (3 items), financial (5 items), explaining to others (3 items), childcare (3 items), and community services (3 items). Each item reflects a specific need, e.g. 'I need more information about my child's condition or disability'. Parents rate items on a 3 point scale, 1 = no help needed, 2 = not sure, and 3 = yes help needed. A total needs score is computed by counting the number of times parents indicate 'yes help needed'. Correspondence ratings between mother and father ratings of .52 and stability ratings (test-retest coefficients) of .67 and .81 for mothers and fathers, respectively, have been reported (Bailey & Simeonsson, 1988). Factor analyses confirmed the 6-subscale structure for mothers (Bailey et al., 1992). Although mothers expressed significantly more needs than fathers, needs were relatively independent from other demographic variables such as race, SES, birth order and disability type (Bailey et al., 1992).

#### 5.2.3.5 Caregiving Self Efficacy Scale (CSES)

The CSES (Hastings & Brown, 2002) was adapted for use in this sample. The scale was originally developed for use in research involving families of young children with autism engaged in early intervention. The

CSES concerns parental feelings about their role as a caregiver. Five items are rated on a 7-point Likert scale (1 = 'not at all', 7 = 'very'). Items concern parents' perception of their level of confidence, difficulties, effectiveness, satisfaction and control in regards to the care of their child. A total caregiving score is computed by adding the items scores (range 5-35). Hastings & Brown (2002) reported good internal consistency (Cronbach's alpha = .92). It should be noted that Hastings and Brown used the measure to assess caregiving efficacy related to dealing with behaviour problems of a child with autism. In the current studies caregiving efficacy relates to the general care for a child with spina bifida and/or hydrocephalus or a child with asthma.

#### 5.2.3.6 The Strengths and Difficulties Questionnaire-Parent Report (SDQ)

The SDQ (Goodman, 1997) is a parent rated 25 item behavioural screening questionnaire for use with children aged 4 to 16 years. Twenty-five items refer to positive and negative attributes. The 25 items generate 5 subscale scores: conduct problems, hyperactivity and inattention, emotional symptoms, peer problems and pro-social behaviour. A total difficulties score can be computed by summing the first four subscale scores. A test-retest reliability coefficient (intraclass correlation) of .85 has been reported for the SDQ total score (Goodman, 1999). The SDQ correlated highly with widely used Rutter questionnaires (Elander & Rutter, 1996) and the Child Behavior Checklist (Achenbach, 1991) and was equally able to discriminate between high and low risk samples providing support for its reliability and validity (Goodman, 1997; Goodman & Scott, 1999). The SDQ seemed particularly useful for the purpose of this study because of its brevity, and the availability of both UK population norms and comparison data for a sample of children with hemiplegia (Goodman, 1998; Goodman & Graham, 1996; Meltzer, Gatward, Goodman, & Ford, 2000).

#### 5.2.3.7 Handicap-related Problems for Parents Inventory (HPPI)

The HPPI (Wallander & Marullo, 1997) consist of 17 items concerning the most commonly reported sources of problems experienced by parents of children with physical disabilities. The problems are defined such that they do

not have to be directly brought on by the child or be a direct effect of the child's disability. The response format, however, reflects a perceived association between problem and disability by the parent. An 8-point Likert scale is used to rate the items (0 = not at all; 7 = every day or more), comprising three subscales: mother/child social (HPPI-MCS), mother's life (HPPI-ML), and child's health & services (HPPI-CHS). The parent/child social subscale concerns problems in social systems as well as in child behaviour and leisure activities. The mother's life subscale regards problems for the mother in areas relatively more independent of the child and immediate family. The child health and services addresses problems and special services directly related to the child's condition. A total scale score can be computed by summing the subscale scores. The HPPI showed moderate correlations with a measure of daily hassles and scores discriminated between specific disabilities and conditions, establishing concurrent validity of the instrument. Furthermore the HPPI scores correlated with mother's mental health and physical symptoms, social support and child behaviour problems, supporting the construct validity of the instrument. Alpha internal consistency estimates of .87, .81, .80 and .71 for the total scale and the HPPI-MCS, HPPI-ML and HPI-CHS, respectively, have been reported (Wallander & Marullo, 1997).

#### 5.2.3.8 Parenting Stress Index-Short Form Modified (PSI-SF49)

Parents completed a modified version of the parenting stress index - short form (PSI-SF36; Abidin, 1995). For the original PSI-SF36, a 5-point Likert scale is used to rate 36 items (1 = strongly agree, 5 = strongly disagree). The PSI-SF36 contains three subscales: parental distress, parent-child dysfunctional interaction, and difficult child. A total stress score can be computed by summing the subscale scores. Test-retest reliability coefficients range from .68 - .85 for the subscale and total scores. Alpha reliability coefficients for the subscales of parental distress, parent-child dysfunctional interaction, and difficult child of .87, .80, and .85, respectively, have been reported (Abidin, 1995). Alpha internal consistency of the total stress score was .91 (Abidin, 1995).

The order and wording of the items of the original PSI-SF36 was maintained, interspersing an additional 14 items in a random manner. The 14 additional items were worded similarly to the original items of the PSI-SF36, but the items refer to positive character traits of the child and pleasant experiences associated with raising a child with a disability/chronic illness. The choice for the items was guided by a pilot study concerning pleasant and bothersome experiences of parents raising a child with spina bifida and/or hydrocephalus and a review of the literature. The pilot study involved 20 telephone interviews with parents of children with spina bifida and/or hydrocephalus regarding positive and negative experiences associated with raising a child with a disability. Seven of the 14 items concerned the parent, e.g., 'Since having this child I feel I have grown as a person', 'Since having this child I have a greater understanding of other people'. Four items referred to the child, e.g., 'My child has a lot to give to other people', 'My child is a fighter and does not give up easily', and three items referred to family characteristics, e.g., 'Since having this child, my family has become closer to one another'. Parents rated the items using the 5-point Likert scale of the original PSI-SF36. A more detailed description of the adapted scale and its psychometric properties is reported in Chapter 6.

#### 5.2.3.9 Brief COPE

The Brief COPE (Carver, 1997) is a shortened version of the COPE inventory (Carver, Scheier, & Weintraub, 1989). The Brief COPE was developed to make the instrument more acceptable to respondents, i.e. less time involved to complete and less redundancy of the items. The Brief COPE contains 28 items comprising 14 scales: Active Coping, Planning, Positive Reframing, Acceptance, Humour, Religion, Emotional Support, Instrumental Support, Self-Distraction, Denial, Venting, Substance Use, Behavioural Disengagement and Self-Blame. Respondents rate their extent of use of a coping strategy on a 4-point scale (1 = have not been doing this at all, 4 = have been doing this a lot). The Brief COPE compared well to the full length COPE in terms of its factor structure. Alpha coefficients for internal consistency all exceeded .50, providing support for the internal reliability of the abbreviated scales (Carver, 1997). Analyses were performed to



investigate the factor structure of the Brief COPE. Results of these analyses are described in paragraph 5.3

#### 5.2.3.10 Family Satisfaction Scale (FSS)

The FSS (Olson & Wilson, 1992) is a measure that assesses two of the three dimensions of the Circumplex Model of marital and family systems (Olson et al., 1983). It contains 14 items, which comprise two subscales: family cohesion and family adaptability. Family cohesion is defined as the emotional bonding between family members. Family adaptability refers to the ability of a marital or family system to change its power structure, role relationships and relationship rules in response to situational and developmental stress. The 14 items of the FSS are rated on a 5-point Likert scale (1 = dissatisfied, 5 = extremely satisfied).

Factor analyses did not confirm the 2-factor structure of the FSS, i.e. the principal component factor analysis with varimax rotation revealed just one factor. Olson and Wilson (1992) therefore concluded that although the FSS provides two subscales, the total score is most empirically valid. Therefore only the total scale will be used in the current studies. A test-retest correlation coefficient of .75 and a Cronbach alpha internal consistency coefficient of .92 have been reported for the total scale (Olson & Wilson, 1992).

### 5.3 Scale development and data reduction.

An exploratory factor analysis was conducted to investigate the factor structure of the Brief COPE (Carver, 1997) using the combined dataset of samples 1, mothers of children with spina bifida and hydrocephalus, and 2, mothers of children with asthma. The analysis was conducted to investigate the relationship between the coping strategies and served the purpose of reducing the number of variables. Carver (1997) stated that it might be more informative to study the diversity of coping response separately rather than to apply the widely used distinction between problem focused and emotion focused coping strategies (Carver et al., 1989). However, for the purpose of the current studies it seemed more appropriate to investigate the underlying

structures of the different coping strategies. This could reduce the number of variables and allow for studying the relationships between groups of coping strategies and parental adjustment.

The initial principal component analysis generated three factors with eigenvalues greater than one. The scree plot also showed discontinuity after three factors. This 3-factor solution explained 54% of the variance. The factor loadings for this solution are shown in Table 1.

The first two factors were named 'problem focused coping' and 'emotion focused coping', in accordance with existing coping literature (e.g. Lazarus & Folkman, 1984). The third factor was named 'Religious Coping'. Problem focused coping refers to attempts of the individual 'to alter the troubled transaction between person and environment through efforts directed at the environment or the self'. Emotion focused coping refers to attempts of the individual 'to regulate emotional states that are associated with stress' (Thompson & Gustafson, 1996b, p9). As religious coping only reflected one single item, religious coping was omitted from further analyses. Based on the factor analyses 'emotion focused coping' and 'problem focused coping' subscale scores were computed by summing the respective coping strategy scores. Descriptive statistics for the 2 subscales and their interrelations are presented in Table 2. As is shown in Table 2 there is a significant moderate correlation between problem- and emotion focused coping.

The internal consistency of the Brief COPE was also investigated. The Cronbach's alpha reliability coefficient for the total Brief COPE was .83. Alpha coefficients for the 2 coping subscales were .83 and .75 for 'problem focused' coping and 'emotion focused' coping, respectively.

Table 1: Brief COPE - Principal Components Varimax Rotated Factor Loadings (N=413).

	Factor 1 Problem Focused Coping	Factor 2 Emotion Focused Coping	Factor 3 Religious Coping
Brief Cope			
Coping strategy			
Acceptance	<b>.66</b>	-.07	-.08
Active coping	<b>.78</b>	.17	.04
Emotional support	<b>.64</b>	.06	.28
Humour	<b>.42</b>	.30	-.39
Instrumental support	<b>.73</b>	.04	.24
Planning	<b>.79</b>	.17	.04
Positive reframing	<b>.72</b>	.12	-.13
Behavioural			
disengagement	-.05	<b>.76</b>	.06
Denial	.01	<b>.66</b>	.20
Self blame	.24	<b>.73</b>	-.03
Self distraction	.38	<b>.53</b>	-.30
Substance use	-.05	<b>.54</b>	-.13
Venting	.27	<b>.68</b>	.03
Religion	.21	.09	<b>.79</b>

Table 2: Descriptive Statistics and Pearson correlations between 2 factors of the Brief COPE (N = 413)

	<u>Mean</u>	<u>SD</u>	PFC	EFC
Factors <sup>a</sup>				
PFC	31.50	8.60	1.00	.37*
EFC	18.15	5.37	--	1.00

<sup>a</sup> PFC = Problem Focused Coping; EFC = Emotion Focused Coping. The PFC and EFC scores are computed by summing the respective 7 and 6 coping strategy scores. For both factors a high score reflect more use of the coping strategies.

\* p <.001.

Several studies will be discussed in the next few chapters. Each chapter will outline the specific participant pool and measures used for the purpose of the described study. Although the studies have separate aims, together they make it possible to evaluate the processes underlying parental adjustment to childhood disability, and more specifically to investigate the role of positive contributions of child with a disability/chronic illness in parental adjustment. The transactional stress and coping model of adjustment to disability and chronic illness (Thompson et al., 1993a) provides the framework for this main question. This model was chosen as it distinguishes itself from other models by incorporating the ecological-systems theory. More specifically, the model takes into account that the adjustment of one person in the family affects the adjustment of other family members. In other words it acknowledges the relationship between parent and child adjustment. This notion seems important as research findings suggest that parent adjustment is not so much affected by the severity of their child's disability per se as by child adjustment problems.

## CHAPTER 6

### Study 1: Pain and Gain –

#### Reliability and Validity of a Modified Parenting Stress Index

The parenting stress index (Abidin, 1995) is a widely used instrument to assess the extent to which the parent-child dyad is under stress. Parenting stress is seen as a function of child characteristics, parent characteristics and situational factors. The index can be used for parents of children aged 1 month - 12 years. There are two versions of the instrument: an extensive full-length test (PSI) and a short form (PSI-SF36), which is derived directly from the full-length version. The PSI contains 120 items, yielding 13 subscales, comprising two domains: Child Domain and Parent Domain. A total stress score can be computed by summing the child and parent domain scores. Parents rate the items on a 5-point Likert scale (1 = strongly agree, 5 = strongly disagree). The PSI-SF36 contains 36 items, directly derived from the PSI, using identical wording and the same rating scale. The PSI-SF36 can be administered in less than 10 minutes and yields three subscales: parental distress, dysfunctional interaction, and difficult child. A total stress score can be computed by adding the subscale scores.

The current study involves the PSI-SF36, therefore only this version will be discussed in further detail. The PSI-SF36 subscale 'parental distress' (PSI-PD) reflects the distress a mother/father is experiencing within the parental role as a function of personal factors directly related to parenting. The subscale 'parent child dysfunctional interaction' (PSI-PCDI) focuses on the discrepancy between parent's perception of the child and parent's expectations and reflects that the mother/father does not feel reinforced as a parent by the interaction with the child. The difficult child subscale (PSI-DC) refers to the behavioural characteristics of the child that make it difficult to manage. These characteristics are often rooted in the temperament of the child, but also include learned patterns of defiant, non-compliant and demanding behaviour. Finally, the PSI-SF36 total stress score gives an indication of the overall level of stress a mother/father is experiencing within the role of a parent (Abidin, 1995).

## 6.1 Psychometric properties of the PSI-SF36

### 6.1.1 Reliability

Reliability refers to the accuracy (consistency and stability) of measurement by a test (Isaac & Michael, 1995, p134). Stability over time can be evaluated by retesting the individual with the identical test, whereby the test-retest correlation coefficient reflects the degree in response variation by the individual from one occasion to the next. Consistency of a test refers to the homogeneity of the test, i.e. the extent to which the items within a test are similar in content. Consistency can be evaluated using Spearman-Brown split-half correlations or Cronbach's Alpha coefficient of internal consistency.

Test-retest reliability coefficients ranged from .68 - .85 for the PSI-SF36 subscale and total scores (Abidin, 1995). An Alpha reliability coefficient for the total stress scale of .91 has been reported. Alpha coefficients for the subscales PSI-PD, PSI-PCDI, and PSI-DC ranged from .80 to .87 (Abidin, 1995).

### 6.1.2 Validity

"Validity information indicates the degree to which a test is capable of achieving certain aims. Tests are used for several types of judgement and for each type of judgement a different type of investigation is required to establish validity" (Isaac & Michael, 1995 , p128). The most commonly used categories of validity are: a) face validity, the extent to which the test items are acceptable to both test user and participant, within the context that the test is being used; b) content validity, the extent to which the test reflects the subject matter about which conclusions are to be drawn; c) predictive validity, the extent to which the test can be used to make predictions; d) concurrent validity, the extent to which the test relates to other tests which purport to measure the same construct; and e) construct validity, the extent to which certain explanatory concepts or constructs account for the performance on the test (Isaac & Michael, 1995, p128-131; Rust & Golombok, 1995, pp78-81).

Most research regarding the validity of the parenting stress index is conducted using the full-length PSI. However, as "the parenting stress index-

short form is a direct derivative of the full length PSI, it is likely it will share in the validity of the full length PSI" (Abidin, 1995, p61). The PSI manual extensively describes research in support of the validity of the PSI. Below a selection of the validity research is discussed.

#### 6.1.2.1 Content validity

Abidin (1995) reported a correlation between the PSI and PSI-SF36 total score of .94. The correlation coefficients between the PSI child domain score and PSI-SF36 subscale scores PSI-DC and PSI-PCDI were .87 and .73 respectively. The correlation coefficients between the PSI parent domain and the PSI-SF36 subscale scores PSI-PD and PSI-PCDI, are .92 and .50, respectively. Abidin (1995) explained the lower correlation between the PSI domains and the PSI-PCDI scale (.50 and .73) by the fact that the PSI-PCDI subscale contains items of both PSI child and parent domain; hence the correlation with either domain is relatively low.

#### 6.1.2.2 Predictive validity

To establish predictive validity of the PSI, the relationship between PSI scores and child developmental level, disabilities and behaviour has been investigated. In general, research findings support the notion that parents of children with developmental delays, disabilities and behaviour problems experience higher levels of parenting stress. For example, parents of children aged 18-72 months with disabilities, including cerebral palsy, autism, multiple disabilities, genetic disorders and general delays, reported more stress across both PSI 'Child Domain' and 'Parent Domain' than parents with non-disabled children (Beckman, 1991). In a longitudinal study involving children with Down's syndrome, hearing impairments and neurological impairment, mothers of less developmentally advanced children reported more stress (Hanson & Hanline, 1990). Similarly, mothers of children with spina bifida scored higher than matched controls on both domains and total stress (Kazak & Marvin, 1984). Cameron and Orr (1989) reported that child behaviour problems, disability and level of independence were related to higher Parent Domain scores. In the same study, behaviour problems and degree of developmental delay accounted for 50% in the variance of total stress. In a more recent

study, mothers of children with disabilities aged 1-12 years scored higher than the norm-group on the Child Domain, but not on the Parent Domain (Innocenti, Huh, & Boyce, 1992). This result suggested that although stresses related to child variables are different for mothers of children with disabilities than those for mothers of normal children, stresses related to parent variables are similar.

#### 6.1.2.3 Concurrent Validity

Support for the concurrent validity comes from the relative few studies correlating PSI scores with scores on tests tapping into the same construct. For example, significant correlations have been reported between the PSI and the Family Impact Questionnaire (FIQ). The FIQ (Donenberg & Baker, 1993) evaluates parents' perceptions of the impact of the child on their family. It is commonly used to indicate levels of stress related to parenting (e.g. Baker, Heller, & Henker, 2000). Moderate correlations were found between the PSI child domain scores and FIQ in families of children with behaviour problems (Donenberg & Baker, 1993).

#### 6.1.2.4 Construct validity

Extensive research is available to support the construct validity of the PSI. For example, relationships have been found between parenting stress and family resources, social support, parental coping, and family functioning. According to theory lower levels of stress are associated with more available resources and support, successful coping, higher sense of competence and more cohesive families. Research confirms these associations, therefore providing support for the construct validity of the PSI. For example Kazak and Marvin (1984) reported that total stress scores were negatively correlated with family network size and total support network in a sample of mothers of children with spina bifida. Similarly, in a study involving children with various disabilities, significant correlations were found between stress and formal support for both parents (Beckman, 1991).

Studies involving parents of young children revealed associations between coping strategies and parenting stress total scores (Bramlett, Hall, Barnett, & Rowell, 1995; Jarvis & Creasey, 1991). More specifically, positive



reappraisal was associated with decreased levels of stress, whilst escape-avoidance coping was associated with increased levels of stress (Jarvis & Creasey, 1991).

Parenting stress has also been associated with family functioning, i.e. family cohesion and adaptability. Greater stress in families of children with Down's syndrome, motor impairment or developmental delay of unknown origin, was associated with poorer family functioning as characterised by low levels of adaptability and cohesion (Krauss, 1993). Similarly, higher levels of family cohesion and adaptation were associated with lower levels of parenting stress in parents of children with facial port wine stains (Miller, Pit-ten Cate, Watson, & Geronemus, 1999).

## 6.2 Criticism of the PSI-SF36

Personal experience when using the PSI-SF36 (Miller, Pit-ten Cate, & Johann-Murphy, 2001; Miller et al., 1999) revealed that some parents find the PSI items to be too negative in focus. All items of the PSI-SF36 are formulated in negative terms, focusing on stressors in the parent-child system. For example: 'I feel trapped by my responsibility as a parent'; 'my child is not able to do as much as I expected'; and 'I expected to have closer and warmer feelings for my child than I do and this bothers me'. Although parents can indicate that they do not agree with the statements, the negative wording of the items can be disconcerting. This conclusion was supported by the experiences of colleagues, using the PSI-SF36 with parents of children with autism and learning difficulties (T. Brown & R.P. Hastings, personal communication, November 1999).

In addition, it could be argued that if items are all worded in the same direction this may influence the respondent's mood, therefore affecting the responding bias. As items on the PSI-SF36 are all worded in negative terms, the respondent may become relatively sad which could affect self-valence (see Sedikides, 1992, for a review). This may result in parents over-reporting problems.

Furthermore the PSI-SF36 does not allow for positive contributions of the parent-child system, but only for the absence of negative factors at best.

In line with the assumption that stressors are additive (Abidin, 1995), it could be argued that positive gains may have a protective role. Most research has focused on negative aspects of disability. These negative factors impose a risk for adjustment problems for both child and parent. Brown and Harris (1978, p 47) suggested that some risk factors could be called protective factors, because although the presence of a factor may hold a threat, their absence protects the individual. In that sense, findings of research focusing on risk factors may be used to identify protective factors. However, the emphasis of these studies remains on the negative aspects associated with disability. To date few studies have focused on the role of positive factors associated with raising a child with a disability. Focusing on positive as well as negative characteristics of parenting may facilitate a better understanding of the processes that mediate adjustment in parents raising a child with a disability.

### 6.3 Reliability and validity of a modified parenting stress index

In order to make the PSI-SF36 more acceptable to respondents, and to allow for measurement of positive gains from the parent-child system, 13 items were added to the PSI-SF36. The current study was conducted to address two questions regarding the modified scale. Firstly, what is the impact of the additional items on the psychometric properties of the PSI-SF36? Secondly, what is the value added by the items, i.e., do they only make the instrument less disconcerting and therefore more acceptable to parents and do they add to our understanding of parents' experiences of stress? To answer these questions the factor structure and the psychometric properties of the modified PSI-SF will be investigated.

#### 6.3.1 Hypotheses

In this study the following hypotheses will be tested:

- 1) Psychometric properties of the PSI-SF36 will be unchanged after interspersing positive items.
- 2) The added positive items will form a separate factor or factors, rather than load on the original factors identified by Abidin (1995).

- 3) This new factor will contribute to construct validity, i.e. it will contribute to explaining variance in related constructs such as family functioning and caregiving efficacy.

### 6.3.2 Data analyses

To test hypothesis 1 the factor structure, reliability and validity of the modified PSI-SF36 will be investigated and compared to original psychometric data. Factor analyses will be used to test the factor structure of the modified PSI-SF36. Cronbach's alpha coefficients will be computed to test the internal consistency of the measure. The predictive validity will be tested in 3 ways. First, t-tests will be performed to test for differences in PSI scores between children functioning 'below average' and 'average or above'. It is expected that parents of children with developmental delay will have higher stress scores than parents of children functioning average or above. Second, analyses of variance will be used to test for differences in stress scores between disability groups. It is expected that parents of children with both conditions, i.e. both physical and mental development may be affected, will report the highest levels of stress. Third, predictive validity will be established by identifying the association between the PSI-SF36 and child behaviour problems using t-test. It is expected that more behaviour problems will be associated with higher levels of stress.

Pearson correlations and regression analyses will be used to investigate the concurrent and construct validity of the modified PSI-SF36. Measures of family needs, impact of disability on the family, and handicap related problems for parents will be used to establish concurrent validity. Moderate to high correlations will be expected between these measures and the PSI-SF36. It is also expected that these measure will explain significant amounts of variance in the PSI total score.

To establish construct validity the associations between the modified PSI-SF36 and measures of coping, caregiving efficacy and family functioning will be investigated. It is expected that problem focused coping, perceptions of caregiving efficacy, and family cohesion and adaptation will be associated with lower levels of stress whilst emotion focused coping will be associated with increased levels of parenting stress.

To test hypothesis 2 additional factor analyses will be performed, including the original PSI-SF36 items and the new positive items. It is expected that the positive items will form a separate factor or factors in addition to the 3 original factors.

Pearson correlations and regression analyses will be used to test hypothesis 3. The regression analyses will test models in which in step 1 the original scales of the PSI-SF36 are entered and in step 2 the positive items. This way the significance of the percentage of additional variance explained by the positive items can be determined. As discussed, positive gain associated with raising a child with a disability may moderate the relationship between disability parameters and parent adjustment. Therefore it is expected that the additional items will mainly contribute to the construct validity of the measure.

## 6.4 Method

### 6.4.1 Participants and procedure.

Sample 1 and the recruitment procedure have been described in Chapter 6. The current sample included 325 families of children with spina bifida and/or hydrocephalus. Families completed two questionnaires, whereby the 2<sup>nd</sup> questionnaire was mailed to parents approximately 6 months after receiving the first. Ethical approval for this study was obtained from the Ethics committee of the Department of Psychology, University of Southampton. Informed consent was obtained from each participant.

### 6.4.2 Measures

Chapter 5 gives detailed descriptions of all measures used in this study. Therefore only a brief description of the measures used for the purpose of this particular study is outlined here.

#### *Parenting Stress Index-Short Form Modified (PSI-SF49)*

Parents completed a modified version of the PSI-SF36 (Abidin, 1995). The order and wording of the items of the original PSI-SF36 was maintained, interspersing an additional 14 items in a random manner. The 14 additional

items were worded similarly to the original items of the PSI-SF36, but in positive terms. The items refer to positive character traits of the child and pleasant experiences associated with raising a child with spina bifida and/or hydrocephalus. The choice for the items was guided by a pilot study concerning pleasant and bothersome experiences of parents raising a child with spina bifida and/or hydrocephalus and a review of the literature. Seven of the 14 items concerned the parent, e.g., 'Since having this child I feel I have grown as a person', 'Since having this child I have a greater understanding of other people'. Four items referred to the child, e.g., 'my child has a lot to give to other people', 'my child is a fighter and does not give up easily', and three items referred to family characteristics, e.g., 'Since having this child, my family has become closer to one another'. Parents rated the items using the 5-point Likert scale of the original PSI- SF36 (see Appendix E). It must be noted that although originally 14 items were added, unfortunately the 5-point rating scale for one item (item 47) was not printed correctly, i.e. the numbers were omitted. A substantial number of parents did not answer this item, hence the item, 'Since having this child, my family has become more caring', was omitted for all analyses.

Parents rated all items on a 5-point Likert scale is used to rate 36 items (1 = strongly agree, 5 = strongly disagree). The original PSI-SF36 contains three subscales: parental distress, parent-child dysfunctional interaction, and difficult child. A total stress score can be computed by summing the subscale scores.

#### *Handicap-related Problems for Parents Inventory (HPPI)*

The HPPI (Wallander & Marullo, 1997) consists of 17 items concerning the most commonly reported sources of problems experienced by parents of children with physical disabilities. An 8-point Likert scale is used to rate the items (0 = not at all, 7 = every day or more), comprising three subscales: parent/child social, parent's life, and child's health & services. The parent/child social subscale concerns problems in social systems as well as in child behaviour and leisure activities. The parent's life subscale regards problems for the parent in areas relatively more independent of the child and immediate family. The child health and services subscale addresses problems

and special services directly related to the child's condition. A total scale score can be computed by summing the subscale scores.

#### *Disability parameters.*

Several questions were included to determine the type and severity of the disability. Severity of disability was defined in terms of the child's ability to walk, urinary and bowel function, weight and the occurrence of pressure sores. In addition, six questions regarding the child's functional impairment as defined by difficulties with activities of daily life were included, i.e. washing, dressing, eating, continence, finding way, and walking ordinary distances. In addition parents rated 1 item on the child's developmental status (1 = below average, 2 = average, 3 = above average).

#### *The Strength and Difficulties Questionnaire*

The SDQ (Goodman, 1997) is a parent rated 25 item behavioural screening questionnaire for use with children aged 4 to 16 years. The 25 items generate 5 subscale scores: conduct problems, hyperactivity and inattention, emotional symptoms, peer problems and prosocial behaviour. A total difficulties score can be computed by summing the first four subscale scores.

#### *Impact on the Family Scale*

The impact on the family scale is a nine-item scale concerning how the child with a disability has affected the family as a whole. The scale was adapted from Goodman and Yude (R. Goodman, personal communication, May 1999). Items reflect possible effects, e.g. 'less time for other children' or 'we have become more caring'. In addition the parent can indicate 'no effect'. The items are scored 0 or 1. A total 'family impact score' can be computed by adding the item scores (range 0-9). If parents indicate the child has had 'no effect' on the family as a whole, the family impact score is 0.

#### *Caregiving Self Efficacy Scale (CSES)*

The CSES (Hastings & Brown, 2002) was adapted for use in this sample. The scale was originally developed for use in research involving

families of young children with autism engaged in early intervention. The CSES concerns parental feelings about their role as a caregiver. Five items are rated on a 7-point Likert scale (1 = 'not at all', 7 = 'very'). Items concern parents' perception of their level of confidence, difficulties, effectiveness, satisfaction and control in regards to the care of their child. A total caregiving score is computed by adding the items scores (range 5-35).

#### *Family Needs Survey (FNS)*

The Family Needs Survey (FNS) (Bailey et al., 1992; Bailey & Simeonsson, 1988) was adapted for use in this British sample. The adapted FNS consists of 32 items, yielding six subscales: information (7 items), family and social support (8 items), professional support (3 items), financial (5 items), explaining to others (3 items), childcare (3 items), and community services (3 items). Each item reflects a specific need, e.g. 'I need more information about my child's condition or disability'. Parents rate items on a 3 point scale, 1 = no help needed, 2 = not sure, and 3 = yes help needed. A total score can be computed by counting the number of times parents choose the 'yes help needed' option. For the purpose of this study only the total needs score will be used.

#### *Family Satisfaction Scale (FSS)*

The FSS (Olson & Wilson, 1992) contains 14 items, which comprise two subscales: family cohesion and family adaptability. Family cohesion is defined as the emotional bonding between family members. Family adaptability refers to the ability of a marital or family system to change its power structure, role relationships and relationship rules in response to situational and developmental stress. The 14 items of the FSS are rated on a 5-point Likert scale (1 = dissatisfied, 5 = extremely satisfied). A total score can be computed by summing the 2 subscale scores. This total score will be used in this study.

#### *Brief COPE*

The Brief COPE (Carver, 1997) contains 28 items comprising 14 scales: Active Coping, Planning, Positive Reframing, Acceptance, Humour,

Religion, Emotional Support, Instrumental Support, Self-Distraction, Denial, Venting, Substance Use, Behavioural Disengagement and Self-Blame. Respondents rate their extent of use of a coping strategy on a 4-point scale (1 = have not been doing this at all, 4 = have been doing this a lot). Factor analyses revealed a 3-factor structure (see paragraph 6.3). The 1<sup>st</sup> factor, problem focused coping, comprises of the scales: acceptance, active coping, emotional support, humour, instrumental support, planning, and positive reframing. The 2<sup>nd</sup> factor, emotion focused coping, comprises of the scales: behavioural disengagement, denial, self blame, self distraction, substance use and venting. The religion scale formed a 3<sup>rd</sup> factor, however, this 3<sup>rd</sup> factor will not be used in further analyses.

## 6.5 Results

Reliability data for measures used to validate the modified PSI-SF49 are reported in Table 3.

Table 3: Cronbach's alpha internal consistency coefficient for current sample

Measure	Cronbach's Alpha
HPPI	
HPPI-MCS	.92
HPPI-ML	.80
HPPI-CHS	.76
Total	.92
Impact on Family	.66
CSES	.79
FNS	.93
FSS	.94

The value for most Cronbach's alpha internal consistency coefficients is higher than .8, indicating satisfactory reliability of these measures.



### 6.5.1 Factor structure of the PSI-SF36 (the original scale)

In accordance with Abidin (1995), a principal component factor analyses with varimax rotation was used to examine the factor structure of the PSI-SF36 (the original parenting stress index short form). Principal component factor analyses are conducted to investigate if variables within a group of variables form coherent subsets that are relatively independent of each other. These variables are combined into factors, which reflect underlying processes that account for the correlations between the variables. A varimax rotation is a variance maximizing procedure. It is used to maximize the variance of factor loadings by making high loadings higher and low ones lower for each factor (Tabachnick & Fidell, 2001, p595).

The initial principal components analysis generated six factors with eigenvalues greater than one. The scree plot showed discontinuity after four factors. However, the 4-factor solution, explaining 52% of the variance, showed various items loading significantly on more than one factor. This solution made comparisons with the original PSI-SF36 as well as clinical interpretation more difficult. The 3-factor solution accounting for 47% of the variance showed a basic structure similar to that reported by Abidin (1995) (Table 4). Factor 1 included all 12 items of the Parental Distress subscale. Factor 2 included nine items of the Parent-Child Dysfunctional Interaction subscale and Factor 3 included the 11 of the 12 items making up the subscale 'Difficult Child'. Eleven items received loadings greater than 0.3 on more than one factor. The analyses reported by Abidin (1995) also showed 10 cross-loadings.

Results of the factor analyses partially confirm hypothesis 1. The addition of positive items has not changed the factor structure of the original PSI-SF36.

Table 4: Parenting Stress Index-Short Form (PSI-SF36) - Principal components varimax rotated factor loadings (N=317).

	Factor 1		Factor 2		Factor 3
	Parental		Parent-Child		Difficult
	Distress		Dysfunctional		Child
			Interaction		
PSI-SF36					
Item #					
1	<b>.43</b>	(.60/.67)	<b>.42</b>		.28
2	<b>.55</b>	(.58/.47)	-.02		<b>.45</b>
3	<b>.62</b>	(.57/.61)	.21		.35
4	<b>.65</b>	(.59/.52)	.03		.23
5	<b>.69</b>	(.61/.58)	-.04		.32
6	<b>.49</b>	(.56/.48)	.23		-.00
7	<b>.60</b>	(.61/.62)	.18		.22
8	<b>.57</b>	(.52/.50)	.07		.39
9	<b>.71</b>	(.63/.51)	.17		.14
10	<b>.69</b>	(.60/.47)	.16		.08
11	<b>.66</b>	(.60/.47)	.26		.05
12	<b>.75</b>	(.63/.55)	.25		.07
13	.24		<b>.66</b>	(.52/.46)	.10
14	.11		<b>.78</b>	(.53/.33)	.09
15	.14		<b>.74</b>	(.52/.51)	-.01
16	.08		<b>.72</b>	(.41/.41)	.20
17	.19		<b>.65</b>	(.52/.42)	.08
18	.20		-.07	(.48/.46)	<b>.54</b>
19	.15		<b>.56</b>	(.49/.42)	.17
20	.31		.13	(.47/.36)	<b>.47</b>
21	.23		.04	(.51/.43)	<b>.68</b>
22	.17		<b>.43</b>	(.54/.39)	.11
23	.13		<b>.60</b>	(.44/.50)	.11

24	.03	<b>.57</b>	(.42/.43)	.31
25	.14	.29		<b>.58</b> (.54/.55)
26	.04	<b>.51</b>		.25 (.40/.34)
27	.01	<b>.44</b>		<b>.57</b> (.50/.56)
28	.16	<b>.41</b>		<b>.61</b> (.56/.50)
29	.04	.16		<b>.70</b> (.57/.36)
30	.08	.25		<b>.70</b> (.47/.50)
31	.29	.01		<b>.50</b> (.49/.44)
32	.15	.25		<b>.63</b> (.42/.41)
33	.14	.43		<b>.55</b> (.40/.32)
34	.12	<b>.43</b>		<b>.59</b> (.45/.50)
35	.22	.29		<b>.59</b> (.56/.44)
36	.19	.04		<b>.69</b> (.60/.54)

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Note: Loadings reported by Abidin (1995) for two samples (N=270 and N=530, respectively) appear in parentheses. The first sample consisted of mothers who completed the PSI during a well-child check for day care, kindergarten, or first grade at a group paediatric practice in a small city in Virginia, USA. The second sample consisted of mothers bringing their children to the same group practice for the child's 1-year well care visit. The PSI was administered as part of a routine screening of all parents and was an integrated part of the comprehensive health care services provided.

#### 6.5.2 Factor structure of the PSI-SF49 (the modified scale)

To investigate the added value of the positive items further factor analyses were conducted. The initial principal components analyses including all 49 items generated 10 factors with eigenvalues greater than one. The scree plot showed discontinuity after 4 factors. The 4 factor rotated solution accounted for 45% of the variance. The factor loadings for this solution are shown in Table 5. The first 3 factors reflected the original PSI-SF36 factor structure. Seven of the additional 13 positive items loaded on Factor 4. Three positive items had a loading greater than 0.4 on Factor 2 (parent-child dysfunctional interaction) and one item had a loading greater than 0.3 on Factor 1 (parental distress).

Table 5: Parenting Stress Index Short Form Modified (PSI-SF49) – Principal components varimax rotated factor loadings (N=310)

	Factor 1 Parental Distress	Factor 2 Parent-Child Dysfunctional Interaction	Factor 3 Difficult Child	Factor 4 Positive Gain
PSI-SF49				
Item #				
1	<b>.41</b>	.21	.39	.28
2	<b>.55</b>	.03	<b>.43</b>	-.19
3	<b>.61</b>	.12	.40	.12
4	<b>.67</b>	.08	.20	-.14
5	<b>.70</b>	-.07	.31	-.10
6	<b>.48</b>	.14	.04	.19
7	<b>.60</b>	.04	.29	.12
8	<b>.55</b>	-.03	<b>.45</b>	.06
9	<b>.71</b>	.10	.15	.13
10	<b>.67</b>	.10	.14	.14
11	<b>.64</b>	.21	.09	.10
12	<b>.75</b>	.23	.10	.10
13	.26	<b>.58</b>	.17	.23
14	.12	<b>.69</b>	.18	.20
15	.16	<b>.79</b>	.03	-.08
16	.07	<b>.58</b>	.29	.29
17	.24	<b>.73</b>	.09	.03
18	.20	-.03	<b>.48</b>	-.06
19	.17	<b>.69</b>	.16	-.08
20	.30	.18	<b>.44</b>	-.10
21	.24	.12	<b>.62</b>	-.17
22	.15	.18	.24	<b>.42</b>

23	.15	<b>.52</b>	.17	.20
24	.02	<b>.43</b>	<b>.41</b>	.26
25	.16	.22	<b>.61</b>	-.02
26	.04	<b>.42</b>	.30	.18
27	.03	.36	<b>.61</b>	.15
28	.14	.28	<b>.69</b>	.19
29	.06	.12	<b>.71</b>	-.04
30	.10	.14	<b>.72</b>	.13
31	.28	.03	<b>.48</b>	-.12
32	.15	.18	<b>.65</b>	.02
33	.14	.29	<b>.62</b>	.13
34	.10	.31	<b>.65</b>	.16
35	.24	.28	<b>.59</b>	-.04
36	.18	.04	<b>.68</b>	-.12
Positive 1*	.06	.13	-.10	<b>.55</b>
Positive 2	-.06	<b>.65</b>	.17	.17
Positive 3	.13	<b>.49</b>	.11	.06
Positive 4	.08	.14	-.08	<b>.61</b>
Positive 5	.07	.13	-.07	<b>.61</b>
Positive 6	-.28	.02	-.25	.16
Positive 7	-.11	.10	.11	.25
Positive 8	.17	-.04	.10	<b>.64</b>
Positive 9	.17	.06	.06	<b>.64</b>
Positive 10	-.06	.02	-.02	<b>.69</b>
Positive 11	-.05	.13	-.08	<b>.69</b>
Positive12	-.05	<b>.66</b>	.16	.10
Positive13	.34	.16	-.04	.21

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\* 1) Since having this child I feel I have grown as a person; 2) my child has a pleasant personality/character; 3) my child has a lot to give to other people; 4) Having this child has helped me to learn new things/skills; 5) Raising this child helps putting life into perspective; 6) since having this child, I have more often

put other peoples interest before my own; 7) my child is a fighter and does not give up easily; 8) Since having this child, my family has become closer to one another; 9) Since having this child my family has become more tolerant and accepting; 10) Since having this child I have become more determined to face up to challenges; 11) Since having this child I have a greater understanding of other people; 12) My child is loving and caring; 13) Since having this child, I have developed new interest.

Based on these findings, only the seven positive items loading on Factor 4 were retained for final analyses, and of these five items refer to parent characteristics and two to family characteristics (see Table 5). All items concerning child characteristics were omitted. The principal components factor analysis with varimax rotation was repeated including (36 + 7) 43 items (PSI-SF43). The satisfactory 4-factor solution accounted for 48% of the variance. The factor loadings for this solution are shown in Table 6.

Table 6: Parenting Stress Index Short Form Modified (PSI-SF43) - Principal components varimax rotated factor loadings (N=310)

	Factor 1 Parental Distress	Factor 2 Parent-Child Dysfunctional Interaction	Factor 3 Difficult Child	Factor 4 Positive Gain
PSI-SF43				
Item #				
1	<b>.42</b>	.28	.35	.28
2	<b>.58</b>	.03	<b>.40</b>	-.17
3	<b>.63</b>	.13	.37	.13
4	<b>.67</b>	.09	.17	-.13
5	<b>.71</b>	-.04	.28	-.07
6	<b>.47</b>	.16	.03	.19
7	<b>.60</b>	.10	.25	.12
8	<b>.58</b>	-.01	<b>.41</b>	.08
9	<b>.71</b>	.12	.13	.15
10	<b>.69</b>	.12	.10	.17
11	<b>.65</b>	.22	.07	.13
12	<b>.75</b>	.24	.07	.12
13	.24	<b>.60</b>	.17	.23
14	.09	<b>.72</b>	.18	.19
15	.14	<b>.81</b>	.03	-.06
16	.06	<b>.61</b>	.30	.27
17	.20	<b>.73</b>	.10	.01
18	.23	-.10	<b>.50</b>	-.05
19	.17	<b>.65</b>	.17	-.07
20	.33	.13	<b>.45</b>	-.09
21	.27	.06	<b>.63</b>	-.17
22	.13	.23	.22	<b>.40</b>
23	.12	<b>.56</b>	.18	.19

24	.02	<b>.45</b>	<b>.42</b>	.22
25	.16	.23	<b>.60</b>	-.00
26	.04	<b>.44</b>	.30	.18
27	.01	.35	<b>.62</b>	.13
28	.16	.29	<b>.68</b>	.19
29	.07	.10	<b>.71</b>	-.05
30	.09	.13	<b>.73</b>	.10
31	.32	.02	<b>.46</b>	-.10
32	.17	.16	<b>.66</b>	.02
33	.14	.32	<b>.62</b>	.10
34	.12	.31	<b>.65</b>	.14
35	.24	.27	<b>.58</b>	-.06
36	.22	.01	<b>.67</b>	-.13
Positive 1*	.03	.12	-.07	<b>.56</b>
Positive 4	.05	.15	-.06	<b>.60</b>
Positive 5	.06	.11	-.05	<b>.63</b>
Positive 8	.18	-.02	.10	<b>.65</b>
Positive 9	.17	.06	.04	<b>.64</b>
Positive 10	-.01	.01	.00	<b>.70</b>
Positive 11	-.06	.11	-.07	<b>.70</b>

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\* 1) Since having this child I feel I have grown as a person; 4) Having this child has helped me to learn new things/skills; 5) Raising this child helps putting life into perspective; 8) Since having this child, my family has become closer to one another; 9) Since having this child my family has become more tolerant and accepting; 10) Since having this child I have become more determined to face up to challenges; 11) Since having this child I have a greater understanding of other people.

Three factors are named in accordance with the PSI-SF36, and the fourth factor is named 'positive gain'. Descriptive statistics for the four corresponding subscales and their interrelations are presented in Table 7.



Table 7: Descriptive Statistics and Pearson correlations between the 4 subscales of the Modified Parenting Stress Index-Short Form (PSI-SF43) (N=318)

	<u>Mean</u>	<u>SD</u>	PD	PCDI	DC	PG
Subscales <sup>a</sup>						
Total Stress <sup>b</sup>	94.63	24.23	.88**	.84**	.83**	.20**
PD	31.33	10.05	1.00	.54**	.56**	.19*
PCDI	26.60	7.92	--	1.00	.69**	.26**
DC	36.59	10.41	--	--	1.00	.09
PG	15.30	4.59	--	--	--	1.00

<sup>a</sup> PD = Parental Distress; PCDI = Parent Child Dysfunctional Interaction; DC = Difficult Child; PG = Positive Gain. For the original 3 subscales of the PSI-SF36, a high score reflects high stress. For the subscale 'Positive Gain' a low score reflects more gain.

<sup>b</sup>Total stress score is computed by adding 3 original PSI-SF36 subscale scores

\* p <.01 \*\* p<.001

As shown in Table 7 moderate positive relationships between the original PSI-SF36 scales exist. Significant positive relationships were also found between 'positive gain' and the subscales 'Parental Distress and 'Parent-Child Dysfunctional Interaction', i.e. *more* positive gain is associated with *less* parental distress and *less* interaction problems. No significant relationship was found between 'positive gain' and 'Difficult Child'. This indicates that perceived positive contributions of the child to the family are independent of the perceived difficulties in managing the child.

### 6.5.3 Reliability

In addition to the factor analyses, the internal consistency of the PSI-SF43 was investigated. The Cronbach's alpha reliability coefficient for the

total PSI-SF43 was .93. Alpha coefficients for the three original subscales were .89, .83, and .89 for parental distress, parent-child dysfunctional interaction and difficult child, respectively. The alpha coefficient for the fourth subscale 'positive gain' was .79. The coefficients for the total stress scale and the original three subscales are similar to the ones reported for the original PSI-SF36. Abidin (1995) reported an alpha reliability coefficient of .91 for the total stress scale and .87, .80 and .85 for the subscales parental distress, parent-child dysfunctional interaction and difficult child, respectively.

#### 6.5.4 Validity

##### 6.5.4.1 Face validity and content validity

The choice for the additional items was based on literature review and input from parents raising a child with a disability. Items were presented in a format similar to the original PSI-SF36 but phrased positively. Also rather than focusing on possible problems they stressed potential gains associated with raising a child (with a disability). Parents did not report any difficulties with the format of the new items. Most parents answered all questions on the PSI-SF43. No systematic data has been gathered in regards to the content validity of the new items. However, the factor analyses solution suggests that the seven additional items, whilst all loading on the same factor, tap into a domain not previously covered by items of the PSI-SF36.

##### 6.5.4.2 Predictive validity: Relationships with disability, developmental status and child behaviour

###### *Disability*

To investigate the predictive validity of the PSI-SF43 several analyses were performed. Pearson correlation coefficients were used to investigate the relationship with disability parameters, i.e. severity and functional impairment, and the PSI-SF43 subscales. Severity of disability was only moderately related to the PSI-SF43 subscale scores parental distress ( $r = .12, p < .05$ ) and positive gain ( $r = -.13, p < .05$ ). Functional impairment was positively related to stress and negatively to gain, i.e. parents of children with more severe functional impairment

reported more stress and more positive gain (see Table 8). Regression analyses revealed that the three original PSI-SF36 subscales explained 2% and 10% of variance in severity of disability and functional impairment, respectively. If the 4<sup>th</sup> subscale 'positive gain' was entered in the model, the amount of variance explained increased significantly (by 3 and 7% for severity of disability and functional impairment, respectively) (Appendix F1 and F2).

Table 8: Correlations between the PSI-SF43 and other measures

	PSI-SF43 <sup>a</sup>				
	DC	PCDI	PD	Total	PG
Other measures:					
Disability Parameters (N=310-315)					
Severity of Disability	.04	.04	.12*	.07	-.13*
Activities of Daily Living	.26***	.19**	.28***	.29***	-.21***
Strengths and Difficulties Questionnaire (SDQ, N=314-321) <sup>b</sup>					
Hyperactivity	.49***	.38***	.24***	.43***	-.04
Peer problems	.40***	.43***	.39***	.48***	.09
Conduct problems	.54***	.46***	.26***	.49***	.14*
Emotional problems	.49***	.39***	.38***	.49***	.05
Pro-social behaviour	-.37***	-.42***	-.24***	-.40***	-.09
Total SDQ	.66***	.57***	.44***	.66***	.07
Impact on Family <sup>c</sup> (N=318-324)					
Total Score	.41***	.28***	.53***	.49***	-.10
Handicap related Problems for Parents Inventory <sup>d</sup> (N=312-319)					
Child's health/services	.40***	.29***	.40***	.43***	-.12*
Mother/child social	.63***	.53***	.54***	.67***	.07
Mother's life	.39***	.28***	.59***	.50***	.05
Total	.59***	.46***	.58***	.64***	.04
Family Needs Scale <sup>e</sup> (N=293-297)					
FNS total	.22***	.20***	.27***	.28***	.02

Caregiving Self Efficacy <sup>f</sup> (N=313-318)					
Total Score	-.46 <sup>***</sup>	-.47 <sup>***</sup>	-.43 <sup>***</sup>	-.53 <sup>***</sup>	-.27 <sup>***</sup>
Coping strategies <sup>g</sup> (N= 316-322)					
Problem focused	.21 <sup>***</sup>	.08	.16 <sup>**</sup>	.18 <sup>**</sup>	-.25 <sup>***</sup>
Emotion focused	.43 <sup>***</sup>	.45 <sup>***</sup>	.62 <sup>***</sup>	.58 <sup>***</sup>	.15 <sup>**</sup>
Family Satisfaction Scale <sup>h</sup> (N=314-318)					
Adaptability	-.46 <sup>***</sup>	-.47 <sup>***</sup>	-.64 <sup>***</sup>	-.61 <sup>***</sup>	-.32 <sup>***</sup>
Cohesion	-.50 <sup>***</sup>	-.49 <sup>***</sup>	-.69 <sup>***</sup>	-.66 <sup>***</sup>	-.28 <sup>***</sup>
FSS total	-.50 <sup>***</sup>	-.50 <sup>***</sup>	-.69 <sup>***</sup>	-.66 <sup>***</sup>	-.29 <sup>***</sup>

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

<sup>a</sup>For the original 3 subscales of the PSI-SF36, a high score reflects high stress. For the subscale 'Positive Gain' a low score reflects more gain. The total score is computed by adding the original PSI-SF36 subscale scores; DC= Difficult Child, PCDI = Parent Child Dysfunctional Interaction, PD = Parental Distress, PG = Positive Gain; <sup>b</sup>SDQ scores: a high score reflects more problems except for prosocial behaviour. For prosocial behaviour, a low score reflects absence of prosocial behaviour; <sup>c</sup>Impact on family: a high score reflect high impact (mostly negative, e.g. parents have less time for themselves); <sup>d</sup>HPPI: a high score reflects more problems; <sup>e</sup>FNS: a high score reflects high needs; <sup>f</sup>CSES: a high score reflects more efficacy; <sup>g</sup>Coping: problem focused coping reflects the use of the following coping strategies: acceptance, active coping, planning, humour, instrumental support, emotional support and positive reframing. Emotion focused coping reflects the use of the coping strategies: behavioural disengagement, denial, self-blame, self-distraction, substance use and venting. For both problem and emotion focused coping a high score reflects more use of coping strategy; <sup>h</sup>FSS: a high score reflects more satisfaction, more cohesion and more adaptability

Multivariate analyses of variance were conducted to test for disability group differences. No significant main effect was found for disability. Univariate tests revealed significant differences between disability groups (spina bifida alone, hydrocephalus alone, both spina bifida and hydrocephalus) for two original subscales (PSI-DC and PSI-PCDI) (see Table 9). Although the mean stress scores of parents with children with hydrocephalus are higher than scores of parents with children with SB or both conditions, post hoc analyses failed to identify significant differences between specific disability groups.

Table 9: Means and Standard Deviations for PSI-SF43 subscales by disability group and MANOVA summary (N=318)

	SB (N=44)		HC (N=197)		SB+HC (N=77)			
	Mean	SD	Mean	SD	Mean	SD	F	df
Multivariate $\lambda = .96$							1.50	8,624
PSI DC	34.21	10.55	38.07	10.25	34.35	10.02	5.08**	2,315
PSI PCDI	25.36	9.40	27.49	7.60	25.14	7.56	3.12*	2,315
PSIPD	31.02	8.17	31.93	10.06	29.78	10.99	1.28	2,315
Positive gain	15.66	5.21	15.32	4.29	14.81	4.81	.56	2,315

\* p <.05 \*\* p <.01

#### *Developmental status*

Relationships between PSI-SF43 and child development were investigated using t-tests. Significant differences were found for PSI-SF43 total score and original subscale scores by the child's developmental status (delayed versus average or above). Parents of children with developmental delays reported higher stress levels than parents with children with a developmental level average or above. No significant difference between developmental groups was found for positive gain scores (Table 10).

Table 10: Descriptive statistics and t-values for the subscales and total scores of the PSI-SF43 by developmental status

	Below average		Average or above		t	df
	Mean	SD	Mean	SD		
PSI DC	38.46	10.21	34.29	10.25	3.62 <sup>***</sup>	317
PSIPCDI	28.69	7.49	24.01	7.68	5.49 <sup>***</sup>	318
PSIPD	32.49	9.70	29.74	10.20	2.45 <sup>***</sup>	315
PSI total	99.82	23.25	88.06	23.85	4.42 <sup>***</sup>	313
Positive gain	14.89	4.16	15.67	5.03	-1.51	319

<sup>\*\*\*</sup> p<.001

#### *Child Behaviour*

To investigate the relationship between PSI-SF43 and child behaviour Pearson correlation coefficients were computed between the PSI-SF43 original subscale, total and subscale 'positive gain' scores and the SDQ. Furthermore, regression analyses were conducted to investigate the variance explained by the subscale positive gain in addition to the variance explained by the original subscales of the PSI-SF43. Significant positive relationships were found between the PSI-SF43 original subscale and total scores and the SDQ (see Table 8). Only behavioural conduct was significantly related to the subscale 'positive gain' ( $r = .14$   $p < .05$ ), i.e. when parents report more conduct problems, they report less positive gain.

Regression analyses revealed that the three original subscales of the PSI-SF43 explained 45% of the variance on total SDQ. The PSI-SF43 original subscales explained 18-31% of the variance on the SDQ subscale scores. If the 4<sup>th</sup> subscale 'positive gain' was entered in the model, the amount of variance explained of SDQ subscale or total scores did not increase significantly (Appendix F3 - F8).

#### 6.5.4.3 Concurrent validity: Relationships with family needs, impact on family and handicap related problems

Pearson correlation coefficients were used to investigate the relationship between the PSI-SF43 and the FNS, Impact on Family scale and HPPI (see Table 8). Significant relationships were found between these scales and the PSI-SF43 total and original subscales scores. Higher levels of family needs, greater impact and more handicap-related problems were associated with higher levels of parenting stress. Only the HPPI subscale child health and services showed a significant relation with positive gain. Interestingly, more problems were associated with more positive gain. Regression analyses were conducted to investigate the relationship between the PSI-SF43 and FNS, Impact on Family and HPPI measures. Regression analyses revealed that the three original subscales of the PSI-SF43 explained 9%, 32%, and 45% of the variance on Total FNS, Impact on Family Total score and total HPPI scale, respectively. If the 4<sup>th</sup> subscale 'positive gain' was entered in the models, the amount of variance explained on total FNS, total impact and total HPPI scores did not increase significantly. However, a significant increase was found for the HPPI subscale 'child health and service' (from 21% to 24%) (Appendix F9).

#### 6.5.4.4 Construct validity: Relationships with family functioning, caregiving efficacy and coping

Pearson correlation coefficients were used to investigate the relationship between the PSI-SF43 and the FSS (total and subscale scores), CSES and the Brief COPE (see Table 8). Significant relationships were found between the FSS total and subscale scores and the PSI-SF43 total, original subscales and positive gain scores. Lower levels of stress and higher levels of positive gain were associated with better family functioning as characterised by higher levels of satisfaction, adaptability and cohesion. Significant relationships were also found between the PSI-SF43 and the CSES. Higher levels of caregiving confidence were associated with lower levels of stress and higher levels of positive gain. Significant positive relationships were found between the use of emotion focused coping and PSI-SF43 subscale and total scores and positive gain. Problem focused coping was significantly correlated

with two of the subscales, PSI-DC and PSI-PD and the total score, but not with PSI-PCDI. Higher levels of stress were associated with more use of problem focused coping strategies. The positive gain subscale showed a negative correlation with problem focused coping indicating that more use of problem focused coping strategies was associated with higher levels of positive gain.

Regression analyses revealed that the three original subscales of the PSI-SF43 explained 51% of the variance on Total Family Satisfaction Scale, and 44 and 51% of the variance on the subscales adaptability and cohesion, respectively. If the 4<sup>th</sup> subscale 'positive gain' was entered in the model, the amount of variance explained on total FSS and the subscales adaptation and cohesion increased significantly (variance explained = 53%, 48% and 53% respectively). Similar results were found for the CSES. Regression analyses revealed that the three original subscales of the PSI-SF43 explained 27% of the variance on CSES. If the 4<sup>th</sup> subscale 'positive gain' was entered in the model, the amount of variance explained on CSES increased significantly (29%). For coping strategies the pattern is mixed. The original subscales of PSI-SF43 explain significant proportions of variance in problem focused and emotion focused coping (5 and 40% respectively). Entering the subscale 'positive gain' did change the variance in problem focused coping significantly but not in emotion focused coping (see Appendix F10 – F15).

## 6.6 Discussion

A modified version of the PSI-SF36, was administered as part of a study regarding stress, coping and family functioning in families with children with spina bifida and/or hydrocephalus. The PSI-SF36 was modified for two reasons: to make it more acceptable to parents and to assess positive gain in this population. The acceptability to parents is not measured directly but the response rate of 81% may partly reflect improved acceptability of the scale.



*Hypothesis 1: Psychometric properties PSI-SF36 will be unchanged after interspersing positive items.*

The first hypothesis was confirmed. The modified scale corresponded well with the original PSI-SF36. Factor analyses revealed a similar factor structure for the items of the original scale, i.e. items contributed to similar dimensions in this study as in the study using the unmodified questionnaire (Abidin, 1990). The new PSI-SF43 and the subscale 'positive gain', both had good internal consistency. Validity analyses showed that the psychometric properties of the PSI-SF36 remained unchanged.

*Hypothesis 2: The added positive items will form separate factor, rather than load on the original factors identified by Abidin (1995).*

Hypothesis 2 was also confirmed. Seven of the additional positive items loaded on a 4<sup>th</sup> factor, which was named 'positive gain'. There were no significant cross-loadings for these seven items on the existing factors, confirming that the positive items tap into a domain not previously covered by the PSI-SF36.

*Hypothesis 3: This new factor will contribute to construct validity, i.e. it will contribute to explaining variance in related constructs such as family functioning and caregiving efficacy.*

To investigate the added value of the extra items several analyses were conducted. Although the subscale positive gain does not add substantially to the concurrent validity of the PSI-SF36, it does contribute to the predictive validity and substantially to the construct validity of the scale. Therefore hypothesis 3 is confirmed. Positive gain has a place in the underlying theoretical framework of stress and adjustment as shown by its relationship to the related concepts of coping, family functioning and caregiving efficacy.

## 6.7 Summary

The study described in this chapter concerned the factor structure and psychometric properties of the modified PSI-SF36. The scale was modified to make it more acceptable to parents and to measure the positive impact of raising a child with a disability. Factor analyses showed that the positive items formed a separate factor in addition to the three original factors of the PSI-SF36. Interestingly, parents of children with more severe physical and medical problems, as measured by severity of disability, functional impairment and HPPI-CHS, reported higher levels of positive gain. These findings may hint at a relationship between the stressfulness of the situation and positive gain. Park et al (1996), who reported significant correlations between the stressfulness of negative events and stress related growth in college students, have provided some support for such relationship. It should be noted though that Park et al (1996) were not able to replicate this finding in subsequent studies.

Further analyses confirmed that the positive items added mainly to the construct validity of the PSI-SF36, without jeopardizing its reliability and validity. Construct validity essentially tests the theory underlying the instrument. Therefore the subscale 'positive gain' may prove its purpose in understanding of processes of stress and adjustment to disability. So far research involving positive contributions of people with disabilities has been sparse. As described in Chapters 2 and 3 most research has focused on the negative impact of a child with a disability on the family and only a few studies have focused on positive outcomes. However, from the perspective of stress theory it is plausible that families might derive some positive effects from a stressful event (Summers et al., 1989). Theories of psychological reorganisation in the aftermath of traumatic events have stressed that 'adversity can lose some of its harshness through cognitive adaptations which can restore comforting views of ourselves, other people and the world' (Affleck & Tennen, 1996, p900). In other words cognitive coping efforts in response to adverse events may result in personal gains, e.g. personal growth and family cohesion. These positive outcomes may further enhance psychological and social well-being. In terms of perceived positive contributions of children with disabilities, it could be argued

that the adjustment outcomes for parents who reported higher levels of positive gain associated with their child with a disability differ from those of parents reporting lower levels of positive gain. In other words, positive gain may moderate the relationship between disability and adjustment outcomes. The affect of positive gain on the relationship between disability parameters and adjustment will be investigated in Chapter 12.

## Chapter 7

### Study 2: Parenting stress and positive gain in a general UK population sample

As described in the previous chapter, the positive items of the PSI-SF43 formed a separate factor 'positive gain' without jeopardizing the original psychometric properties of the PSI-SF36. Analyses showed that the positive gain factor contributes mainly to the construct validity of the instrument. The positive gain scale also contributed some to the predictive validity of the scale, i.e. parents of children with more severe disability and functional impairments reported significantly higher levels of positive gain. In addition the subscale positive gain explained an additional percentage of variance in severity and functional impairment over and above the original subscales of the PSI-SF36.

Results of the study described in Chapter 6 also indicated that parenting stress levels are much higher in mothers of children with spina bifida and/or hydrocephalus than in the American norm sample of the PSI-SF36. What remains unclear is how positive gain experiences in parents of children with spina bifida and/or hydrocephalus compare to positive gain levels in parents of children in the general population. As discussed in Chapter 3 there are some studies that have focused on positive perceptions of parents of children with disabilities. However, none of these studies have made comparisons between parents of children with and without disabilities. One exception is a study by Turnbull, Behr and Tollefson (as cited in Summers et al., 1989). They did not find qualitative differences in perceived positive contributions of children with mental retardation compared to those of healthy children. To date no report of quantitative differences in positive contributions of children with and without disabilities is available. Therefore the current study aimed to investigate perceived positive gain in a UK general population sample. The following questions were addressed:

- 1) To what extent do parents of children in a UK general population sample experience stress and positive gain associated with raising a child aged 6-12 years?
- 2) How do a UK general population sample and the sample of families of children with spina bifida and hydrocephalus (Sample 1) compare on measures of parenting stress and positive gain?
- 3) Are the relationships between stress and positive gain similar or different for the general population and spina bifida and hydrocephalus groups (Samples 1 and 3)?

Hypotheses: It was expected that the mothers in the UK general population sample would report similar levels of parenting stress as mothers in the US norm sample. It was further predicted that parents of children with spina bifida and hydrocephalus would experience more parenting stress but also more positive gain than parents in the general population sample. Although mean differences in levels of stress and gain were expected, it was also hypothesised that the strength of the associations between stress and gain would be similar in both groups.

## 7.1 Method

### 7.1.1 Participants and procedure

As described in Chapter 5, Sample 3 families were recruited via three mainstream schools in the Southampton area. Schools were asked to distribute questionnaires amongst parents of children aged 6-12. Parents were asked to complete the questionnaire for their oldest child attending the school. The current sample includes 168 families who returned a completed questionnaire. Ethical approval for this study was obtained from the Ethics Committee of the Department of Psychology, University of Southampton. Informed consent was obtained from each participant.

### 7.1.2 Measures

The questionnaire contained the Parenting Stress Index-Short Form Modified (PSI-SF43) and some question on demographic characteristics (see Appendix D). Chapter 5 gives a detailed description of the PSI-SF43. Therefore only a brief description is outlined here.

#### *Demographic characteristics*

Questions were included regarding the age of the child, age of the person completing the questionnaire, family constellation, and the educational level and employment status of both parents.

#### *Parenting stress Index-Short Form Modified (PSI-SF43)*

The PSI-SF43 is a modified version of the PSI-SF36 (Abidin, 1995), randomly interspersing seven additional items. In contrast to the original items of the PSI-SF36, these additional items were worded positively and refer to positive character traits of the child and pleasant experiences associated with raising the child. All items are rated using a 5-point Likert scale (1 = strongly agree; 5 = strongly disagree). Factor analyses showed that the seven additional items formed a separate factor 'positive gain', without jeopardizing the factor structure and psychometric properties of the original PSI-SF36.

## 7.2 Results

Ninety-five percent (N = 157) of the questionnaires were completed by the child's mother. The child's age ranged from 5 to 14 years (Mean = 8.81, SD = 1.85). The age of the mothers ranged from 25 to 49 years (Mean = 38.84, SD = 4.88). Most children lived with both parents (N = 149, 89%), nine (5%) lived with mother only, six (4%) lived with their mother and her partner, one (1%) lived with father only and three (2%) lived in other circumstances. The number of children living at home ranged from 1 to 5 (Mean = 2.23, SD = .74). Additional sample characteristics are shown in Table 11.

Table 11: Frequency and percentage distribution for demographic characteristics

	N	%
<b>Gender child</b>		
Boy	92	54.8
Girl	74	44.0
Not specified	2	1.2
<b>Education mother</b>		
Basic education (up to GCSE)	70	42.7
Further education (A levels/HND)	46	28.0
Higher education (Degree/GNVQ)	48	29.3
<b>Education father</b>		
Basic education (up to GCSE)	54	35.3
Further education (A levels/HND)	32	20.9
Higher education (Degree/GNVQ)	67	43.8
<b>Employment mother</b>		
Employed	137	82.0
Unemployed	30	18.0
<b>Employment father</b>		
Employed	153	96.2
Unemployed	6	3.8

### 7.2.1 Parenting stress and positive gain

The total stress scores for the current sample ranged from 40 to 146 with a mean of 78.05 (75<sup>th</sup> percentile) and standard deviation of 19.98. This mean score is higher than the mean of the norm sample of the PSI-SF36 (Effect Size = .46). Twenty-one percent of the current sample scored within

the clinical significant range, i.e. a total stress score of 91 or above. This percentage is twice as high as expected based on the PSI-SF36 US norms. Means and standard deviations for the four PSI-SF43 subscale scores are presented in Table 12. Mean scores for the three original PSI-SF36 subscales are just above average compared to the norms, most markedly on the subscale Parent Child Dysfunctional Interaction for which the mean fell in the 70<sup>th</sup> percentile. For the current sample Cronbach alpha reliability coefficients for the three original PSI-SF36 subscales Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child were .86, .85 and .88, respectively. The alpha coefficients for the Total Stress scale and the additional Positive Gain scale were .94 and .78, respectively. These coefficients are similar to those reported for the original PSI-SF36 (Abidin, 1995) and to those reported in Chapter 7.

Analyses were conducted to investigate differences between stress and positive gain scores of parents of children in general population and parents of children with spina bifida and/or hydrocephalus. Independent sample t-tests revealed that parents of children in the general population experienced significantly lower levels of total parenting stress than parents of children with spina bifida and/or hydrocephalus (Mean = 78.05, SD = 19.98 and Mean = 94.54, SD = 24.24 for Samples 3 and 1, respectively,  $t(398) = 7.54, p < .001$ ). Multivariate analyses of variance showed that parents of children in the general population had lower scores on all subscales of the PSI-SF43, indicating that parents of children in the general population reported lower levels of parenting stress, and lower levels of positive gain (see Table 12).



Table 12: Descriptive statistics, MANOVA results and Effect Sizes (ES) for the subscales of the PSI-SF43 for the general population sample (Sample 3) and a sample of parents of children with spina bifida/hydrocephalus (Sample 1).

	Sample 3 (N=167)	Sample 1 (N=318)			
	Mean (SD)	Mean (SD)	F <sup>b</sup>	df	ES
Multivariate					
$\lambda = .81$			28.43	4,480	
PD <sup>a</sup>	27.81 (7.91)	31.28 (10.07)	15.01	1,483	-.37
PCDI	22.47 (6.80)	26.63 (7.92)	33.11	1,483	-.53
DC	27.77 (8.23)	36.63 (10.37)	91.60	1,483	-.84
PG	16.76 (4.21)	15.24 (4.55)	12.79	1,483	.34

<sup>a</sup>PD=parental distress; PCDI=Parent child dysfunctional interaction; DC=Difficult Child; PG = Positive Gain. For the original 3 subscales of the PSI-SF36, a *high* score reflects *high* stress. For the positive gain subscale a *low* score reflects *high* gain.

<sup>b</sup>all significant at  $p < .001$  level

### 7.2.2 Demographic characteristics

Chi square statistics and t-tests were conducted to investigate differences in demographic characteristics of this general population sample (Sample 3) and the sample of families of children with spina bifida and hydrocephalus (Sample 1). Children in the general population sample were significantly younger than the children in the clinical groups (Mean age = 8.81, SD = 1.85 and Mean age = 9.37, SD = 2.15 for Samples 3 and 1, respectively,  $t(358) = 3.13, p < .01$ ). Also, the number of children living at home was smaller for the general population sample than for Sample 1 (Mean = 2.23, SD = .74 and Mean = 2.55, SD = 1.35 for Samples 3 and 1 respectively,  $t(523) = 3.63, p < .001$ ). No differences were found for mother's age or child gender. The general population sample included more 2-parent families than Sample 1. Mothers and fathers of children in the general population sample were better educated than parents in Sample 1. A higher percentage mothers and fathers in general population were employed than in the Sample 1 (see Table 13).

Table 13: Demographic characteristics and Chi square statistics for Samples 3 and 1

Variable	Sample 3 ( N=168)		Sample 1 (N=553)		df	$\chi^2$
	N	%	N	%		
Child's gender					1	.03
Girls	74	45	181	45		
Boys	92	55	218	55		
Family constellation					1	18.68**
2-parent family	156	94	307	79		
1-parent family	10	6	81	21		
Mother's education					2	14.86*
Basic	70	43	223	58		
Further	46	28	96	25		
Higher	48	29	63	17		
Father's education					2	14.01*
Basic	54	35	163	51		
Further	32	21	71	22		
Higher	67	44	88	27		
Mother employed					1	60.98**
Yes	137	82	180	46		
No	30	18	209	54		
Father employed					1	15.85**
Yes	153	96	281	84		
No	6	4	55	16		

\*p<.003; \*\*p<.001

Pearson correlation coefficients, t-tests and analyses of variance were used to investigate the relationships between the demographic characteristics and the dependent variables stress and positive gain. No significant relationships were found between parenting stress or positive gain and the child's age,

number of children living at home, and mother's level of education. However, significant relationships were found between parenting stress and family constellation (Mean = 86.56, SD = 1.35 and Mean = 99.47, SD = 25.25 for 2-parent and 1-parent families respectively,  $t(474) = -4.27$ ,  $p < .001$ ); father's employment status (Mean = 86.08, SD = 22.91 and Mean = 97.35, SD = 23.71 for employed and unemployed fathers respectively,  $t(503) = 3.17$ ,  $p < .01$ ); and mother's employment status (Mean = 84.84, SD = 22.08 and Mean = 92.74, SD = 24.94 for employed and unemployed mothers respectively,  $t(564) = 3.95$ ,  $p < .001$ ). Thus, 1-parent families and families where father or mother is unemployed reported more parenting stress. Positive gain was significantly related to mother's employment status (Mean = 16.44, SD = 4.54 and Mean = 15.53, SD = 4.63 for employed and unemployed mothers respectively,  $t(570) = -2.32$ ,  $p < .05$ ); and father's education  $F(2,414) = 4.09$ ,  $p < .05$ ), i.e. families where the father received higher education reported less positive gain than families where fathers received basic education. Therefore analyses of covariance were conducted to investigate the differences in stress and positive gain scores between samples whilst controlling for differences in demographic characteristics. The difference in total parenting stress levels remained significant even after controlling for the differences in demographic characteristics (See Table 14).

Table 14: ANCOVA results for total stress score (N=396)

Source	Type III Sum of Squares	df	F
<u>Between Subjects</u>			
<u>Covariates:</u>			
Family constellation	650	1	1.30
Father's education	109	1	.22
Mother's employment status	761	1	1.52
Father's employment status	955	1	1.91
<u>Factor:</u>			
Sample	12436	1	24.82 <sup>***</sup>
<u>Error</u>	195417	390	(501.07)

Value enclosed in parentheses represents mean square error

\* p<.05

\*\* p<.01

\*\*\* p<.001

Similarly, multivariate analyses of covariance were conducted to test for differences between the samples on the four subscales of the PSI-SF-43 whilst controlling for differences in demographic characteristics. Again, differences in parenting stress subscale scores and positive gain remained significant (see Table 15).

Table 15: MANCOVA result for 4 subscale scores of the PSI-SF43 (N=396)

Source <sup>a</sup>	Type III Sum of Squares	df	F
Between Subjects			
<u>Covariates:</u>			
Family constellation			
Multivariate $\lambda = .98$		4,387	1.86
PD	234	1	2.75
PCDI	78	1	1.42
DC	2	1	.02
PG	93	1	4.82*
Father's education			
Multivariate $\lambda = .95$		4,387	3.40**
PD	173	1	2.03
PCDI	7	1	.13
DC	0	1	.00
PG	145	1	7.49**
Mother's employment status			
Multivariate $\lambda = .91$		4,387	2.85*
PD	1	1	.01
PCDI	14	1	.26
DC	530	1	6.14*
PG	27	1	1.41
Father's employment status			
Multivariate $\lambda = .98$		4,387	1.22
PD	229	1	2.69
PCDI	4	1	.07
DC	190	1	2.20
PG	1	1	.06

Factor:

Sample

Multivariate $\lambda = .86$		4,387	16.04 <sup>***</sup>
PD	358	1	4.20 <sup>*</sup>
PCDI	735	1	13.45 <sup>***</sup>
DC	4289	1	49.74 <sup>***</sup>
PG	109	1	5.63 <sup>*</sup>

Error

PD	33222	390	(85.19)
PCDI	21313	390	(54.65)
DC	33633	390	(86.24)
PG	7566	390	(19.40)

---

<sup>a</sup>PD=parental distress; PCDI=Parent child dysfunctional interaction;  
DC=Difficult Child; PG = Positive Gain.

Values enclosed in parentheses represent mean square errors

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

### 7.2.3 Relationships between parenting stress and positive gain

To investigate the relationships between stress and positive gain in the general population sample and to compare these to the sample of mothers of children with spina bifida and hydrocephalus, Pearson correlation coefficients were computed (see Table 16). Moderate relationships between the three original PSI-SF36 subscales were found. In addition, significant positive relationships were found between total stress and the three stress subscale scores and the sub scale 'positive gain', i.e. higher levels of parenting distress are associated with lower levels of positive gain.

Table 16: Pearson correlations between the four subscales of the PSI-SF43 (N=167)

Scales <sup>a</sup>	PD	PCDI	DC	PG
Total Stress <sup>b</sup>	.85** (.88)	.87** (.84)	.89** (.83)	.31* (.20)
PD	1.00	.61** (.54)	.60** (.56)	.36** (.19)
PCDI	--	1.00	.71** (.69)	.31* (.26)
DC	--	--	1.00	.15* (.09)
PG	--	--	--	1.00

<sup>a</sup>PD=parental distress; PCDI=Parent child dysfunctional interaction; DC=Difficult Child; PG = Positive Gain. For the original 3 subscales of the PSI-SF36, a *high* score reflects *high* stress. For the positive gain subscale a *low* score reflects *high* gain.

<sup>b</sup>Total stress is computed by adding the 3 original PSI-SF36 subscale scores  
\* p<.05; \*\* p<.001

Note: Values enclosed in parentheses represent correlation coefficients for Sample 1, mothers of children with spina bifida and hydrocephalus.

To compare the strength of the associations between the parenting stress and positive gain in the two samples (see Table 16) Fisher r to Z transformations were performed ( $Z = \frac{1}{2} \log_e \left( \frac{1+r_{xy}}{1-r_{xy}} \right)$ ). Equality of the correlations can be tested using the ratio  $Z_1 - Z_2 / \sigma_{(Z_1 - Z_2)}$  where  $\sigma_{(Z_1 - Z_2)} = \left( \frac{1}{(N_1 - 3)} + \frac{1}{(N_2 - 3)} \right)$ . The  $Z_1 - Z_2 / \sigma_{(Z_1 - Z_2)}$  ratios are presented in Table 17. The relationships between stress scores and positive gain were similar in both samples, i.e. none of the  $Z_1 - Z_2 / \sigma_{(Z_1 - Z_2)}$  ratios was significant. In other words, the strength of the associations between the constructs was similar in both samples.



Table 17:  $Z_1-Z_2/\sigma_{(Z_1-Z_2)}$  ratios for correlations between positive gain and stress total and subscale scores in Samples 1 and 3.

Correlations	$Z_1-Z_2/\sigma_{(Z_1-Z_2)}$ ratio
Positive gain	
x total stress score	1.20
x Parental Distress	1.90
x Parent Child Dysfunctional Interaction	.50
x Difficult child	.60

### 7.3 Summary and Discussion

Parents of children attending mainstream schools in the Southampton region completed the PSI-SF43 to investigate the extent to which these parents perceive parenting stress and positive gain associated with raising their child. Although several studies have compared levels of parenting distress in families of children with and without disabilities, no study has compared positive experiences associated with raising a child with or without a disability. Therefore the current study was conducted to investigate not only parenting stress but also positive gain levels in a general population sample. In addition, comparisons were made between stress and positive gain levels in this sample and in a sample of families of children with spina bifida and hydrocephalus.

*Question 1: To what extent do parents of children in a UK general population sample experience stress and positive gain associated with raising a child aged 6-12 years?*

It was expected that parents in the UK general population sample would report similar levels of parenting stress as parent in the US norm sample. However, parents in this general population sample experienced higher average levels of parenting distress (Mean score in 70<sup>th</sup> percentile). Twenty percent of parents experienced clinical significant levels of parenting



distress. This percentage is twice as high as in the PSI-SF36 US norm population. It is not known why stress levels in the current UK sample are elevated compared to the US norms. There are some differences in demographic characteristics between the UK and US samples, i.e. children in the current sample were older than in the norm sample, more parents received higher education and more mothers were currently employed. However, child age and parent education status were not significantly associated with the outcome variable parenting stress in this sample. Although mother's employment status was related to parenting stress, the direction of the effect was in the opposite direction, i.e. employed mothers reported less stress. The differences could reflect cultural differences in reporting parenting stress. Alternatively they could merely be a result of sampling procedures. Positive gain scores were normally distributed ranging from 7 to 32 (Mean = 16.78, SD=4.21).

*Question 2: How do a UK general population sample and the sample of families of children with spina bifida and hydrocephalus (Sample 1) compare on measures of parenting stress and positive gain?*

It was hypothesised that parents in the UK general population sample (Sample 3) would report lower levels of stress and lower levels of positive gain than mothers of children with spina bifida and hydrocephalus (Sample 1). This hypothesis was confirmed. Parents in the general population sample reported lower levels of stress than parents in Sample 1. The largest difference between samples was found for the subscale Difficult Child (Effect Size -.84) and the subscale Parent Child Dysfunctional Interaction (Effect Size -.53). The subscale Difficult Child focuses on stresses relating to managing the child's behaviour. The subscale Parent Child Dysfunctional Interaction reflects parents' feelings that their children do not meet their expectations or that the interactions with their child do not reinforce them as a parent. Given the problems of children with spina bifida and/or hydrocephalus it is not surprising that parents in this sample score higher on these subscales. Interestingly, parents of children with spina bifida and hydrocephalus also reported higher levels of positive gain than parents in the general population sample (Effect Size .34). Thus, although these children put higher demands

on the parent and the parent-child relationship, parents are also able to perceive (and value) the positive contributions of their children to the family. Differences on the stress and positive gain scales remained significant even after controlling for differences between samples on demographic characteristics.

*Question 3: Are the relationships between stress and positive gain similar or different for the two samples (Samples 1 and 3)?*

Results supported the hypothesis that the strength of the associations between the constructs would be similar in the two samples. Pearson correlation coefficients were used to investigate the relationships between positive gain and parenting stress total and subscales scores. For both samples positive relationships were found between the parenting stress and positive gain scores, i.e. higher levels of parenting distress are associated with lower levels of positive gain. The strength of the association between gain and stress in the two samples were not significantly different. This indicates that although there are mean differences in levels of stress and gain, the relationships between the constructs are similar for both samples.

The findings from this study further support previous literature that mothers of children with disabilities are at risk for experiencing increased levels of parenting stress (e.g. Miller et al., 1992). Results also emphasise the importance of the inclusion of comparison groups rather than to rely solely on norms provided, especially if measures are developed in other countries than where the research takes place. The levels of parenting stress in the current sample were higher compared to the US norms, but lower than the levels reported by mothers of children with spina bifida and hydrocephalus. These differences remained significant even after controlling for differences in demographic characteristics between the samples.

Levels of perceived positive gain were also lower in the general population sample than in the sample of mothers of children with spina bifida and hydrocephalus. The differences in positive gain levels may reflect stress related benefits associated with raising a child with a disability. As discussed in Chapter 7, reported levels of positive gain were associated with disability,

appraisals, resources and the use of coping strategies. More specifically, higher levels of positive gain were associated with increased functional impairment, higher levels of caregiving efficacy and family satisfaction and more use of problem focused coping. These findings supported not only the construct validity of the PSI-SF43, but are also in line with theoretical frameworks such as the revised stress and coping model (Folkman, 1997). Following such frameworks, differences in levels of positive gain between the two samples may reflect differences in the extent mothers experience stressful situations whilst parenting. Mothers of children with disabilities may encounter many more stressors whilst raising their child than mothers in the general population sample. These adverse events and the adaptation responses may not only be linked to negative outcome/emotions, i.e. increased levels of parenting stress, but also to positive outcome/emotions, i.e. perceived positive gain.

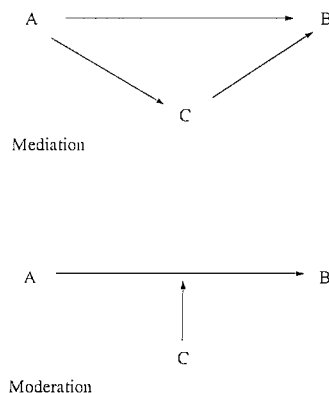
## Chapter 8

### Study 3: Coping - mediator or moderator of the relationship between disability and adjustment?

In the literature on stress and adjustment, coping has been an important construct. However both mediation and moderation has been used to describe the impact of coping on the relationship between stressors and adjustment outcome. For example, Thompson et al (1993a) stated that coping mediates the illness – outcome relationship, whilst Wallander et al. (1989a) described that coping moderates the association between the child's physical disorder and individual adjustment.

As discussed in Chapter 1 the difference between mediation and moderation in models of adjustment to disability is not always clear. A mediator specifies how a given effect occurs, whilst a moderator specifies the conditions under which the effect occurs and the conditions under which the size and direction of the effect vary (Baron & Kenny, 1986). Figure 14 illustrates mediating and moderating models of the effects of C on the relationships between A and B.

Figure 14: Path diagram of mediation and moderation



For example if the relationship between illness parameters (A) and parent adjustment (B) is associated with coping (C) such that illness parameters influence the use of coping strategies and the use of coping strategies predicts parent adjustment, coping acts as a mediator. If the relationship between illness parameters (A) and parent adjustment (B) is different for mothers perceiving high and low positive gain, positive gain (C) moderates the relationship.

Holmbeck (1997) noted inconsistencies in the use of the terms mediator and moderator. He identifies four types of problems: a) vague or interchangeable use of the terms; b) inconsistencies between terminology and the underlying conceptualisation of the variables used; c) use of data-analytic procedures that fail to test for mediated and moderated effects, and d) a mismatch between written text and diagrammatic figures (Holmbeck, 1997, p599). These problems seem also apparent in the stress, coping and adjustment literature. For example, the transactional stress and coping model uses the term mediator to describe the impact of coping, whilst it is hypothesised that coping acts as a buffer between illness and adjustment outcome, i.e. acts as a moderator (Thompson & Gustafson, 1996b). Similarly in the disability-stress-coping model, stress processing factors are portrayed as mediators (see Figure 5, Chapter 1), whilst Wallander et al. (1989a) describe that the impact of the child's physical disorder on individual adjustment is moderated by a variety of resistance factors including social ecological, intrapersonal and stress processing factors, e.g. coping.

The distinction between a mediating or moderating effect is critical when testing a model. Therefore the current study aimed to investigate the role of coping in adjustment to disability in terms of both mediation and moderation. Regression analyses will be conducted to test for mediation and moderation effects of coping on the illness – adjustment outcome relationship. Analyses will be conducted to test for mediation and moderation. If coping mediates the effect of illness parameters on parent adjustment outcome, we would expect to see that the independent contribution of illness parameters on parent adjustment is reduced once coping is entered in the regression analysis. If coping moderates the relationship between illness parameters and parent adjustment we would expect a significant interaction

effect (illness parameters x coping) whilst controlling for the effects of illness and coping (Baron & Kenny, 1986; Holmbeck, 1997).

## 8.1 Method

### 8.1.1 Participants and procedure.

The sample and procedure have been described in Chapter 5. The sample included 325 families of children with spina bifida and/or hydrocephalus, for whom a complete dataset was obtained. Families completed two questionnaires within a 6-8 month period.

### 8.1.2 Measures

Chapter 5 gives detailed descriptions of all measures used in this study. Therefore measures used for the current study will only briefly be mentioned here.

#### *Disability parameters.*

Several illness parameters were included in the questionnaire. For the purpose of this study a disability composite score (DCS) was computed by summing standardised scores for severity of disability, functional impairment and handicap related problems-child health and services. Severity of disability reflects the child's ability to walk, urinary and bowel continence, weight and the occurrence of pressure sores. Functional impairment is defined by the extent to which the child experiences problems with activities of daily life including washing, dressing, eating, continence, finding way, and walking ordinary distances. Parents rated each question on a 3-point scale: 0 = no problems, 1 = slight problems and 3 = major problems. A total functional impairment score was computed by summing the item scores. The subscale child's health and services of the HPPI (Wallander & Marullo, 1997) concerns problems and special services directly related to the child's condition. The subscale comprises of five items, scored on an 8-point Likert scale (0 = not at all, 7 = every day or more).

### *Brief COPE*

The Brief COPE (Carver, 1997) contains 28 items comprising 14 scales. Respondents rate their extent of use of a coping strategy on a 4-point scale (1 = have not been doing this at all, 4 = have been doing this a lot). Factor analyses revealed a 3-factor structure (see Chapter 5). The 1<sup>st</sup> factor, problem focused coping comprises of the scales: acceptance, active coping, emotional support, humour, instrumental support, planning, and positive reframing. The 2<sup>nd</sup> factor, emotion focused coping comprises of the scales: behavioural disengagement, denial, self-blame, self-distraction, substance use and venting. Religion formed a 3<sup>rd</sup> factor. This 3<sup>rd</sup> factor was not used for the purposes of this study as it represented only one coping scale, i.e. religious coping. For the purpose of this study a Coping Composite Score (CCS) was computed by adding the standardised problem and emotion focused coping scores.

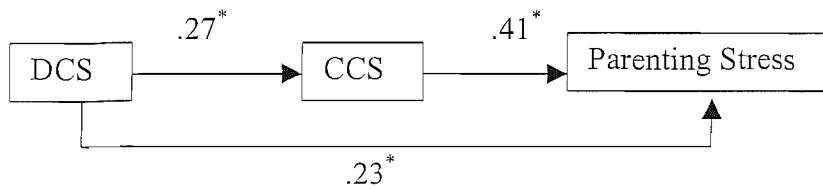
### *Parenting Stress Index-Short Form Modified (PSI-SF43)*

Parents completed a modified version of the PSI-SF36 (Abidin, 1995). The order and wording of the items of the original PSI-SF36 was maintained, interspersing an additional seven items in a random manner. The seven additional items were worded similarly to the original items of the PSI-SF36, but in positive terms. Parents rated all items on a 5-point Likert scale (1 = strongly agree, 5 = strongly disagree). The original PSI-SF36 contains three subscales: parental distress, parent-child dysfunctional interaction, and difficult child. A total stress score can be computed by summing the subscale scores. Only this total stress score was used in the current study.

## 8.2 Results

Regression analyses were used to test for the mediating and moderating effects of coping on the impact of disability on parental adjustment (Baron & Kenny, 1986; Holmbeck, 1997). The mediation model is presented in Figure 15.

Figure 15: Model of coping mediation of the effects of disability parameters on parenting stress (N=301)



Note: DCS = Disability Composite Score; CCS = Coping Composite Score

\* p < .001

Regression analyses supported the hypothesis that coping mediates the effects of disability on parenting stress. Figure 15 shows that disability has both direct and indirect influences on parental adjustment. The direct link is larger than the indirect link via coping. More specifically, the direct effect of disability on parenting stress is .23 and the indirect effect .11 (.27x.41).

The moderation analyses were undertaken by adding interaction terms into the regression analyses (Baron & Kenny, 1986; Holmbeck, 1997). Interaction terms were derived from the product of the z-transformed scores of the predictor variables, i.e. disability and coping composite scores. Results of the regression analyses are presented in Table 18.



Table 18: Summary of linear regression analyses for disability and coping predicting parenting stress (N=301)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
DCS	3.52	.56	.34*
Step 2			
DCS	2.36	.53	.23*
CCS	6.06	.76	.41*
Step 3			
DCS	2.34	.53	.23*
CCS	6.04	.76	.41*
DCS*CCS	-.14	.30	-.02

Note.  $R^2 = .12$  for Step 1 ( $p < .001$ );  $\Delta R^2 = .16$  for Step 2 ( $p < .001$ ),  $\Delta R^2 = .00$  for Step 3 (ns); DCS = disability composite score; CCS = coping composite score; \*  $p < .001$

The regression model for parenting stress was significant. Disability and coping composite scores independently predicted parenting stress. However there was no significant interaction effect, i.e. the relationship between disability and parenting stress does not change as a function of coping.

### 8.3 Conclusion

The mediation analyses revealed that coping partially mediates the relationship between disability and parenting stress. In contrast, no support for a moderation effect of coping on the relationship between disability and parenting stress was found. The implication of these analyses is that coping can be appropriately incorporated as one route via which disability parameters might influence adjustment in parents (mediation), as suggested by the transactional stress and coping model.

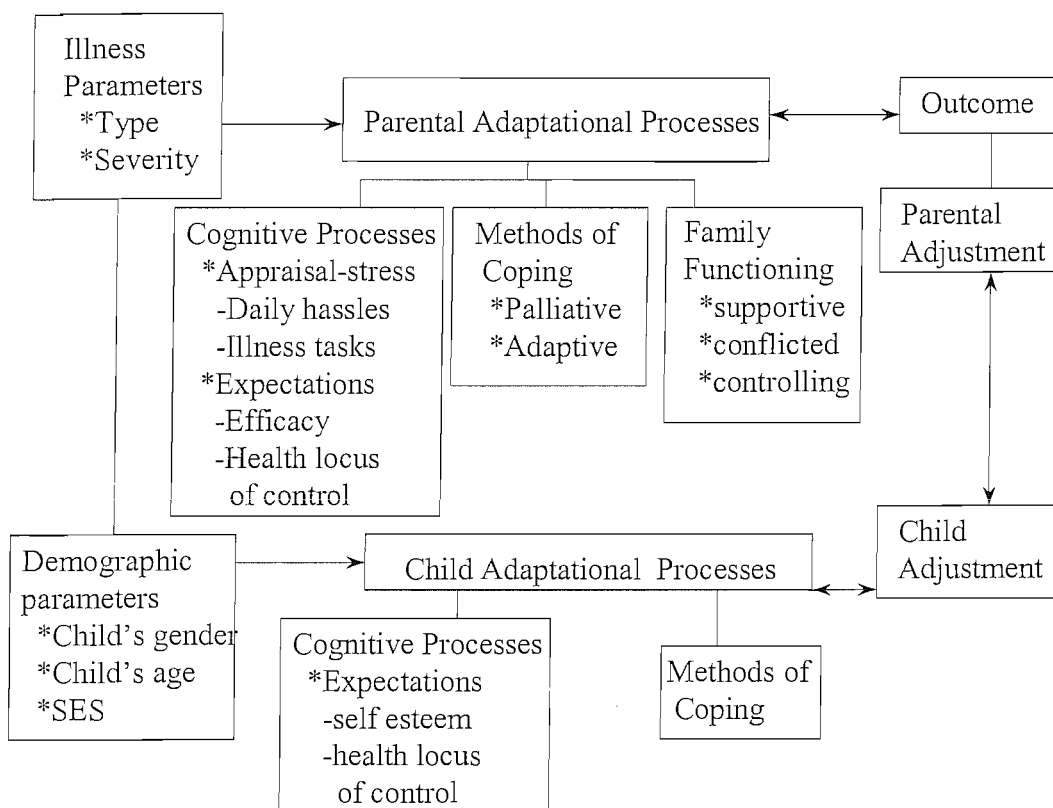
## CHAPTER 9

### **Study 4: Testing the transactional stress and coping model of adjustment to disability in mothers of children with spina bifida and hydrocephalus**

The transactional stress and coping model of adjustment to disability (Thompson et al., 1993a; Thompson et al., 1993b; Thompson et al., 1994) is shown in Figure 16. The model views the disability as a potential stressor, i.e. risk factor, to which individuals and the family as a whole adjust as a function of their resources. The model attempts to incorporate the ecological-systems theory (Bronfenbrenner, 1977) by emphasising that the impact of a disability on the psychological adjustment of an individual is mediated via the levels of stress and adjustment experienced by other family members. Adjustment therefore refers to both parental adjustment and child adjustment and their interrelationships (Thompson & Gustafson, 1996b). In the model, illness parameters reflect the type of illness/disability and its severity. According to the model the illness-outcome relationship is mediated by psychosocial processes, e.g. the use of coping and family functioning.

Many studies have supported the role of adaptation processes in psychological adjustment to chronic illness and disability. For example mothers of children with spina bifida with more supportive families and marriages and less conflictive and controlling families reported less psychological symptoms (Kronenberger & Thompson, 1992b). In the same sample demographic variables, medical severity of the child's condition and mother's appraised stress accounted for 32% of the variance in maternal psychological adjustment, i.e. depression, anxiety and global distress (Kronenberger & Thompson, 1992a).

Figure 16: The transactional stress and coping model of adjustment to disability (From Thompson & Gustafson, 1996b, p142)



The impact of various disability and adaptation variables has mostly been studied in isolation rather than in the context of a model. Most studies use regression analyses to investigate the associations between the measured variables. Authors conclude that their findings support the role of adaptation processes in psychological adjustment to disability when a large proportion of the variance in the outcome variable, adjustment, is accounted for. Regression analyses can indeed confirm the association between the outcome variable, i.e. adjustment, and predictor variables, e.g. illness parameters and adaptation processes. Technically, regression analyses could also be used to investigate interaction effects using product terms. However the interaction between the different variables is often not or just partially tested.

The current study was conducted to test the transactional stress and coping model using Structural Equation Modelling (SEM). SEM can be used to

examine the relationships between one or more independent variables (IV) and one or more dependent variables (DV). Both IV's and DV's can be measured variables or latent variables. SEM takes a confirmatory approach to the data analyses, therefore it lends itself for testing hypotheses regarding the a priori specified pattern of inter-variable relations (Byrne, 1994, p3). SEM allows for simultaneous effects of all the relationships within the model. This is especially useful when testing complex and multidimensional models. One of the advantages of SEM is that it allows for testing of indirect effects (mediating roles of variables or factors). Furthermore, when relationships between latent variables are examined using SEM, the relationships are free of measurement error, as the error has been estimated and removed, leaving only common variance (Tabachnick & Fidell, 2001). For this study SEM seemed particularly useful as this statistical procedure allows the model to be "tested in a simultaneous analysis of the entire system of variables to determine the extent to which it is consistent with the data" (Byrne, 1994, p3). In other words, SEM could be used to determine how well the proposed transactional stress and coping model of adjustment to disability applies to a sample of families of children with spina bifida and/or hydrocephalus.

## 9.1 Method

### 9.1.1 Participants

Participants for this study were 290 families for which a complete dataset was obtained. The participant pool was a subgroup of Sample 1, i.e. the 325 mothers of children with spina bifida and hydrocephalus completing two sets of questionnaires (see Chapter 5). There were no significant differences between the 35 families with incomplete datasets and the remaining 290 on demographic characteristics or outcome variables. The current sample included 43 parents of a child with spina bifida alone, 177 parents of children with hydrocephalus alone, and 70 parents of children with both conditions. Mother's ages ranged from 24 to 55 (Mean = 38.45, SD = 6.31) and father's ages ranged from 25 to 62 (Mean = 40.98, SD = 6.87). The mean age of the children (167 boys and 123 girls) was 9.42 (SD = 2.19), ranging from 6 to 14.

### 9.1.2 Measures

All measures were described in Chapter 5. Therefore only a brief description of the measures used for the purpose of the current study will be included in this chapter.

#### 9.1.2.1 Illness parameters

##### *Severity of Disability*

Based on literature several questions were included to determine the type and severity of the disability. Severity of disability was defined in terms of the child's ability to walk, urinary and bowel function, weight and the occurrence of pressure sores. This measure was adapted from the scheme used by Dorner (1975). For each category parent rated the child's best level of ability, with a high score indicating less ability. A severity of disability score is computed by summing the category scores (range 0-12).

##### *Functional Impairment*

The functional impairment measure was adapted from a measure Goodman used in his studies involving children with hemiplegia (R. Goodman, personal communication, May 1999). Six questions regarding the child's difficulties with activities of daily life were included, i.e. washing, dressing, eating, continence, finding way, and walking ordinary distances. These items were rated using a 3-point scale (0 = no problems, 1 = slight problems, 2 = major problems).

##### *Handicap-related Problems for Parents Inventory (HPPI)*

The HPPI (Wallander & Marullo, 1997) consists of 17 items concerning the most commonly reported sources of problems experienced by parents of children with physical disabilities. The problems are defined such that they do not have to be directly brought on by the child or be a direct effect of the child's disability. The response format, however, reflects a perceived association between problem and disability by the parent. An 8-point Likert scale is used to rate the items (0 = not at all; 7 = every day or more), comprising three subscales: child's health & services (HPPI-CHS; 5 items), mother child social (HPPI-MCS; 8 items), and mother's life (HPPI-ML; 4

items). For this study only the first two subscales were used as the HPPI-ML subscale regards problems for the mother in areas relatively more independent of the child and immediate family. The HPPI-CHS addresses problems and special services directly related to the child's condition. The HPPI-MCS concerns problems in social systems as well as in child behaviour and leisure activities.

#### 9.1.2.2 Adaptation Processes

##### *Family Functioning - Family Satisfaction Scale (FSS)*

The FSS (Olson & Wilson, 1992) is a 14-item instrument assessing family satisfaction on the dimensions of cohesion and adaptability. Fourteen items are rated on a 5-point Likert scale (1 = dissatisfied, 5 = extremely satisfied). Family cohesion is defined as the emotional bonding in a family. Family adaptability is defined as the ability of a family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress. A total FSS score is computed by adding the scores of each item, whereby a high score indicates high satisfaction, i.e. the family is perceived as more cohesive and adaptive. The authors report that the total score is most useful for research purposes, because the total scale score is most valid and reliable as indicated by internal consistency and test-retest statistics. Therefore only the total score was used in this study.

##### *Coping - Brief COPE*

The Brief COPE (Carver, 1997) is a shortened version of the COPE inventory (Carver et al., 1989). The Brief COPE contains 28 items comprising 14 scales: Active Coping, Planning, Positive Reframing, Acceptance, Humour, Religion, Emotional Support, Instrumental Support, Self-Distraction, Denial, Venting, Substance Use, Behavioural Disengagement and Self-Blame. Respondents rate their extent of use of a coping strategy on a 4-point scale (1 = have not been doing this at all, 4 = have been doing this a lot). The Brief COPE compared well to the full length COPE in terms of its factor structure. Alpha coefficients for internal consistency all exceeded .50, providing support for the internal reliability of the abbreviated scales (Carver, 1997). For the

current sample an exploratory factor analyses was conducted, which identified three factors (see Chapter 5). The first factor included the coping strategies Active Coping, Planning, Positive Reframing, Acceptance, Humour, Emotional Support and Instrumental Support and was named 'Problem focused Coping'. The second factor (Emotion focused Coping) included the coping strategies, Self-Distraction, Denial, Venting, Substance Use, Behavioural Disengagement and Self-Blame. The coping strategy Religion formed a factor on its own. For the purposes of this study the third factor was not included in the analyses.

#### *Efficacy - Caregiving Self Efficacy Scale (CSES)*

The CSES (Hastings & Brown, 2002) was originally developed for use with families of children with autism. The scale concerns parental feelings regarding their role as a caregiver. Five items concerning parents' perception of their level of confidence, difficulties, effectiveness, satisfaction and control in regards to the care of their child with a disability were rated on a 7-point Likert scale (1 = not at all, 7 = very). A total score was computed by summing the item scores.

#### 9.1.2.3 Child Adjustment

##### *The Strength and Difficulties Questionnaire (SDQ)*

The SDQ (Goodman, 1997) is a parent rated 25 item behavioural screening questionnaire for use with children aged 4 to 16 years. The 25 items generate five subscale scores: conduct problems, hyperactivity and inattention, emotional symptoms, peer problems and pro-social behaviour. A total difficulties score can be computed by summing the first four subscale scores.

#### 9.1.2.4 Parent Adjustment

##### *Parenting Stress Index-Short Form Modified (PSI-SF43)*

Parents completed the PSI-SF43 (Abidin, 1995); see also Chapter 6), a modified version of the Parenting Stress Index-Short Form (Abidin, 1995). A 5-point Likert scale is used to rate 43 items (1 = strongly agree, 5 = strongly disagree). The PSI-SF43 contains 4 subscales: parental distress, parent-child

dysfunctional interaction, difficult child and positive gain. A total stress score can be computed by summing the first three (original) subscale scores.

## 9.2 Results

### 9.2.1 Illness parameters

Severity of disability and child functional impairment scores ranged from 0 to 11 and 0 to 12, respectively. The mean severity of disability score was 2.80 (SD = 2.40), the mean child functional impairment score was 4.97 (SD = 3.19). HPPI subscale scores ranged from 0-28 and 0-56, for the HPPI-CHS and HPPI-MCS, respectively. Mean scores for the HPPI-CHS and HPPI-MCS were 13.68 (SD = 9.17) and 17.66 (SD = 15.50), respectively.

### 9.2.2 Adaptation Processes

The FSS scores ranged from 14 to 70, with a mean score of 43.95 (SD = 10.96). The mean score for the CSES was 29.17 (SD = 4.88), ranging from 15 to 35. Means and standard deviations for the coping scales are reported in Table 19.



Table 19: Means and standard deviations for coping scales (N=290)

Variable	Mean	SD
Problem Focused Coping (range 14-55)	31.69	8.58
Active Coping	4.75	1.88
Planning	4.72	1.84
Positive Reframing	4.36	1.71
Acceptance	6.11	1.87
Humour	3.04	1.48
Emotional Support	4.17	1.67
Instrumental Support	4.54	1.76
Emotion Focused Coping (range 12-42)	18.65	5.56
Self-Distraction	3.61	1.47
Denial	2.51	1.07
Venting	3.46	1.56
Substance Use	2.48	1.16
Behavioural Disengagement	2.48	.92
Self-Blame	4.10	1.88

Note: Scores for all coping subscales ranged from 2-8, except for Behavioural Disengagement (range 2-7).

### 9.2.3 Child Adjustment

Means and standard deviations for subscale and total SDQ scores are presented in Table 20. Means and standard deviation for a general population sample and a sample of children with hemiplegia are also reported for comparison.

Table 20: Descriptive statistics and Effect Sizes (ES) for SDQ subscale and total scores for current sample (N=290), the norm sample and a clinical sample of children with hemiplegia

Variable	Current Sample		Norm Sample <sup>a</sup>		ES	Clinical Sample <sup>b</sup>		ES
	Mean	SD	Mean	SD		Mean	SD	
Conduct problems	2.23	1.87	1.6	1.7	.34	2.7	1.6	-.25
Hyperactivity	5.51	2.76	3.5	2.6	.72	4.7	2.3	.29
Emotional symptoms	3.92	2.61	1.9	2.0	.77	3.2	1.5	.28
Peer problems	3.43	2.40	1.5	1.7	.80	2.8	1.8	.26
Pro-social behaviour	7.41	2.36	8.6	1.6	.50	6.9	2.1	.22
Total SDQ score	15.09	6.97	8.4	5.8	.96	13.6	6.1	.21

<sup>a</sup> (Meltzer et al., 2000)

<sup>b</sup> personal communication R Goodman, September 1999

#### 9.2.4 Parent Adjustment

Means and standard deviations for the PSI-SF43 subscale and total scores are presented in Table 21. As a group the parents in this study met the criteria for clinically significant levels of stress, i.e. scores at or above the 90<sup>th</sup> percentile. However, it should be noted that 41.7% of the sample had scores below this cut-off point.

Table 21: Descriptive statistics and percentiles for PSI-SF43 subscale and total scores

Variable	Range	Mean	SD	Percentile
Difficult child	15-59	36.72	10.41	95
Parent child dysfunctional interaction	12-52	26.76	7.97	90
Parental distress	12-59	31.19	9.95	80
Total score	43-156	94.67	24.31	95

#### 9.2.5 Preliminary analyses.

Based on the model in Figure 16, indicators of illness, adaptation processes and parent adjustment were identified. In this study illness parameters included severity of disability, activities of daily living and the two HPPI subscale scores. Three types of adaptation processes were measured: efficacy, coping and family functioning using the CSES, Brief COPE and FSS scores respectively. Child adjustment was defined as child behaviour problems whilst parent adjustment was defined as parenting stress. Child adaptation processes were not assessed, as these were considered less appropriate to be rated by parents. Appendix G presents the means, standard deviations and Appendix H presents Pearson's product moment correlations of all variables used to investigate the model.

Preliminary confirmatory factor analyses were conducted to test the appropriateness of the different measurement models for the latent variables in the model. Results are presented in Appendix I. The initial illness parameter model showed poor fit, i.e. comparative fit index (CFI) < .90. Although Wallander and Marullo (1997) proposed a model in which the HPPI variables are integrated with disease/disability parameters, examining the relationships between the indicator variables revealed a low correlation between severity of disability and HPPI-MCS ( $r = .15$ ). Severity of disability reflects the level of functional impairment and is therefore the core indicator of disability. Furthermore, severity of disability, activities of daily living and HPPI-CHS are

variables referring directly to the child's condition whereas the HPPI-MCS subscale refers to problems in various social systems, e.g. family, as well as child behaviour. Therefore, HPPI-MCS was excluded from the measurement model. Analyses were run to test the appropriateness of the modified illness parameters measurement model. The normed fit index of this modified measurement model increased to 1.00, indicating good fit. The normed fit index (NFI) is reported, as this measurement model was a just-identified model, i.e. there was a one to one correspondence between the data and the structural parameters (number data point = number free estimates). Therefore the model had no degrees of freedom and a CFI could not be computed. Other measurement models, i.e. coping models, child behaviour and parenting stress all showed good fit (see Appendix I). Therefore these measurement models remain unchanged in the overall model.

A hierarchical linear regression analyses was performed to identify the disability and adaptation process and child adjustment variables significantly associated with parental outcome, i.e. parenting distress. These results are presented in Table 22. Results of the regression analyses indicate that 75% of the variance in parenting stress can be explained by disability parameters, coping, family functioning, efficacy, and child behaviour. Although the regression clearly confirms the association between parenting stress and these variables, the relationships between the predictor variables is not taken into account. Therefore, additional analyses were performed using Structural Equation Modelling.

Table 22: Hierarchical multiple regression analysis of disability, adaptation processes, child behaviour and parenting stress (N=290)

Variable	Step 1		Step 2		Step 3	
	Beta	t	Beta	t	Beta	t
<b>Illness</b>						
Severity disability	-.16	-2.51*	-.05	-1.23	.01	.15
Functional Impairment	.24	3.38**	.15	3.19**	.09	2.11*
HPPI-child health and services	.38	6.59***	-.05	-.95	-.07	-1.58
<b>Adaptation processes</b>						
COPE-problem focused coping			-.08	-2.04*	-.07	-2.11*
COPE-emotion focused coping			.21	4.76***	.17	4.36***
HPPI-mother child social interaction			.42	7.88***	.32	6.52***
FSS total			-.33	-8.11***	-.33	-8.70***
Efficacy			-.11	-2.83**	-.06	-1.51
<b>Child behaviour</b>						
SDQ total score					.30	7.69***

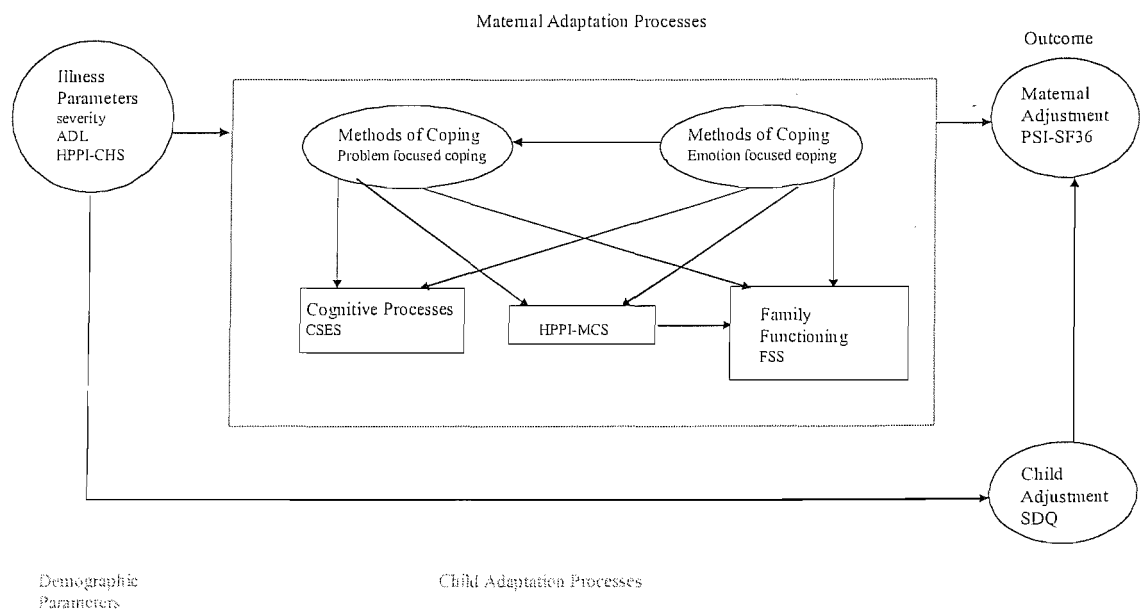
Note:  $R^2 = .23^{***}$  for Step 1;  $R^2$  change =  $.46^{***}$  for Step 2;  $R^2$  change =  $.05^{***}$  for step 3  
 \* $p < .05$       \*\* $p < .01$       \*\*\* $p < .001$

### 9.2.6 Testing the transactional stress and coping model of adjustment to disability

Figure 17 shows how the transactional stress and coping model was transformed into a path model that could be tested using SEM. For each variable the associated measure used is indicated. This model is a reduced version of the model presented in Figure 16. Boxes represent measured or observed variables; circles indicate latent variables. As mentioned in the previous paragraph, parameters regarding child adaptation processes were not measured and therefore were excluded from the model. Demographic variables are also not included. Furthermore links between variables are directional pathways rather than correlations. The path model shows both direct paths linking disability parameters to child behaviour and indirect paths

linking disability parameters through adaptation processes or child behaviour to parenting distress.

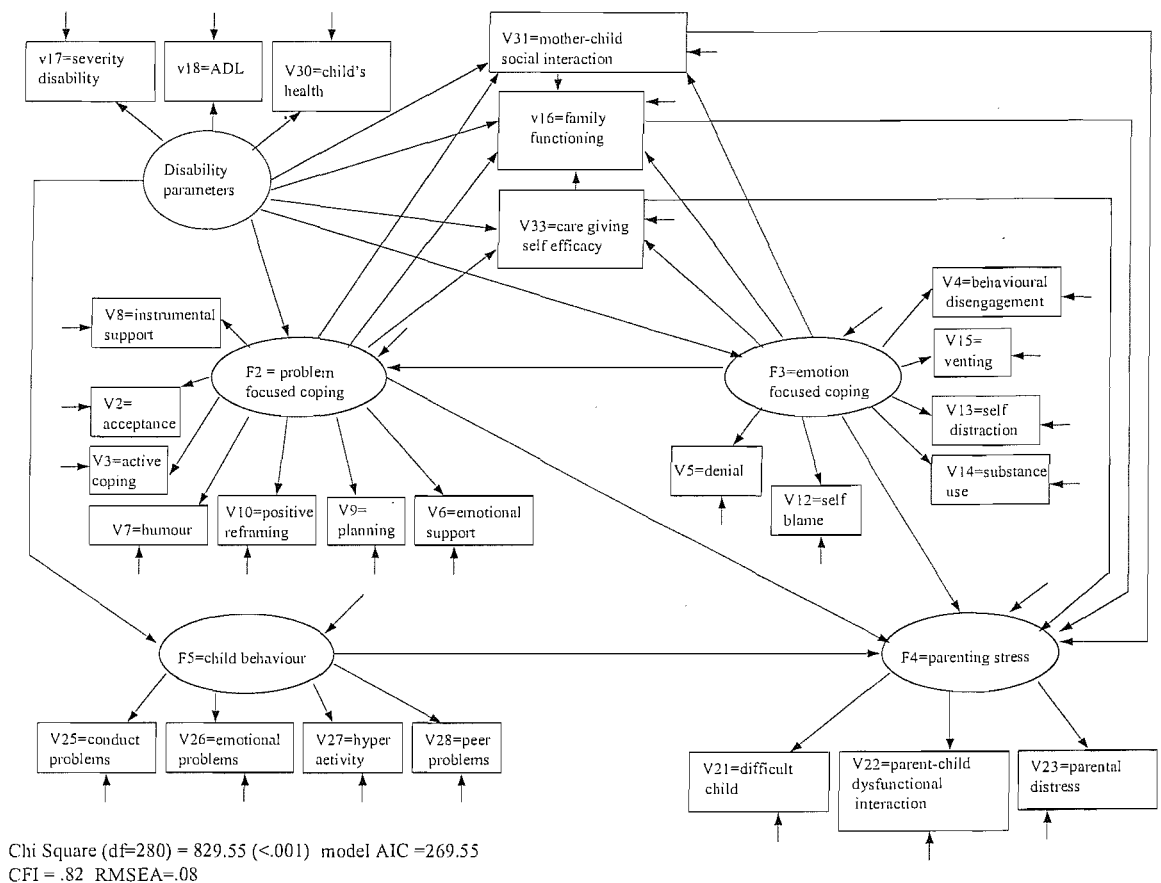
Figure 17: Path model relating disability, child behaviour problems, caregiving efficacy, parental coping, family functioning and parenting stress



It should be noted that the path linking the latent variables 'emotion focused coping' and 'problem focused coping' is unidirectional. The relationship between problem focused and emotion focused coping is best described as a correlation. However, in the SEM application EQS (Bentler, 1995) it is not possible to allow for a correlation between dependent variables. Emotion focused and problem focused coping are dependent variables as well as predictor variables. Initially, reciprocal pathways between emotion focused and problem focused were suggested. Preliminary analyses testing the model with these reciprocal paths revealed however that the pathway problem focused coping to emotion focused coping was not significant, whereas the pathway emotion focused coping to problem focused coping was. This may be explained by the fact that emotion focused coping has been

associated with poorer adjustment and therefore may necessitate, i.e. predict, the use of problem focused coping. In contrast problem focused coping has been associated with better adjustment outcomes and therefore may not predict the use of emotion focused coping. Therefore the model in which the relationship between emotion focused and problem focused coping is depicted as a unidirectional pathway has been used in this study. Figure 18 shows the structural model as tested using EQS and fit indices.

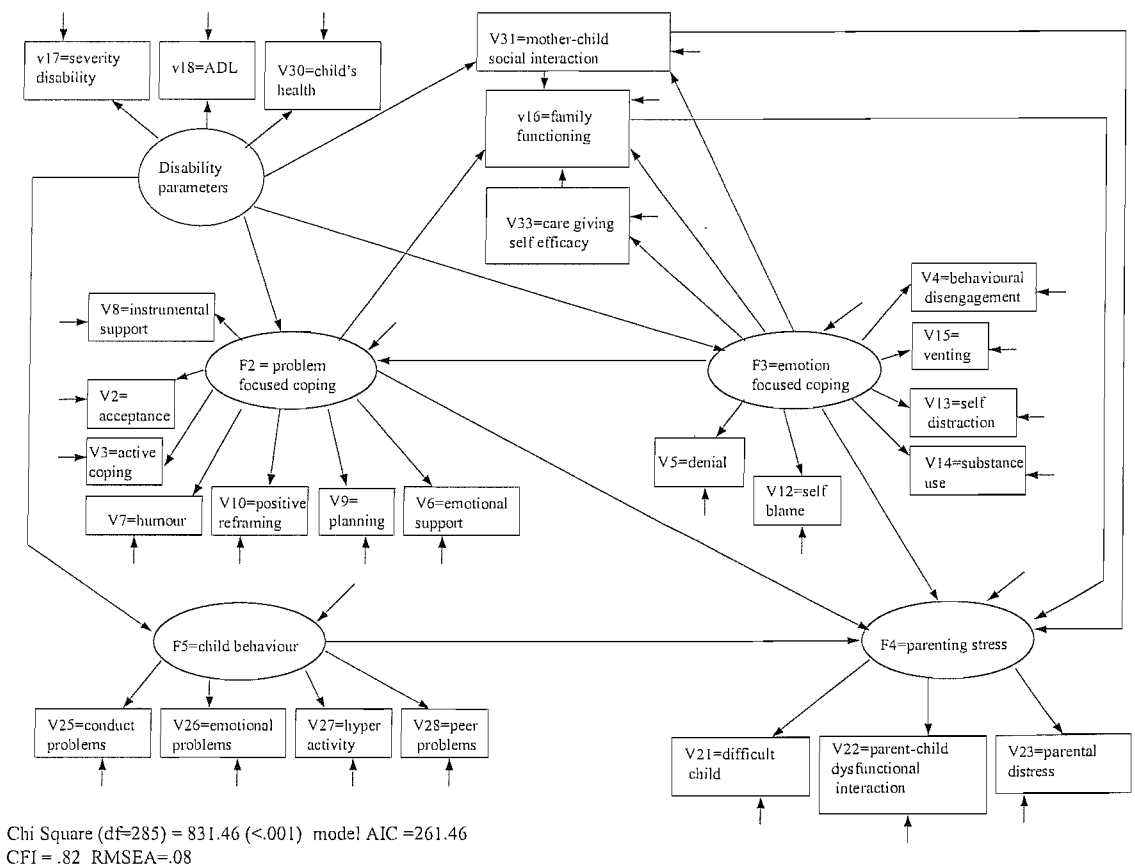
Figure 18: Structural model relating disability, child behaviour problems, caregiving efficacy, parental coping, family functioning and parenting stress



After initial analyses, non-significant paths were eliminated and the fit of this model was again estimated (see Figure 19). Excluding non-significant paths allows for a more parsimonious model to be tested, increasing statistical power. Although preliminary confirmatory factor analyses confirmed the

appropriateness of the measurement models for the latent variables, overall structural model fit was not good (Chi-square = 831.46, df = 285,  $p < .001$ ; CFI = .82), i.e. the fit between the sample covariance matrix and the estimated population covariance matrix was poor. Inspection of the standardised residual covariances and results of the Lagrange multiplier test suggested changes to the model. For example, there was a sizeable residual (.45) between the variables severity of disability and functional impairment, suggesting the illness parameter measurement model did not adequately estimate the relationship between these two variables.

Figure 19: Reduced structural model relating disability, child behaviour problems, caregiving efficacy, parental coping, family functioning and parenting stress

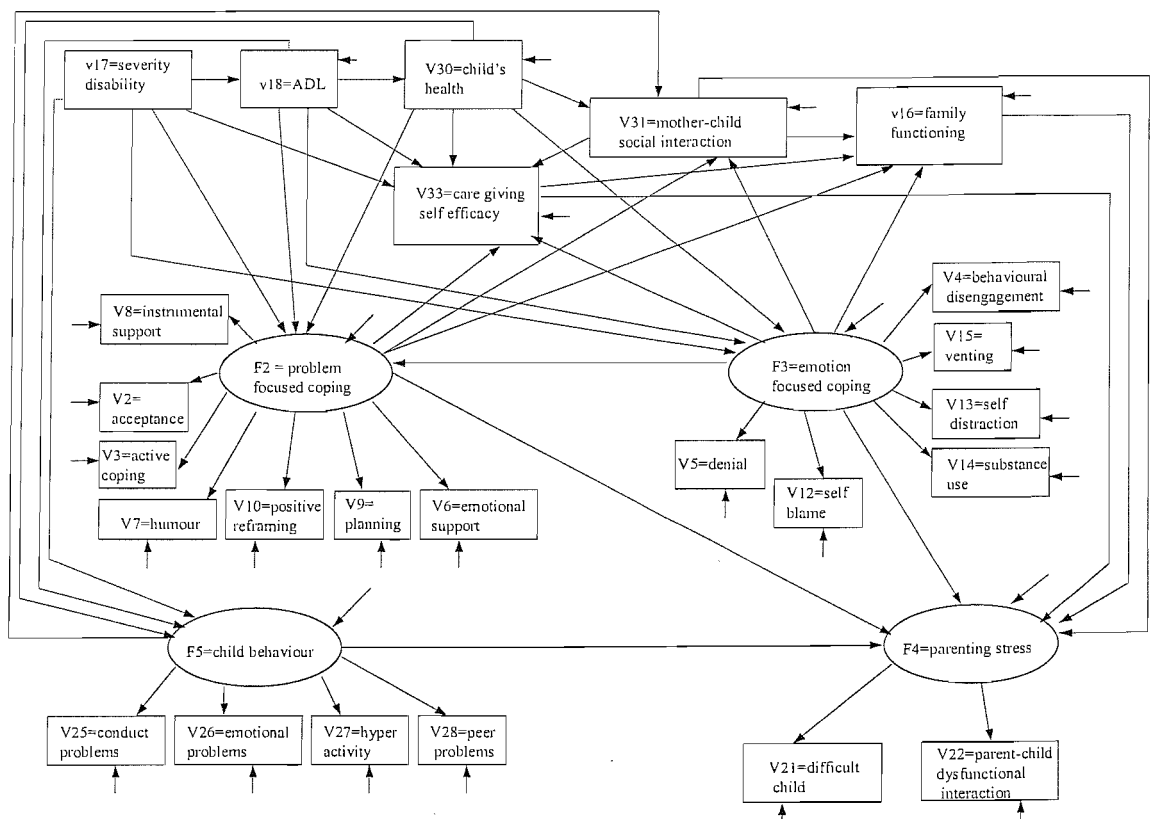


In accordance to the Disability-Stress-Coping model of adaptation to physical disability (Wallander et al., 1989b) additional pathways between the disability indicators were added and, more importantly, the illness parameters



latent variable is removed. A direct link was also proposed between child behaviour and mother-child interaction as measured by the HPPI-MCS. This path was added as the HPPI-MCS scale refers not only to interaction problems within family but also to problems in child behaviour and discipline. Furthermore the subscale parental distress was omitted, as this scale seemed to act differently from the other two scales. For example, it had the smallest loading on the parenting stress latent variable. Finally, in the restructured model it was hypothesised that the effect of illness parameters on family functioning is mediated by coping and efficacy. Therefore, the direct pathways between illness parameters and family functioning were omitted. The revised structural model is shown in Figure 20.

Figure 20: Revised structural model relating disability, child behaviour problems, caregiving efficacy, parental coping, family functioning and parenting stress

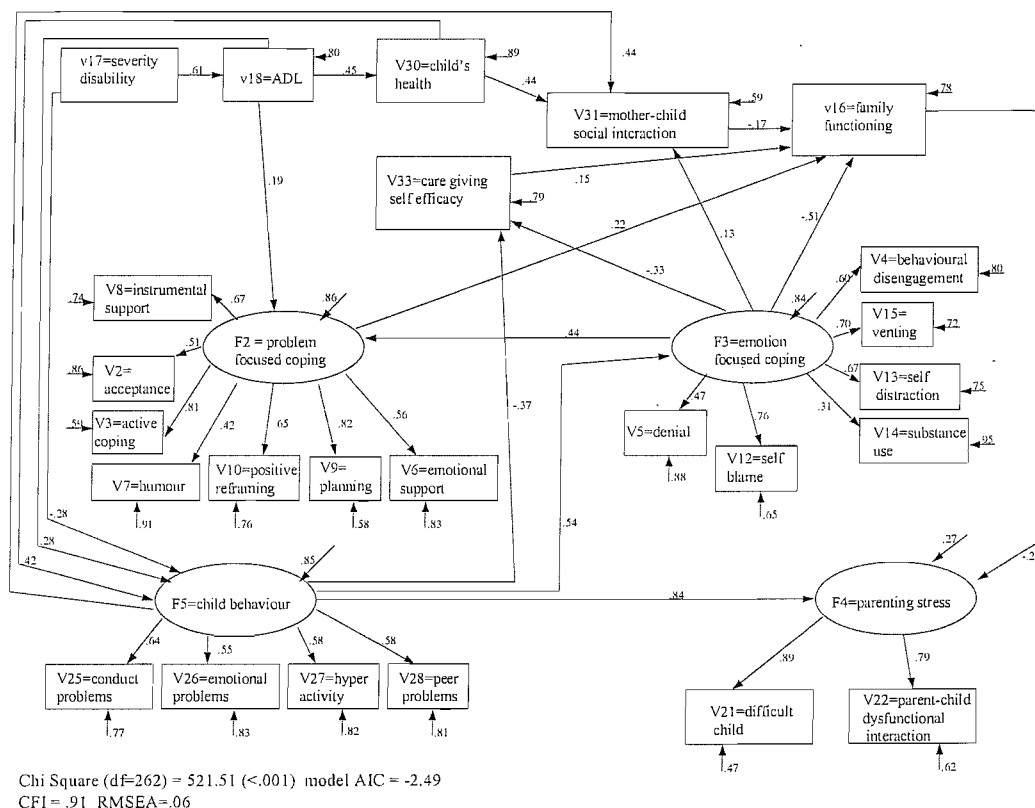


Chi Square (df=249) = 545.18 (<.001) model AIC =47.18  
CFI = .89 RMSEA=.06

The test of this revised model showed a substantial improvement over the original model (CFI=.89). Eleven paths in the revised model were non-significant paths. These paths reflected links between illness parameters and adaptation processes, i.e. associations between severity of disability and functional impairment and emotion focused coping, associations between severity of disability and HPPI-CHS and problem focused coping, association between functional impairment and HPPI-CHS and caregiving efficacy; links between adaptation processes and parent adjustments, i.e. associations between problem focused coping and caregiving efficacy and parenting stress; links between adaptation processes, i.e. association between problem focused coping and caregiving efficacy and HPPI-MCS; and a link between the illness parameters functional impairment and HPPI-CHS. Although the Chi square of the revised model with insignificant pathways omitted was still significant (Chi-square = 562.91, df = 260,  $p < .001$ ), the Chi-square was approximately two times the model's degrees of freedom, providing a rough indication the model may fit the data (Tabachnick & Fidell, 2001, p721).

Based on the Lagrange Multiplier Test, a test to determine whether unrestricting certain pathways would lead to a model that, statistically, better represents the data (Dunn, Everitt, & Pickles, 1993, p65-67), direct links between child behaviour and parental efficacy and emotion focused coping, respectively, were added. It seems plausible that child behaviour is associated with parental adaptation responses, i.e. efficacy and coping. It illustrates that parents not only have to adapt to illness-related demands but also to the behaviour of the child. Furthermore the pathways establish indirect links between child behaviour and parental adjustment via parental adaptation processes. As a result of adding these paths, other paths became insignificant and needed to be eliminated. More specifically paths between emotion focused coping and parenting stress, HPPI-CHS and emotion focused coping and HPPI-MCS and caregiving efficacy were omitted. Analysis of the final model, presented in Figure 21, resulted in a significant decrease of the Chi Square ( $\Delta$  Chi Square = 41.40;  $\Delta$  df = 2;  $p < .001$ ) and acceptable fit (CFI=.91).

Figure 21: Reduced revised structural model relating disability, child behaviour, caregiving efficacy, problems, parental coping, family functioning and parenting stress



The fit indices (i.e. CFI=.91 and RMSEA=.06) reflect a satisfactory fit between expected and observed covariance matrices, and provide support for the validity of the model. Results suggest that parental adaptation processes and child adjustment problems mediate the relationship between a child's disability and parental adjustment. For example, increased functional impairment is associated with increased use of problem focused coping strategies, which in turn are linked with increased family satisfaction. Family satisfaction is negatively associated with parenting distress, i.e. higher levels of satisfaction are linked with lower levels of parenting stress. Examination of the structural parameter estimates reveals that child adjustment problems are the strongest indicator of parenting stress. This implies that not the disability itself but the associated behavioural problems cause difficulties for parents.

### 9.3 Discussion

This study was conducted to test the transactional stress and coping model of adjustment to disability. Parents in this sample reported on the condition of their child, and the child's adjustment as well as on family functioning, parental coping, efficacy, and adjustment. Scores on the subscales of the HPPI were higher than scores reported by Wallander and Marullo (1997) in a sample of mothers of children with impaired motor or sensory functions (effect sizes for HPPI-CHS and HPPI-MCS are .43 and .35, respectively). Scores on the Brief COPE indicated that parents make more use of problem focused strategies than emotion focused strategies. The total FSS score was lower than the mean reported by Olson and Wilson (Olson & Wilson, 1992) for a large general population sample (effect size = -.28). The CSES mean was slightly higher than the mean reported by Hasting and Brown (2002) in a sample of children with mental retardation, i.e. parents rated themselves as more efficacious. It should be noted however that scores in the current sample reflect parents' efficacy in caring for their disabled child, whereas in the study of Hasting and Brown ratings reflected parent's efficacy in dealing with the behaviour problems of their child with mental retardation. Hence comparison of these scores may have limited value. Parents reported more behavioural problems than parents of children in the general population. However, their level of problems was quite similar to a sample of children with hemiplegia (see Table 20). Stress scores confirmed previous findings (e.g. Miller et al., 1992; Wallander et al., 1989b; Wallander et al., 1990) that parents of children with disabilities experience elevated levels of stress (effect size = 1.06).

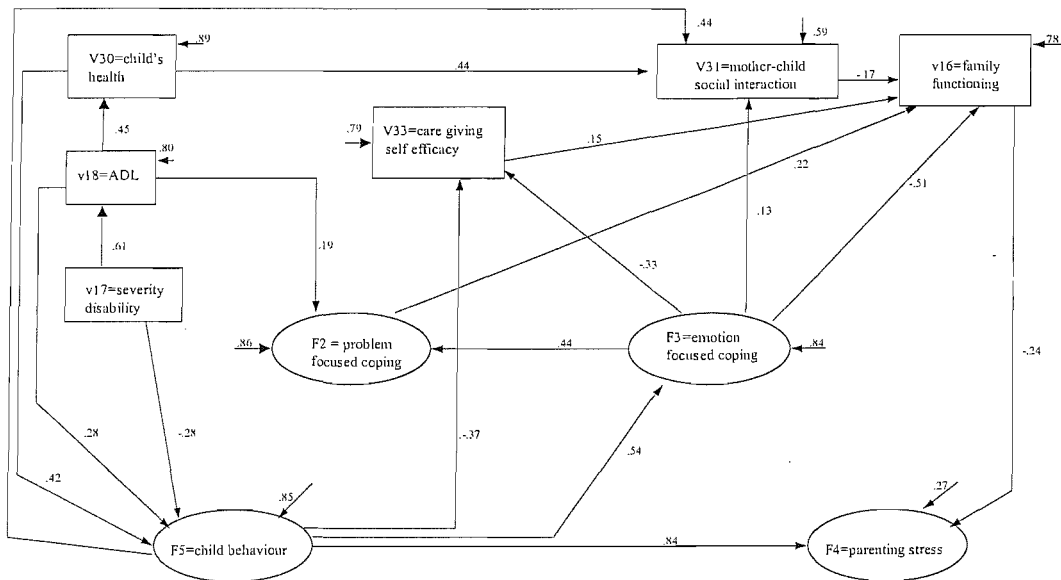
Initial regression analyses confirmed strong associations between disability parameters, family functioning, parental coping and efficacy, child behaviour and parenting stress. This finding is consistent with previous literature regarding the role of adaptation processes in parental adjustment to disability. Structural equation modelling was used to test the extent to which the data collected in this sample of parents of children with spina bifida and/or hydrocephalus conforms to the pathways of the hypothesised model. First confirmatory factor analyses were conducted to test the fit of the different

measurement models. Then, the overall model was tested. After omitting the insignificant pathways the fit of the model remained poor (CFI = .82). A revised structural model was proposed in which the disability measurement model was altered. Instead of constructing a latent disability variable, direct links between the measured disability variables and other measurement models were added, as well as direct paths between disability variables themselves. The direct paths between illness parameters and family functioning were omitted, suggesting that other adaptation processes, i.e. efficacy and coping, mediate the effect of illness parameters on family functioning. Furthermore a direct link between child behaviour and mother-child interaction patterns was proposed. These modifications were believed not to violate the theoretical framework upon which the model is based. However, these new pathways did produce a less parsimonious set of relationships between variables. This model was then tested and after taking out insignificant pathways and the addition of two paths between child behaviour and parental efficacy and emotion focused coping, respectively, resulted in good fit (CFI=.91). The restructured model explained 93% of the variance in parenting stress ( $1 - \text{error}^2 = 1 - .27^2$ ). This not only confirms the associations between the variables in the model but also, more importantly, provides further support for the model itself.

Further examination of the parameter estimates shows the strongest relationship amongst the model components exists between child adjustment (parent rated behaviour problems) and parent adjustment (parenting stress). This finding supports previous results reported by Floyd and Gallagher (1997) that the presence of significant behaviour problems was more important than disability type in determining parenting stress. As parenting stress reflects difficulties in the parent child interaction and difficulties in managing the behavioural characteristics of the child this may not be so surprising.

The results of this study provided support for the hypothesised indirect links between disability parameters and parenting stress. The indirect links, both via parental adaptation processes and child behaviour, indicate that the effect of disability on parenting stress is mediated by the use of coping strategies, mother-child interaction patterns, family functioning and child adjustment. Hereby several different pathways are possible (see Figure 22).

Figure 22: Simplified final structural model of disability, child behaviour problems, caregiving efficacy, parental coping, family functioning and parenting stress



For example, the relationship between problems associated with the child's health and parenting stress can be mediated by i) child behaviour ( $.42 \times .84 = .35$ ); ii) child behaviour, caregiving self efficacy and family functioning ( $.42 \times -.37 \times .15 \times -.24 = -.006$ ); iii) child behaviour, emotion focused coping and family functioning ( $.42 \times .54 \times -.51 \times -.24 = .03$ ); vi) child behaviour, emotion focused coping, problem focused coping and family functioning ( $.42 \times .54 \times .44 \times .22 \times -.24 = -.005$ ); v) child behaviour, emotion focused coping, caregiving efficacy and family functioning ( $.42 \times .54 \times -.33 \times .15 \times -.24 = .003$ ); vi) child behaviour, emotion focused coping, mother child social interaction and family functioning ( $.42 \times .54 \times .13 \times -.17 \times -.24 = .001$ ); vii) mother-child social interaction and family functioning ( $.44 \times -.17 \times -.24 = .02$ ); and viii) child functional impairment, problem focused coping and family functioning ( $.45 \times .19 \times .22 \times -.24 = -.005$ ). The total effect of child's health on parenting stress is therefore  $.39$  ( $.35 + -.006 + .03 + -.005 + .003 + .001 + .02 + -.005$ ).

The hypothesised direct links between disability and child adjustment, and child adjustment and parent adjustment respectively, were confirmed. There are no indirect links between disability parameters and child behaviour. However, because of added pathways between child behaviour and mother-child social interaction and parental coping and efficacy, respectively, indirect links between child behaviour, family functioning and parenting stress are established. For example, the model shows that family functioning is associated with emotion focused coping, which is linked to child behaviour ( $-.51 \times .54 = -.28$ ).

Similarly, family functioning is associated with caregiving efficacy, which links to child behaviour ( $.15 \times -.37 = -.06$ ). Both pathways indicate that more cohesive and adaptive families have children with fewer behavioural problems. This link is mediated by either higher caregiving efficacy or less use of emotion focused coping. The relationship between family functioning and child adjustment is well established and less adaptive family functioning has been consistently associated with poorer child adjustment (see Drotar, 1997, for a review).

With regards to the relationship of adaptation variables it is interesting to note that the use of coping strategies or caregiving efficacy are not directly linked to experiences of stress. Family functioning mediates the pathways between the other two types of adaptation processes and parenting stress. This demonstrates the value of using a statistical technique that allows for simultaneous analysis of the entire system of variables rather than studying the effects of predictor variables on outcome in isolation.

In summary, in this final model, direct pathways between disability indicators and child behaviour are identified as well as indirect paths between disability and parenting stress through adaptation processes. The final model is conceptually similar to the initial model, i.e. the changes have not violated the underlying theoretical framework. The difference from the initial model, however, is that the final model provides numerical estimates for the impact of parts of the system on other parts, i.e. it is quantitative and not just conceptual. The final model also indicates relationships between illness parameters, adaptation processes and outcome variables in ways that are less parsimonious as originally suggested.

## Chapter 10

### **Study 5: Testing the transactional stress and coping model of adjustment to disability in mothers of children with asthma**

The study described in Chapter 9 established that the revised structural stress and coping model adequately describes the processes involved in maternal adaptation to a child's disability, i.e. spina bifida and hydrocephalus. In accordance with the partial categorical approach to the study of adjustment of children with chronic illness and disability (Pless and Perrin, 1985, in Thompson & Gustafson, 1996b), it has been suggested that the model could be applied to all chronic illness and disability groups. The partial categorical approach emphasises the common dimensions of all chronic physical disorders that are of importance to adjustment, whilst recognising disease/illness specific characteristics. Following this approach, illnesses can be organised in terms of biomedical and psychosocial dimensions that are related to adjustment, such as age of onset, functional limitations, and visibility.

Although results of Study 4 (Chapter 9) supported the adequacy of the model in a sample of families of children with spina bifida and hydrocephalus, the extent to which the findings are transferable to other disability/illness groups needs to be tested on other datasets. Therefore, the current study (Study 5) involved testing the model in a different illness group, namely children with asthma.

Asthma is one of the most common chronic illnesses affecting children. It is estimated that approximately 6% of children under the age of 18 years suffer from this condition (Taggart & Fulwood, 1993). Thompson and Gustafson (1996b) reported an even higher prevalence rate of 38 per 100 children aged 0-20 years. In the UK approximately one in seven children aged 2-15 years and one in 25 adults (16 years and over) has asthma symptoms requiring treatment ([www.asthma.org.uk/infofa18.html](http://www.asthma.org.uk/infofa18.html)).

The National Institute of Health defined asthma as a chronic inflammation disorder that causes airflow obstructing and bronchial hyper-responsiveness to a variety of stimuli (e.g. dust mite or cigarette smoke).



Asthma attacks are characterised by breathing difficulties, which manifest themselves as coughing, wheezing or shortness of breath. They vary in frequency and severity within and across children and adolescents. The obstruction of airflow is mostly reversible either spontaneously or with treatment (e.g. inhalers), however, a significant number of children die of asthma each year. For example, in 1997 there were 1584 deaths (children and adults) with asthma registered as the cause in the UK ([www.asthma.org.uk/infofa18.html](http://www.asthma.org.uk/infofa18.html)).

Both parents and their child with asthma may be at risk for psychological adjustment problems. For example, parents of children with asthma perceived their children more difficult to care for than parents of children with no health problems (Eiser, Eiser, Town, & Tripp, 1991). Caregiving demands were directly related to parental well-being in parents of young children with asthma (Svavarsdottir, McCubbin, & Kane, 2000). Carson and Schauer (1992) reported that mothers of children with asthma aged 8-13 years, experienced elevated levels of parenting stress. These mothers perceived the behavioural difficulties of their children harder to manage and reported more problems in the mother-child relationship than mothers in a comparison group of mothers of healthy children (Carson & Schauer, 1992).

In a meta-analytic review, McQuaid, Kopel and Nassau (2000) concluded that children with asthma have more behavioural difficulties, especially in the internalising domain. In addition, they reported that severity of asthma was positively related to behavioural problems, i.e. children with more severe asthma experienced more behavioural difficulties. Children with asthma may also be at risk for social isolation. Graetz and Shute (1995) found that in a sample of children with moderate to severe asthma, those who had more hospitalisations felt lonelier and were less preferred as playmates (Graetz & Shute, 1995). Data from a longitudinal study, suggested a relationship between age of asthma onset and behavioural adjustment. More specifically, children with early onset asthma - symptoms present before 3 years of age - displayed significantly more behavioural problems both at age 4 and age 6 than children whose asthma symptoms developed at a later age (between 3 and 6 years of age) (Mrazek, Schuman, & Klinnert, 1998).

As mentioned earlier, common dimensions can be described for different chronic illness and disability groups. Table 23 describes asthma, spina bifida and hydrocephalus in terms of biomedical and psychosocial dimensions that are related to parent adjustment. As strong associations exist between child adjustment and parent adjustment, aspects of child adjustment are incorporated well.

Table 23 shows that spina bifida, hydrocephalus and asthma are similar on some dimensions and different on others. Significantly, all three conditions require adaptation of the parents, e.g. parents need to deal with the symptoms and treatment of the conditions. It is also important to note that these conditions impact child adjustment as strong associations between child adjustment and parent's adjustment have been found (see Figure 21, Chapter 9,). Asthma requires parents to adapt and also affects child adjustment, therefore this condition seems suitable for testing the transactional stress and coping model. Although other conditions could have been chosen, such as cystic fibrosis or diabetes, the choice for families with asthma was based on the availability of a large sample in the Southampton area. A large sample is required because to use SEM it is suggested that 10 participants are needed for each variable or even better 10 participants for each estimated parameter (Tanaka, 1987). The full model incorporates 25 variables and 66 estimated parameters, therefore a sample size of at least 250 is desirable.

Table 23: Biopsychosocial Organizational Framework (Adapted from Thompson & Gustafson, 1996b, p40)

Dimension	Chronic illness/disability		
	Spina bifida	Hydrocephalus	Asthma
Aetiology			
Genetic	O	X	X
Non-genetic	X	X	X
Age of onset			
Birth	X	X	O
Childhood	O	X	X
Course			
Static	X	X	O
Episodic	O	O	X
Impairment			
Cognitive	X	X	O
Motor	X	X	O
Sensory	X	X	O
Visible	X	O	O
Medical Regimen			
Pills	O	O	X
Inhalants	O	O	X
Surgical intervention	X	X	O
Physical therapy	X	O	O
Child adjustment			
Behavioural	X	X	X
Emotional	X	X	X
Social	X	X	X

The current study was conducted to address the following research questions and hypotheses:

1) How do families of children with asthma compare to families with children with spina bifida and/or hydrocephalus on measures of child illness, family adaptation, and child and parent adjustment? It was expected that the child's health would be more adversely affected in the spina bifida/hydrocephalus sample, i.e. ratings of functional impairment and handicap related problems in

regards to child health and services are expected to be lower in the asthma sample. Therefore, ratings of child and parent adjustment problems (i.e. child behaviour problems and parenting stress) were also expected to be lower in the asthma sample. No differences in ratings of family adaptation were expected.

2) To what extent is the transactional stress and coping model of adjustment to disability consistent with the data of a sample of families of children with asthma? A satisfactory fit was expected between the stipulated model and the observed data.

3) To what extent are the relationships between the constructs within the transactional stress and coping model of adjustment to disability similar or different for the two samples? It was expected that the relationships between the constructs would be similar in both samples.

## 10.1 Method

### 10.1.1 Participants and Procedure

A detailed description of Sample 2 and procedure can be found in Chapter 5. Mothers of children with asthma were recruited via the asthma clinic at Southampton General Hospital. Families were identified using in- and outpatient record sheets. Surveys were sent to 250 families with a child with asthma aged 5-13 years. At the end of a 4-month period a total of 92 completed questionnaires were returned (38%). Unfortunately, for 19 participant data was incomplete reducing the total sample to 73. Mother's ages ranged from 22 to 54 years (Mean = 36.77, SD= 5.74). The mean age of the children (22 girls and 51 boys) was 8.33 years (SD= 2.42), ranging from 4 to 13 years.

### 10.1.2 Measures

All measures have been described in detail in Chapter 5. Therefore, only a brief description of each measure will be presented below.

#### 10.1.2.1 Illness parameters

*Questionnaire to measure perceived symptoms and disability in asthma (Usherwood et al., 1990)*

This questionnaire provides a quantitative measure of symptoms and disability parents perceive in their children with asthma aged 5-14 years. The questionnaire contains 17 items comprising three scales: perceived disability, perceived daytime symptoms and perceived nocturnal symptoms. A total score can be computed by adding the subscale scores. Items are scored on a 5-point Likert scale (0=not at all, 4=every day). Higher scores indicate greater perceived disability or extent of symptoms. The content validity of the three subscales was supported by a principal component analyses with varimax rotation. Internal reliability was established by computing coefficient alpha for each subscale. Coefficient alpha ranged from .71 to .92 for the three scales in two different samples (Usherwood et al., 1990).

#### *Functional impairment*

The functional impairment measure consists of six questions concerning difficulties with daily life activities, e.g. washing, eating and walking ordinary distances. Each item is scored on a 3-point scale (0 = no difficulties, 2 = major problems). A total score is computed by adding the items scores.

#### *Handicap related problems for parents inventory (HPPI)*

The HPPI (Wallander & Marullo, 1997) is a 17-item questionnaire regarding the most commonly reported sources of problems for parents of children with disabilities. Although the problems are defined such that the problems may not be directly linked with the disability or be brought on by the child, the response format reflects a perceived association between problems and disability. Parents rate the items using an 8-point Likert scale (0 = not at all, 7 = every day or more). The items comprise three subscales: child health and services (HPPI-CHS), mother child social (HPPI-MCS) and mother's life. For the purpose of this study only the first two subscales are used. The child health and services subscale reflects problems and special services directly

related to the child's condition. The subscale mother child social taps problems in social systems as well as in child behaviour and leisure activities.

#### 10.1.2.2 Adaptation Processes

##### *Family functioning – Family Satisfaction Scale (FSS)*

The FSS (Olson & Wilson, 1992) is a 14-item measure to assess family satisfaction on the dimensions of cohesion and adaptability. Cohesion reflects the emotional bonding within the family, whilst adaptability concerns the ability of a family system to change in response to situational and developmental challenges. Parents rate the 14 items on a 5-point Likert scale (1 = dissatisfied, 5 = extremely satisfied). The total FSS score, which has good psychometric properties and is therefore the most useful for research purposes, is computed by adding the subscale scores.

##### *Coping – Brief COPE*

The 28 items of the Brief COPE (Carver, 1997) comprise 14 coping scales. Respondents rate the extent of use of each coping strategy on a 4-point scale (1 = have not been doing this at all, 4 = have been doing this a lot). An exploratory factor analyses identified three factors: Problem Focused Coping (includes strategies Active Coping, Planning, Positive Reframing, Acceptance, Humour, Emotional Support and Instrumental Support), Emotion Focused Coping (include strategies Self-Distraction, Denial, Venting, Substance Use, Behavioural Disengagement and Self Blame) and Religion (see Chapter 5).

##### *Efficacy – Caregiving Self efficacy Scale (CSES)*

The CSES (Hastings & Brown, 2002) assesses parental feelings about their role as a caregiver. Five items, rated on a 7-point Likert scale (1 = not at all, 7 = very), are summed to compute a total score.

### 10.1.2.3 Child adjustment

#### *Strengths and Difficulties Questionnaire (SDQ)*

The SDQ (Goodman, 1997) is a parent rated 25 item behavioural screening questionnaire, for use with children 4-16 years of age. The scale comprises of five subscales: conduct problems, hyperactivity and inattentiveness, emotional symptoms, peer problems and pro-social behaviour. A total score can be computed by summing the first four subscale scores.

### 10.1.2.4 Parent Adjustment

#### *Parenting Stress Index Short Form Modified (PSI-SF43)*

The PSI-SF43 is a modified version of the PSI-SF36 (Abidin, 1995) see also Chapter 7). A 5-point Likert scale is used to rate 43 items (1 = strongly agree, 5 = strongly disagree). The PSI-SF43 contains four subscales: Parental Distress, Parent-Child Dysfunctional Interaction, Difficult Child and positive gain. High scores on the three original PSI-SF36 subscales reflect more stress. A high positive gain score reflects less gain. A total stress score can be computed by summing the three original subscale scores.

## 10.2 Results

Descriptive statistics and effects sizes for all measures are presented in Table 24.

Table 24: Descriptive statistics, Effect Sizes (ES) and t-tests for test scores for Sample 2, mothers of children with asthma (N=73) and Sample 1, mothers of children with spina bifida and hydrocephalus (N=290)

Variable	Sample 2		Sample 1		ES	t
	Mean	SD	Mean	SD		
<b>Illness Parameters</b>						
Severity of asthma						
Disability	8.11	7.20				
Nocturnal Symptoms	5.30	2.58				
Daytime Symptoms	6.69	3.42				
Total Score	20.10	11.98				
Child Functional Impairment	1.04	1.52	4.97	3.19	-1.18	15.20**
HPPI-CHS	6.81	7.72	13.68	9.17	-.74	6.53**
HPPI-MCS	6.41	9.44	17.66	15.50	-.74	7.86**
<b>Adaptation processes</b>						
FSS Total	47.25	10.11	43.95	10.96	.30	-2.34*
CSES	28.27	5.42	29.17	4.88	-.18	1.37
Problem Focused Coping	30.15	8.53	31.69	8.58	-.18	1.37
Active Coping	4.63	1.88	4.75	1.88		
Planning	4.32	1.78	4.72	1.84		
Positive Reframing	4.14	1.75	4.36	1.71		
Acceptance	5.82	1.92	6.11	1.87		
Humour	3.03	1.45	3.04	1.48		
Emotional Support	4.04	1.79	4.17	1.67		
Instrumental Support	4.18	1.77	4.54	1.76		
Emotion Focused Coping	16.34	4.45	18.65	5.56	-.43	3.75**
Self-Distraction	3.08	1.34	3.61	1.47		
Denial	2.26	.71	2.51	1.07		
Venting	2.88	1.18	3.46	1.56		
Substance Use	2.33	1.00	2.48	1.16		
Behavioural Disengagement	2.33	.83	2.48	.92		
Self-Blame	3.47	1.58	4.10	1.88		



<b>Child Adjustment</b>						
Total SDQ Score	13.18	6.24	15.09	6.97	- .28	2.14*
Conduct Problems	2.47	2.06	2.23	1.87		
Hyperactivity	5.03	2.87	5.51	2.76		
Emotional Symptoms	3.77	2.35	3.92	2.61		
Peer Problems	1.92	1.83	3.43	2.40		
Pro-Social Behaviour	7.93	1.84	7.41	2.36		
<b>Parent Adjustment</b>						
Total Stress Score	82.85	20.13	94.67	24.31	- .49	4.29**
Difficult Child	32.77	9.05	36.72	10.41		
Parent-Child Dysfunctional Interaction	23.67	6.91	26.67	7.97		
Parental Distress	26.41	8.97	31.19	9.95		

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\*p<.05 \*\*p<.001

### 10.2.1 Illness parameters

Descriptive statistics are shown in Table 24. The severity of asthma scores ranged from 0-12, 0-16, 0-30 and 0-56 for nocturnal symptoms, daytime symptoms, disability and total score, respectively. The mean severity scores are comparable to the scores reported by Usherwood et al. (1990). The child functional impairment, HPPI-CHS and HPPI-MCS scores ranged from 0-8, 0-33 and 0-36, respectively. Mean scores on the HPPI subscales are lower than reported by Wallander and Marullo (1997) for a sample of mothers of children with impaired motor or sensory functions (Effect Sizes for HPPI-CHS and HPPI-MCS are -.37 and -.62 respectively). As expected parents of children with asthma reported significantly fewer functional limitations and fewer handicap related problems, both in the domain of health and services as in the domain of social interaction, child behaviour and leisure activities, than mothers of children with spina bifida and hydrocephalus.

### 10.2.2 Adaptation processes

Means and standard deviations for the family functioning, efficacy and coping measures are presented in Table 24. The FSS total score ranged from 25 to 70. The Mean FSS total score for mothers of children with asthma is similar to the general population mean scores reported by Olson and Wilson (1992), but significantly higher than the mean FSS scores for mothers of

children with spina bifida and hydrocephalus. The CSES score ranged from 14 to 35. Mean CSES scores for mothers of children with asthma are higher than scores reported for mothers of children with autism (Hastings & Brown, 2002). However, the mean CSES scores for Samples 2 and 1 are similar. The scores for problem and emotion focused coping ranged from 14 to 51 and 12 to 35, respectively. Scores for all coping subscales ranged from 2 to 8, except for Denial (range 2-5), Behavioural Disengagement (range 2-7) and Humour (range 2-7). As in Sample 1, mothers of children with asthma use more problem focused strategies than emotion focused strategies. Mean scores for problem focused coping are similar for the two samples. In contrast, mothers of children with asthma use significantly less emotion focused coping strategies than mothers of children with spina bifida and/or hydrocephalus.

#### 10.2.3 Child Adjustment

Descriptive statistics for subscale and total SDQ scores are shown in Table 24. Subscale scores ranged from 0-10, except for peer problems, range 0-9. Total SDQ scores ranged from 2 to 28. Only 58% of children with asthma do not have behavioural problems, 14% score in the borderline range and 29% in the abnormal range. The percentage of behavioural problems in this population is therefore three times as high as in the general population. The percentage of children scoring in the abnormal range for Conduct problems, Hyperactivity, Peer problems and Emotional symptoms is 29%, 34%, 15% and 34%, respectively. As expected, mean total SDQ scores for asthma sample are significantly lower than for children with spina bifida and hydrocephalus. This difference is mainly caused by the disparity in mean scores for the subscale peer problems.

#### 10.2.4 Parent Adjustment

Means and standard deviations for the PSI-SF43 subscale and total scores are presented in Table 24. The mean total stress score of the mothers in this sample is elevated (mean score in 85<sup>th</sup> percentile). As a group, total stress scores of mothers of children with asthma do not reach a clinically significant level, i.e. mean scores are below the 90<sup>th</sup> percentile. However, 35%

of the sample had score above this cut-off point. This percentage is three times as high as in the general population. The percentile ranks for the subscales Difficult Child, Parent-Child Dysfunctional Interaction and Parental Distress are 85, 75 and 55, respectively. This indicates that mothers perceive their child and the interaction with their child more challenging / stressful than mothers of children in the general population. However, levels of parental distress are average. As expected, mothers of children with asthma reported significantly lower levels of parenting stress than mothers of children with spina bifida and hydrocephalus in all domains.

#### 10.2.5 Preliminary analyses:

A hierarchical linear regression analysis was performed to identify the chronic illness, adaptation and child adjustment variables significantly associated with parental outcome, i.e., parenting stress. The results are presented in Table 25. Results of the regression analysis indicate that 70% of the variance in parenting stress in mothers of children with asthma can be explained by illness parameters, coping, family functioning, efficacy, and child behaviour.

Table 25: Hierarchical multiple regression analysis of chronic illness, adaptation processes, child behaviour and parenting stress (N=73)

Variable	Step 1		Step 2		Step 3	
	Beta	t	Beta	t	Beta	t
<b>Illness</b>						
Asthma symptoms	-.17	-1.06	-.05	-.37	-.08	-.77
Functional Impairment	.27	1.95	.15	1.21	.08	.83
HPPI-child health and services	.40	2.26*	.15	.68	.08	.42
<b>Adaptation processes</b>						
COPE-problem focused coping			-.02	-.22	.01	.16
COPE-emotion focused coping			.33	3.08**	.20	2.27*
HPPI-mother child social interaction			.07	.37	.11	.70
FSS total			-.34	-3.24**	-.21	-2.35*
Efficacy			.01	.09	-.12	-1.53
<b>Child behaviour</b>						
SDQ total score					.50	6.07***

Note:  $R^2 = .25^{***}$  for Step 1;  $R^2$  change =  $.27^{***}$  for Step 2;  $R^2$  change =  $.18^{***}$  for step 3

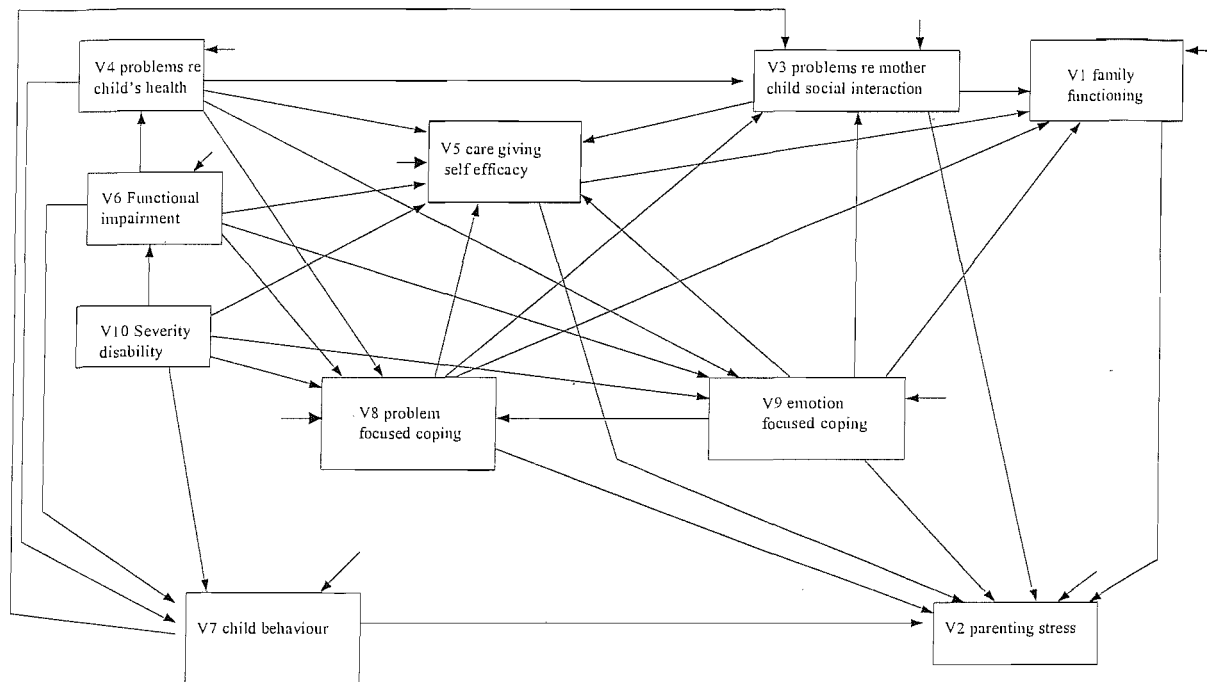
\* $p < .05$

\*\* $p < .01$

\*\*\* $p < .001$

Additional analyses to test the transactional stress and coping model of adjustment to disability were performed using structural equation modelling. Appendix J presents Pearson's product moment correlations of all variables used to investigate the model. As a result of the small sample size testing the same model as described in Chapter 9 was not feasible. Instead a path model using only manifest variables was tested. A model based on manifest variables was expected to differ from the model including both manifest and latent variables, as mostly total scores rather than subscale scores were incorporated and because the relationship between latent variables is free of measurement error. Therefore, the initial revised structural model (Figure 20, Chapter 9) was adapted to include only manifest variables and tested for the Sample 1, mothers of children with spina bifida and hydrocephalus. This model is presented in Figure 23.

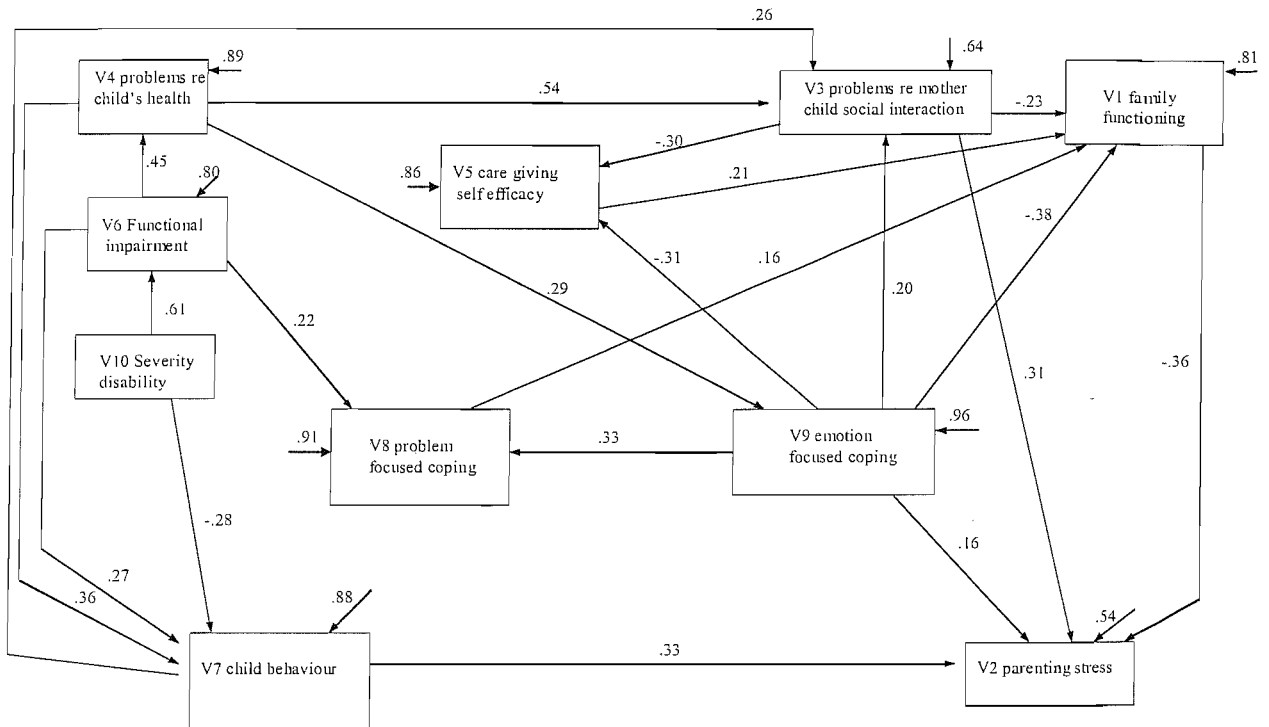
Figure 23: Measurement path model (adapted from Figure 20, Chapter 9),  
 Sample 1 (N=290).



Chi Square (df=13) = 50.68 (p<.001) model AIC = 24.68  
 CFI = .97 RMSEA=.10 (90% confidence interval .07 - .13)

Testing the fit of this measurement model resulted in a comparative fit index of .97. However not all pathways proved to be significant. These 11 pathways were therefore omitted. The final model for Sample 1 is presented in Figure 24.

Figure 24: Reduced measurement path model, Sample 1 (N=290)



Chi Square (df=24) = 71.85 (p<.001) model AIC = 23.85  
CFI = .96 RMSEA=.08 (90% confidence interval .06 - .11)

In the model adaptation processes and child adjustment mediate the effect of illness parameters on parent adjustment. The final measurement path model is quite similar to the structural path model described in Chapter 9. Both models showed good fit, i.e. data are consistent with the specific models.

However there are a few differences:

- A) The model using manifest variables explains 71% of the variance in parenting stress, whilst the model incorporating latent variables explained 93% (1-error<sup>2</sup>).
- B) In the latent model, effects of coping and efficacy on parenting stress are mediated by family functioning. In contrast, in the manifest model both mediated and direct effects of coping and efficacy on parenting stress are maintained.

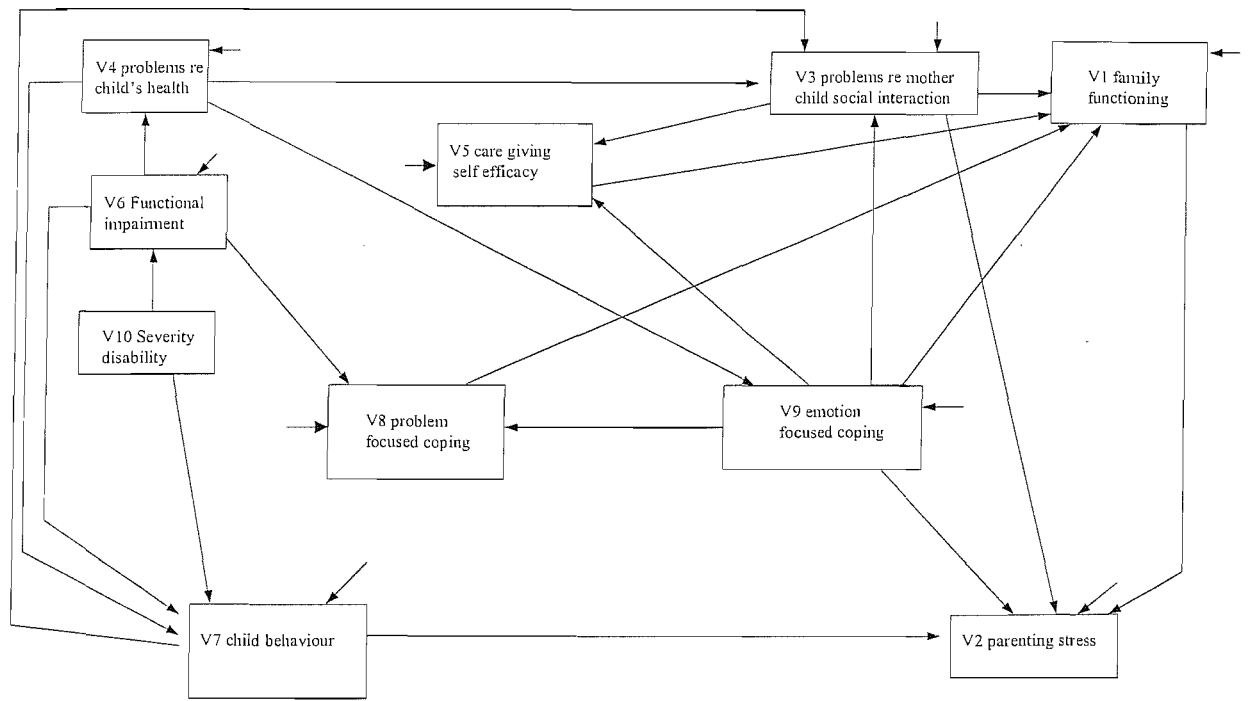
- C) The manifest model incorporates two paths that are not included in the latent model: a link between problems related to mother child social systems and caregiving efficacy and a link between problems related to child's condition and emotion focused coping.
- D) The latent model incorporates paths between child behaviour and emotion focused coping and caregiving efficacy. These paths are not integrated in the manifest model.

These differences do not take away from the fact that both path models support the underlying assumptions of the transactional stress and coping model of adjustment to disability, i.e. adaptation processes and child adjustment mediate the effects of illness parameters on parent adjustment.

#### 10.2.6 Testing the transactional stress and coping model of adjustment to disability in a sample of mothers of children with asthma

Results from the previous paragraph established acceptable fit of the reduced measurement model for Sample 1. This model was then applied to Sample 2, mothers of children with asthma (see Figure 25).

Figure 25: Reduced measurement path model applied to Sample 2, mothers of children with asthma (N=73)

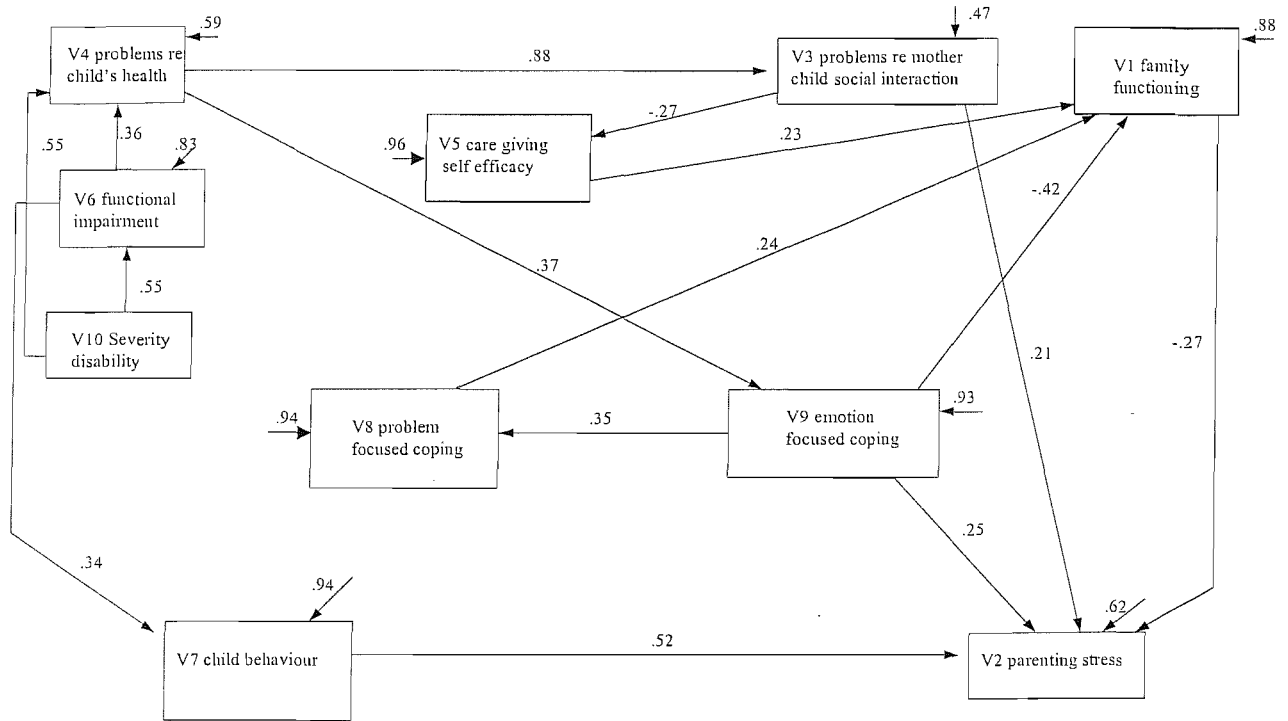


Chi Square (df=24) = 69.97 (p<.001) model AIC = 21.97  
CFI = .87 RMSEA=.16 (90% confidence interval .12 - .21)

Results of structural equation modelling using EQS indicated poor fit between the observed and expected covariance matrices (CFI = .87). Based on an inspection of the measurement equations and results of the Lagrange multiplier test, insignificant paths were omitted and one additional pathway, from severity of asthma to problems associated with child's condition, was added. This pathway indicates a direct link between severity of asthma and problems associated with child's condition as well as a mediated effect via the child's functional limitations. This pathway was believed not to violate the transactional stress and coping model. These changes improved the model substantially, i.e. testing the revised measurement model indicated acceptable fit (CFI=.97). These results support the hypothesis that the data of Sample 2 would be consistent with the transactional stress and coping model. The revised measurement path model is presented in Figure 26.



Figure 26: Final measurement path model for Sample 2 (N=73)



Chi Square (df=30) = 42.20 (p=.07) model AIC = -17.80  
 CFI = .97 RMSEA=.08 (90% confidence interval .00 - .12)

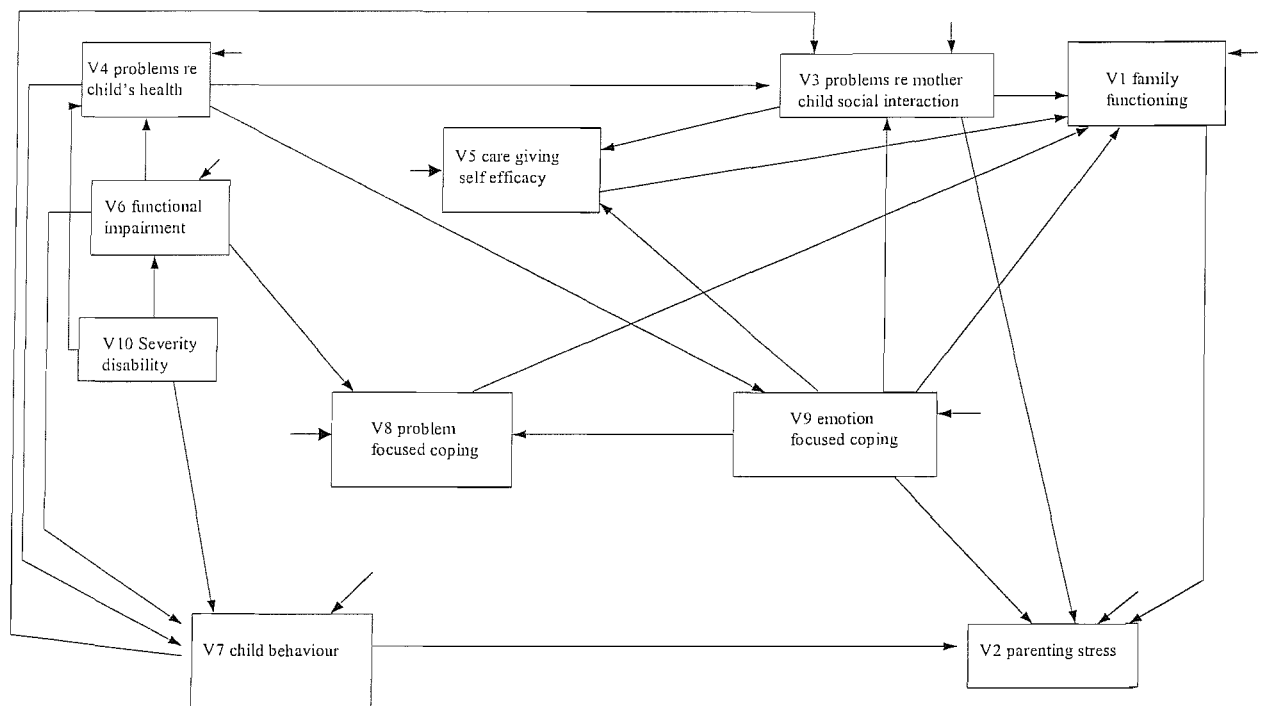
The model for Sample 2 is more parsimonious than the model for Sample 1. The (omitted) insignificant paths for Sample 2 included: 1) direct link between problems associated with mother child interaction systems and family satisfaction; 2) direct link between child behaviour and problems associated with mother child social interaction systems; 3) direct link between emotion focused coping and problems associated with mother child social interaction systems; 4) direct link of emotion focused coping and caregiving efficacy; 5) direct link between severity of asthma and child behaviour; 6) direct link between problems associated with child's condition and child behaviour; and 7) direct link between functional limitation and problem focused coping. One additional path was included, i.e. the association between severity of asthma and problems associated with child's condition. It is believed that these alterations do not jeopardize the theoretical framework of the model. In Samples 1 and 2, the relationship between illness parameters and parental

adjustment is mediated by adaptation processes and child adjustment, therefore supporting the transactional stress and coping model of adjustment to disability. In the next paragraph the equality of the models will be formally tested using a multigroup analysis.

### 10.2.7 Multigroup analyses:

To examine the extent to which the models were different for Samples 1 and 2, i.e. to test for differences in the strength of the associations between variables within the model, a multigroup analysis was conducted. The model used for this analysis included all paths that were significantly different from 0 in either sample. This model is shown in Figure 27.

Figure 27: Combined measurement path model for Samples 1 and 2



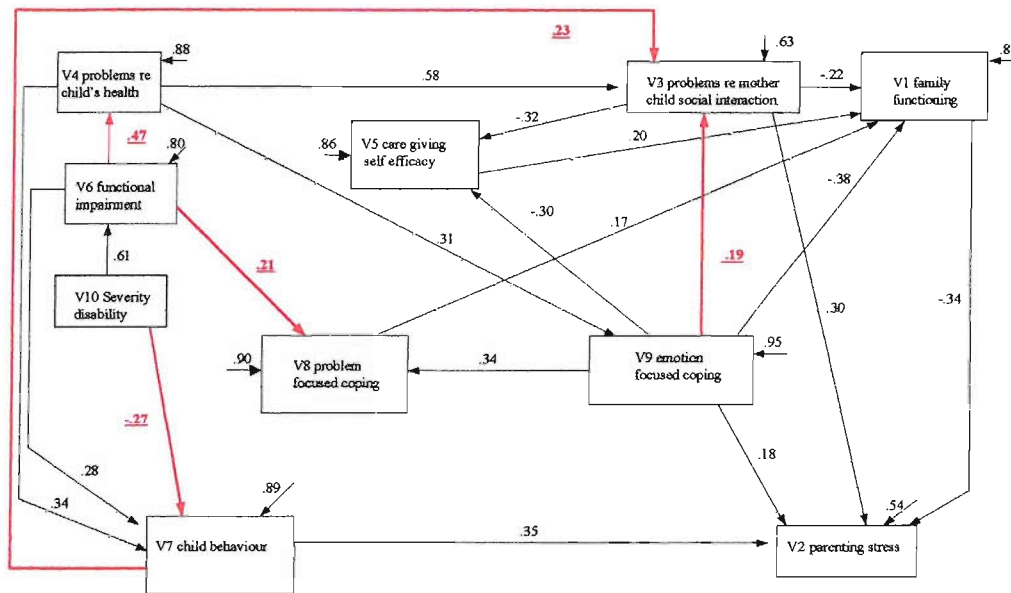
Separate structural equation models were estimated for the two samples. In the first analysis parameters were allowed to vary across the two groups. In the next analysis parameters for all paths in both models were constrained to be equal. Although the fully unconstrained model converged without problems

( $\chi^2$  (df = 46) = 108.14), the fully constrained model did not. Therefore fit indices between fully constrained and unconstrained models could not be compared to determine differences in fit. Instead several analyses were conducted to determine which paths could be constrained without significantly worsening the fit of the model. First, paths were constrained one by one to test for significant changes in Chi-square. Second, all paths that did not cause a significant change in Chi-square individually were constrained simultaneously. This resulted in a partially constrained model, in which six paths were allowed to vary across groups ( $\chi^2$  (df = 62) = 122.56;  $\Delta\chi^2$  (df = 16) = 14.42, ns). Final analyses were conducted to test if path coefficients for the six unconstrained paths significantly differed from zero in either sample. Four paths were not significantly different from zero for the asthma sample, one path was not significantly zero for the Sample 1. One path was significant in both samples, however the strength of the association differed for each sample. In the final analyses the coefficients for five unconstrained paths were set to zero for respective samples ( $\chi^2$  (df = 67) = 123.77;  $\Delta\chi^2$  (df = 5) = 1.21, ns). The final models are presented in Figure 28.

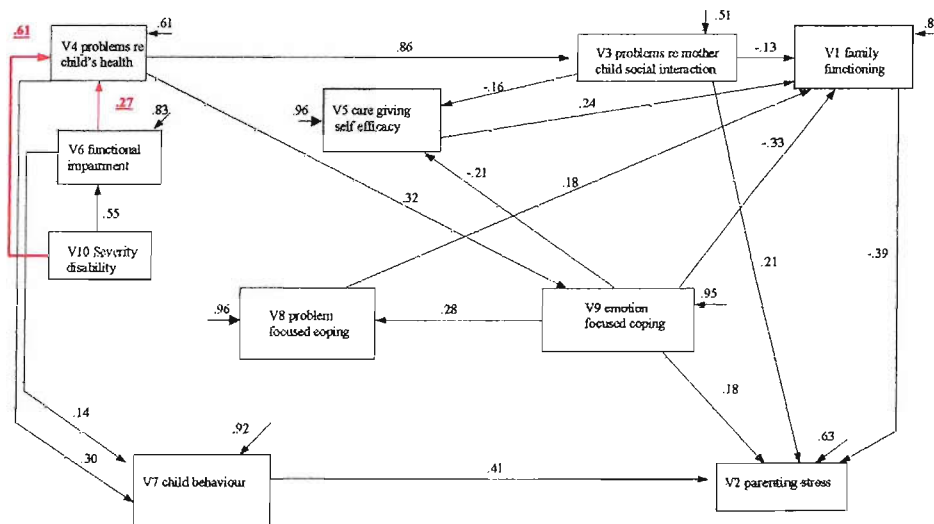
Results of the multigroup analyses showed few differences in models for the two samples. In Sample 1, mothers of children with spina bifida and hydrocephalus, four paths are incorporated for which path coefficient in the asthma sample did not significantly differ from zero. Specifically, the associations between child behaviour and emotion focused coping and problems associated with mother child social interaction patterns, the link between severity of disability and child behaviour, and the pathway between functional impairment and problem focused coping were omitted from the model for the asthma sample. Similarly one path in the model for the asthma sample, namely the link between severity of disability and problems associated with the child's condition is omitted for Sample 1. Differences between path coefficients indicate that the association between functional impairments and problems associated with the child's condition is stronger in Sample 1, mothers of children with spina bifida and hydrocephalus, than in the Sample 2, mothers of children with asthma. Results of the multigroup analyses therefore only partially support the hypothesis that the relationships

between the constructs within the transactional stress and coping model would be similar for both samples.

Figure 28: Measurement path models as a function of disability/chronic illness.



SBHC sample (N=290)



Asthma sample (N=73)

### 10.3 Discussion

This study was conducted to test the transactional stress and coping model of adjustment to disability in a sample of families of children with asthma. Unfortunately the number of returned questionnaires was lower than anticipated (N = 73, response rate 38%). Several steps were taken to ensure a good response rates: 1) the questionnaire was relatively short, 2) sensitive information was kept to a minimum, 3) personalised letters were sent, 4) freepost return envelopes were provided, 5) questionnaires originated from the University, 6) after two weeks families were send reminder letters, and 7) the questionnaire was deemed to be of interest to parents as questions concerned their child with asthma. In a recent review (Edwards et al., 2002) these factors were all shown to increase the odds of response to postal questionnaires. The sample size (N=73) did not provide enough power to test the model incorporating both manifest and latent variables. Therefore a reduced model, including only manifest variables was used to test the extent to which the data conforms to the pathways specified. Three research questions were addressed:

*1 How do families of children with asthma compare to families with children with spina bifida and/or hydrocephalus on measures of child illness, family adaptation, and child and parent adjustment?*

Mothers reported on the asthma symptoms of their child as well as functional impairment and problems associated with their child's condition. They further completed questionnaires on adaptation, i.e. efficacy, coping and family functioning, and child and parent adjustment. Scores on these measures were compared with scores of comparison or norm samples (if available) and with scores of mothers of children with spina bifida and hydrocephalus. Asthma severity scores in this sample are comparable to scores reported by Usherwood et al (1990). As expected, functional impairment scores for children with asthma were lower than for children with spina bifida and hydrocephalus, indicating fewer limitations. This is not surprising as children with spina bifida and hydrocephalus may be more physically impaired than children with asthma. Mothers of children with

asthma further reported fewer problems associated with the child's condition, both in the area of health and services as in the domain of mother child social interaction patterns. Scores for the HPPI subscales were also lower than reported by Wallander and Marullo (1997) for a sample of parents of children with motor and sensory impairments. Motor and sensory impairment may necessitate more medical intervention (e.g. therapies) or may restrict parents more in social interaction (e.g. wheelchair accessibility or issues with transport) than a respiratory condition such as asthma. Therefore the amount and frequency of problems associated with such conditions may be higher than for asthma.

No differences between the two samples were expected on measures of adaptation. This hypothesis was only partially supported. Like mothers of children with spina bifida and hydrocephalus, mothers of children with asthma make more use of problem focused coping strategies than emotion focused strategies. Mothers of children with asthma use problem focused strategies to the same extent as mothers of children with spina bifida, however they make less use of emotion focused strategies. Scores for family satisfaction in the asthma sample are comparable to scores reported by Olson and Wilson (1992) for a large general population sample and higher than scores reported in Sample 1, i.e. mothers of children with asthma are more satisfied with the emotional bonds and adaptability of the family than mothers of children with spina bifida and hydrocephalus. CSES scores are similar for the two samples, and higher than scores reported for mothers of children with autism (Hastings & Brown, 2002). Like mothers of children with spina bifida and hydrocephalus, mothers of children with asthma feel more efficacious in the care of their child than mothers of children with autism in dealing with their child's difficult behaviour.

Mothers of children with asthma reported elevated levels of child behaviour problems. In contrast to existing literature (see McQuaid et al., 2000, for a review), data for the current sample do not suggest a clear distinction between the level of internalising versus externalising problems. As expected, mean scores for total behavioural problems in the asthma sample are lower than mean scores for Sample 1. This difference is caused by a distinction in levels of peer problems, i.e. children with spina bifida and

hydrocephalus have significantly more peer problems than children with asthma.

Finally, mothers of children with asthma experience elevated levels of parenting stress. Although the mean total stress score is below the clinical significant range, the percentage of parents experiencing clinical significant levels of stress is three times as high as in the general population. Mothers of children with asthma report more problems in dealing with their child's behaviour and problems in the mother child relationship, supporting findings by Carson and Schauer (1992). As expected, parenting stress levels of mothers with asthma are lower than those reported by mothers of children with spina bifida and hydrocephalus. These differences are apparent on all subscale and total scores.

In summary, compared to available norm and general population samples, mothers of children with asthma reported elevated child and parent adjustment problems and average levels of family satisfaction. In the current sample levels of functional impairment, problems associated with the child's condition, and scores on measures of child and parent adjustment are lower, levels of family satisfaction are higher, and perceived efficacy is similar compared to the levels reported by mothers of children with spina bifida and hydrocephalus.

## *2 To what extent is the transactional stress and coping model of adjustment to disability consistent with the data of a sample of families of children with asthma?*

Initial regression analyses showed that illness, adaptation and child adjustment variables could explain 70% of the variance in parent adjustment. Results therefore support the existence of strong associations between these concepts. Structural equation modelling was used to test the extent to which the pathways in the transactional stress and coping model conform to the data for the asthma sample. Due to a smaller sample size than anticipated, the tested model only incorporated manifest variables. The model was first tested for data of Sample 1 (see also Chapter 9) and showed good fit (CFI=.96). Analyses using data from asthma sample revealed a few insignificant pathways. These pathways were therefore omitted. After the addition of a

direct link between severity of asthma and problems associated with child's condition, testing the model resulted in good fit (CFI=.97). The final model explained 62% of the variance in parent adjustment. In conclusion, results data of the asthma sample conforms to the transactional stress and coping model of adjustment to disability, i.e. the relationship between illness parameters and parental adjustment is mediated by adaptation processes and child adjustment.

*3 To what extent are the relationships between the constructs within the transactional stress and coping model of adjustment to disability similar or different for the two samples?*

By answering the first two research questions, it has become clear that there are mean differences between Samples 1 and 2 on measures of disability/illness, adaptation and parent and child adjustment. Furthermore, structural equation modelling has shown that the transactional stress and coping model of adjustment disability applies to both families of children with spina bifida and hydrocephalus and families of children with asthma. The question that arises next is to what extent the mean differences change the strength of the associations between the variables within the model. To answer this question a multigroup analyses was performed. The model tested incorporated all pathways that were significant in either sample. Separate structural equation models were estimated for the two samples. In the first analyses parameters for all paths were allowed to vary across the two groups. In the second analyses all paths that did not cause a significant change in Chi-square individually were constrained simultaneously. The Chi square difference between the unconstrained and partially constrained model was not significant ( $\Delta\chi^2$  (df = 16) = 14.42, ns), i.e. the fit of the model does not drop by constraining these parameters. Constraining any of the remaining six unconstrained paths resulted in a significant worsening of the fit, indicating a moderating effect of child's condition. Results of a final analysis showed that for four paths in the model for the asthma sample and for one path in the model for the spina bifida and hydrocephalus sample coefficients did not significantly differ from zero. One path coefficient was significant in both groups. More specifically, the associations between severity of disability and



child behaviour and problems related to the child's condition, between functional impairment and problem focused coping and problems associated with the child's condition, and between child behaviour and emotion focused coping and problems associated with mother child social interaction patterns, differ in strength between the two samples. For children with asthma the relationship between severity of disability and child behaviour was fully mediated. For children with spina bifida and hydrocephalus the relationship between severity of disability and problems associated with the child's condition was fully mediated by functional impairment, whilst for children with asthma both direct and indirect links were found. The link between functional impairment and problems associated with the child's condition was stronger for children with spina bifida and hydrocephalus than for children with asthma. In addition functional impairment was directly linked to problem focused coping in the spina bifida sample whilst this relationship is fully mediated in the asthma sample. Finally, only for the spina bifida sample problems associated with social interaction of mother were directly associated with child adjustment problems and emotion focused coping.

In summary:

The study provides further evidence to support the transactional stress and coping model of adjustment to disability. Although mean differences were apparent between two samples on measures of illness, adaptation and child and parent adjustment, for both samples adaptation processes and child adjustment mediate the relationship between illness and parent adjustment. The differences in strength of associations between some variables in the model, indicates a moderation effect of the child's condition. However, the underlying theoretical assumptions of the transactional stress and coping model of adjustment to disability are not violated. The study therefore provides strong support for the model.

## Chapter 11

### **Study 6: The effect of age and gender on the illness-outcome relationship**

The transactional stress and coping model incorporates demographic characteristics such as socio-economic status and child's age. Few studies have however investigated the effects of demographic characteristics on the illness-outcome relationship. Beckman (1983) investigated the impact of demographic characteristics on stress in families of young children with disabilities, e.g. Down's syndrome, spina bifida and cerebral palsy. Results only showed an association between stress and the number of parents in the home (single mothers reporting more stress) but not with other demographic variables including socio-economic status, maternal age, and number of siblings. Some suggestion has been made that mothers of older children with disabilities and mothers of boys experience higher stress levels (Bristol as cited in Beckman, 1983). Orr, Cameron, Dobson and Day (1993) hypothesised that as a result of the changing nature of the child and the increasing expectations associated with growing older, parents of older children with developmental delays would experience higher levels of stress than parents of younger children. Results of their study showed that parents of children in middle childhood experienced higher levels of parenting stress than parents of children in preschool or adolescents, therefore only partially supporting their hypothesis. In a study involving parents of children with developmental disabilities, Boyce, Behl, Mortensen and Akers (1991) showed that child age and gender were not significantly correlated with parenting stress and did not predict child related stress. However, when all variables were considered together, raising a son with disabilities appeared to be more related to parenting stress than raising a daughter with disabilities. In summary research into the impact of child age and gender is sparse and inconclusive. This study will address this by investigating if child age and gender moderate the illness-outcome relationship.

## 11.1 Hypotheses and suggested analyses

The aims of this study then are to investigate if child age and gender would moderate the illness-outcome relationship. It was hypothesised that child age and gender would not affect the illness - adaptation – adjustment relationships. To test the hypothesis regarding child age, a regression analyses will be conducted, regressing illness parameters, adaptation processes, age and their interactions on parenting stress. To test the impact of gender, partial correlations will be computed between illness parameters and parenting stress, controlling for adaptation processes, for both boys and girls and the significance of the difference of the correlation coefficients will be tested.

## 11.2 Method

### 11.2.1 Participants and measures

Participants and measures have been described in Chapter 5. For the purpose of this study Sample 1, mothers of children with spina bifida and hydrocephalus, and Sample 2, mothers of children with asthma, will be pooled together. Only families for which complete datasets were obtained were included (see Chapter 9 and 10), reducing the subject pool to 363. Illness parameters included functional impairment and HPPI-CHS scores. Adaptation processes were indicated by measures of coping, caregiving efficacy, family satisfaction and HPPI-MCSI. Parent adjustment was measured as parenting stress.

### 11.2.2 Data preparation

For the analysis an illness composite score was computed, by summing Z-transformed scores for functional impairment and handicap related problems related to child health and services. Similarly an adaptation composite score was computed by adding Z-transformed scores for family satisfaction, coping, efficacy and handicap related problems associated with mother child social interactions. As the effects of emotion focused coping and handicap related problems associated with mother child social interactions on

parenting stress were in the opposite direction to the effects of problem focused coping, family satisfaction and caregiving efficacy, these variables were reverse scored after standardisation.

### 11.3 Results

#### 11.3.1 Age

Regression analyses were conducted to test for moderation effects of age on the illness – adaptation – adjustment outcome relationship. Parenting stress (PSI total score) indicated adjustment outcome. Interaction terms were derived from the product of the Z-transformed scores of illness, adaptation, and age, respectively. Results of the regression analyses are presented in Table 26.

As shown in Table 26, the regression model for parenting stress was significant. The illness composite and adaptation composite scores together explained 61% of the variance in parenting stress; however no direct effect or interaction effects were found for age. This indicates that age does not moderate the illness-adaptation-adjustment relationship.

Table 26: Summary of linear regression analyses for illness, adaptation processes and child age predicting parenting stress (N=363)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
ICS	.28	.03	.48*
Step 2			
ICS	.13	.02	.22*
ACS	-.23	.01	-.67*
Step 3			
ICS	.12	.02	.22*
ACS	-.23	.01	-.67*
Child Age	.03	.03	.03
Step 4			
ICS	.10	.02	.18*
ACS	-.24	.01	-.69*
Child Age	.06	.04	.06
ICS*ACS	-.08	.01	-.04
ICS* Child Age	-.03	.02	-.06
ACS*Child Age	-.18	.01	-.06

Note.  $R^2 = .23$  for Step 1 ( $p < .001$ );  $\Delta R^2 = .38$  for Step 2 ( $p < .001$ ),  $\Delta R^2 = .00$  for Step 3 (ns);  $\Delta R^2 = .01$  for Step 4 (ns); ICS = Illness composite score, ACS = adaptation composite score

\*  $p < .001$

### 11.3.2 Gender

To test the moderation effect of gender, partial correlations between illness composite and total stress scores, controlling for adaptation, were computed for boys and girls. The difference between the partial correlations was tested (Baron & Kenny, 1986). To test the difference between correlation first Fisher  $r$  to  $Z$  transformation were performed:  $Z = \frac{1}{2} \log_e \left( \frac{1+r_{xy}}{1-r_{xy}} \right)$ . Then, a test if the two groups show equal correlation is provided by the ratio:  $Z_1 - Z_2 / \sigma_{(Z_1 - Z_2)}$  where  $\sigma_{(Z_1 - Z_2)} = \left( \frac{1}{(N_1 - 3)} + \frac{1}{(N_2 - 3)} \right)$  (Hays, 1981), p466-467). The partial correlations between illness composite score and total stress, controlling for adaptation, were .24 and .37 for girls ( $n=142$ ) and boys ( $n=215$ ), respectively. The ratio  $Z_1 - Z_2 / \sigma_{(Z_1 - Z_2)}$  for girls and boys  $-1.27$  was not significant, indicating no moderation effect of gender.

### 11.4 Summary

This study was conducted to test for the impact of child age and gender on the illness-adaptation-outcome relationship. Regression analyses showed that child age does not affect the relationships between the child's condition, adaptation processes and parenting stress. Similarly, comparisons of the partial correlations between the illness composite score and parent adjustment revealed no significant differences between boys and girls. These results are in line with the expectation that neither age nor gender would moderate the illness – adaptation - adjustment outcome relationships.

## Chapter 12

### Study 7: Positive gain and the illness - outcome relationship

As described in Chapters 1 and 2 most studies involving children with disabilities have focused on the detrimental or negative affects of disability on individual family members, mostly the parents or child itself, and family functioning. However, some research has included positive contributions of the child with a disability to the family. These studies merely describe positive contributions, e.g. source of happiness, source of family closeness, and few try to incorporate the notion of positive contributions into theoretical frameworks of adjustment to disability. Theories of psychological reorganisation in the aftermath of traumatic events such as the theory of cognitive adaptation to threat (Taylor, 1983), the revised stress and coping model (Folkman, 1997) or the taxonomic theory of psychological control appraisals (Thompson S.C., 1985) may provide further insights on how facing up to challenges may lead to positive mental, physical or social outcomes. These theories share an assumption that adaptation processes, especially cognitive coping, can to some extent alleviate the threat of stressful events and ultimate result in positive adjustment outcomes (Affleck & Tennen, 1996).

Study 1 (Chapter 6) showed that positive gain was to some extent associated with parenting stress. However, positive gain seemed a different feature of outcome rather than an endpoint at the opposite side of the same spectrum. It remains unclear how illness parameters and adaptation processes affect perceptions of positive gain. This question will be addressed in Study 7. Furthermore, it has been suggested that the perception of positive contributions may lead to better psychological, physical and social outcomes (e.g. Thompson S.C., 1985). In other words perceptions of positive gain may affect the illness-outcome relationship. Therefore Study 7 was designed to investigate the effect of positive gain on the relationships in the transactional stress and coping model of adjustment to disability.

## 12.1 Research questions, hypotheses and suggested analyses

The first question addressed by Study 7 is the extent to which illness parameters and adaptation processes are associated with perceptions of positive gain in mothers of children with disabilities/chronic illnesses. It was expected that both illness parameters and adaptation processes are linked with perceptions of positive gain. More specifically, it is expected that adaptation processes, especially problem focused coping and caregiving efficacy, in response to the child's functional impairment and problems in regards to the child's health are associated with higher levels of perceived positive gain. This hypothesis will be tested using hierarchical regression analyses, whereby positive gain will be regressed on illness parameter and adaptation processes.

Study 7 was further designed to investigate the association between perceived positive gain and the relationships in the transactional stress and coping model of adjustment to disability. More specifically it was expected that positive gain would moderate the illness-outcome relationship, i.e. high levels of perceived positive gain would protect against the affect of disability/illness on adjustment outcome. More specifically, for parents perceiving high levels of gain the relationship between disability/illness related variables and parenting stress would be weaker than for parents perceiving lower levels of positive gain. Several analyses will be conducted to address this hypothesis. First regression analyses will be conducted, testing the main and interaction effects of illness parameters, adaptation process and positive gain on parenting stress. Moderation will be supported when the interaction effect (i.e. illness x positive gain) is significant, whilst controlling for the effects of illness and positive gain (Baron & Kenny, 1986; Holmbeck, 1997).

Second, a multi-group analysis in SEM will be used to test the revised transactional stress and coping model described in Chapter 9 as a function of positive gain. Support for a moderation effect will emerge when the multi-group models are found to fit the data better when parameter estimates are allowed to vary across groups than when they are constrained to be equal. Based on theoretical models described in Chapter 2, that all emphasise the role of active or problem focused coping and positive perceptions/outcome, it



was expected that the path between illness parameters and problem focused coping was most likely to be affected by differences in levels of perceived positive gain.

## 12.2 Method

### 12.2.1 Participants

Data from Samples 1, mothers of children with spina bifida and hydrocephalus, and 2, mothers of children with asthma, were merged to address the research questions. Only families for whom complete datasets were obtained were included (see Chapter 9 and 10). The total sample therefore contained 363 participants. Data for this total sample were included in the regression analyses to test mediation and moderation effects. As data for the full structural model were not available for Sample 2, only data from Sample 1 (N=290) were used for the multigroup analysis.

### 12.2.2 Measures and data preparation

Measures used for this study included disability parameters (functional impairment and HPPI-CHS), adaptation processes (brief COPE, FSS, HPPI-MCS, and CSES), parent adjustment and positive gain (PSI-SF43). A full description of these measures was presented in Chapter 5

For the regression analyses to test moderation effects of positive gain, an illness composite score was computed by summing Z-transformed scores for functional impairment and handicap related problems related to child health and services. Similarly an adaptation composite score was computed by adding Z-transformed scores for family satisfaction, coping, efficacy and handicap related problems associated with mother child social interactions. As the effect of emotion focused coping and handicap related problems associated with mother child social interactions on parenting stress were in the opposite direction to the effect of problem focused coping, family satisfaction and caregiving efficacy, these variables were reverse scored after standardisation. Interaction terms were derived from the product of the Z-transformed composite scores of functional impairment and adaptation, and positive gain.

For the multigroup analysis using SEM, Sample 1 was divided at the median with respect to positive gain. Parents who scored 15 or less were classified as high positive gain and parents with scores greater than 15 were classified as low positive gain.

### 12.3 Results

#### 12.3.1 Effect of illness and adaptation processes on perceived positive gain

Regression analyses were used to test for the effects of illness parameters and adaptation processes on positive gain. Results are presented in Table 27.

Table 27: Hierarchical multiple regression analysis of illness parameters, adaptation processes, and positive gain (N=363)

Variable	Step 1		Step 2	
	Beta	t	Beta	t
<b>Illness</b>				
HPPI-child health and services	-.03	-.56	-.17	-2.39*
Functional Impairment	-.21	-3.40**	-.19	-3.46**
<b>Adaptation processes</b>				
FSS total			-.26	-4.58**
HPPI-mother child social interaction			.12	1.55
Efficacy			-.14	-2.62**
COPE-problem focused coping			-.29	-5.69***
COPE-emotion focused coping			.06	1.05

Note:  $R^2 = .05^{***}$  for Step 1;  $R^2$  change =  $.21^{***}$  for Step 2

\* $p < .05$

\*\* $p < .01$

\*\*\* $p < .001$

These results indicate that 27% of the variance in positive gain can be predicted by illness parameters and adaptation processes. More specifically increases in problems associated with child's condition and functional limitations, more use of problem focused coping, and increased levels of family satisfaction and caregiving efficacy are associated with higher levels of perceived positive gain. These findings support hypothesis 1.

### 12.3.2 Positive gain as moderator of the illness-adaptation-adjustment outcome relationship

#### 12.3.2.1 Regression analyses

Regression analyses were conducted to test for moderation effects of positive gain on the illness - outcome relationship. Results of the regression analyses are presented in Table 28.

Table 28 reveals direct effect of illness and adaptation processes on parenting stress. It should be noted that conforming to the theoretical stress and coping models, adaptation partially mediates the effect of illness on adjustment outcome. This mediation effect is illustrated by step 1 and step 2 in the regression analysis, i.e. illness parameters initially make a significant independent contribution to the prediction of parenting stress. However, when adaptation variables were entered, the contribution made by illness parameters was reduced, i.e. the strength of the effect of illness on parenting stress decreases when adaptation processes are included in the equation.

The main effect for positive gain was not significant, however, there was an interaction effect. Specifically, the interaction term ICS \*positive gain in step 4 was significant. Therefore it was concluded that positive gain moderated the effect of illness on parenting stress, i.e. the relationship between illness and parenting stress changes as a function of positive gain.

Table 28: Hierarchical multiple regression analyses for illness parameters, adaptation processes and positive gain predicting parenting stress (N=363)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
ICS	.28	.03	.48**
Step 2			
ICS	.13	.02	.22**
ACS	-.23	.01	-.67**
Step 3			
ICS	.12	.02	.21**
ACS	-.24	.01	-.68**
Positive gain	-.02	.04	-.02
Step 4			
ICS	.10	.03	.18**
ACS	-.24	.01	-.69**
Positive Gain	-.05	.04	-.05
ICS*ACS	.01	.01	.07
ICS* Positive Gain	.05	.02	.08*
ACS* Positive Gain	.02	.01	.08

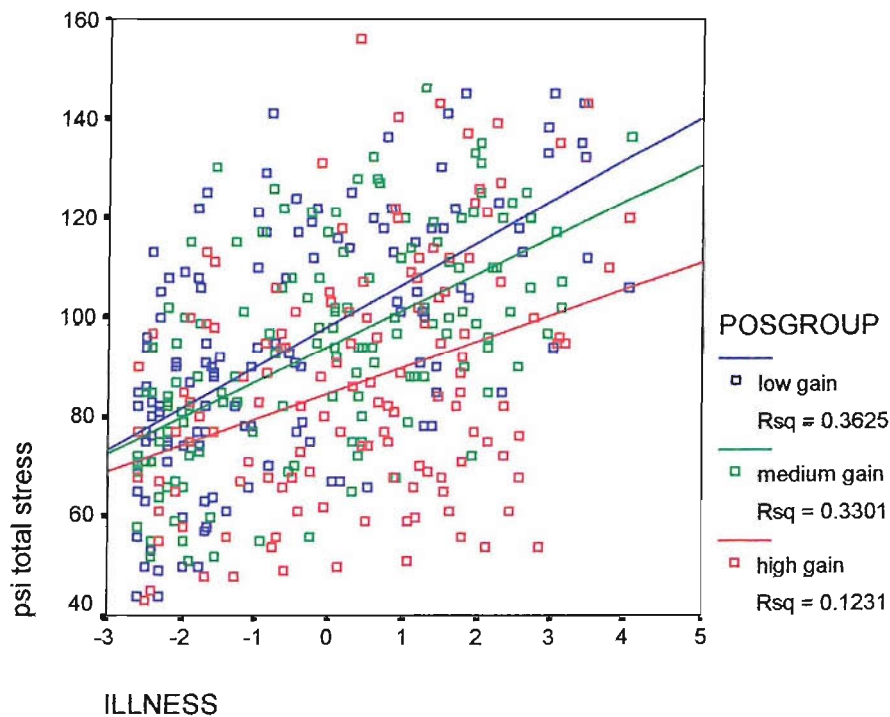
Note.  $R^2 = .23$  for Step 1 ( $p < .001$ );  $\Delta R^2 = .38$  for Step 2 ( $p < .001$ ),  $\Delta R^2 = .00$  for Step 3 (ns);  $\Delta R^2 = .01$  for Step 4 (ns); ICS = Illness Composite Score, ACS = Adaptation Composite Score

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

To further investigate the moderation effect of positive gain a data plot was derived based on the guidelines developed by Aiken and West (1991). Figure 29 shows predicted mother's parenting stress scores by illness values,

derived from the regression equation, for low, medium and high levels of positive gain. Figure 29 illustrates that at low levels of illness there was little effect of varying levels of positive gain. Conversely, at higher levels of illness mothers with higher levels of positive gain reported less parenting stress. In other words, the illness-outcome relationship is stronger for the low positive gain group ( $\beta=.36$ ) than for the high positive gain group ( $\beta=.12$ ), i.e. perceived positive gain protects against the effect of illness parameters on parenting stress.

Figure 29: Plots of predicted parenting stress as a function of illness for three levels of positive gain



### 12.3.2.2 Multigroup analysis

For this analysis only data for Sample 1 were used. Table 29 presents the means, standard deviations of the measures used in this study as well as t-test statistics for differences between high and low gain groups. In accordance with the results discussed in Chapter 6, significant differences

between high and low gain groups were found for child's functional impairment, caregiving efficacy, parental problem focused coping, family functioning and total stress score. High gain is associated with more functional impairment, higher levels of efficacy, more use of problem focused strategies, higher levels of family satisfaction and lower levels of parenting stress.

Table 29: Means, standard deviations and t-test statistics for all measures for high and low gain groups (N=290)

	High Gain (N=152)		Low Gain (N=138)		t (288)
	Mean	SD	Mean	SD	
Severity of disability	2.98	2.43	2.59	2.35	-1.37
Child's Functional Impairment	5.45	2.98	4.45	3.34	-2.69**
Child's Health	14.30	9.19	12.99	9.14	-1.21
Mother-child social interaction	17.18	15.33	18.19	15.72	.55
Caregiving self efficacy	30.10	4.46	28.14	5.12	-3.49***
Problem focused coping	33.22	8.48	30.02	8.41	-3.22**
Emotion focused coping	18.11	4.95	19.24	6.12	1.74
Family Functioning	46.52	10.61	41.11	10.67	-4.33***
SDQ-total	14.95	7.07	15.25	6.88	.364
Parenting stress-total	91.55	24.23	98.10	24.03	2.31*

\* p<.05, \*\* p<.01, \*\*\* p<.002

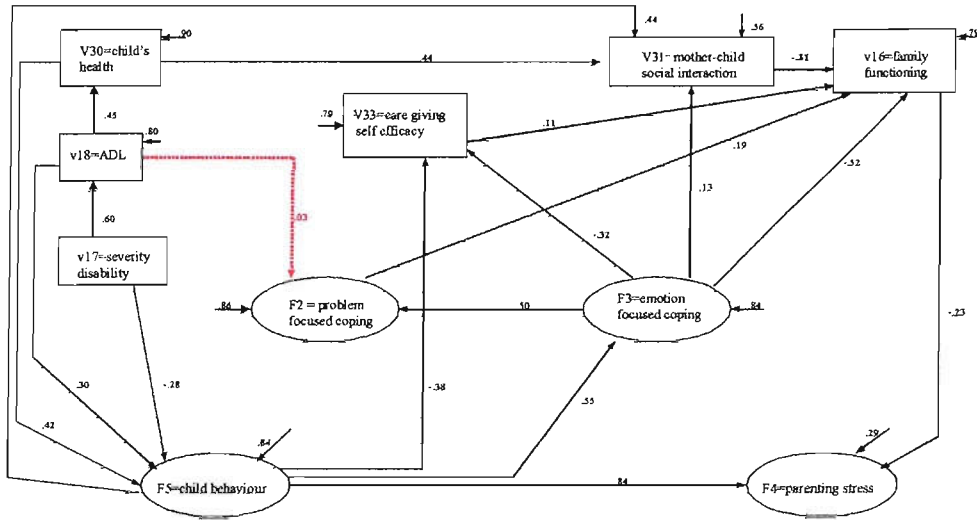
The first step in a multi-group analysis is to assess whether there are differences in the sample correlation matrices. If there is no difference, the correlation matrices could be simply estimates of the same single population matrix. Therefore it would not be appropriate to investigate different model specifications. When there are differences, models in which some parameters

are allowed to differ can be evaluated in order to account for the observed discrepancies (Dunn et al., 1993, p134). EQS was used to test for differences in correlation matrices for high and low gain groups. Means and standard deviations for the two groups are presented in Appendix K, the correlation matrices of the two groups are shown in Appendix L. The EQS program to test the equality of the two matrices resulted in a Chi square goodness of fit statistic of 711.42 (N = 290, 560),  $p < .001$ . Therefore the hypothesis that the two matrices are identical was rejected.

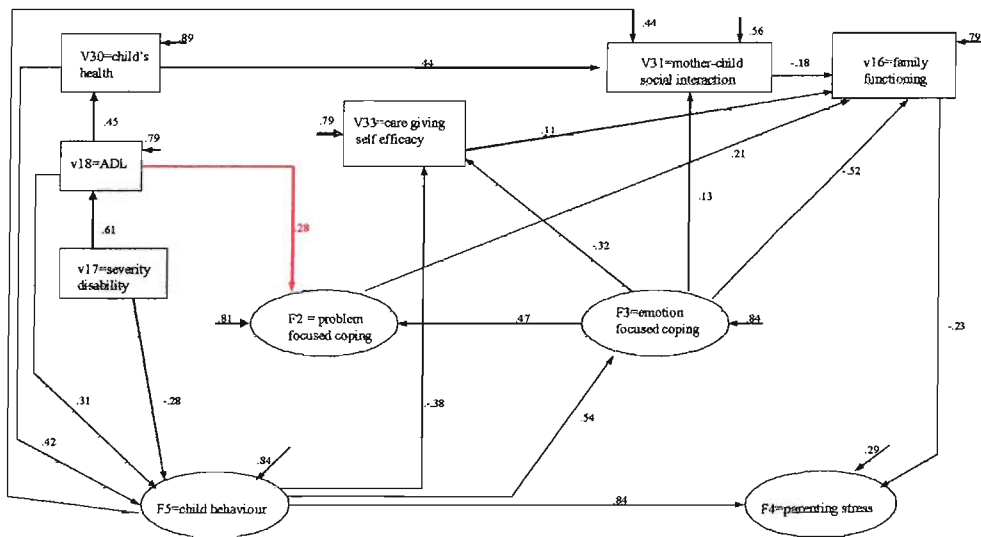
Separate structural equation models were then estimated for the high and low gain families. In the first analysis parameters for all paths in both models were constrained to be equal in high and low gain groups ( $\chi^2 = 873.53$ ;  $df = 586$ ;  $p < .001$ ). In the second analysis parameters for all paths were allowed to vary across the 2 groups ( $\chi^2 = 766.55$ ;  $df = 524$ ;  $p < .001$ ). The Chi-square difference between the constrained and unconstrained models was significant ( $\Delta \chi^2 = 106.98$ ;  $\Delta df = 62$ ;  $p < .001$ ), i.e. the fit of the model improves when parameters are allowed to vary across groups, indicating a moderating effect of positive gain. However, it was hypothesised that positive gain would affect some but not all paths within the model. For example, the factor loadings for the latent variables were not expected to vary across groups. Therefore, a third analysis was conducted, fitting a more restricted model. The Lagrange multiplier test was used to determine whether releasing any of the cross-group constraints would lead to an improvement in fit. It appeared that releasing seven constraints would significantly improve fit ( $p < .05$ ). Six constraints were not released as they regarded error terms (4) or paths within measurement models (2). Releasing one constraint between different constructs within the model would significantly improve the model fit, i.e. the constraint between child functional impairment and problem focused coping. Testing these models resulted in an improvement of fit ( $\Delta \chi^2 = 4.90$ ;  $\Delta df = 1$ ;  $p < .05$ ). The path models are shown in Figure 30.

Inspection of the structural coefficients revealed that the link between child functional impairment and problem focused coping proved significant only in the high gain group. Problem focused coping only mediates between child functional impairment and parenting stress (via family functioning) in parents reporting higher levels of positive gain.

Figure 30: Model of structural paths among disability, child behaviour, caregiving efficacy, parental coping, family functioning and parenting stress as a function of level of positive gain.



LOW POSITIVE GAIN (n=138)



HIGH POSITIVE GAIN (n=152)



## 12.4 Discussion

The aims of this study were two-fold. First, the study was conducted to test the association between illness parameters and adaptation processes and positive gain in mothers of children with spina bifida and hydrocephalus and mothers of children with asthma. It was hypothesised that increased functional impairment and problems associated with the child's condition as well as increased levels of problem focused coping and caregiving efficacy would be associated with higher levels of perceived positive gain. This hypothesis was supported by results of regression analyses. In addition, higher levels of family satisfaction predicted higher levels of positive gain.

The second aim of this study was to assess the effect of positive gain on the relationship between illness parameters and parenting stress. It was expected that positive gain would moderate the illness-outcome relationship. This moderating effect of positive gain was tested in two ways. The first statistical analysis focused on hierarchical regression procedures. For this analysis data from both samples 1 and 2 were included. These analyses identified positive gain as a moderator of the relationship between illness parameters and parenting stress. Mothers with high levels of positive gain reported less parenting stress when their child had a high level of functional impairment and condition related problems. The second approach made use of a multigroup analysis in SEM. For this analyses only data from Sample 1, mothers of children with spina bifida were included. Again, positive gain was found to moderate the relationships within the structural stress and coping model of adjustment to disability. More specifically, the multigroup analysis showed that problem focused coping only mediated the relationship between the child's functional impairment and parenting stress in the high positive gain group. These results show that the adaptation processes are less effective in protecting against the impact of illness on parenting stress in parents who perceive less positive contributions. Results of these two analyses confirm the hypothesis that positive gain would moderate the illness-outcome relationship.

This study is a first attempt to investigate the role of positive gain on the relationships within the transactional stress and coping model. It adds to the existing literature in that it emphasises that differences in adjustment

outcomes for families of children with disabilities may be related to the extent in which the families can identify positive contributions of the child with a disability to the family. Some theoretical frameworks have been developed to explain positive outcome associated with adverse events, but few discuss the effect the positive outcomes may have on the relationships within the stress and coping models. For example, Folkman (1997) points to the adaptational importance of positive states for the stressor-adjustment relationship by suggesting that positive psychological states help sustain renewed coping effort to deal with the chronic stressor.

Although the current study has confirmed the association between positive gain and adaptation processes, further research is needed to investigate the precise mechanisms in which positive gain affects these relationships. For example, it may be that parents that are perceptive to the positive contributions of the child are also more likely to use problem focused coping strategies in response to stresses associated with their child's disability. Alternatively, it may be that the effective use of individual and social resources in response to stresses related to child's disability, leads to growth and greater well-being of the parents, enabling them to identify positive contributions. Although the multi-group analyses described in this chapter gives some insight in the way in which positive gain affects the relationships between disability, adaptation process and adjustment outcomes, it does not provide information needed to test how positive gain and adaptation affect each other. This could be tested in a longitudinal study of family adjustment to child disability.

## Chapter 13

### Discussion

This thesis examines the relationships between illness parameters, adaptation processes and adjustment outcomes in families of children with physical disability or chronic illness. In addition, the affect of perceived positive gain on these relationships was investigated. Three main questions were addressed:

- 1) How does the addition of items to assess perceived positive gain affect the psychometric properties of the modified Parenting Stress Index?
- 2) How well does the transactional stress and coping model fit the observed data in samples of mothers of children with spina bifida and/or hydrocephalus and mothers of children asthma?
- 3) How does perceived positive gain affect the relationships between illness parameters, adaptation processes and adjustment outcome in mothers of children with a disability / chronic illness?

To answer these questions, seven studies or sub studies were conducted, each with its own aims and hypotheses. The first set of studies concerned the development of a measure of perceived positive gain (Study 1-2). The second set of studies assessed the appropriateness of the transactional stress and coping model of adjustment to describe the relationships between illness parameters, adaptation processes and adjustment outcome in samples of children with physical disability, i.e. spina bifida and hydrocephalus, or chronic illness, i.e. asthma (Study 3-5). The last set of studies addressed factors that might modify the illness-outcome relationships, i.e. age, gender and positive gain (Study 6 and 7).

The current chapter will show how results of the studies help to address the three main questions of the thesis. In addition limitations of study design and sampling procedures will be discussed. Finally suggestions for future research will be made.

## 13.1 Answering the core questions

### 13.1.1 How does the addition of items to assess perceived positive gain affect the psychometric properties of the modified Parenting Stress Index?

Fourteen items measuring perceived positive gain were added to the PSI-SF36. The purpose of this was twofold: first to make the PSI-SF36 more acceptable to parents, second to develop a measure of perceived positive gain. The formulation of the items was guided by literature review and empirical data. The addition of the 14 positive items to the PSI-SF36 did not jeopardize the psychometric properties of the original sub and total scales (Study 1). Factor analyses revealed a similar factor structure for the PSI-F36 as reported by Abidin (Abidin, 1995). The three factor solution accounted for 47% of the variance. Results further showed that the seven of the 14 positive items loaded on a separate factor, which was labelled 'Positive Gain'. Five positive items referred to parent characteristics, e.g. 'since having this child I feel I have grown as a person', and two to family characteristics, e.g. 'since having this child my family has become closer to one another'. Correlations between the three original subscales was high (range .54 to .88), whilst correlation between the three original subscales and the positive gain scale were moderate (.19 to .26). The reliability and validity of the original PSI-SF36 was maintained. Internal consistency coefficients remained high, i.e. Cronbach's alpha coefficients ranged from .83 to .93 for sub and total scales. Validity was investigated by relating the sub and total scale scores to measures of child development, disability and behaviour (predictive validity), family needs, family impact, and handicap related problems for parents (concurrent validity), and coping, caregiving efficacy and family functioning (construct validity). Parents of children with more severe functional impairment, developmental delays or behavioural problems reported higher levels of parenting distress. Similarly in support of concurrent validity parents reporting more needs, more impact of disability and more handicap related problems, also reported higher levels of parenting distress. Support for the construct validity was provided by findings that parents who use more problem focused and less emotion focused coping strategies, who feel more

efficacious in caregiving and more satisfied with their family cohesiveness and adaptability reported less parenting distress. These results clearly confirm that the psychometric properties of the PSI-SF36 were not jeopardized by the addition of the positive items.

The reliability and validity of the positive gain scale were also assessed. Internal reliability coefficient of the positive gain scale was quite acceptable ( $\alpha = .79$ ). Support for the predictive and construct validity of the scale was provided by findings that positive gain is affected by levels of functional impairment and associated with concepts of coping, family functioning and caregiving efficacy. More specifically, higher levels of perceived positive gain were associated with more functional impairment, higher levels of caregiving efficacy, more use of problem focused strategies, and higher levels of family satisfaction. These findings support hypothesised links between active or cognitive coping and positive outcome (e.g. Lawton et al., 1991; Taylor, 1983) and is consistent with previous findings that positive contributions are associated with active coping and social support (Hastings et al., 2002). It is interesting that severity of disability and increased functional limitations of the child were associated with higher levels of positive gain. Park et al. (1996) suggested that stress related growth may be associated with stressfulness of events, i.e. that growth is more likely to result from situations for which resolution is more difficult. It may be that especially limitations in performing daily live activities, such as walking, toileting, dressing and eating, rather than the level of cognitive functioning, put strong demands on mothers. Resolving these issues on a daily basis may therefore ultimately result in higher levels of perceived positive gain.

One reason for including the positive items in the PSI-SF36 was to make the instrument more acceptable to parents. Previous experience with this measure had shown that some parents object to the negative wording. This may not only affect the respondent's mood and therefore responding bias, but it may also jeopardize response rate. The extent to which the positive items made the measure more acceptable to parents was not formally tested. However the response rate of 80% indicated that the measures included in survey 2 did not negatively affect parent's decision to take part in the study.

The question arises if the positive gain measure should be considered a subscale of the PSI-SF or could be considered a separate measure. The seven items load on a separate factor without cross loadings above .2 on any of the original subscales of the PIS-SF36. Furthermore positive gain only shows moderate correlations with the subscales Difficult Child, Parent Child Dysfunctional Interaction and Parental Distress or Total stress score. This indicates that positive gain taps into a domain not previously covered by the PIS-SF36. Results further indicate that the concepts of parenting stress and positive gain do not form two poles at different ends of one spectrum, but rather that positive gain refers to a different feature of adjustment outcome, i.e. positive gain is a separate isolatable feature of family's response to disability. Therefore it can be assumed that the items of the positive gain scale could be used separately. It will depend on the research questions if it proves useful to administer the PSI-SF36 as well, in which case the modified PSI-SF43 could be used.

Another question concerns the usefulness and meaning of positive gain in a general population sample. Findings of Study 2 suggested that parents of children with spina bifida and hydrocephalus experience more positive gain (and more parenting stress) than parents in children in general population sample. It is not clear however, if experiences of positive gain are comparable between the two samples. The concept of positive gain as presented in this thesis relates very much to the experience of raising a child with a disability, which is considered a challenge or even threat. It is questionable if such gain would have the same meaning when applied to a general population sample. Findings of Folkman and Moskowitz (2000) suggest that people in stressful caregiving roles may appraise ordinary events as positive to offset the negative consequences of adverse events. It may be that parents are more susceptible to the 'rewards' of raising a child when this child is disabled. Therefore differences in positive gain between Samples 1 and 3 may reflect differences in susceptibility rather than actual differences in gain associated with parenting.

13.1.2 How well does the transactional stress and coping model fit the observed data in samples of mothers of children with spina bifida and/or hydrocephalus and mothers of children asthma?

Several stress and coping models of adjustment to disability have been developed (see Chapter 1). The transactional stress and coping model is one of the models frequently applied in studies concerning families with children with chronic illness and physical disability. The model was chosen to provide the framework for the studies in this thesis because in contrast with other models of adjustment to disability, this model proposes a relationship between child and parent adjustment. Results of several studies including children with spina bifida and hydrocephalus or asthma have shown high prevalence rates of behavioural problems in these samples. The transactional stress and coping model of adjustment to disability allows for estimating the effect of illness/disability on parent adjustment whilst controlling for child adjustment problems. In other words the effects of illness parameters and child behavioural problems on parenting stress are simultaneously tested.

Results of studies 4 and 5 confirm strong associations between the variables in the model, i.e. regression analyses showed that 75 and 70% of the variance in parenting stress can be predicted by illness parameters, adaptation processes and child adjustment in both mothers of children with spina bifida as in mothers of children with asthma, respectively. These results are in line with previous studies, (e.g. Kronenberger & Thompson, 1992b). However these studies have not taken into account relationships between predictor variables. Therefore SEM was used to allow for testing of simultaneous effect of all variables in the model. The model was first tested in Sample 1, 290 mothers of children with spina bifida and hydrocephalus. Initially the model proved too restricted and some revisions were made. The main revision concerned the latent variable of disability. Instead of constructing this latent disability variable, direct links between disability parameters themselves and other measurement models were proposed. The revised model showed good fit with the data ( $CFI=.91$ ) and could explain 93% of the variance in mother's adjustment, i.e. parenting stress. Unfortunately Sample 2 was not large enough to test the same model, as SEM requires at least 10 participants per variable. Therefore a path model, rather than a

structural model incorporating latent variables, was tested. The main difference between such models is that in path model relationships between variables are affected by measurement error, whilst in the structural model measurement error is estimated and removed when considering the relationship between latent variables. The use of SEM was still preferred over regression analyses as simultaneous effects of all relationships between variables in the model are tested. The path model was first tested in Sample 1 before applying it to Sample 2. In both samples a good fit between model and sample data was established. A third analysis was necessary to test for differences between the samples. More specifically, a multigroup analysis was conducted to compare the strength of the association between variables in the model for the two samples. Results showed that although the strength of associations between certain variables differed between samples, the underlying theory of the model were the same for both groups. In other words, the differences in path coefficients did not violate the assumption that adaptation processes mediate the relationship between illness parameters and adjustment outcomes. This is an important finding, as it not only lends support for the conceptual model, but also for the partial categorical approach. This approach emphasises the common dimensions of different illnesses and disabilities, whilst recognising disease specific characteristics. The finding that the model fits data of both samples reflects commonalities, whilst the differences in strength of associations may results from disease specific features. For example, the finding that the strength of the association between functional impairment and problems associated with child's health and services differs between Samples 1 and 2, may reflect mean differences in level of impairment. It is not surprising that children with spina bifida and hydrocephalus experience more difficulties with daily live activities such as walking and dressing. Therefore problems associated with the child's condition may reflect to great extent these functional limitations. Although mothers of children with asthma also reported associated problems, these problems may to lesser extent reflect functional limitations as children with asthma are quite able to perform such activities. Therefore it is understandably that the strength of the association between functional



limitation and problems associated with the child's condition is stronger for Sample 1 than for Sample 2.

For both samples there is a strong correlation between child adjustment and parent adjustment. This association is also apparent in the path model with path coefficients of .35 and .41 for Samples 1 and 2 respectively. This may not be surprising as parenting stress reflects, amongst other things, the behavioural difficulties that make the child hard to manage, e.g. non-compliant or demanding behaviour (Abidin, 1995). Both children with spina bifida and hydrocephalus and children with asthma are reported to have significantly more behavioural problems than children in general population samples (Ammerman et al., 1998; Donders et al., 1992; McQuaid et al., 2000; Wallander et al., 1989a). For the current samples results of studies 4 and 5 showed that the effect size for conduct problems was greater than .3 for either sample. The measure of parenting stress, especially the subscale 'Difficult Child' will reflect these problems, affecting the association between the two measures.

It should be noted that the analysis in SEM are based on correlation and covariance matrices. Although the directions of paths are stipulated by the theoretical framework of the model tested, SEM does not provide a test of causality. Causality can only be accurately tested in longitudinal or experimental designs.

### 13.1.3 How does perceived positive gain affect the relationships between illness parameters, adaptation processes and adjustment outcome in mothers of children with a disability / chronic illness?

Studies of adjustment to disability / chronic illness have focused mainly on adjustment problems and do not take into account positive aspects that may be associated with raising a child with a disability. The revised stress and coping model (Folkman, 1997) and the two factor model of caregiving appraisal and psychological wellbeing (Lawton et al., 1991) propose that positive outcomes/emotions may affect the relationship between adverse situations and adjustment. Results of the studies in this thesis revealed that high positive gain was associated with more functional impairment, higher

levels of efficacy, more use of problem focused strategies, higher levels of family satisfaction and lower levels of parenting stress. These results confirm previous findings that positive contributions are associated with adaptation processes. In addition the results show an association of positive gain with illness parameters and parent adjustment outcome. It should be noted that when the child is more functionally dependent on the parent, parents report more positive gain. This is interesting as most research stresses the detrimental affect of increased care demands on parental well-being. It may be that the stressfulness of the situation affects the level of positive outcome. Although initial findings by Park et al (1996) provided support for such association, they were not able to replicate their finding in subsequent studies.

T-tests revealed differences between high and low gain groups on a range of variables. However such analyses could not be used to describe the way in which positive gain influences the illness-outcome relationship. Therefore additional analyses, i.e. regression analyses and a multi-group analysis using SEM were performed. Results of the first regression analysis showed that a significant amount of variance (27%) in positive gain can be explained by illness parameters and adaptation processes. More specifically the adaptation processes significantly associated with higher levels of perceived positive gain included problem focused coping, caregiving efficacy and family satisfaction. This finding supports models that propose that the successful use of adaptation processes such as coping may lead to positive outcomes, e.g. stress related growth. For example the revised stress and coping model (Folkman, 1997) proposes that adaptation processes mediate between illness parameters and both negative and positive outcomes.

The results further support the suggestion that especially active coping and control affect outcome. Active coping strategies have been consistently put forward to affect positive outcome (Folkman, 1997; Park, 1998; Taylor, 1983; Thompson S.C., 1981). The importance of control and its effect on positive outcome has been emphasised by Taylor (1983). Similarly Affleck and Tennen (1993) reported findings that control was associated with emotional well-being in parents of prematurely born children. Results of Study 7 reveal similar results, i.e. problem focused coping and caregiving efficacy significantly predict positive gain whilst emotion focused coping does not.

Problem focused coping refers to strategies that are aimed at dealing with the adverse situation and include acceptance, active coping, positive reappraisal, planning and support. Caregiving efficacy reflects the extent to which the mother feels confident in her role as a caregiver and incorporates feelings of control e.g. 'to what extent do you feel in control of the care of your child with spina bifida/hydrocephalus'.

Results of the second regression analyses showed significant main effects for illness parameters and adaptation processes and an interaction effect for illness x positive gain when predicting parenting stress. This indicates a moderation effect of positive gain. Specifically, the relationship between illness parameters and parenting stress is moderated by positive gain such that the association between illness and parenting stress is weaker for mothers reporting high gain levels than for mother reporting low gain levels. These results support the suggestion that uplifts, i.e. things that make you feel good, may neutralize or moderate the effects of adverse situations on psychological wellbeing (Lawton et al., 1991). Additional multigroup analyses confirmed positive gain moderates the illness –outcome relationships. Specifically, mothers in the high positive gain group were more able to mobilise problem focused coping in dealing with illness related problems. In other words, adaptation processes are more effective in protecting against the impact of illness parameters on parenting stress in mothers perceiving higher positive gain levels.

#### 13.1.4 Summary

Results of the studies in this thesis have addressed the main questions. In summary, the positive gain scale did not jeopardize the psychometric properties of the PSI-SF36 (Abidin, 1995). In addition the reliability and validity of the positive gain scale were satisfactory. The transactional stress and coping model of adjustment to disability fitted data derived from mothers of children with spina bifida and hydrocephalus and mothers of children with asthma equally well. This finding not only provides support for the model itself but also for the partial categorical approach which emphasises the importance of dimensions common to all disabilities/chronic illnesses, whilst recognising specific illness features. Finally the last set of

studies showed that positive gain moderates the relationship between illness and adjustment outcome. More specifically, perceived positive gain protects against the adverse events of illness. High gain is associated with more functional impairment, higher levels of efficacy, more use of problem focused strategies, higher levels of family satisfaction and lower levels of parenting stress.

Results of these studies further emphasise the importance of including positive outcome in studies of adjustment to adverse situations. As Rutter (1990) stated, understanding of the processes underlying resilience may provide us with directions for prevention and intervention. Rutter (1990) further suggested that protection against the negative affects of adverse situation may result from successful engagement with the stressor. This notion is reflected in the few models incorporating positive outcome in models of stress and coping. For example Folkman (1997) proposed that successful coping may lead to favourable outcomes and positive affects. Positive outcome may also result from meaning based coping with the distress caused by unfavourable resolutions. She further suggested that positive psychological states help sustain renewed coping efforts to deal with the adverse event (Folkman, 1997). This is an important suggestion as it explains not only how positive and negative emotions can co-occur, but also underlines the adaptational significance of positive outcome in the stressor-adjustment outcome relationship. Similarly, in the two-factor model of caregiving appraisal and psychological well-being (Lawton et al., 1991) the objective stressor, caregiver resources and subjective appraisals affect both positive and negative outcomes. Lawton et al. (1991) stated that positive and negative affect are clearly distinguishable and both contribute to our understanding of psychological well-being. They further suggested that uplifts, i.e. things that make you feel good, may neutralize or moderate the effects of adverse situations on psychological wellbeing (Lawton et al., 1991). Unfortunately, whilst there are ample studies focusing on negative outcomes of stress, studies including positive outcomes are sparse and mostly rely on anecdotal evidence. Of course, research into the detrimental effects of adverse events is important, especially as it is essential not to underestimate the feelings of despair, suffering and loss people may experience when faced with adverse

situations. Research has guided the development of different models and provided insight in the relationships between stressors, adaptation processes and adjustment outcomes. However thus far factors promoting resilience remain poorly understood. Findings of the studies in this thesis have confirmed the co-occurrence of positive and negative outcomes associated with raising a child with a physical disability / chronic illness. They further provided evidence of a protective effect of perceived positive gain on the illness outcome relationship.

The studies in this thesis offer support for the utilisation of stress and coping models of adjustment to disability. Results are in accordance with previous reports that families of children with disabilities or chronic illnesses are at increased risk for psychosocial adjustment problems. The studies add to existing literature however in using SEM to test the relationships between illness parameters, adaptation processes and adjustment outcomes. SEM is especially useful in testing complex models. The fact that the transactional stress and coping model of adjustment fitted data of two separate samples provides strong support for the model. Another significant addition to the literature is provided by the studies involving perceived positive gain. A measure of perceived positive gain was developed which showed acceptable psychometric properties. In addition the affect of positive gain on the relationships between illness parameters, adaptation process and adjustment outcome was investigated. Results are promising as positive gain was shown to moderate the illness outcome relationship, i.e. perceived positive gain protect against the detrimental effect of illness parameters on psychosocial adjustment outcome. The fact that these findings applied to two samples including mothers of children with different conditions indicates that these findings can be generalised across conditions as they do not seem unique to just one group.

### 13.2 Limitations

Some methodological limitations of the studies need to be discussed. First the recruitment procedures for Sample 1 may not have resulted in a representative group of mothers of children with spina bifida and

hydrocephalus. Families were identified via a register maintained by the Association of Spina Bifida and Hydrocephalus. It is not known how representative this register is of all UK families with children with these conditions. It may be that families with relatively more problems are also more likely to contact ASBAH. Similarly it could be that more highly educated parents are more likely to utilize such resources. However, some assurance is found in the fact that the sample showed substantial variation in distribution of severity of disability and associated problems. Demographic characteristics of families also showed a good spread across ranges. In addition other studies involving families of children with spina bifida and hydrocephalus recruited via local NHS hospitals showed similar distributions (Stevenson & Pit-ten Cate, 2003). It should be noted that a potential sample bias is most likely to affect mean scores. The fact that Mean scores on most variables were quite comparable with results reported previously for similar samples provides further assurance that the sampling procedures has not negatively affected the results.

A second concern regards response rates. Forty-four percent of the families of children with spina bifida and hydrocephalus contacted returned the first questionnaire (N = 553). Of this Sample 399 families indicated that they could be contacted for future research, and hence were sent a second questionnaire. This time 80% of the respondents returned the questionnaire. For the asthma Sample 38% of the families contacted replied. These response rates appear relatively low, especially as every care was taken to ensure good response rates, following guidelines provided by Edwards et al (2002). The fact that less than half the contacted families replied may not mean that the samples are unrepresentative. For example, in a study regarding the impact of ascertainment and recruitment procedures in a sample of children with hemiplegia, Goodman and Yude (1996) reported that hard and easy to recruit participants from high and low ascertainment areas had very similar demographic, medical, cognitive and behavioural characteristics.

Response rates obviously have affected sample sizes. It was unfortunate that only 90 mothers of children with asthma could be recruited as therefore the sample did not provide enough power to test a structural stress

and coping model. Testing the path models in both samples has provided useful information regarding the utility of the model in different samples. However, testing a structural model would have had the advantage of measurement free relationships between latent variables.

Three further limitations concern the design of the studies. A first methodological limitation lies in the cross sectional design of the studies. Concurrent assessments and correlation based analyses limit the extent to which causal inferences can be made. Secondly, data for Sample 1 was collected in two stages. The time gap between completing the two questionnaires was 6 – 9 months. This may have affected the results. Measurements taken at time 1 included only predictor variables, e.g. illness parameters and child behaviour. These variables are believed to be relatively stable over time. Therefore it is expected that the timeframe has had a limited impact. Finally, the studies in this thesis involve the use of mothers as single sources of information. Mono-source approaches to data gathering do not allow evaluations of common method variance explanations for the findings. In other words the strength of the relationships between variables in the model may be exaggerated as a result of shared measurement variance. To address this issue attempts were made to recruit fathers of children with asthma. Participating mothers were asked permission to contact the father of their child. Although quite a high percentage of mothers consented, very few fathers returned the questionnaire. Therefore it was not feasible to include father data in the analyses.

### 13.3 Theoretical implications

Results of the studies in this thesis support existing stress and coping models of adjustment to disability to the extent that adaptation processes mediate the relationships between illness parameters and adjustment outcomes. In addition, results support the notion that the level of child adjustment is associated with the psychological adjustment of the parent. The use of the transactional stress and coping model of adjustment to disability (Thompson et al., 1993a; Thompson et al., 1993b; Thompson et al., 1994) is therefore appropriate as it views the disability / illness as a potential stressor

to which individuals and the family as a whole adapt as a function of their resources and emphasises that the level of stress and adjustment experienced by other family members mediates the psychological adjustment of the individual. It is important to take into account the interrelationships between the variables in the model as relationships may be less parsimonious and therefore the model more complicated than previously depicted. Also, analyses in this thesis clearly show adaptation processes, i.e. coping, mediate the illness outcome relationship. The difference between mediation and moderation is important in understanding the processes that affect adjustment to disability.

Results of the studies also show that the sole focus on the detrimental effects of disability is unjust and existing literature has to be extended to include positive outcomes. Attempts have been made to incorporate positive outcomes in stress and coping models (e.g. Folkman, 1997) but the processes underlying positive outcomes are not yet clear. Although these models can provide a framework from which further inquiry may proceed, the affect of positive outcome on the relationship between illness parameters and negative adjustment outcomes is not accounted for. It is important to recognize that adverse events can ultimately lead to both positive and negative outcomes and that positive outcome may moderate the illness adjustment outcome relationship.

#### 13.4 Implications for clinical practice

Support and treatment programs for families of children with disabilities / chronic illnesses have been guided by stress and coping research. As research typically has focused on the detrimental effects of disability on the family, health care professionals have been trained to look out for signs of maladjustment, e.g. depression. Little attention has been given to possible positive outcomes. A change in attitude about disability and its effect on families is necessary. Too often it is assumed that the impact of a child with a disability / chronic illness is negative and positive outcomes are dismissed as denial or not being able to face up to reality. In stead, health care providers should appreciate reports of positive adjustment outcomes. Perceived positive



outcomes of a child's disability / chronic illness may capture an important part of the caregiver experience and may even facilitate effective coping.

Therefore, health care professionals should be ready to recognize and encourage positive affects as these may help families to continue to face up to the daily challenges associated with raising a child with a disability /chronic illness. In addition positive perceptions may become intervention goals itself when working with families of children with disabilities/chronic illnesses.

### 13.5 Suggestions for future research

Following the previous paragraphs some directions for future research become apparent. First future research would benefit from a longitudinal design. Such studies would be appropriate as adjustment to disability is deemed an ongoing process and could address questions of causality. The literature would be enhanced by such approach as to date no longitudinal studies concerning the relationships between illness parameters, adaptation processes and adjustment outcomes have been published. Causality is therefore inferred from theory. Using cross sectional designs to test theoretically based models in which directional effect are specified gives some guidance for understanding the underlying processes of adjustment to disability. However longitudinal or experimental data is necessary to test causal relationships. Second the use of multiple informants could address problems of shared measurement variance and strengthen the validity of the findings. Different informants would be tenable, e.g. health professionals could be asked to report on the child's condition, fathers could report on family functioning, and teachers on child behaviour.

Future studies could also attempt to include information from the child itself, especially in regards to child adaptation. Like most models, the transactional stress and coping model views the disability/illness as a stressor to which individual family members have to adapt. The model differs from other models in that it incorporates the notion that family adaptation, whereby parent and child adjustment mutually affect each other. It could be argued that a child's adaptation efforts are affected by parent adaptation processes as children may tend to mirror their parent's reaction to stress and subsequent

coping strategies. Such findings may be important when planning interventions.

Finally the current findings regarding the affect of positive gain on the illness-outcome relationship warrant further research. The current findings of moderation effects are exiting. Future studies could test stress and coping models that incorporate positive outcome and specifically address the affect of positive gain on parents' ability to cope with their child's illness/disability. Such research efforts could enhance our understanding of factors promoting resilience and therefore provide guidance for prevention and intervention.

## APPENDIX A

**T-test and Chi-square analyses to test for differences between  
respondents and non-respondents Time 2 Survey**

## Descriptive statistics and t-values for respondents and non-respondents

	Respondents		Non-Respondents		t	df
	Mean	SD	Mean	SD		
Demographic characteristics						
Age child	9.41	2.16	9.20	2.11	.76	396
Age mother	38.61	6.42	36.63	5.42	2.46	393
Age father	41.05	6.83	39.44	5.70	1.76	355
Number of children	2.54	1.32	2.62	1.46	-.49	381
Disability characteristics						
Severity of disability	2.84	2.40	3.22	2.84	-1.11	378
Activities of daily living	5.09	3.19	5.11	3.15	-.04	394

\*p<.05

Percentage distribution and Chi-square statistics for respondents and non-respondents

	Respondents		Non-Respondents		N
	%	%	$\chi^2$	df	
Demographic characteristics					
Gender Child			.79	1	399
Girl	44	50			
Boy	56	50			
Child lives with			6.37	7	395
Both parents	69	66			
Mother only	18	22			
Father only	1	0			
Mother and partner	7	7			
Grandparents	0	0			
Foster parents	3	1			
Other	1	4			
Education mother			17.28*	7	383
5 or more GCSE	31	23			
2 or more A levels	5	1			
GNVQ	9	11			
A level equivalent	11	11			
HND	2	0			
Degree	13	6			
Degree equivalent	4	1			
None of the above	25	46			
Education father			6.09	7	322
5 or more GCSE	17	14			
2 or more A levels	5	2			
GNVQ	13	9			
A level equivalent	6	3			
HND	8	10			
Degree	14	10			
Degree equivalent	5	7			
None of the above	32	45			
Employment mother			.97	1	389
Employed	48	41			
Unemployed	53	59			
Employment father			3.40	1	336
Employed	85	76			
Unemployed	15	24			
Disability characteristics					
Disability			4.75	3	399
Spina bifida	14	11			
Hydrocephalus	63	64			
Both	24	24			
Cognitive functioning child			2.15	1	395
Average or above	45	36			
Below average	55	64			

\*p<.05

## APPENDIX B

Questionnaires Sample 1,  
mothers of children with spina bifida and hydrocephalus

# CHILD HEALTH AND DEVELOPMENT STUDY

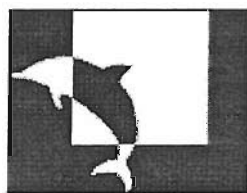
April 1999 - March 2002

Jim Stevenson & Ineke Pit-ten Cate

CENTRE FOR RESEARCH INTO  
PSYCHOLOGICAL DEVELOPMENT



DEPARTMENT OF PSYCHOLOGY  
UNIVERSITY OF SOUTHAMPTON



HIGHFIELD, SOUTHAMPTON, SO17 1BJ  
TEL:023-80595452

Dear Parent,

Thank you for agreeing to complete this questionnaire. Although it looks long, most people find it fairly straightforward. Your replies will help us to find out more about spina bifida and hydrocephalus. Your answers are strictly confidential and will only be used for our research.

Most of our questions can be answered by ticking the box next to the correct answer. Other questions need a written reply. If we have left you too little space for these written answers please continue your answer in the space at the back of the questionnaire. If you have any difficulty completing this questionnaire, please do not hesitate to contact us by phone or letter.

With many thanks,

Yours sincerely,

Jim Stevenson

Ineke Pit-ten Cate

Centre for Research into Psychological Development  
Department of Psychology, University of Southampton, 02380 595452 or 594592

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**Please note: If you have more than one child with Spina Bifida and/or Hydrocephalus, please complete this questionnaire for the oldest affected child within the age range 6-12 years.**

Child's sex:

Girl

Boy

Child's date of birth: .....

Date questionnaire completed: .....

Name of person completing the questionnaire: .....

Relationship to child with Spina Bifida  
and/or Hydrocephalus: .....

Date of birth of mother or first caregiver:

\_\_\_/\_\_\_/\_\_\_.

Date of birth of father or second caregiver:

\_\_\_/\_\_\_/\_\_\_.



**BIRTH AND DEVELOPMENT**

To find out more about Spina Bifida and Hydrocephalus we want to learn about your child's life history, starting at the beginning.

\* Were there any difficulties during the pregnancy? No   
 Yes   
 Please say what

\* Were you or the doctors worried about the baby during the pregnancy? No   
 Yes

\* Did the birth occur on the expected date or was it early or late? On   
 time  
 Early   
 Late   
 Please say how early or late:

\* Was the birth difficult? No   
 Yes   
 Please say what happened

\* How much did the child weigh at birth?  
 .....

\* Were you or the doctors worried about the baby in the first few minutes after birth? No   
 Yes

\* Were there any medical problems in the first few weeks after birth? No   
 Yes

\* How old was your child when you were first fairly certain that it had Spina Bifida and/ or Hydrocephalus:  
 .....

## SPINA BIFIDA/HYDROCEPHALUS

Spina Bifida refers to a fault in the spinal column in which one or more vertebrae fail to form properly, leaving a gap or split. Hydrocephalus is caused by the inability of cerebrospinal fluid to drain into the bloodstream. We want to learn about the severity and nature of your child's Spina Bifida and/or Hydrocephalus.

\* What is your child's disability? (*please tick*)

- Spina Bifida
- Hydrocephalus
- Both

### Spina Bifida:

\* If your child has been diagnosed with Spina Bifida; what is the Level of Lesion: (see diagram below)

(Cervical vertebrae) \_\_\_\_\_

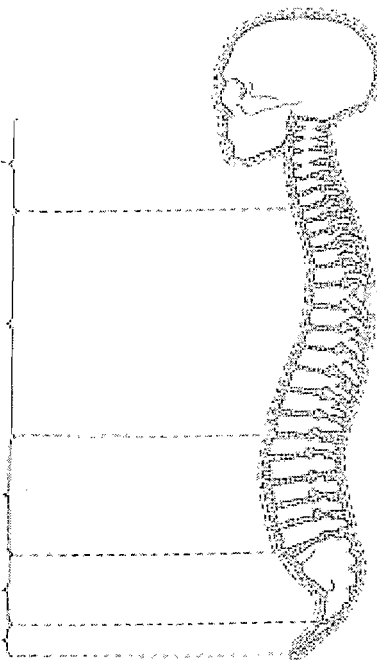
(Thoracic vertebrae - T12 and above) \_\_\_\_\_

(Upper Lumbar - L1-2-3)  
 (Lower Lumbar vertebrae -L4-5) \_\_\_\_\_

(Sacral vertebrae - S1 and below) \_\_\_\_\_

(Coccygeal vertebrae) \_\_\_\_\_

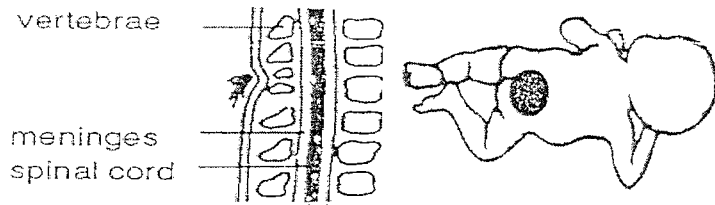
Do not know



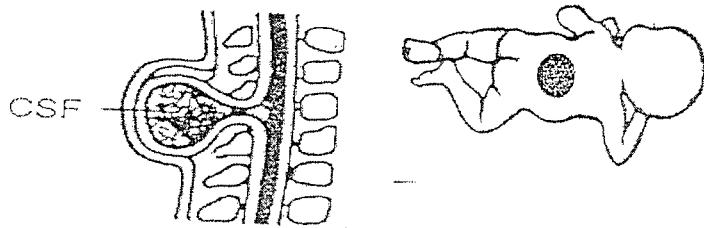
The diagram shows a side view of the human spine. Horizontal dashed lines are drawn across the spine at the following levels: the base of the skull, the top of the neck, the top of the chest, the top of the waist, the top of the pelvis, and the base of the tailbone. Solid lines connect the checkboxes on the left to these corresponding levels on the spine diagram.

\* If your child has been diagnosed with Spina Bifida, which type?  
(see diagram below)

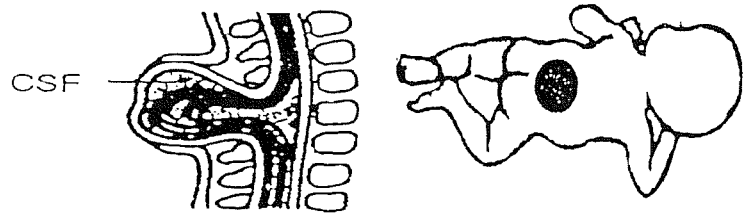
Occulta  
Outer part of vertebrae not completely joined. Spinal cord and covering (meninges) undamaged. Hair often at sight of defect.



Cystica - Meningocele  
Outer part of vertebrae split. Spinal cord normal. Meninges damaged and pushed out through opening

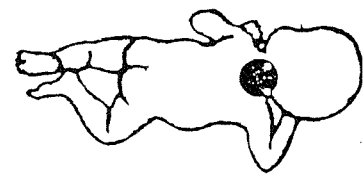


Cystica - Myelomeningocele  
Outer part of vertebrae split. Spinal cord and meninges damaged and pushed out through opening. Possible hydrocephalus.



Encephalocele  
Part of brain pushed out through a defect in the skull

Spinal cord unaffected



### Hydrocephalus:

Cerebrospinal fluid (CSF) is a clear fluid which is produced all the time in the cavities or ventricles inside the brain. It passes from one ventricle to the next through narrow pathways, then circulates around the surface of the brain and is absorbed back into the bloodstream. Hydrocephalus can result when the CSF is prevented from circulating or being reabsorbed, causing the ventricles to swell. In babies and young children the skull bones are not fixed together as they are in later life. Therefore the pressure inside the brain will cause the head to increase in size.

\* If your child has been diagnosed with Hydrocephalus, is the Hydrocephalus:  
(tick all that apply)

Communicating: that is CSF is being prevented from being reabsorbed

Yes     Probably     Not sure     No     Do not know

Non communicating: CSF in the ventricles is not in communication with the spaces outside the brain and spinal cord

Yes    Probably    Not sure    No    Do not know



If yes, is it associated with aqueduct stenosis?      No   
Yes

\* If your child has been diagnosed with Hydrocephalus:

Has it required surgical intervention?      No   
Yes



Please specify

Has it been treated by inserting a shunt device?      No   
Yes



How many shunt revisions have been made?

- 0-2
- 3-5
- 6-10
- 11-20
- 20 or more

Has it been treated by performing a Third Ventriculostomy?      No   
Yes

\* If your child has been diagnosed with Hydrocephalus, is the Hydrocephalus associated with:

- Spina Bifida
- Intracranial haemorrhage
- Meningitis
- Genetic syndrome, please specify .....
- Other, please specify .....
- Do not know

\* Has he/she ever had epileptic fits? (now or in the past)        
No

Yes



Now

Past



How many seizures have occurred in the last six months? .....

\* Does your child have renal problems/infections? No   
 Yes   
 Please specify

\* Does your child have any other medical problems/conditions? No   
 Yes   
 Please specify

\* Is your child left or right handed? Left  Right

\* Does your child use a urinary catheter? No  Yes

\* Does your child have an urinary diversion? No  Yes

\* Does your child wear glasses? No  Yes

\* Does your child have a squint? No  Yes

\* Does your child have a nystagmus?  
 ie rapid involuntary eye movements No  Yes

\* Does your child experience difficulties with:

*Recognising:*

People No  Yes   
 Shapes No  Yes   
 Colours No  Yes

*Finding his/her way:*

In his/her house No  Yes   
 In new places No  Yes

*Finding objects:*

In complex figures/patterns No  Yes   
 On a patterned carpet No  Yes

\* Does your child have difficulty hearing? No   
Yes   
Please specify

\* Does your child have a loss of sensation? No   
Yes   
Please specify

- Limb
- Trunk
- Arms
- Other

\* Does your child regularly complain of pain? No   
Yes   
Please specify

\* Has your daughter started her periods yet? No   
Yes   
What age did they start?

\* Does your child have a latex allergy? No   
Yes

TREATMENT

\* Has your child had these treatments?

a)	Regular physiotherapy	No	<input type="checkbox"/>
		Yes	<input type="checkbox"/>
b)	Regular occupational therapy	No	<input type="checkbox"/>
		Yes	<input type="checkbox"/>
c)	Regular speech therapy	No	<input type="checkbox"/>
		Yes	<input type="checkbox"/>
d)	Operations	No	<input type="checkbox"/>
		Yes	<input type="checkbox"/>
e)	Medicines for fits or absences	No	<input type="checkbox"/>
		Yes	<input type="checkbox"/>
f)	Help from Educational Psychologist	No	<input type="checkbox"/>
		Yes	<input type="checkbox"/>
g)	Help from a Child Guidance Clinic or Child Psychiatrist	No	<input type="checkbox"/>
		Yes	<input type="checkbox"/>
h)	Other	No	<input type="checkbox"/>
		Yes	<input type="checkbox"/>

If you have answered yes to any of the questions on treatment, please give details about the sort of treatment, when it started, when it stopped, and how often it happened.

a) .....

b) .....

c) .....

d) .....

e) .....

f) .....

g) .....

h) .....

## CURRENT PHYSICAL ABILITY

The following questions ask about your child's **current level** of physical ability. For each question please tick one box in the table that corresponds to the most accurate description of his/her **best level** of ability.

\* In terms of your child's **ability to walk** please tick one box that describes his/her **best** ability.

- No limitation (walks normally).
- Walks independently but with some limitation eg has difficulty walking, walks more slowly, unable to run, able to get up off floor and climb stairs but only with difficulty. Poor co-ordination.
- Able to walk, but only with aids or assistance. May have a wheelchair for intermittent use.
- Unable to walk, uses a wheelchair. May be able to stand with support.
- Unable to walk, wheelchair user. Is totally dependent on carers for mobility in wheelchair or buggy.

\* In terms of your child's **urinary function** please tick one box that describes his/her **best** ability

Does your child have full control or use an appliance?

- Full control or catheterises?
- Urostomy
- Occasional incontinence, leakage etc
- Regularly wets bed, frequent leakage

\* In terms of your child's **bowel function** please tick one box that describes his/her **best** ability.

- Full control or satisfactory schedule
- Controlled by medication or enema washouts
- Occasional incontinence
- Frequent soiling

\* In terms of your child's **weight** please tick one box that applies.

- Weight regarded as normal - not on diet
- Weight regarded as normal - on diet
- Regarded as overweight

\* In terms of your child's **pressure sores** please tick one box that applies.

- None
- Occasional
- Persistent



## SCHOOL AND LEARNING

Children with Spina Bifida and/or Hydrocephalus attend all types of schools. Some children with Spina Bifida and/or Hydrocephalus have special learning difficulties while others have none.

\* What sort of school does your child go to?

Ordinary class in ordinary school

Special unit in ordinary school

Special School

↓ ↓  
Is the special unit or school mainly for:

- Physical Disability
- Moderate learning difficulties
- Severe learning difficulties
- Emotional or behavioural problems
- Other - please say what:

\* Does your child have difficulties with specific subjects at school?

Reading  No  Yes

Spelling  No  Yes

Handwriting  No  Yes

Maths  No  Yes

Art  No  Yes

Computers  No  Yes

Science and CDT  No  Yes

P.E and Games  No  Yes

\* Apart from the school subjects we have just asked about, have any other activities at home or school posed particular problems?

\* Does your child have particular difficulty organising school work?

No  
 Yes

\* Does your child have any problems with memory?

No  
 Yes

└─┬─┬─▶ Please say what

\* Does your child have any problems with communicating?

No  
 Yes

└─┬─┬─▶ Please say what

\* Overall, how does your child's performance at school compare with the average for a child of that age?

About average  
 Delayed  
 Above average

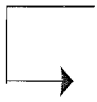
↓      └─┬─▶

Roughly what age level is your child at?

**STATEMENT OF SPECIAL EDUCATION NEED?**

\* Does your child have a Statement of their special educational needs?

- No
- Being drawn up at the moment
- Yes



Has that led to the school and Local Education Authority providing the extra help needed?

- No extra help needed
- Extra help needed but none provided
- Some extra help, but not as much as needed
- The right amount of extra help is being provided

\* If your child has a Statement, or if one is being drawn up at the moment, who first decided that a Statement was needed?

- We did
- The school did
- Other - please specify:
- Not applicable

Extra Help

\* Does this child receive any extra help in school? No   
Yes   
Please specify

Friendships

\* Does your child have difficulty getting on with other children (not counting brothers or sisters)? No   
Yes   
Please specify

Teasing and Bullying

\* Are teasing or bullying problems for your child? No   
Yes   
Please specify

## FAMILY BACKGROUND

We are also interested in your family for a number of reasons. For example, does being part of a large family make it easier or harder for a child to cope with a disability? If you think we are being too nosey, just don't answer the question!

\* The child lives with: (please tick one box)

- |                          |   |                          |                                |                          |                    |
|--------------------------|---|--------------------------|--------------------------------|--------------------------|--------------------|
| <input type="checkbox"/> | Both biological parents   | <input type="checkbox"/> | Mother only                    | <input type="checkbox"/> | Mother and partner |
| <input type="checkbox"/> | Father only   | <input type="checkbox"/> | Father and partner             | <input type="checkbox"/> | Grandparents       |
| <input type="checkbox"/> | One foster or adoptive parent                                   | <input type="checkbox"/> | Two foster or adoptive parents |                          |                    |
| <input type="checkbox"/> | Other ( <i>please specify and give number of carers</i> ) _____ |                          |                                |                          |                    |

\* Please list the names and date of birth of any brothers and sisters (including half and step-brothers and sisters, if they also live at home). If an only child, please write none.

\* Are there any other family members who are affected by Spina Bifida or Hydrocephalus?

No	<input type="checkbox"/>
Yes	<input type="checkbox"/>

↓  
Please say who they are (brother, mother, grandfather, aunt, and so on)

\* How many people are now living at home?

\* What languages are spoken at home?

\* Are there any problems with your home, such as damp or too little space?

No	<input type="checkbox"/>
Yes	<input type="checkbox"/>

↓  
Please specify

\* Have you made any adaptations to your home to facilitate your affected child?

No	<input type="checkbox"/>
Yes	<input type="checkbox"/>

↓  
Please specify

\* Are there any problems with the area you live in?  
For example is it unsafe, unfriendly or lacking in playgrounds?

No	<input type="checkbox"/>
Yes	<input type="checkbox"/>

↓  
Please state what the problems are.

\* What date did you join ASBAH? .....

\* Have you been members of other parents' organisations for disabled children?

No	<input type="checkbox"/>
Yes but not any longer	<input type="checkbox"/>
Yes, still member	<input type="checkbox"/>

↳ Please say which organisation(s):

\* Parents work

	<u>Mother/ First Caregiver</u>		<u>Father/ Second Caregiver</u>	
Are you employed at present?	No	<input type="checkbox"/>	No	<input type="checkbox"/>
	Yes	<input type="checkbox"/>	Yes	<input type="checkbox"/>
Occupation:	.....		.....	
Job Title:	.....		.....	
Are you self-employed?	No	<input type="checkbox"/>	No	<input type="checkbox"/>
	Yes	<input type="checkbox"/>	Yes	<input type="checkbox"/>
Do you employ more than 4 people?	No	<input type="checkbox"/>	No	<input type="checkbox"/>
	Yes	<input type="checkbox"/>	Yes	<input type="checkbox"/>

\* Parents Education

Please describe the qualifications you hold:

	<u>Mother/ First Caregiver</u>	<u>Father/Second Caregiver</u>
5 or more G.C.S.E's	<input type="checkbox"/>	<input type="checkbox"/>
2 or more A levels	<input type="checkbox"/>	<input type="checkbox"/>
Vocational Qualification (GNVQ)	<input type="checkbox"/>	<input type="checkbox"/>
A level equivalent	<input type="checkbox"/>	<input type="checkbox"/>
HND	<input type="checkbox"/>	<input type="checkbox"/>
Degree	<input type="checkbox"/>	<input type="checkbox"/>
Degree equivalent	<input type="checkbox"/>	<input type="checkbox"/>
None of the above	<input type="checkbox"/>	<input type="checkbox"/>

## FAMILY NEEDS

Many families of children with special needs have expressed a desire for information or support. Listed below are some needs commonly identified by families. It would be helpful to us if you would check in the appropriate columns on the right for all the topics. At the end there is a place for you to describe other topics not included in the list.

TOPICS		No	Not Sure	Yes
<b>Information</b>				
1	How children grow and develop			
2	How to play or talk with my child			
3	How to teach my child			
4	How to handle my child's behaviour			
5	Information about any condition my child might have			
6	Information about services that are presently available for my child			
7	Information about the services my child might receive in the future			
<b>Family &amp; Social Support</b>				
1	Talking with someone in my family about concerns			
2	having friends to talk to			
3	Finding more time for myself			
4	Helping my partner accept any condition our child might have			
5	Helping our family discuss problems and reach solutions			
6	Helping our family support each other during difficult times			
7	Deciding who will do household chores, child care, and other family tasks			
8	Deciding on and doing family recreational activities			
<b>Financial</b>				
1	Paying for expenses such as food, housing, medical care, clothing, or transportation			
2	Paying for day care, or other services my child needs			
3	Counselling or help in getting a job			
4	Paying for baby-sitting			
5	Paying for toys that my child needs			
<b>Explaining to Others</b>				
1	Explaining my child's condition to other family members			
2	How to respond when friends, neighbours, or strangers ask questions about my child			
3	Finding material about other families who have a child like mine			

TOPICS		No	Not Sure	Yes
<b>Child Care</b>				
1	Locating baby-sitters who are willing and able to care for my child			
2	Locating a day care programme or pre-school for my child			
3	Getting appropriate care for my child during religious services			
<b>Professional Support</b>				
1	Meeting with a minister, priest, or rabbi			
2	Meeting with a counsellor (psychologist, social worker, treatment specialist)			
3	More time to talk to my child's teacher			
<b>Community Services</b>				
1	Meeting & talking with other parents who have a child like mine			
2	Locating a doctor who understands me and my child's needs			
3	Locating a dentist who will see my child			

Other: please list other topics on which you would like information or other forms of support you would like to have.

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## THE IMPACT OF SPINA BIFIDA/HYDROCEPHALUS

Up until this point we have mainly asked about physical problems. We also want to find out about the effect of these problems on you, your child and the family as a whole.

\* How much are the following problems interfering with your child's life? (For each type of problem, please tick the best answer - first box for "No problem", second box if it is a minor nuisance only, or third box if the problem is greatly interfering with your child's life.)

	No problem	A minor nuisance	Makes a big difference
Physical problems interfering with everyday life, sport and so on.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Teasing by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Learning problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Epileptic fits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional or behavioural problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\* Does your child have any difficulty with the following everyday activities?

	No problems	Slight problems	Major problems
Washing and bathing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eating a meal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Continence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Finding own way around without getting lost	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking ordinary distances without getting too tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\* Please describe any other activities that have posed particular problems:

\* What are your child's favourite hobbies and spare time activities?

\* How has your child's Spina Bifida/Hydrocephalus affected the family as a whole? (Tick all that have applied over the last 12 months)

No effect	
Parents have less time for themselves	
Mother can't go back to work	
More arguments between parents	
Less time for the other children	
Sisters and brothers have to help more	
We have become more caring	
More tension at home	
Fewer outings or holidays	
Other - please say what:	

\* How has your child responded to the Spina Bifida/Hydrocephalus (and any other medical problems)? For each of the following, please tick the first box for False, the second box for Partly True, or the third box for True.

	<b>False</b>	<b>Partly True</b>	<b>True</b>
Accepts it. Makes the best of it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Won't talk about it. Pretends it's not so.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets angry about it. Resents it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets sad. Cries about it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lacks self-confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uses disability to gain sympathy or as an excuse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relies too much on help from adults and other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\* If you were starting again at the beginning, what would be the most helpful bits of advice anyone could give you?

## CAREGIVING

Below are several questions that ask about how you feel about your role as a caregiver for your child with Spina Bifida/Hydrocephalus. Please read each question, and place a circle around the number on the scale that reflects your own views. If your views are described best by the end points of the scale, please circle either number 1 or number 7. If your views are somewhere in between the two end points, please select a position on the scale that reflects where you feel your views should be placed. Please select a response for all of the questions.

**How confident are you in caring for your child with Spina Bifida/Hydrocephalus?**

1      2      3      4      5      6      7  
Not at all      Very confident  
confident

**How difficult do you personally find it to deal with the care of your child with Spina Bifida/Hydrocephalus?**

1      2      3      4      5      6      7  
Very difficult      Not at all difficult

**To what extent do you feel that the way you care for your child with Spina Bifida/Hydrocephalus has a positive effect?**

1      2      3      4      5      6      7  
Has no positive      Has a very  
effect at all      positive effect

**How satisfied are you with the way in which you care for your child with Spina Bifida/Hydrocephalus?**

1      2      3      4      5      6      7  
Not satisfied      Very satisfied  
at all

**To what extent do you feel in control of the care of your child with Spina Bifida/Hydrocephalus?**

1      2      3      4      5      6      7  
Not in      Very much  
control at all      in control

## RATING SCALE OF CHILD'S ACTUAL BEHAVIOUR

Please indicate what you feel to be your child's actual competence on each question, in your opinion. First decide what kind of child he or she is like, the one described on the left or right, and then indicate whether this is just sort of true or really true for your child. Thus, for each item, check one of four spaces.

Really True for my child	Sort of True for my child	OR	Really True for my child		Sort of True for my child
<i>SAMPLE ITEM</i>					
2. _____	My child would rather play outdoors in his/her spare time	OR	My child would rather watch TV	_____	_____
<hr style="border-top: 1px dashed black;"/>					
1. _____	My child is really good at his/her school work	OR	My child can't do the school work assigned	_____	_____
2. _____	My child finds it hard to make friends	OR	For my child it's pretty easy	_____	_____
3. _____	My child does really well at all kinds of sports	OR	My child isn't very good when it comes to sports.	_____	_____
4. _____	My child is good looking	OR	My child isn't very good-looking	_____	_____
5. _____	My child is usually well-behaved	OR	My child is often not well-behaved	_____	_____
6. _____	My child often forgets what he/she learns	OR	My child can remember things easily	_____	_____
7. _____	My child has a lot of friends	OR	My child doesn't have many friends	_____	_____
8. _____	My child is better than others his/her age at sports	OR	My child can't play as well	_____	_____
9. _____	My child has a nice physical appearance	OR	My child doesn't have such a nice physical appearance	_____	_____
10. _____	My child usually acts appropriately	OR	My child would be better if he/she acted differently	_____	_____
11. _____	My child has trouble figuring out the answers in school	OR	My child almost always can figure out the answers	_____	_____
12. _____	My child is popular with others his/her age	OR	My child is not very popular	_____	_____
13. _____	My child doesn't do well at new outdoor games	OR	My child is good at new games right away	_____	_____
14. _____	My child isn't very attractive	OR	My child is pretty attractive	_____	_____
15. _____	My child often gets in trouble because of things he/she does	OR	My child usually doesn't do things that get him/her in trouble	_____	_____

## CHILD HEALTH-RELATED QUALITY OF LIFE

We would like to get a picture of your child's life over the past month, and also how you feel about this. The questions are divided into different areas covering various aspects of your child's daily life. We ask you to place a tick on the scale to indicate where you believe your child to be in comparison with any other child of the same age. Please read the example below very carefully; it shows you how to answer the questions, before starting to answer the questions on the following pages.

### EXAMPLE

#### A. Reading

Possible problems that children have with reading include: Difficulty reading hard words; making many spelling mistakes; unable to understand what he or she is reading; a reading age of a child several years younger; unable to read at all.

If your child can read better than other children of the same age, you should tick here.

Better than children of the same age 

✓							
---	--	--	--	--	--	--	--

 Cannot read at all

If your child cannot read at all, you should tick this box along the scale.

Better than children of the same age 

						✓	
--	--	--	--	--	--	---	--

 Cannot read at all

If your child has some reading difficulties, you may tick here.

Better than children of the same age 

					✓		
--	--	--	--	--	---	--	--

 Cannot read at all

Or you may tick somewhere around here.

Better than children of the same age 

		✓					
--	--	---	--	--	--	--	--

 Cannot read at all

Please place a tick (✓) along the scale to indicate where you believe your child to be in comparison with any other child of the same age.

**1. Getting about and using hands**

Possible problems include: Clumsy; difficulty running; difficulty walking; unable to control movements; uses a wheelchair; confined to bed.

Over the past month how well has your child performed in this area?

Better than children of the same age 

--	--	--	--	--	--	--	--

 Confined to bed

How satisfied have you been with your child's performance in this area?

Very satisfied 

--	--	--	--	--	--	--	--

 Not satisfied at all

**2. Doing things for his or herself**

Possible problems include: Cannot do up buttons or laces; cannot use a knife to cut food; needs help with feeding; difficulties in washing or dressing; totally unable to look after self.

Over the past month how well has your child performed in this area?

Better than children of the same age 

--	--	--	--	--	--	--	--

 Totally unable to look after self

How satisfied have you been with your child's performance in this area?

Very satisfied 

--	--	--	--	--	--	--	--

 Not satisfied at all

**3. Soiling or wetting**

Possible problems include: Bed wetting; wetting self during the day; some soiling; no control over bladder and bowels.

Over the past month how well has your child been in this area?

Better than children of the same age 

--	--	--	--	--	--	--	--

 No control

How satisfied have you been with your child's performance in this area?

Very satisfied 

--	--	--	--	--	--	--	--

 Not satisfied at all

**4. School**

Possible problems include: Finding school boring, unable to sit still for too long; finding school work difficult; needing extra help at school; attending a special class at school; going to a special school full-time; not able to go to school at all.

Over the past month how well has your child been getting on at school?

Better than children of the same age 

--	--	--	--	--	--	--	--

 Not able to go to school at all

How satisfied have you been with your child's performance in this area?

Very satisfied 

--	--	--	--	--	--	--	--

 Not satisfied at all

**5. Out of school activities**

Possible problems include: Not very good at sport and other outdoor activities; can only do a few out of school activities, such as listening to music with friends or playing computer games; cannot go swimming; unable to take part in any out of school activities.

Over the past month how well has your child performed the above?

Better than children 

--	--	--	--	--	--	--	--

 Unable to take part in any out of school activities.

How satisfied have you been with your child's performance in this area?

Very satisfied 

--	--	--	--	--	--	--	--

 Not satisfied at all

**6. Friends**

Possible problems include: No special friends; a lot of arguing and bickering; few close friends; often teased or bullied; no friends at all.

Over the past month how well has your child been able to get on with friends?

Better than children 

--	--	--	--	--	--	--	--

 No friends at all

How satisfied have you been with your child's performance in this area?

Very satisfied 

--	--	--	--	--	--	--	--

 Not satisfied at all

**7. Family relationships**

Possible problems include: Not feeling very affectionate towards the family; not well-behaved; unpleasant arguments with parents; constant quarrels with parents and brothers or sisters.

Over the past month how well has your child been getting on with your family?

Better than children 

--	--	--	--	--	--	--	--

 Constant arguments

How satisfied have you been with your child's performance in this area?

Very satisfied 

--	--	--	--	--	--	--	--

 Not satisfied at all

**8. Discomfort due to bodily symptoms**

Possible problems include: itchiness; discomfort; tiredness; breathlessness; feeling sick; vomiting; fits or faints; severe pain.

Over the past month how well has your child been with regard to the above?

Better than children of the same age								Severe pain and/or other discomfort
--------------------------------------	--	--	--	--	--	--	--	-------------------------------------

How satisfied have you been with your child's ability to cope with this?

Very satisfied								Not satisfied at all
----------------	--	--	--	--	--	--	--	----------------------

**9. Worries**

Possible problems include: Panicking; easily frightened; worries often; worries all the time.

Over the past month how anxious and worried has your child been?

Better than children of the same age								Worried all the time
--------------------------------------	--	--	--	--	--	--	--	----------------------

How satisfied have you been with your child's level of anxiety and worried feelings?

Very satisfied								Not satisfied at all
----------------	--	--	--	--	--	--	--	----------------------

**10. Depression**

Possible problems include: Feeling sad; feeling unhappy; feeling miserable; feeling life is hopeless; being depressed most of the time.

Over the past month how well has your child's mood been?

Better than children of the same age								Depressed all the time
--------------------------------------	--	--	--	--	--	--	--	------------------------

How satisfied have you been with your child's mood?

Very satisfied								Not satisfied at all
----------------	--	--	--	--	--	--	--	----------------------

**11. Seeing**

Possible problems include: Unable to read small print; needs glasses; cannot see well enough to get about; unable to recognise a friend on the other side of the street even with glasses; totally blind.



Over the past month how well has your child's sight been?

Better than children of the same age 

--	--	--	--	--	--	--

 Totally blind

How satisfied have you been with your child's sight?

Very satisfied 

--	--	--	--	--	--	--

 Not satisfied at all

### 12. Communication

Possible problems include: Some difficulty understanding what other people are saying; unable to hear very well; not able to make yourself understood; difficulty communicating in other ways; totally unable to let people know what you need.

Over the past month how well has your child performed the above?

Better than children of the same age 

--	--	--	--	--	--	--

 Totally unable to communicate his or her needs

How satisfied have you been with your child's performance in this area?

Very satisfied 

--	--	--	--	--	--	--

 Not satisfied at all

### 13. Eating

Possible problems include: Faddy, picky, greedy; raids the fridge; can't stop eating; starving self; only takes liquids; can't eat by mouth; not eating at all or always stuffing self with food.

Over the past month how well has your child been eating?

Better than children of the same age 

--	--	--	--	--	--	--

 Not eating at all or always eating too much

How satisfied have you been with your child's performance in this area?

Very satisfied 

--	--	--	--	--	--	--

 Not satisfied at all

### 14. Sleep

Possible problems include: Some difficulty getting to sleep; waking during the night, once, twice or several times; waking up very early in the morning; tired during the day; hardly sleeping at all or constantly tired.

Over the past month how well has your child been sleeping?

Better than children of the same age 

--	--	--	--	--	--	--

 Hardly sleeping at all or constantly tired.

How satisfied have you been with your child's sleep?

Very satisfied 

--	--	--	--	--	--	--	--

 Not satisfied at all

**15. Appearance**

Possible problems include: Spots on face; birth marks; skinny; fat; very small for his or her age; body has an unusual shape; has an unusual appearance.

Over the past month how has your child's appearance been?

Better than children of the same age 

--	--	--	--	--	--	--	--

 Very unusual appearance

How satisfied have you been with the way your child looks?

Very satisfied 

--	--	--	--	--	--	--	--

 Not satisfied at all

Now try to consider all the different areas this questionnaire has covered.

Over the past month how do you think the quality of your child's life has been?

Better than children of the same age 

--	--	--	--	--	--	--	--

 Very poor quality of life

Please add here any comments about your child that would help us to understand your answers better.

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Thank you for being so helpful.

## GENERAL HEALTH AND BEHAVIOUR

This is the last section of the questionnaire and it needs no written answers - so please keep going. This part of the questionnaire tells us about some of your child's strengths, as well as areas with room for improvement! It would help us if you answered all items as best as you can even if you are not absolutely certain or the item seems daft.

Please give the answers on the basis of the child's behaviour over the last six months.

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

Continued on next page:-

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

No	Yes - minor difficulties	Yes - definite difficulties	Yes - severe difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have answered “Yes”, please answer the following questions about these difficulties:

Do the difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do the difficulties interfere with your child’s everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
Home Life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friendships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Classroom Learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure Activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**CAN WE CONTACT YOUR CHILD'S TEACHER?**

In previous studies, it has been very helpful to get teachers to fill in a brief questionnaire on each child. Could we have your permission to send a questionnaire to your child's teacher to see how things are at school. The replies will be completely confidential and will only be used to help our research.

I am **willing/unwilling\*** for my child's teacher to be contacted to fill in a confidential questionnaire.

Child's First Name: .....

Child's Surname .....

Name of School: .....

Address of School: .....  
.....  
.....

Phone No. (If known): .....

Name of Class Teacher: .....

Your Signature: .....

Today's Date: .....

\*Please delete as appropriate

**THANK YOU VERY MUCH FOR YOUR HELP**

Please check that you have not missed out any pages by mistake. When you have finished, please return the questionnaire to us in the reply-paid envelope.

*If there is anything else you would like to tell us about your child's behaviour please use the back page.*

**RETURN SLIP**

If you would be interested in participating in a following stage of our research, please state your name, address, phone number below and return in the reply-paid envelope.

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**Name:**

**Address:**

**Telephone  
Number:**

**Child's First  
Name:**

**Child's  
Surname**

----- **THANK YOU FOR YOUR TIME** -----

# FAMILIES OF CHILDREN WITH SPINA BIFIDA AND / OR HYDROCEPHALUS

April 1999 - March 2002

Ineke Pit-ten Cate

CENTRE FOR RESEARCH INTO  
PSYCHOLOGICAL DEVELOPMENT



DEPARTMENT OF PSYCHOLOGY  
UNIVERSITY OF SOUTHAMPTON



HIGHFIELD, SOUTHAMPTON, SO17 1BJ  
TEL:023-80595452

Dear Parent/Guardian,

Thank you for agreeing to complete this questionnaire. Your replies will help me to find out more about families raising a child with spina bifida and hydrocephalus. In particular, it will tell me about the difficulties families have encountered and how families have responded. Your answers are strictly confidential and will only be used for our research

All questions can be answered by ticking a box or circling a number. If you have any difficulty completing this questionnaire, please do not hesitate to contact me by telephone or letter.

With many thanks

Ineke Pit-ten Cate

Centre for Research into Psychological Development  
Department of psychology  
University of Southampton  
Highfield  
Southampton SO17 1BJ  
02380-595452

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Our Reference

Your name

Child's name

Date questionnaire completed .....



## AREA OF DIFFICULTIES SCALE

The fact that your child has spina bifida and/or hydrocephalus may sometimes create difficulties for you. By difficulties I mean a situation where no effective solution is immediately available to you. Below are listed areas in which difficulties often happen.

Please indicate how frequently or often difficulties have happened in each area in the *past 6-12 months* because of your child's spina bifida/hydrocephalus. That is, consider only those difficulties in each area that are in your mind related to your child's disability. These difficulties do not have to be your child's fault. Rather, they may have happened only because of the fact that she/he has spina bifida/hydrocephalus and there may not have been anything else she/he could have done about it. Your child may not even have been aware of the difficulty. Also note that you are asked how frequently difficulties happened, not how much concern or distress they caused you. Just estimate for each area how often difficulties related to your child's disability came up in the last 6-12 months and circle the number underneath the alternative that best fits your estimate.

	<i>Not At All</i>	<i>Once</i>	<i>Once Every month</i>	<i>Once Every Fort- night</i>	<i>Once Every Week</i>	<i>Twice Every Week</i>	<i>Every Other Day</i>	<i>Every Day Or More</i>
1. my child's education	0	1	2	3	4	5	6	7
2. my child's relationship with other children, excluding siblings	0	1	2	3	4	5	6	7
3. my child's relationship with other family members, excluding myself	0	1	2	3	4	5	6	7
4. my child's health	0	1	2	3	4	5	6	7
5. my child's health care and therapies	0	1	2	3	4	5	6	7
6. my child's transportation	0	1	2	3	4	5	6	7
7. my child's leisure or fun time	0	1	2	3	4	5	6	7
8. my child's behaviour and discipline	0	1	2	3	4	5	6	7
9. my child's feeding, dressing and hygiene	0	1	2	3	4	5	6	7
10. my relationship with my child	0	1	2	3	4	5	6	7
11. my relationship with my spouse/partner	0	1	2	3	4	5	6	7
12. my relationship with other family members	0	1	2	3	4	5	6	7
13. my relationship with friends	0	1	2	3	4	5	6	7
14. my job, education or housework	0	1	2	3	4	5	6	7
15. my families finances	0	1	2	3	4	5	6	7
16. my personal aspirations	0	1	2	3	4	5	6	7
17. my spiritual or religious life	0	1	2	3	4	5	6	7

PARENTING : RAISING A CHILD WITH SPINA BIFIDA AND OR HYDROCEPHALUS

The following questions ask you about your feelings associated with raising a child with spina bifida and/or hydrocephalus. It is important for me to find out the ways parents feel about raising a child with a disability in order to help others who may have difficulty. Therefore even though this is a long section and some questions may appear less relevant than others, it would be very helpful for me if you could fill it in and please give an answer to each question.

While you may not find an answer which exactly states your feelings, please mark the answer that comes closest to describing how you feel. Your first reaction to each question should be your answer.

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not Sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
1. Since having this child, I feel I have grown as a person	1	2	3	4	5
2. I often have the feeling that I can not handle things very well	1	2	3	4	5
3. I find myself giving up more of my life to meet my child's needs than I ever expected	1	2	3	4	5
4. I feel trapped by my responsibilities as a parent	1	2	3	4	5
5. My child has a pleasant personality/character	1	2	3	4	5
6. Since having this child, I have been unable to do new and different things	1	2	3	4	5
7. Since having this child, I feel that I am almost never able to do things that I like to do	1	2	3	4	5
8. I am unhappy with the last purchase of clothing I made for myself	1	2	3	4	5
9. My child has a lot to give to other people	1	2	3	4	5
10. There are quite a few things that bother me about my life	1	2	3	4	5
11. Having this child has caused more difficulties than I expected in my relationship with my spouse (male/female friend/partner)	1	2	3	4	5
12. I feel alone and without friends	1	2	3	4	5
13. Having this child has helped me to learn new things/skills	1	2	3	4	5
14. When I go to a party I usually expect not to enjoy myself	1	2	3	4	5
15. I am not as interested in people as I used to be	1	2	3	4	5
16. Raising this child helps putting life into perspective	1	2	3	4	5
17. I don't enjoy things as I used to	1	2	3	4	5

CONTINUED ON NEXT PAGE →



	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not Sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
18. My child rarely does things for me that make me feel good	1	2	3	4	5
19. Most times I feel that my child does not like me and does not want to be close to me	1	2	3	4	5
20. Since having this child, I have more often put other people's interest before my own	1	2	3	4	5
21. My child smiles at me much less than I expected	1	2	3	4	5
22. When I do things for my child I get the feeling that my efforts are not appreciated very much	1	2	3	4	5
23. When playing, my child does not often giggle or laugh	1	2	3	4	5
24. My child is a fighter and does not give up easily	1	2	3	4	5
25. My child does not seem to learn as quickly as most children	1	2	3	4	5
26. My child does not seem to smile as much as most children	1	2	3	4	5
27. My child is not able to do as much as I expected	1	2	3	4	5
28. Since having this child, my family has become closer to one another	1	2	3	4	5
29. It takes a long time and it is very hard for my child to get used to new things	1	2	3	4	5
30. I feel that I am: 1 not very good at being a parent 2 a person who has trouble being a parent 3 an average parent 4 a better than average parent 5 a very good parent  (please select which applies to you and circle number)	1	2	3	4	5
31. I expected to have closer and warmer feelings for my child than I do and this bothers me	1	2	3	4	5
32. Since having this child, my family has become more tolerant and accepting	1	2	3	4	5
33. Sometimes my child does things that bother me just to be mean	1	2	3	4	5
34. My child seems to cry or fuss more often than most children	1	2	3	4	5

CONTINUED ON NEXT PAGE →

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not Sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
35. Since having this child, I have become more determined to face up to challenges	1	2	3	4	5
36. My child generally wakes up in a bad mood	1	2	3	4	5
37. I feel that my child is very moody and easily upset	1	2	3	4	5
38. My child does a few things which bother me a great deal	1	2	3	4	5
39. Since having this child, I have a greater understanding of other people	1	2	3	4	5
40. My child reacts very strongly when something happens that my child does not like	1	2	3	4	5
41. My child gets upset easily over the smallest thing	1	2	3	4	5
42. My child's sleeping or eating schedule was much harder to establish than I expected	1	2	3	4	5
43. My child is loving and caring	1	2	3	4	5
44. I have found that getting my child to do something or to stop doing something is: 1 much harder than I expected 2 somewhat harder than I expected 3 about as hard as I had expected 4 somewhat easier than I had expected 5 much easier than I had expected (please select which applies to you and circle number)	1	2	3	4	5
45. Think carefully and count the number of things which your child does that bother you. For example dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. Please circle the number which includes the number of things you counted 1: 10+ 2: 8-9 3: 6-7 4: 4-5 5: 1-3 (please select which applies to you and circle number)	1	2	3	4	5
46. There are some things my child does that really bother me a lot	1	2	3	4	5
47. Since having this child, my family has become more caring	1	2	3	4	5
48. My child turned out to be more of a difficulty than I had expected	1	2	3	4	5
49. My child makes more demands on me than most children	1	2	3	4	5
50. Since having this child, I have developed new interests	1	2	3	4	5

## COPING WITH DIFFICULTIES

In this section I want to get some idea of how parents cope with difficulties in bringing up children with spina bifida and/or hydrocephalus. It is important for me to find out the ways parents have coped with difficulties in order to help others who may have difficulty.

Please read each item and think about whether you used this way of dealing with difficulties in bringing up our child. By difficulties we mean such things as sleeping difficulties, embarrassing behaviours, worries about the child's future, your own feelings about having a child with a disability or anything else you yourself feel to be a difficulties. Obviously different people deal with things in different ways, but we are interested in how you have tried to deal with the difficulties you have experienced. Each item says something about a particular way of coping. We want to know to what extent you have been doing what the item says in *the past 6-12 months*: How much or how frequently. Do not answer on the basis of whether it seems to be working or not-just whether or not you are doing it. Use the response choices. Try to rate each item separately in your mind from the others. Make the answers as true for you as you can

	<i>I have not been doing this at all</i>	<i>I have been doing this a little bit</i>	<i>I have been doing this a medium amount</i>	<i>I have been doing this a lot</i>
1. I have been turning to work or other activities to take my mind off things	1	2	3	4
2. I have been concentrating my efforts on doing something about the situation I am in	1	2	3	4
3. I have been saying to myself "this is not real"	1	2	3	4
4. I have been using alcohol or drugs to make myself feel better	1	2	3	4
5. I have been getting emotional support from others	1	2	3	4
6. I have been giving up trying to deal with it	1	2	3	4
7. I have been taking action to try to make the situation better	1	2	3	4
8. I have been refusing to believe that is has happened	1	2	3	4
9. I have been saying things to let my unpleasant feelings escape	1	2	3	4
10. I have been getting help and advice from other people	1	2	3	4
11. I have been using alcohol or other drugs to help me get through it	1	2	3	4
12. I have been trying to see it in a different light, to make it seem more positive	1	2	3	4
13. I have been criticising myself	1	2	3	4

CONTINUED ON NEXT PAGE →



	<i>I have not been doing this at all</i>	<i>I have been doing this a little bit</i>	<i>I have been doing this a medium amount</i>	<i>I have been doing this a lot</i>
14. I have been trying to come up with a strategy about what to do	1	2	3	4
15. I have been getting comfort and understanding from someone	1	2	3	4
16. I have been giving up the attempt to cope	1	2	3	4
17. I have been looking for something good in what is happening	1	2	3	4
18. I have been making jokes about it	1	2	3	4
19. I have been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping or shopping	1	2	3	4
20. I have been accepting the reality of the fact that is has happened	1	2	3	4
21. I have been expressing my negative feelings	1	2	3	4
22. I have been trying to find comfort in my religion or spiritual beliefs	1	2	3	4
23. I have been trying to get advice or help from other people about what to do	1	2	3	4
24. I have been learning to live with it	1	2	3	4
25. I have been thinking hard about what steps to take	1	2	3	4
26. I have been blaming myself for things that happened	1	2	3	4
27. I have been praying or meditating	1	2	3	4
28. I have been making fun of the situation	1	2	3	4

## FAMILY SATISFACTION

This is the last section of the questionnaire, - please keep going! This part tells us about how you feel about your family. Please read each question and tick the box on the scale that best describes your feelings. It would help me if you answered all items even if you are not absolutely certain or the item seems daft.

### HOW SATISFIED ARE YOU.....

	<i>Dissatisfied</i>	<i>Somewhat Dissatisfied</i>	<i>Generally Satisfied</i>	<i>Very Satisfied</i>	<i>Extremely Satisfied</i>
1. ....with how close you feel to the rest of your family	1	2	3	4	5
2. ....with your ability to say what you want in your family	1	2	3	4	5
3. ....with your family's ability to try new things	1	2	3	4	5
4. ....with how often you or your spouse/partner make decisions in your family	1	2	3	4	5
5. ....with how much you and your spouse/partner argue with each other	1	2	3	4	5
6. ....with how fair the criticism is in your family	1	2	3	4	5
7. ....with the amount of time you spend with your family	1	2	3	4	5
8. ....with the way you talk to each other to solve family difficulties	1	2	3	4	5
9. ....with your freedom to be alone when you want to	1	2	3	4	5
10. ....with how strictly you stay with who does what chores in your family	1	2	3	4	5
11. ....with your family's acceptance of your friends	1	2	3	4	5
12. ....with how clear it is what your family expects of you	1	2	3	4	5
13. ....with how often you make decisions as a family, rather than individually	1	2	3	4	5
14. ....with the number of fun things your family does together	1	2	3	4	5

**THANK YOU VERY MUCH FOR YOUR HELP !**

**Please check that you have not missed out any pages by mistake. When you have finished, please return the questionnaire to me in the reply-paid envelope.**

Ineke Pit-ten Cate  
Centre for Research into Psychological Development  
Department of Psychology  
University of Southampton  
Highfield  
Southampton, SO17 1BJ  
02380-595452

**THANK YOU VERY MUCH FOR YOUR TIME**



## APPENDIX C

### Questionnaire Sample 2, mothers of children with asthma

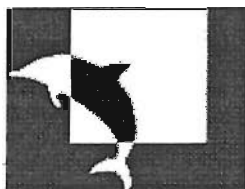
Mothers of children with asthma  
April 2002 - June 2002

Ineke Pit-ten Cate

CENTRE FOR RESEARCH INTO  
PSYCHOLOGICAL DEVELOPMENT



DEPARTMENT OF PSYCHOLOGY  
UNIVERSITY OF SOUTHAMPTON



HIGHFIELD, SOUTHAMPTON, SO17 1BJ  
TEL:023-80595452

Dear Parent/Guardian,

Thank you for agreeing to complete this questionnaire. Your replies will help me to find out more about families raising a child with asthma. In particular, it will tell me about the difficulties families have encountered and how families have responded.

There is no requirement for you to complete this questionnaire. Participation is entirely voluntary and you are entitled to withdraw from this research at any point. All information volunteered in this questionnaire is CONFIDENTIAL. No details will be passed on to any other source.

All questions can be answered by ticking a box or circling a number. If you have any difficulty completing this questionnaire, please do not hesitate to contact me by telephone or letter.

The questionnaire is divided into nine sections with clear instructions for each section. This is not a test and there are no right or wrong answers. Please answer all questions as openly and honestly as possible. Read each question carefully, but respond on the basis of your first reaction and do not spend too long on each question. The questionnaire should take approximately 30 minutes to complete.

I very much appreciate your help in this study.

With many thanks,

Ineke Pit-ten Cate

Centre for Research into Psychological Development  
Department of psychology  
University of Southampton  
Highfield  
Southampton SO17 1BJ  
023-80595452

**SECTION 1: YOUR CHILD**

Child's gender:

Girl

Boy

Child's date of birth:

.....

Your date of birth:

.....

Does your child have any difficulty with the following everyday activities?

	No problems	Slight problems	Major problems
Washing and bathing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eating a meal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Continence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Finding own way around without getting lost	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking ordinary distances without getting too tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall, how does your child's performance at school compare with the average for a child of that age?

Above average

/

About average/

Delayed

## SECTION 2 YOUR CHILD'S ASTHMA

Over the last *3 months*

	Every day	Most days	Some days	A few days	Not at all
1. Has your child been wheezy during the day	1	2	3	4	5
2. Has your child coughed during the day	1	2	3	4	5
3. Has your child complained of being short of breath	1	2	3	4	5
4. Has your child complained of a pain in the chest	1	2	3	4	5
5. Exertion (e.g. running) has made your child breathless	1	2	3	4	5
6. Your child has stayed indoors because of wheezing or coughing	1	2	3	4	5
7. His/her asthma has stopped your child from playing with his/her friends	1	2	3	4	5
8. During term time, your child's education has suffered due to his/her asthma	1	2	3	4	5
9. Asthma has stopped your child from doing all the things that a boy/girl should do at his/her age	1	2	3	4	5
10. Your child's asthma has interfered with his/her life	1	2	3	4	5
11. Asthma has limited your child's activities	1	2	3	4	5
12. Taking his/her inhaler or other treatment has interrupted your child's life	1	2	3	4	5
13. Your child's asthma has limited your activities	1	2	3	4	5
14. You have to make adjustments to family life because of your child's asthma	1	2	3	4	5
15. Your child has coughed at night	1	2	3	4	5
16. Your child's sleep has been disturbed by wheezing or coughing	1	2	3	4	5
17. Your child has been woken up by wheezing or coughing	1	2	3	4	5



### SECTION 3 GENERAL HEALTH AND BEHAVIOUR

This part of the questionnaire tells us about some of your child's strengths, as well as areas with room for improvement! It would help us if you answered all items as best as you can even if you are not absolutely certain or the item seems daft.

Please give the answers on the basis of the child's behaviour over the last six months.

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

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

No	Yes - minor difficulties	Yes - definite difficulties	Yes - severe difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have answered “Yes”, please answer the following questions about these difficulties:

How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do the difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do the difficulties interfere with your child’s everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
Home Life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friendships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Classroom Learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure Activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



## SECTION 4 AREA OF DIFFICULTIES SCALE

The fact that your child has asthma may sometimes create difficulties for you. By difficulties I mean a situation where no effective solution is immediately available to you. Below are listed areas in which difficulties often happen.

Please indicate how frequently or often difficulties have happened in each area in the *past 6-12 months* because of your child's asthma. That is, consider only those difficulties in each area that are in your mind related to your child's asthma. These difficulties do not have to be your child's fault. Rather, they may have happened only because of the fact that she/he has asthma and there may not have been anything else she/he could have done about it. Your child may not even have been aware of the difficulty. Also note that you are asked how frequently difficulties happened, not how much concern or distress they caused you.

Just estimate for each area how often difficulties related to your child's asthma came up in the last 6-12 months and circle the number underneath the alternative that best fits your estimate.

	Not At All	Once	Once Every month	Once Every Fort- night	Once Every Week	Twice Every Week	Every Other Day	Every Day Or More
1. my child's education	0	1	2	3	4	5	6	7
1. my child's relationship with other children, excluding siblings	0	1	2	3	4	5	6	7
2. my child's relationship with other family members, excluding myself	0	1	2	3	4	5	6	7
3. my child's health	0	1	2	3	4	5	6	7
4. my child's health care and therapies	0	1	2	3	4	5	6	7
5. my child's transportation	0	1	2	3	4	5	6	7
6. my child's leisure or fun time	0	1	2	3	4	5	6	7
7. my child's behaviour and discipline	0	1	2	3	4	5	6	7
8. my child's feeding, dressing and hygiene	0	1	2	3	4	5	6	7
9. my relationship with my child	0	1	2	3	4	5	6	7
10. my relationship with my spouse/partner	0	1	2	3	4	5	6	7
11. my relationship with other family members	0	1	2	3	4	5	6	7
12. my relationship with friends	0	1	2	3	4	5	6	7
13. my job, education or housework	0	1	2	3	4	5	6	7
14. my families finances	0	1	2	3	4	5	6	7
15. my personal aspirations	0	1	2	3	4	5	6	7
16. my spiritual or religious life	0	1	2	3	4	5	6	7

## SECTION 5 CAREGIVING

Below are several questions that ask about how you feel about your role as a caregiver for your child with asthma. Please read each question, and place a circle around the number on the scale that reflects your own views. If your views are described best by the end points of the scale, please circle either number 1 or number 7. If your views are somewhere in between the two end points, please select a position on the scale that reflects where you feel your views should be placed. Please select a response for all of the questions.

**How confident are you in caring for your child with asthma?**

1      2      3      4      5      6      7  
Not at all      Very confident  
confident

**How difficult do you personally find it to deal with the care of your child with asthma?**

1      2      3      4      5      6      7  
Very difficult      Not at all difficult

**To what extent do you feel that the way you care for your child with asthma has a positive effect?**

1      2      3      4      5      6      7  
Has no positive      Has a very  
effect at all      positive effect

**How satisfied are you with the way in which you care for your child with asthma?**

1      2      3      4      5      6      7  
Not satisfied      Very satisfied  
at all

**To what extent do you feel in control of the care of your child with asthma?**

1      2      3      4      5      6      7  
Not in      Very much  
control at all      in control

## SECTION 6 PARENTING : RAISING A CHILD WITH ASTHMA

The following questions ask you about your feelings associated with raising a child with asthma. It is important for me to find out the ways parents feel about raising a child with asthma in order to help others who may have difficulty. Therefore even though this is a long section and some questions may appear less relevant than others, it would be very helpful for me if you could fill it in and please give an answer to each question.

While you may not find an answer, which exactly states your feelings, please mark the answer that comes closest to describing how you feel. Your first reaction to each question should be your answer.

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not Sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
1. Since having this child, I feel I have grown as a person	1	2	3	4	5
2. I often have the feeling that I can not handle things very well	1	2	3	4	5
3. I find myself giving up more of my life to meet my child's needs than I ever expected	1	2	3	4	5
4. I feel trapped by my responsibilities as a parent	1	2	3	4	5
5. My child has a pleasant personality/character	1	2	3	4	5
6. Since having this child, I have been unable to do new and different things	1	2	3	4	5
7. Since having this child, I feel that I am almost never able to do things that I like to do	1	2	3	4	5
8. I am unhappy with the last purchase of clothing I made for myself	1	2	3	4	5
9. My child has a lot to give to other people	1	2	3	4	5
10. There are quite a few things that bother me about my life	1	2	3	4	5
11. Having this child has caused more difficulties than I expected in my relationship with my spouse (male/female friend/partner)	1	2	3	4	5
12. I feel alone and without friends	1	2	3	4	5
13. Having this child has helped me to learn new things/skills	1	2	3	4	5
14. When I go to a party I usually expect not to enjoy myself	1	2	3	4	5
15. I am not as interested in people as I used to be	1	2	3	4	5
16. Raising this child helps putting life into perspective	1	2	3	4	5
17. I don't enjoy things as I used to	1	2	3	4	5

CONTINUED ON NEXT PAGE →



	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not Sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
18. My child rarely does things for me that make me feel good	1	2	3	4	5
19. Most times I feel that my child does not like me and does not want to be close to me	1	2	3	4	5
20. Since having this child, I have more often put other people's interest before my own	1	2	3	4	5
21. My child smiles at me much less than I expected	1	2	3	4	5
22. When I do things for my child I get the feeling that my efforts are not appreciated very much	1	2	3	4	5
23. When playing, my child does not often giggle or laugh	1	2	3	4	5
24. My child is a fighter and does not give up easily	1	2	3	4	5
25. My child does not seem to learn as quickly as most children	1	2	3	4	5
26. My child does not seem to smile as much as most children	1	2	3	4	5
27. My child is not able to do as much as I expected	1	2	3	4	5
28. Since having this child, my family has become closer to one another	1	2	3	4	5
29. It takes a long time and it is very hard for my child to get used to new things	1	2	3	4	5
30. I feel that I am: 1 not very good at being a parent 2 a person who has trouble being a parent 3 an average parent 4 a better than average parent 5 a very good parent  (please select which applies to you and circle number)	1	2	3	4	5
31. I expected to have closer and warmer feelings for my child than I do and this bothers me	1	2	3	4	5
32. Since having this child, my family has become more tolerant and accepting	1	2	3	4	5
33. Sometimes my child does things that bother me just to be mean	1	2	3	4	5
34. My child seems to cry or fuss more often than most children	1	2	3	4	5

CONTINUED ON NEXT PAGE →

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not Sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
35. Since having this child, I have become more determined to face up to challenges	1	2	3	4	5
36. My child generally wakes up in a bad mood	1	2	3	4	5
37. I feel that my child is very moody and easily upset	1	2	3	4	5
38. My child does a few things which bother me a great deal	1	2	3	4	5
39. Since having this child, I have a greater understanding of other people	1	2	3	4	5
40. My child reacts very strongly when something happens that my child does not like	1	2	3	4	5
41. My child gets upset easily over the smallest thing	1	2	3	4	5
42. My child's sleeping or eating schedule was much harder to establish than I expected	1	2	3	4	5
43. My child is loving and caring	1	2	3	4	5
44. I have found that getting my child to do something or to stop doing something is: 1 much harder than I expected 2 somewhat harder than I expected 3 about as hard as I had expected 4 somewhat easier than I had expected 5 much easier than I had expected <p>(please select which applies to you and circle number)</p>	1	2	3	4	5
45. Think carefully and count the number of things which your child does that bother you. For example dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. Please circle the number which includes the number of things you counted 1: 10+ 2: 8-9 3: 6-7 4: 4-5 5: 1-3 <p>(please select which applies to you and circle number)</p>	1	2	3	4	5
46. There are some things my child does that really bother me a lot	1	2	3	4	5
47. Since having this child, my family has become more caring	1	2	3	4	5
48. My child turned out to be more of a difficulty than I had expected	1	2	3	4	5
49. My child makes more demands on me than most children	1	2	3	4	5
50. Since having this child, I have developed new interests	1	2	3	4	5

## SECTION 7 COPING WITH DIFFICULTIES

In this section I want to get some idea of how parents cope with difficulties in bringing up children with asthma. It is important for me to find out the ways parents have coped with difficulties in order to help others who may have difficulty.

Please read each item and think about whether you used this way of dealing with difficulties in bringing up our child. By difficulties we mean such things as sleeping difficulties, embarrassing behaviours, worries about the child's future, your own feelings about having a child with asthma or anything else you yourself feel to be a difficulties. Obviously different people deal with things in different ways, but we are interested in how you have tried to deal with the difficulties you have experienced. Each item says something about a particular way of coping. We want to know to what extent you have been doing what the item says in *the past 6-12 months*: How much or how frequently. Do not answer on the basis of whether it seems to be working or not - just whether or not you are doing it. Use the response choices. Try to rate each item separately in your mind from the others. Make the answers as true for you as you can

	<i>I have not been doing this at all</i>	<i>I have been doing this a little bit</i>	<i>I have been doing this a medium amount</i>	<i>I have been doing this a lot</i>
1. I have been turning to work or other activities to take my mind off things	1	2	3	4
2. I have been concentrating my efforts on doing something about the situation I am in	1	2	3	4
3. I have been saying to myself " this is not real"	1	2	3	4
4. I have been using alcohol or drugs to make myself feel better	1	2	3	4
5. I have been getting emotional support from others	1	2	3	4
6. I have been giving up trying to deal with it	1	2	3	4
7. I have been taking action to try to make the situation better	1	2	3	4
8. I have been refusing to believe that is has happened	1	2	3	4
9. I have been saying things to let my unpleasant feelings escape	1	2	3	4
10. I have been getting help and advice from other people	1	2	3	4
11. I have been using alcohol or other drugs to help me get through it	1	2	3	4
12. I have been trying to see it in a different light, to make it seem more positive	1	2	3	4
13. I have been criticising myself	1	2	3	4

CONTINUED ON NEXT PAGE →



	<i>I have not been doing this at all</i>	<i>I have been doing this a little bit</i>	<i>I have been doing this a medium amount</i>	<i>I have been doing this a lot</i>
14. I have been trying to come up with a strategy about what to do	1	2	3	4
15. I have been getting comfort and understanding from someone	1	2	3	4
16. I have been giving up the attempt to cope	1	2	3	4
17. I have been looking for something good in what is happening	1	2	3	4
18. I have been making jokes about it	1	2	3	4
19. I have been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping or shopping	1	2	3	4
20. I have been accepting the reality of the fact that is has happened	1	2	3	4
21. I have been expressing my negative feelings	1	2	3	4
22. I have been trying to find comfort in my religion or spiritual beliefs	1	2	3	4
23. I have been trying to get advice or help from other people about what to do	1	2	3	4
24. I have been learning to live with it	1	2	3	4
25. I have been thinking hard about what steps to take	1	2	3	4
26. I have been blaming myself for things that happened	1	2	3	4
27. I have been praying or meditating	1	2	3	4
28. I have been making fun of the situation	1	2	3	4

## SECTION 8 FAMILY SATISFACTION

This part tells us about how you feel about your family. Please read each question and tick the box on the scale that best describes your feelings. It would help me if you answered all items even if you are not absolutely certain or the item seems daft.

### HOW SATISFIED ARE YOU.....

	<i>Dissatisfied</i>	<i>Somewhat Dissatisfied</i>	<i>Generally Satisfied</i>	<i>Very Satisfied</i>	<i>Extremely Satisfied</i>
1. ....with how close you feel to the rest of your family	1	2	3	4	5
2. ....with your ability to say what you want in your family	1	2	3	4	5
3. ....with your family's ability to try new things	1	2	3	4	5
4. ....with how often you or your spouse/partner make decisions in your family	1	2	3	4	5
5. ....with how much you and your spouse/partner argue with each other	1	2	3	4	5
6. ....with how fair the criticism is in your family	1	2	3	4	5
7. ....with the amount of time you spend with your family	1	2	3	4	5
8. ....with the way you talk to each other to solve family difficulties	1	2	3	4	5
9. ....with your freedom to be alone when you want to	1	2	3	4	5
10. ....with how strictly you stay with who does what chores in your family	1	2	3	4	5
11. ....with your family's acceptance of your friends	1	2	3	4	5
12. ....with how clear it is what your family expects of you	1	2	3	4	5
13. ....with how often you make decisions as a family, rather than individually	1	2	3	4	5
14. ....with the number of fun things your family does together	1	2	3	4	5



**SECTION 9 Family Background**

I am also interested in your family for a number of reasons. For example, does being part of a large family make a difference? If you think we are too nosey, just don't answer the question

\* The child lives with: (please tick one box)

<input type="checkbox"/> Both biological parents	<input type="checkbox"/> Mother only	<input type="checkbox"/> Mother and partner
<input type="checkbox"/> Father only	<input type="checkbox"/> Father and partner	<input type="checkbox"/> Grandparents
<input type="checkbox"/> One foster or adoptive parent	<input type="checkbox"/> Two foster or adoptive parents	
<input type="checkbox"/> Other ( <i>please specify and give number of carers</i> )		

---

\* How many children are living at home .....

\* Parents work

	<u>Mother/ First Caregiver</u>		<u>Father/ Second Caregiver</u>
Are you employed at present?	No <input type="checkbox"/>		No <input type="checkbox"/>
	Yes full time <input type="checkbox"/>		Yes full time <input type="checkbox"/>
	Yes part time <input type="checkbox"/>		Yes part time <input type="checkbox"/>
Occupation:	.....		.....

\* Parents Education

Please describe the qualifications you hold:

	<u>Mother/ First Caregiver</u>	<u>Father/Second Caregiver</u>
5 or more G.C.S.E's	<input type="checkbox"/>	<input type="checkbox"/>
2 or more A levels	<input type="checkbox"/>	<input type="checkbox"/>
Vocational Qualification (GNVQ)	<input type="checkbox"/>	<input type="checkbox"/>
A level equivalent	<input type="checkbox"/>	<input type="checkbox"/>
HND	<input type="checkbox"/>	<input type="checkbox"/>
Degree	<input type="checkbox"/>	<input type="checkbox"/>
Degree equivalent	<input type="checkbox"/>	<input type="checkbox"/>
None of the above	<input type="checkbox"/>	<input type="checkbox"/>

## CAN WE CONTACT YOUR CHILD'S FATHER/SECONDARY CAREGIVER?

In previous studies, it has been very helpful to get fathers/ secondary caregivers to fill in a brief questionnaire on each child. Could we have your permission to send a questionnaire to your child's father / secondary caregiver to ask him about his views on child behaviour and family functioning.. The replies will be completely confidential and will only be used to help our research.

I am **willing/unwilling\*** for my child's father / secondary caregiver to be contacted to fill in a confidential questionnaire.

Name \_\_\_\_\_

Address

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**THANK YOU VERY MUCH FOR YOUR HELP !**

**Please check that you have not missed out any pages by mistake. When you have finished, please return the questionnaire to me in the reply-paid envelope.**

Ineke Pit-ten Cate  
Centre for Research into Psychological Development  
Department of Psychology  
University of Southampton  
Highfield  
Southampton, SO17 1BJ  
02380-595452

**THANK YOU VERY MUCH FOR YOUR TIME**

## APPENDIX D

Questionnaire Sample 3, general population sample

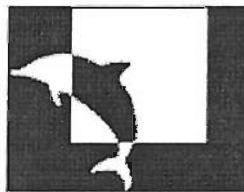
Parenting Survey  
November 2001

Ineke Pit-ten Cate

CENTRE FOR RESEARCH INTO  
PSYCHOLOGICAL DEVELOPMENT



DEPARTMENT OF PSYCHOLOGY  
UNIVERSITY OF SOUTHAMPTON



HIGHFIELD, SOUTHAMPTON, SO17 1BJ  
TEL:023-80595452

Dear Parent/Guardian,

Thank you for agreeing to complete this questionnaire. Your replies will help me to find out more about experiences of parents. More specifically, your answers will tell me about things you may find difficult or rewarding.

Your participation is voluntary and you may withdraw your participation any time. Personal information will not be released to or viewed by anyone other than the researchers involved in this project.

All questions can be answered by ticking a box or circling a number. If you have any difficulty completing this questionnaire, please do not hesitate to contact me by telephone or letter.

With many thanks

Ineke Pit-ten Cate

Centre for Research into Psychological Development  
Department of psychology  
University of Southampton  
Highfield  
Southampton SO17 1BJ  
02380-595452

---

---

You are the child's

Mother

Father

Other namely, .....

Your date of birth: .....

Child's gender:

Girl

Boy

Child's date of birth: .....

## PARENTING

The following questions ask you about your feelings associated with raising a child. Some questions may appear less relevant than others but it would be very helpful for me if you could fill it in and please give an answer to each question. The questions on the following pages ask you to mark an answer which best describes your feelings. While you may not find an answer which exactly states your feelings, please mark the answer that comes closest to describing how you feel. Your first reaction to each question should be your answer.

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not Sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
1. Since having this child, I feel I have grown as a person	1	2	3	4	5
2. I often have the feeling that I can not handle things very well	1	2	3	4	5
3. I find myself giving up more of my life to meet my child's needs than I ever expected	1	2	3	4	5
4. I feel trapped by my responsibilities as a parent	1	2	3	4	5
5. My child has a pleasant personality/character	1	2	3	4	5
6. Since having this child, I have been unable to do new and different things	1	2	3	4	5
7. Since having this child, I feel that I am almost never able to do things that I like to do	1	2	3	4	5
8. I am unhappy with the last purchase of clothing I made for myself	1	2	3	4	5
9. My child has a lot to give to other people	1	2	3	4	5
10. There are quite a few things that bother me about my life	1	2	3	4	5
11. Having this child has caused more difficulties than I expected in my relationship with my spouse (male/female friend/partner)	1	2	3	4	5
12. I feel alone and without friends	1	2	3	4	5
13. Having this child has helped me to learn new things/skills	1	2	3	4	5
14. When I go to a party I usually expect not to enjoy myself	1	2	3	4	5
15. I am not as interested in people as I used to be	1	2	3	4	5
16. Raising this child helps putting life into perspective	1	2	3	4	5
17. I don't enjoy things as I used to	1	2	3	4	5

CONTINUED ON NEXT PAGE →

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not Sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
18. My child rarely does things for me that make me feel good	1	2	3	4	5
19. Most times I feel that my child does not like me and does not want to be close to me	1	2	3	4	5
20. Since having this child, I have more often put other people's interest before my own	1	2	3	4	5
21. My child smiles at me much less than I expected	1	2	3	4	5
22. When I do things for my child I get the feeling that my efforts are not appreciated very much	1	2	3	4	5
23. When playing, my child does not often giggle or laugh	1	2	3	4	5
24. My child is a fighter and does not give up easily	1	2	3	4	5
25. My child does not seem to learn as quickly as most children	1	2	3	4	5
26. My child does not seem to smile as much as most children	1	2	3	4	5
27. My child is not able to do as much as I expected	1	2	3	4	5
28. Since having this child, my family has become closer to one another	1	2	3	4	5
29. It takes a long time and it is very hard for my child to get used to new things	1	2	3	4	5
30. I feel that I am: 1 not very good at being a parent 2 a person who has trouble being a parent 3 an average parent 4 a better than average parent 5 a very good parent  (please select which applies to you and circle number)	1	2	3	4	5
31. I expected to have closer and warmer feelings for my child than I do and this bothers me	1	2	3	4	5
32. Since having this child, my family has become more tolerant and accepting	1	2	3	4	5
33. Sometimes my child does things that bother me just to be mean	1	2	3	4	5
34. My child seems to cry or fuss more often than most children	1	2	3	4	5

CONTINUED ON NEXT PAGE →



	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not Sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
35. Since having this child, I have become more determined to face up to challenges	1	2	3	4	5
36. My child generally wakes up in a bad mood	1	2	3	4	5
37. I feel that my child is very moody and easily upset	1	2	3	4	5
38. My child does a few things which bother me a great deal	1	2	3	4	5
39. Since having this child, I have a greater understanding of other people	1	2	3	4	5
40. My child reacts very strongly when something happens that my child does not like	1	2	3	4	5
41. My child gets upset easily over the smallest thing	1	2	3	4	5
42. My child's sleeping or eating schedule was much harder to establish than I expected	1	2	3	4	5
43. My child is loving and caring	1	2	3	4	5
44. I have found that getting my child to do something or to stop doing something is: 1 much harder than I expected 2 somewhat harder than I expected 3 about as hard as I had expected 4 somewhat easier than I had expected 5 much easier than I had expected (please select which applies to you and circle number)	1	2	3	4	5
45. Think carefully and count the number of things which your child does that bother you. For example dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. Please circle the number which includes the number of things you counted 1: 10+ 2: 8-9 3: 6-7 4: 4-5 5: 1-3 (please select which applies to you and circle number)	1	2	3	4	5
46. There are some things my child does that really bother me a lot	1	2	3	4	5
47. Since having this child, my family has become more caring	1	2	3	4	5
48. My child turned out to be more of a difficulty than I had expected	1	2	3	4	5
49. My child makes more demands on me than most children	1	2	3	4	5
50. Since having this child, I have developed new interests	1	2	3	4	5

## Family Background

I am also interested in your family for a number of reasons. For example, does being part of a large family make a difference? If you think we are too nose, just don't answer the question

\* The child lives with: (please tick one box)

<input type="checkbox"/> Both biological parents	<input type="checkbox"/> Mother only	<input type="checkbox"/> Mother and partner
<input type="checkbox"/> Father only	<input type="checkbox"/> Father and partner	<input type="checkbox"/> Grandparents
<input type="checkbox"/> One foster or adoptive parent	<input type="checkbox"/> Two foster or adoptive parents	
<input type="checkbox"/> Other ( <i>please specify and give number of carers</i> )		

---

\* How many children are living at home .....

\* Parents work

	<u>Mother/ First Caregiver</u>		<u>Father/ Second Caregiver</u>	
Are you employed at present?	No	<input type="checkbox"/>	No	<input type="checkbox"/>
	Yes full time	<input type="checkbox"/>	Yes full time	<input type="checkbox"/>
	Yes part time	<input type="checkbox"/>	Yes part time	<input type="checkbox"/>
Occupation:	.....		.....	

\* Parents Education

Please describe the qualifications you hold:

	<u>Mother/ First Caregiver</u>		<u>Father/Second Caregiver</u>
5 or more G.C.S.E's	<input type="checkbox"/>		<input type="checkbox"/>
2 or more A levels	<input type="checkbox"/>		<input type="checkbox"/>
Vocational Qualification (GNVQ)	<input type="checkbox"/>		<input type="checkbox"/>
A level equivalent	<input type="checkbox"/>		<input type="checkbox"/>
HND	<input type="checkbox"/>		<input type="checkbox"/>
Degree	<input type="checkbox"/>		<input type="checkbox"/>
Degree equivalent	<input type="checkbox"/>		<input type="checkbox"/>
None of the above	<input type="checkbox"/>		<input type="checkbox"/>

**THANK YOU VERY MUCH FOR YOUR HELP!**

**Please check that you have not missed out any pages by mistake. When you have finished, please return the questionnaire to me in the reply-paid envelope.**

Ineke Pit-ten Cate  
Centre for Research into Psychological Development  
Department of Psychology  
University of Southampton  
Highfield  
Southampton, SO17 1BJ  
023-80595452

**THANK YOU VERY MUCH FOR YOUR TIME**

## APPENDIX E

Modified PSI-SF49 (additional items are printed in bold)

PSI-SF49

The following questions ask you about your feelings associated with raising a child with spina bifida and/or hydrocephalus. It is important for me to find out the ways parents feel about raising a child with a disability in order to help others who may have difficulty. Therefore even though this is a long section and some questions may appear less relevant than others, it would be very helpful for me if you could fill it in and please give an answer to each question.

While you may not find an answer, which exactly states your feelings, please mark the answer that comes closest to describing how you feel. Your first reaction to each question should be your answer.

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not Sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
1. Since having this child, I feel I have grown as a person	1	2	3	4	5
2. I often have the feeling that I can not handle things very well	1	2	3	4	5
3. I find myself giving up more of my life to meet my child's needs than I ever expected	1	2	3	4	5
4. I feel trapped by my responsibilities as a parent	1	2	3	4	5
5. My child has a pleasant personality/character	1	2	3	4	5
6. Since having this child, I have been unable to do new and different things	1	2	3	4	5
7. Since having this child, I feel that I am almost never able to do things that I like to do	1	2	3	4	5
8. I am unhappy with the last purchase of clothing I made for myself	1	2	3	4	5
9. My child has a lot to give to other people	1	2	3	4	5
10. There are quite a few things that bother me about my life	1	2	3	4	5
11. Having this child has caused more difficulties than I expected in my relationship with my spouse (male/female friend/partner)	1	2	3	4	5
12. I feel alone and without friends	1	2	3	4	5
13. Having this child has helped me to learn new things/skills	1	2	3	4	5
14. When I go to a party I usually expect not to enjoy myself	1	2	3	4	5
15. I am not as interested in people as I used to be	1	2	3	4	5
16. Raising this child helps putting life into perspective	1	2	3	4	5
17. I don't enjoy things as I used to	1	2	3	4	5

CONTINUED ON NEXT PAGE →



	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not Sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
18. My child rarely does things for me that make me feel good	1	2	3	4	5
19. Most times I feel that my child does not like me and does not want to be close to me	1	2	3	4	5
20. <b>Since having this child, I have more often put other people's interest before my own</b>	1	2	3	4	5
21. My child smiles at me much less than I expected	1	2	3	4	5
22. When I do things for my child I get the feeling that my efforts are not appreciated very much	1	2	3	4	5
23. When playing, my child does not often giggle or laugh	1	2	3	4	5
24. <b>My child is a fighter and does not give up easily</b>	1	2	3	4	5
25. My child does not seem to learn as quickly as most children	1	2	3	4	5
26. My child does not seem to smile as much as most children	1	2	3	4	5
27. My child is not able to do as much as I expected	1	2	3	4	5
28. <b>Since having this child, my family has become closer to one another</b>	1	2	3	4	5
29. It takes a long time and it is very hard for my child to get used to new things	1	2	3	4	5
30. I feel that I am: 1 not very good at being a parent 2 a person who has trouble being a parent 3 an average parent 4 a better than average parent 5 a very good parent  <p>(please select which applies to you and circle number)</p>	1	2	3	4	5
31. I expected to have closer and warmer feelings for my child than I do and this bothers me	1	2	3	4	5
32. <b>Since having this child, my family has become more tolerant and accepting</b>	1	2	3	4	5
33. Sometimes my child does things that bother me just to be mean	1	2	3	4	5
34. My child seems to cry or fuss more often than most children	1	2	3	4	5

CONTINUED ON NEXT PAGE →

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not Sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
35. Since having this child, I have become more determined to face up to challenges	1	2	3	4	5
36. My child generally wakes up in a bad mood	1	2	3	4	5
37. I feel that my child is very moody and easily upset	1	2	3	4	5
38. My child does a few things which bother me a great deal	1	2	3	4	5
39. Since having this child, I have a greater understanding of other people	1	2	3	4	5
40. My child reacts very strongly when something happens that my child does not like	1	2	3	4	5
41. My child gets upset easily over the smallest thing	1	2	3	4	5
42. My child's sleeping or eating schedule was much harder to establish than I expected	1	2	3	4	5
43. My child is loving and caring	1	2	3	4	5
44. I have found that getting my child to do something or to stop doing something is: 1 much harder than I expected 2 somewhat harder than I expected 3 about as hard as I had expected 4 somewhat easier than I had expected 5 much easier than I had expected (please select which applies to you and circle number)	1	2	3	4	5
45. Think carefully and count the number of things which your child does that bother you. For example dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. Please circle the number which includes the number of things you counted 1: 10+ 2: 8-9 3: 6-7 4: 4-5 5: 1-3 (please select which applies to you and circle number)	1	2	3	4	5
46. There are some things my child does that really bother me a lot	1	2	3	4	5
47. Since having this child, my family has become more caring	1	2	3	4	5
48. My child turned out to be more of a difficulty than I had expected	1	2	3	4	5
49. My child makes more demands on me than most children	1	2	3	4	5
50. Since having this child, I have developed new interests	1	2	3	4	5

## APPENDIX F

### Regression Tables PSI-SF43



F1: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting severity of disability (N=309)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	-.01	.02	-.05
PSIPCDI	-.01	.02	-.03
PSIPD	.04	.02	.17*
Step 2			
PSIDC	-.02	.02	-.08
PSIPCDI	.01	.03	.02
PSIPD	.04	.02	.19**
Positive Gain	-.09	.03	-.17**

Note.  $R^2 = .02$  for Step 1(ns);  $R^2 = .03$  for Step 2 ( $p < .01$ )

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

F2: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting activities of daily living (N=314)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	.06	.02	.18*
PSIPCDI	-.02	.03	-.05
PSIPD	.07	.02	.21**
Step 2			
PSIDC	.04	.02	.13
PSIPCDI	.01	.03	.03
PSIPD	.08	.02	.24***
Positive Gain	-.19	.04	-.27***

Note.  $R^2 = .10$  for Step 1(p<.001);  $R^2 = .07$  for Step 2 (p <.001)

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

F3: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting behaviour problems (SDQ total score) (N=313)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	.33	.04	.50 <sup>***</sup>
PSIPCDI	.17	.05	.19 <sup>**</sup>
PSIPD	.05	.04	.07
Step 2			
PSIDC	.33	.04	.49 <sup>***</sup>
PSIPCDI	.18	.05	.20 <sup>**</sup>
PSIPD	.05	.04	.07
Positive Gain	-.06	.07	-.04

Note.  $R^2 = .47$  for Step 1( $p < .001$ );  $R^2 = .00$  for Step 2 ( $p$  ns)

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

F4: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting conduct problems (SDQ conduct score) (N=315)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	.09	.01	.47 <sup>***</sup>
PSIPCDI	.05	.02	.20 <sup>**</sup>
PSIPD	-.02	.01	-.11
Step 2			
PSIDC	.09	.01	.48 <sup>***</sup>
PSIPCDI	.04	.02	.18 <sup>**</sup>
PSIPD	-.02	.01	-.12 <sup>*</sup>
Positive Gain	.03	.02	.08

Note.  $R^2 = .32$  for Step 1 ( $p < .001$ );  $R^2 = .01$  for Step 2 ( $p$  ns)

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

F5: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting emotional problems (SDQ emotion score) (N=315)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	.09	.02	.37 <sup>***</sup>
PSIPCDI	.02	.02	.05
PSIPD	.04	.02	.15 <sup>*</sup>
Step 2			
PSIDC	.09	.02	.36 <sup>***</sup>
PSIPCDI	.02	.02	.06
PSIPD	.04	.02	.15 <sup>*</sup>
Positive Gain	-.02	.03	-.03

Note.  $R^2 = .26$  for Step 1( $p < .001$ );  $R^2 = .00$  for Step 2 ( $p$  ns)

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

F6: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting hyperactivity (SDQ hyperactivity score) (N=314)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	.12	.02	.45 <sup>***</sup>
PSIPCDI	.04	.02	.11
PSIPD	-.02	.02	-.07
Step 2			
PSIDC	.11	.02	.44 <sup>***</sup>
PSIPCDI	.05	.02	.14
PSIPD	-.02	.02	-.06
Positive Gain	-.06	.03	-.10

Note.  $R^2 = .25$  for Step 1 ( $p < .001$ );  $R^2 = .01$  for Step 2 ( $p$  ns)

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

F7: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting peer problems (SDQ peer score) (N=315)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	.03	.02	.15*
PSIPCDI	.07	.02	.23**
PSIPD	.04	.02	.18**
Step 2			
PSIDC	.03	.02	.15*
PSIPCDI	.07	.02	.23**
PSIPD	.05	.02	.19**
Positive Gain	-.01	.03	-.02

Note.  $R^2 = .23$  for Step 1 ( $p < .001$ );  $R^2 = .00$  for Step 2 ( $p$  ns)

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

F8: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting prosocial behaviour (SDQ prosocial behaviour score) (N=315)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	-.04	.02	-.17*
PSIPCDI	-.10	.02	-.32***
PSIPD	.01	.02	.03
Step 2			
PSIDC	-.04	.02	-.17*
PSIPCDI	-.10	.02	-.32***
PSIPD	.01	.02	.03
Positive Gain	-.01	.03	-.02

Note.  $R^2 = .19$  for Step 1 ( $p < .001$ );  $R^2 = .00$  for Step 2 ( $p$  ns)

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



F9: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting Family Needs (FNS total score) (N=292)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	.07	.06	.10
PSIPCDI	.02	.07	.03
PSIPD	.15	.05	.20**
Step 2			
PSIDC	.07	.06	.10
PSIPCDI	.04	.07	.04
PSIPD	.15	.05	.21**
Positive Gain	-.09	.10	-.05

Note.  $R^2 = .08$  for Step 1( $p < .001$ );  $R^2 = .00$  for Step 2 ( $p$  ns)

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

F10: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting family satisfaction (FSS total score) (N=313)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	-.11	.06	-.11
PSIPCDI	-.14	.08	-.10
PSIPD	-.63	.06	-.58 <sup>***</sup>
Step 2			
PSIDC	-.14	.06	-.14 <sup>*</sup>
PSIPCDI	-.07	.08	-.05
PSIPD	-.60	.05	-.56 <sup>***</sup>
Positive Gain	-.42	.10	-.17 <sup>***</sup>

Note.  $R^2 = .50$  for Step 1( $p < .001$ );  $R^2 = .03$  for Step 2 ( $p < .001$ )

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

F11: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting family adaptation (FSS adaptation score) (N=313)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	-.04	.03	-.09
PSIPCDI	-.07	.04	-.11
PSIPD	-.26	.03	-.53 <sup>***</sup>
Step 2			
PSIDC	-.06	.03	-.12
PSIPCDI	-.03	.04	-.05
PSIPD	-.25	.03	-.51 <sup>***</sup>
Positive Gain	-.19	.05	-.18 <sup>***</sup>

Note.  $R^2 = .43$  for Step 1( $p < .001$ );  $R^2 = .03$  for Step 2 ( $p < .001$ )

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

F12: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting family cohesion (FSS cohesion) (N=315)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	-.07	.04	-.11
PSIPCDI	-.07	.05	-.09
PSIPD	-.37	.03	-.58 <sup>***</sup>
Step 2			
PSIDC	-.09	.04	-.14 <sup>*</sup>
PSIPCDI	-.03	.05	-.04
PSIPD	-.36	.03	-.56 <sup>***</sup>
Positive Gain	-.22	.06	-.16 <sup>***</sup>

Note.  $R^2 = .50$  for Step 1( $p < .001$ );  $R^2 = .02$  for Step 2 ( $p < .001$ )

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

F13: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting problem focused coping (N=315)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	.20	.07	.24**
PSIPCDI	-.15	.08	-.14
PSIPD	.08	.06	.10
Step 2			
PSIDC	.16	.06	.20*
PSIPCDI	-.06	.08	-.06
PSIPD	.11	.06	.13
Positive Gain	-.51	.10	-.27***

Note.  $R^2 = .05$  for Step 1(p<.01);  $R^2 = .07$  for Step 2 (p <.001)

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

F14: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales  
emotion focused coping (N=315)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	.02	.03	.04
PSIPCDI	.09	.04	.13*
PSIPD	.29	.03	.53***
Step 2			
PSIDC	.02	.03	.04
PSIPCDI	.09	.04	.12
PSIPD	.29	.03	.53***
Positive Gain	.01	.06	.01

Note.  $R^2 = .40$  for Step 1 ( $p < .001$ );  $R^2 = .00$  for Step 2 ( $p$  ns)

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

F15: Summary of Hierarchical Regression Analyses for PSI-SF43 sub-scales predicting care-giving self-efficacy (N=312)

Variable	<u>B</u>	<u>SE B</u>	$\beta$
Step 1			
PSIDC	-.09	.03	-.19**
PSIPCDI	-.14	.04	-.23**
PSIPD	-.10	.03	-.20**
Step 2			
PSIDC	-.10	.03	-.21**
PSIPCDI	-.11	.04	-.18**
PSIPD	-.09	.03	-.18**
Positive Gain	-.17	.05	-.16**

Note.  $R^2 = .28$  for Step 1( $p < .001$ );  $R^2 = .02$  for Step 2 ( $p < .01$ )

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

## APPENDIX G

Means and standard deviations of variables used for testing the transactional stress and coping model of adjustment to disability in mothers of children with spina bifida and hydrocephalus  
(Study 4, Chapter 9)



Means, standard deviations of variables used for testing the stress and coping model of adjustment to disability

Variable	Mean	SD
V2 - COPE acceptance	6.1103	1.8736
V3 - COPE active coping	4.7517	1.8843
V4 - COPE behavioural disengagement	2.4828	.9196
V5 - COPE denial	2.5138	1.0725
V6 - COPE emotional support	4.1655	1.6680
V7 - COPE humour	3.0414	1.4782
V8 - COPE instrumental support	4.5414	1.7568
V9 - COPE planning	4.7207	1.8437
V10 - COPE positive reframing	4.3621	1.7059
V12 - COPE self blame	4.1000	1.8751
V13 - COPE self distraction	3.6069	1.4732
V14 - COPE substance use	2.4793	1.1563
V15 - COPE venting	3.4621	1.5586
V16 – FSS family functioning	43.9448	10.9578
V17 - Severity of disability	2.7966	2.3959
V18 - Child ADL	4.9724	3.1916
V21 - PSI difficult child	36.7172	10.4137
V22 - PSI dysfunctional interaction	26.7621	7.9689
V23 - PSI parent distress	31.1897	9.9505
V24 - Positive Gain	15.3759	4.6071
V25 - SDQ conduct problems	2.2310	1.8690
V26 - SDQ emotional problems	3.9172	2.6109
V27 - SDQ hyperactivity	5.5103	2.7631
V28 - SDQ peer problems	3.4310	2.3960
V30 - HPPI child health and services	13.6759	9.1711
V31 - HPPI mother-child social interaction	17.6586	15.4983
V33 - CSES care giving efficacy	29.1655	4.8756

## APPENDIX H

Correlation matrix for the variables used for testing the transactional stress and coping model of adjustment to disability in mothers of children with spina bifida and hydrocephalus (Study 4, Chapter 9)

Correlation matrix for the variables used for testing the stress and coping model of adjustment to disability in mothers of children with spina bifida and hydrocephalus

	V2 - COPE Acceptance	V3 - COPE Active coping	V4 - COPE Behavioural disengagement	V5 - COPE Denial	V6 - COPE Emotional support	V7 - COPE Humour	V8 - COPE Instrumental support	V9 - COPE Planning	V10 - COPE Positive reframing	V12 - COPE Self blame	V13 - COPE Self distraction	V14 - COPE Substance use	V15 - COPE Venting	V16 - FSS Family functioning	V17 - Severity of disability	V18 - Child ADL
V2	1.000															
V3	.382	1.000														
V4	-.041	.123	1.000													
V5	-.059	.176	.365	1.000												
V6	.303	.455	.018	.072	1.000											
V7	.222	.303	.174	.091	.215	1.000										
V8	.337	.542	.000	.028	.579	.287	1.000									
V9	.432	.680	.114	.092	.372	.305	.539	1.000								
V10	.392	.514	.089	.080	.317	.341	.351	.564	1.000							
V12	.144	.281	.476	.406	.103	.206	.196	.300	.284	1.000						
V13	.195	.382	.340	.297	.238	.297	.224	.356	.351	.482	1.000					
V14	-.013	.056	.240	.200	-.005	.102	-.070	-.007	.029	.294	.148	1.000				
V15	.163	.305	.471	.329	.213	.387	.239	.315	.219	.472	.477	.197	1.000			
V16	-.011	-.096	-.290	-.208	.054	-.084	-.072	-.148	-.068	-.468	-.401	-.182	-.387	1.000		
V17	.097	.031	.042	-.022	.060	.073	-.011	.022	.073	-.005	.027	.082	.047	-.006	1.000	
V18	.174	.179	.084	.007	.187	.199	.118	.218	.222	.066	.208	.020	.156	-.126	.606	1.000
V21	.080	.186	.301	.133	.087	.197	.209	.283	.162	.327	.388	.140	.402	-.506	.044	.283
V22	-.023	.106	.388	.224	.002	.147	.076	.198	-.037	.395	.304	.126	.367	-.491	.030	.201
V23	.011	.156	.432	.368	.012	.149	.111	.210	.156	.575	.429	.272	.419	-.688	.147	.306
V24	-.148	-.085	.214	.099	-.272	-.081	-.141	-.138	-.261	.175	-.051	.054	.104	-.287	-.133	-.196
V25	.080	.102	.172	.015	.042	.050	.083	.141	.037	.188	.194	-.024	.241	-.237	-.108	.050
V26	.063	.127	.217	.193	.019	.160	.128	.164	.150	.337	.345	.221	.338	-.296	.019	.135
V27	.123	.143	.159	.028	.028	.153	.157	.232	.210	.135	.231	.039	.171	-.186	.039	.323
V28	.029	.164	.116	.169	.037	.070	.085	.208	.085	.258	.257	.159	.164	-.262	-.008	.221
V30	.161	.215	.104	.061	.124	.183	.174	.287	.183	.276	.286	.140	.226	-.258	.283	.454
V31	.160	.266	.285	.160	.120	.226	.191	.341	.230	.386	.375	.212	.355	-.421	.153	.362
V33	-.026	-.229	-.343	-.155	-.074	-.140	-.170	-.277	-.127	-.432	-.345	-.110	-.353	.432	.027	-.147

Correlation matrix for the variables used for testing the stress and coping model of adjustment to disability in mothers of children with spina bifida and hydrocephalus - continued

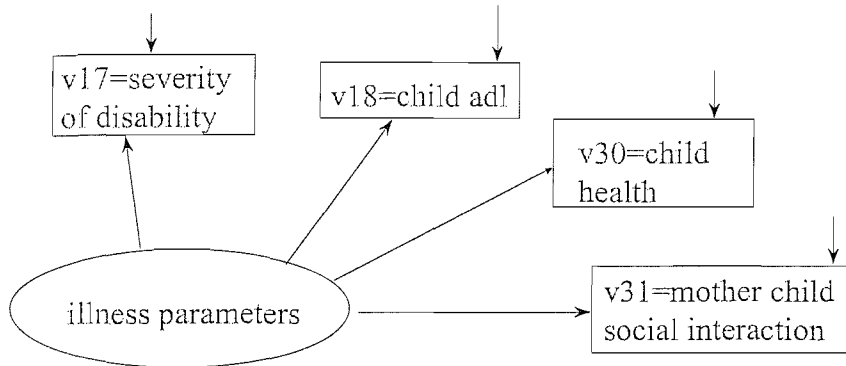
	V21 - PSI difficult child	V22 - PSI dysfunctional interaction	V23 - PSI parent distress	V24 - Positive Gain	V25 - SDQ conduct problems	V26 - SDQ emotional/ problems	V27 - SDQ hyperactivity	V28 - SDQ peer problems	V30 - HPPPI child health and services	V31 - HPPPI mother-child social interaction	V33 - CSES care giving efficacy
V21	1.000										
V22	.694	1.000									
V23	.562	.559	1.000								
V24	.075	.230	.165	1.000							
V25	.554	.494	.278	.142	1.000						
V26	.491	.385	.369	.015	.309	1.000					
V27	.485	.373	.250	-.047	.426	.301	1.000				
V28	.418	.420	.389	.062	.354	.410	.362	1.000			
V30	.428	.283	.413	-.129	.215	.304	.343	.294	1.000		
V31	.659	.537	.561	.053	.402	.367	.354	.474	.692	1.000	
V33	-.457	-.481	-.430	-.221	-.353	-.300	-.310	-.327	-.240	-.445	1.000

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

## APPENDIX I

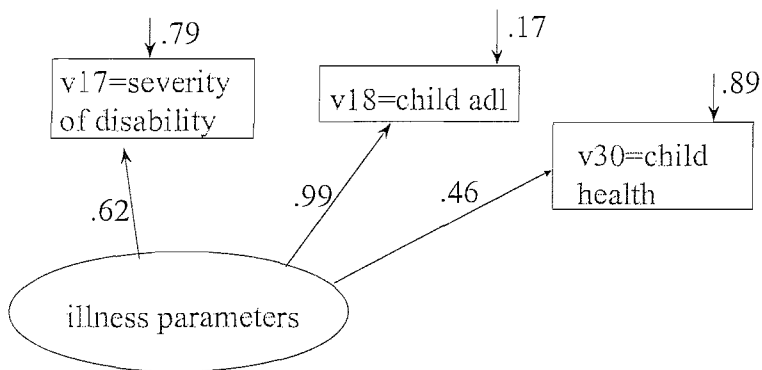
### Measurement models

I1A: Measurement model: illness parameters A



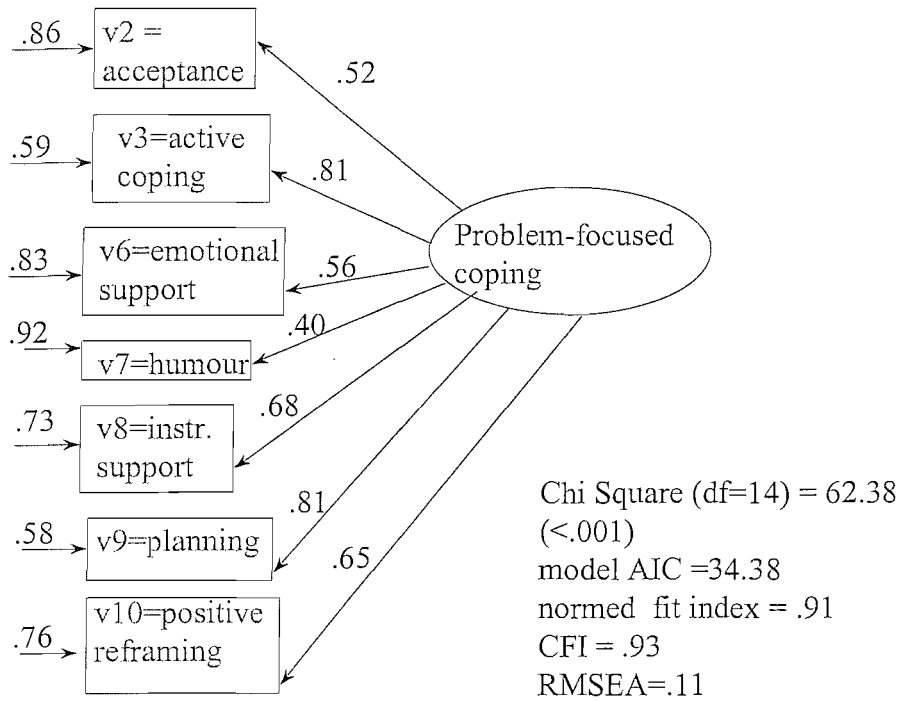
Chi Square (df=2) = 107.08 (p<.001)  
model AIC =103.08  
normed fit index = .73  
CFI = .73  
RMSEA=.43

I1B: Measurement model: illness parameters B

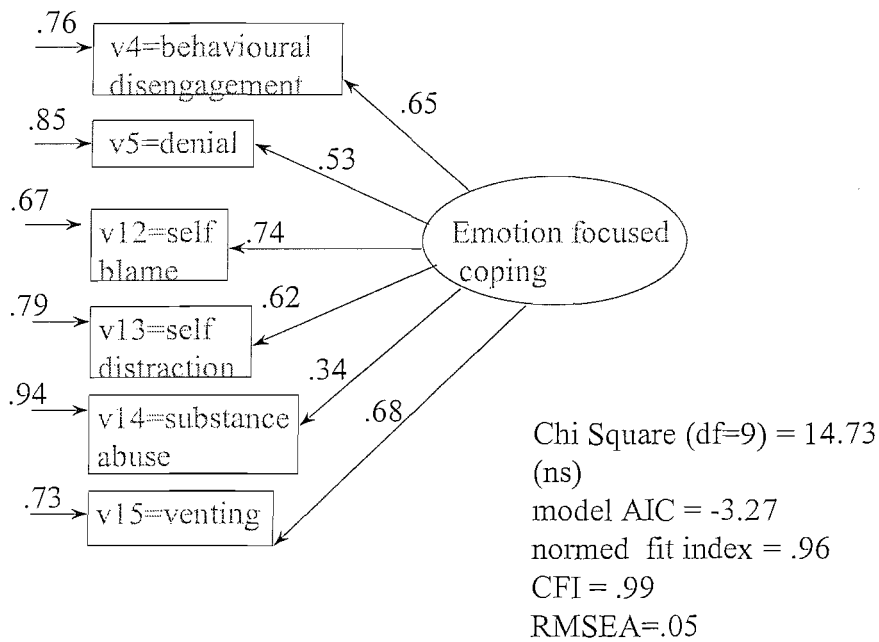


Chi Square (df=0) = 0.00  
model AIC =0.00  
normed fit index = 1.00

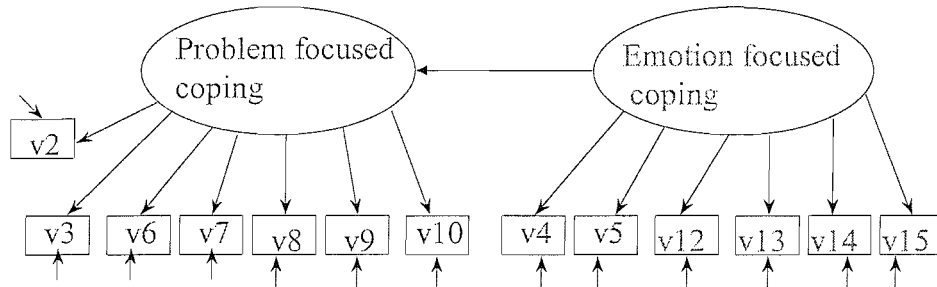
I2: Measurement model: Problem Focused Coping



I3: Measurement model: Emotion Focused Coping

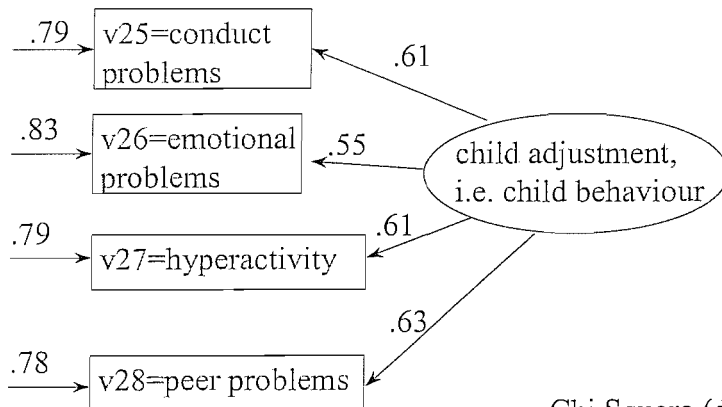


I4: Measurement model: Coping



Chi Square (df=64) = 181.60  
 (p<.001)  
 model AIC = 53.60  
 normed fit index = .85  
 CFI = .90  
 RMSEA=.08

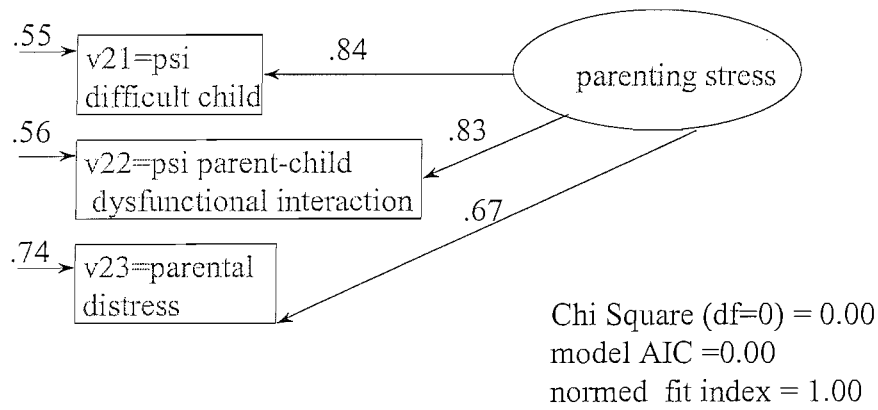
I5: Measurement model: Child Behaviour



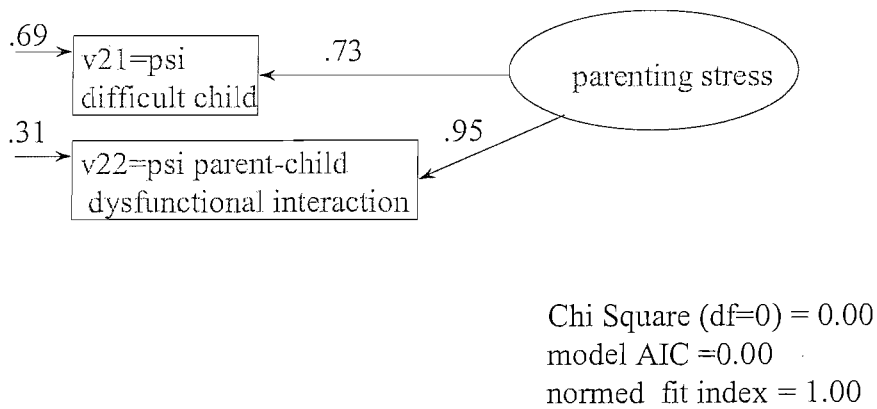
Chi Square (df=2) = 6.88  
 (<.05)  
 model AIC =2.88  
 normed fit index = .96  
 CFI = .97  
 RMSEA=.09



I6A: Measurement model: Parenting Stress A



I6B: Measurement model: Parenting Stress B



## APPENDIX J

Correlation matrix for the variables used for testing the transactional stress and coping model of adjustment to disability in mothers of children with asthma  
(Study 5, Chapter 10)

Correlation matrix for the variables used for testing the stress and coping model of adjustment to disability in mothers of children with asthma

	V1 - FSS total	V2 - PSI total	V3 - HPPJ- mother child social interaction	V4 - HPPJ child health and services	V5 - CSES efficacy	V6 - child functional impairment	V7 - SDQ total	V8 - problem focused coping	V9 - emotion focused coping	V10 - severity of asthma
V1	1.000									
V2	-.555	1.000								
V3	-.280	.470	1.000							
V4	-.182	.452	.884	1.000						
V5	.318	-.244	-.270	-.245	1.000					
V6	-.273	.443	.618	.662	-.123	1.000				
V7	-.346	.694	.277	.294	.069	.335	1.000			
V8	.083	.106	.129	.197	-.038	.031	.022	1.000		
V9	-.385	.560	.349	.369	-.231	.264	.365	.353	1.000	
V10	-.036	.281	.655	.748	-.137	.554	.327	.091	.242	1.000

## APPENDIX K

Means and standard deviations for High and Low Gain groups of variables used for testing the transactional stress and coping model of adjustment to disability  
(Study 7, Chapter 12)

Means, standard deviations of variables used for testing the stress and coping model of adjustment to disability

Variable	Low Gain		High Gain	
	Mean	SD	Mean	SD
V2 - COPE acceptance	6.2961	1.7025	5.9058	2.0322
V3 - COPE active coping	4.8158	1.8714	4.6812	1.9027
V4 - COPE behavioural disengagement	2.3750	.8041	2.6014	1.0219
V5 - COPE denial	2.4145	.9659	2.6232	1.1727
V6 - COPE emotional support	4.5592	1.7291	3.7319	1.4874
V7 - COPE humour	3.1579	1.5273	2.9130	1.4167
V8 - COPE instrumental support	4.8289	1.7746	4.2246	1.6873
V9 - COPE planning	4.8487	1.8797	4.5797	1.7995
V10 - COPE positive reframing	4.7105	1.7172	3.9783	1.6141
V12 - COPE self blame	3.8684	1.7289	4.3551	1.9993
V13 - COPE self distraction	3.6382	1.4941	3.5725	1.4544
V14 - COPE substance use	2.3947	1.0109	2.5725	1.2951
V15 - COPE venting	3.4145	1.5287	3.5145	1.5949
V16 - FSS family functioning	46.5197	10.6049	41.1087	10.6714
V17 - Severity of disability	2.9803	2.4318	2.5942	2.3480
V18 - Child ADL	5.4474	2.9807	4.4493	3.3420
V21 - PSI difficult child	36.2895	10.4150	37.1884	10.4298
V22 - PSI dysfunctional interaction	25.4013	8.0052	28.2609	7.6819
V23 - PSI parent distress	29.8618	9.3349	32.6522	10.4264
V24 - Positive Gain	11.8816	2.2726	19.2246	3.2578
V25 - SDQ conduct problems	2.0855	1.8909	2.3913	1.8381
V26 - SDQ emotional problems	3.8750	2.6352	3.9638	2.5925
V27 - SDQ hyperactivity	5.6842	2.7917	5.3188	2.7286
V28 - SDQ peer problems	3.3026	2.3390	3.5725	2.4581
V30 - HPPI child health and services	14.2961	9.1852	12.9928	9.1400
V31 - HPPI mother-child social interaction	17.1776	15.3287	18.1884	15.7218
V33 - CSES care giving efficacy	30.0987	4.4614	28.1377	5.1164

## APPENDIX L

**Correlation matrix for the variables used for testing the transactional stress  
and coping model of adjustment to disability for High and Low Gain groups  
(Study 7, Chapter 12)**

Correlation matrix for the variables used for testing the stress and coping model of adjustment to disability- High Gain group

	V2 - COPE Acceptance	V3 - COPE Active coping	V4 - COPE Behavioural disengagement	V5 - COPE Denial	V6 - COPE Emotional support	V7 - COPE Humour	V8 - COPE Instrumental support	V9 - COPE Planning	V10 - COPE Positive reframing	V12 - COPE Self blame	V13 - COPE Self distraction	V14 - COPE Substance use	V15 - COPE Venting	V16 - FSS Family functioning	V17 - Severity of disability	V18 - Child ADL
V2	1.000															
V3	.314	1.000														
V4	-.062	.112	1.000													
V5	-.031	.167	.302	1.000												
V6	.319	.488	.020	.174	1.000											
V7	.239	.237	.108	.041	.210	1.000										
V8	.311	.465	.073	.146	.552	.301	1.000									
V9	.430	.615	.169	.064	.358	.241	.526	1.000								
V10	.408	.513	-.002	.017	.336	.394	.392	.536	1.000							
V12	.187	.248	.431	.223	.138	.143	.241	.293	.295	1.000						
V13	.243	.386	.301	.164	.263	.283	.231	.322	.390	.420	1.000					
V14	.016	.060	.069	.042	-.002	.054	-.088	-.010	.070	.246	.174	1.000				
V15	.159	.316	.422	.322	.245	.301	.295	.340	.223	.422	.513	.133	1.000			
V16	-.070	-.116	-.209	-.099	.002	-.150	-.184	-.236	-.157	-.414	-.383	-.185	-.376	1.000		
V17	.062	-.002	-.030	-.152	.031	.074	-.035	-.022	.010	-.087	.014	.108	.047	.006	1.000	
V18	.271	.205	.023	-.102	.231	.181	.141	.244	.208	-.018	.161	.062	.112	-.002	.593	1.000
V21	.135	.216	.302	.081	.121	.251	.335	.368	.193	.323	.450	.192	.477	-.485	-.001	.139
V22	.037	.033	.387	.127	.058	.116	.168	.234	-.024	.338	.270	.164	.336	-.443	-.027	.083
V23	.096	.171	.366	.191	.052	.216	.229	.307	.201	.549	.417	.246	.397	-.639	.023	.207
V24	-.015	-.055	.173	-.029	-.044	-.101	.039	-.052	-.156	.212	.030	-.046	.085	-.324	-.136	-.143
V25	.144	.139	.205	.042	.026	.034	.123	.225	.118	.275	.257	.062	.281	-.251	-.138	-.044
V26	.056	.101	.316	.210	-.001	.128	.182	.215	.172	.371	.365	.190	.406	-.321	.020	.095
V27	.186	.203	.221	.100	.071	.211	.280	.330	.231	.205	.341	.049	.251	-.219	-.023	.273
V28	.172	.255	.151	.170	.087	.085	.188	.330	.210	.351	.303	.142	.228	-.179	-.120	.148
V30	.188	.203	.088	.011	.153	.227	.199	.285	.165	.306	.319	.206	.210	-.241	.179	.332
V31	.209	.270	.222	.098	.196	.263	.290	.415	.291	.369	.434	.305	.358	-.343	.087	.210
V33	-.118	-.235	-.356	-.099	-.111	-.134	-.214	-.343	-.182	-.454	-.386	-.144	-.357	.344	.081	-.077

Correlation matrix for the variables used for testing the stress and coping model of adjustment to disability – high gain group - continued

	<i>V21 - PSI difficult child</i>	<i>V22 - PSI dysfunctional interaction</i>	<i>V23 - PSI parent distress</i>	<i>V24 - Positive Gain</i>	<i>V25 - SDQ conduct problems</i>	<i>V26 - SDQ emotional problems</i>	<i>V27 - SDQ hyperactivity</i>	<i>V28 - SDQ peer problems</i>	<i>V30 - HPPJ child health and services</i>	<i>V31 - HPPJ mother-child social interaction</i>	<i>V33 - CSES care giving efficacy</i>
V21	1.000										
V22	.708	1.000									
V23	.612	.605	1.000								
V24	.220	.306	.212	1.000							
V25	.548	.476	.339	.214	1.000						
V26	.532	.366	.432	.001	.321	1.000					
V27	.547	.457	.393	.107	.458	.329	1.000				
V28	.386	.403	.359	-.011	.345	.381	.422	1.000			
V30	.362	.241	.398	-.062	.154	.346	.441	.281	1.000		
V31	.626	.489	.528	.064	.386	.376	.413	.448	.663	1.000	
V33	-.458	-.421	-.386	-.190	-.374	-.318	-.381	-.367	-.259	-.418	1.000

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



Correlation matrix for the variables used for testing the stress and coping model of adjustment to disability- Low Gain group

	V2 - COPE Acceptance	V3 - COPE Active coping	V4 - COPE Behavioural disengagement	V5 - COPE Denial	V6 - COPE Emotional support	V7 - COPE Humour	V8 - COPE Instrumental support	V9 - COPE Planning	V10 - COPE Positive reframing	V12 - COPE Self blame	V13 - COPE Self distraction	V14 - COPE Substance use	V15 - COPE Venting	V16 - FSS Family functioning	V17 - Severity of disability	V18 - Child ADL
V2	1.000															
V3	.443	1.000														
V4	-.004	.144	1.000													
V5	-.064	.194	.398	1.000												
V6	.262	.429	.083	.025	1.000											
V7	.195	.377	.263	.160	.190	1.000										
V8	.345	.636	-.024	-.049	.577	.249	1.000									
V9	.430	.754	.087	.135	.378	.375	.548	1.000								
V10	.360	.525	.234	.188	.201	.255	.246	.595	1.000							
V12	.138	.327	.495	.537	.148	.300	.208	.336	.353	1.000						
V13	.149	.378	.390	.431	.210	.311	.215	.394	.313	.560	1.000					
V14	-.021	.060	.345	.302	.031	.163	-.033	.007	.027	.318	.131	1.000				
V15	.175	.297	.516	.335	.209	.495	.198	.295	.243	.519	.442	.249	1.000			
V16	-.009	-.099	-.327	-.276	-.021	-.058	-.046	-.097	-.095	-.494	-.460	-.157	-.407	1.000		
V17	.116	.062	.127	.114	.054	.057	-.014	.063	.115	.096	.039	.072	.052	-.064	1.000	
V18	.070	.148	.168	.124	.070	.199	.045	.176	.184	.179	.255	.009	.212	-.339	.615	1.000
V21	.040	.158	.299	.175	.077	.143	.087	.196	.155	.327	.320	.091	.322	-.541	.103	.447
V22	-.045	.207	.370	.293	.038	.226	.041	.192	.032	.427	.365	.072	.403	-.497	.131	.394
V23	-.033	.154	.467	.497	.047	.108	.046	.137	.184	.583	.458	.280	.440	-.723	.303	.448
V24	-.169	-.125	.207	.076	-.207	.039	-.042	-.203	-.156	.059	-.124	.009	.167	-.028	-.101	-.105
V25	.037	.067	.130	-.026	.116	.086	.070	.057	-.019	.087	.126	-.113	.195	-.195	-.061	.174
V26	.076	.156	.132	.178	.056	.204	.075	.108	.139	.308	.323	.250	.266	-.280	.020	.184
V27	.054	.073	.124	-.026	-.065	.073	-.009	.108	.166	.087	.101	.041	.090	-.199	.100	.363
V28	-.086	.075	.077	.161	.012	.065	-.005	.086	-.023	.166	.212	.167	.097	-.336	.124	.312
V30	.125	.224	.139	.120	.055	.121	.125	.282	.182	.273	.246	.096	.249	-.335	.394	.567
V31	.126	.265	.338	.212	.054	.191	.098	.265	.189	.402	.313	.134	.351	-.515	.233	.527
V33	.008	-.247	-.306	-.171	-.155	-.189	-.212	-.255	-.176	-.387	-.330	-.063	-.351	.461	-.059	-.276

Correlation matrix for the variables used for testing the stress and coping model of adjustment to disability- low gain group - continued

	<i>V21 - PSI difficult child</i>	<i>V22 - PSI dysfunctional interaction</i>	<i>V23 - PSI parent distress</i>	<i>V24 - Positive Gain</i>	<i>V25 - SDQ conduct problems</i>	<i>V26 - SDQ emotional problems</i>	<i>V27 - SDQ hyperactivity</i>	<i>V28 - SDQ peer problems</i>	<i>V30 - HPPJ child health and services</i>	<i>V31 - HPPJ mother-child social interaction</i>	<i>V33 - CSES care giving efficacy</i>
V21	1.000										
V22	.687	1.000									
V23	.513	.494	1.000								
V24	-.049	.024	.004	1.000							
V25	.558	.504	.201	.063	1.000						
V26	.445	.414	.311	.003	.294	1.000					
V27	.425	.316	.132	-.068	.406	.273	1.000				
V28	.449	.434	.411	.059	.359	.441	.309	1.000			
V30	.510	.372	.459	-.169	.300	.262	.226	.320	1.000		
V31	.694	.598	.596	.031	.418	.357	.297	.498	.732	1.000	
V33	-.460	-.507	-.438	-.045	-.318	-.289	-.283	-.283	-.263	-.477	1.000

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

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