

RESILIENCE IN FAMILIES OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

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Master of Arts (Psychology) at the
University of Stellenbosch**

The crest of the University of Stellenbosch is centered behind the text. It features a shield with various symbols, topped with a crown and a banner. The banner contains the Latin motto "Perfata coluntur cultus recti".

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March 2010

Declaration

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SUMMARY

Family resilience refers to the family's ability to overcome adversity using inherent and/or acquired strengths and resources. The aim of this study was to identify factors contributing to the successful adaptation, or resilience, of families following the birth or diagnosis of a child with a developmental disability. The study is based on the theoretical frameworks of family resilience proposed by McCubbin and McCubbin (1996) and Walsh (2003), namely the Family Resiliency Model of Family Stress, Adjustment and Adaptation and the Family Resilience Framework. The study population in this study comprised 40 families with a child with a developmental disability living in the Boland region of the Western Cape. One parent from each family was asked to complete a number of quantitative measuring instruments and answer an open-ended question aimed at identifying the strengths and resources contributing to the family's adaptation. Quantitative data was analysed through analyses of variance, Pearson product-moment correlations and a multiple regression analysis. The qualitative data was analysed using thematic content analysis. These analyses revealed that an acceptance of the situation, positive patterns of family communication, commitment and support within the family unit, and a positive attitude with regard to new experiences and challenges facilitate family adaptation and resilience, while negative patterns of communication within the family were found to be inversely related to family adaptation. An inverse association was also found between age of the child with a disability and family adaptation. These findings suggest some possible avenues of intervention by which the adaptation of families with a child with a developmental disability in South Africa can be facilitated or supported.

OPSOMMING

Gesinsveerkragtigheid verwys na die gesin se vermoë om terugslae en teenspoed te oorkom deur die gebruik van bestaande en aangeleerde sterktes en hulpbronne. Die doel van die huidige studie was om kwaliteite te identifiseer wat tot die aanpassing, en dus veerkragtigheid, van gesinne met 'n kind met 'n ontwikkelingsgestremdheid bydra. Die studie is gebaseer op die teoretiese raamwerke wat deur McCubbin en McCubbin (1996) en Walsh (2003) voorgestel is, naamlik die *Family Resiliency Model of Family Stress, Adjustment and Adaptation* en die *Family Resilience Framework*. Veertig gesinne van 'n kind met 'n ontwikkelingsgestremdheid wat in die Boland-gebied in die Wes-Kaap bly, het aan die studie deelgeneem. 'n Reeks kwantitatiewe vraelyste en 'n oopende-vraag is deur een ouer van elke gesin voltooi. Hierdie vraelyste en oopende-vraag was gerig op die identifisering van sterktes en hulpbronne wat tot die suksesvolle aanpassing van die gesin bydra. Die kwantitatiewe data is ontleed deur gebruik te maak van variansieontleding, die berekening van Pearson-produkmomentkorrelasies en meerregressie-ontledings. Die kwalitatiewe data is ontleed deur gebruik te maak van tematiese inhoudsontleding. Die kwantitatiewe en kwalitatiewe ontledings het getoon dat aanvaarding van die situasie, positiewe kommunikasie tussen gesinslede, toegewydheid tot die gesin, gesinseenheid en 'n positiewe houding om krisisse as 'n uitdaging te beskou, belangrike veerkragtigheidskwaliteite is, terwyl negatiewe en opruiende kommunikasie in die gesin omgekeerd met aanpassing verband hou. 'n Omgekeerde verband is ook gevind tussen gesinsaanpassing en die ouderdom van die kind met 'n gestremdheid. Hierdie bevindings kan bydra tot die ontwikkeling van ingrypingsprogramme waardeur die aanpassing van Suid-Afrikaanse gesinne met 'n kind met 'n gestremdheid gefasiliteer en ondersteun kan word.

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Chapter 1

Introduction, Motivation and Aims of the Study

1.1. Introduction

According to a report on the prevalence of disability in South Africa, published by Statistics South Africa (2005), 5% of the South African population lives with a disability. The highest prevalence is among the black population (5.2%), followed by the white (4.5%), coloured (4.2%) and Indian (3.7%) population groups¹. Statistics South Africa (2007) defines disability as,

A physical or mental handicap which has lasted for six months or more, or is expected to last at least six months, which prevents the person from carrying out daily activities independently, or from participating fully in educational, economic or social activities (p. 35).

The report further states that 2.1% of children aged 0 to 9 years and 3% of children aged 10 to 19 years live with a disability. As is evident from these figures, many children in South Africa, and by extension their families, are affected by disability. Since there are still limited social, educational and economic support structures for people with disabilities in South Africa, the burden of care usually falls on the family.

This chapter includes a brief introduction to developmental disabilities and the social, emotional and economic impact the presence of a child with such disabilities has on the family. In addition, the chapter serves to introduce the concept of family resilience and its value in planning and implementing interventions designed to facilitate the adaptation of families of children with

¹ “Statistics South Africa has continued to classify people into population group, since moving away from past apartheid-based discrimination, and monitoring progress in development over time, involves measuring differences in life circumstances by population group. This classification, in common with other countries such as the United States of America which uses a population group-based classification system, is no longer based on a legal definition, but rather on self-classification” (Statistics South Africa, 1999, p. 8).

developmental disabilities. An outline of the presentation of this document concludes the chapter.

1.2. Motivation for the Study

Developmental disability is a term that refers to a permanent cognitive and/or physical impairment that is usually present at birth or occurs in the early years of life. It can, however, occur anytime before the age of 21 years (National Association of Councils on Developmental Disabilities, 2008).

The concept ‘developmental disability’ is used to refer to a range of conditions, including intellectual disability, cerebral palsy, autistic spectrum disorder, spina bifida, cystic fibrosis, learning disability, muscular dystrophy, foetal alcohol spectrum disorder and epilepsy. It is recognised that many people with a developmental disability may experience a number of impairments. More specifically, a developmental disability usually results in significantly reduced capacity in three or more of the following activities of daily living: Communication, learning, mobility, living independently, decision making or self-care. For this reason, many people diagnosed with a developmental disability are in need of ongoing support, in some cases lifelong (Centre for Disease Control and Prevention, 2009; National Association of Councils on Developmental Disabilities, 2008).

Following the diagnosis of a developmental disability, parents and families face a difficult period of accepting and adjusting to this diagnosis. Many parents have difficulty accepting the disability of their child since, they have to re-evaluate the expectations they had for their child (Abidin, cited in Gupta, 2007). They experience feelings of grief and sorrow about the loss of their “normal” child, as well as feelings of uncertainty about the future (Taanila, Järvelin, & Kokkonen, 1998) and their ability to cope with the demands the disability will place on the family (Graungaard & Skov, 2006).

The parenting stress associated with caring for a child with a disability is largely determined by the nature of the disorder. Children that are more demanding of attention due to daily care needs and behavioural problems cause higher levels of parenting and life stress than those requiring less support (Gupta, 2007). It has, however, been shown across numerous studies that parents of children with developmental disabilities show markedly higher levels of parenting and life stress than parents of normally developing children (Beckman, 1991; Gupta, 2007; Horton & Wallander, 2001; Pelchat et al., 1998; Sloper & Turner, 1993).

As mentioned previously, children diagnosed with a developmental disability need ongoing support for many tasks of daily living. This places a high care-giving burden on the family, the stress of which can be further exacerbated by concurrent behavioural problems and low developmental competence (Gupta, 2007). Children and adolescents with developmental disabilities have been found to be at increased risk of mental health problems, as evidenced by behaviour problems, depression and anxiety, which cause an increase in care strain, even causing parents to doubt the efficacy of their parenting (Faust & Scior, 2008). In addition to these factors, having a child with a disability often causes an increase in the social isolation of families. Families may be ostracised by a society that still perceives individuals with disabilities as “damaged”, or they might consciously decide to keep to themselves to protect the child and the family unit from social prejudice (Emerson, 2003; Heiman & Berger, 2008). Either way, these families often do not have access to a supportive and understanding social network that could provide the emotional support necessary to help them deal with the demands of life with a child with a disability.

This social isolation based on society’s misconceptions of individuals with disabilities extends beyond the immediate social environment of these families. In spite of much work in recent years to draw attention to the value, rights and needs of people with disabilities, these individuals and their families are still marginalised (Gross & Hahn, 2004). Social inclusion policies and the

allocation of funds to the provision of appropriate support structures for people with disabilities are still far from ideal, with these individuals' rights often being overlooked and the burden of care still falling squarely on the family.

The availability of resources for people with disabilities and their families is still limited in South Africa (Statistics South Africa, 2005). Families are mostly required to care for and support their child themselves and also bear the cost of any professional services needed. Families from previously disadvantaged ethnic groups in particular have been found to have limited external resources and facilities available to them (Parekh & Jackson, 1997; Statistics South Africa, 2005).

According to Lombard (cited in Parekh & Jackson, 1997), who conducted a study examining the impact of a child with a disability on parents in South African families, white parents experience more stress than black parents as a result of social stigma and isolation, an over-involvement with the child, occupational limitations and a division in the family unit. Black parents, on the other hand, were found to experience greater stress than white families due to the child's incapacity to perform tasks of daily living and self-care, a strain exacerbated by the lack of external resources available to them. Ntombela (cited in Parekh & Jackson, 1997) went further to say that children with disabilities are not readily accepted by modern African families in South Africa, as a result of the increasing urbanisation and westernisation of these families and the associated pressures to strive towards self-realisation and economic success.

Studies evaluating the experiences of families from different cultural and ethnic groups are limited, however, since the majority of studies on the families of children with disabilities in South Africa have been focussed on white families. This research bias is also evident in studies conducted outside South Africa, with the majority of research available having been conducted on urbanised Western populations, with little or no attention being paid to cultural or ethnic

differences (Gatford, 2001). There thus is a need for studies examining the experiences of families from different ethnic groups and their adaptation to the diagnosis of a child with a developmental disability in order to inform policy-making decisions and drive appropriate and culturally sensitive support provision (Parekh & Jackson, 1997).

This aim – to identify avenues of intervention and develop appropriate support structures – is also underlying in the study of family resilience. Family resilience refers to a family’s “capacity to overcome difficult circumstances through the use of inherent and/or acquired resources and strengths” (Hawley, 2000, p. 105).

The study of family resilience arose from a shift in research focus from a pathogenic, deficit-based approach to a strength-based, or salutogenic (Antonovsky, 1979) approach. Rather than attempting to understand behaviour by studying the problems or deficits of individuals and families, researchers became interested in identifying the strengths responsible for adaptive coping in the face of such problems. One of the underlying aims of such studies that strive to identify factors associated with successful coping or resilience is the eventual development of clinical interventions that can focus on “amplifying strengths rather than repairing weaknesses” (Seligman (p. 2), cited in Hawley, 2000).

This approach is also relevant for the families of children with disabilities. In spite of the abovementioned stresses associated with caring for a child with a developmental disability, many such families have been found to adapt successfully and even thrive following the diagnosis (Bayat, 2007; Hastings & Taunt, 2002; Kearney & Griffin, 2001; Wallander & Varni, 1998). By identifying the strengths contributing to resilience in these families, interventions and support programmes can be implemented to strengthen these resources and thus facilitate coping in those families struggling to adapt (Ellis & Hirsch, 2000). Strengthening the family unit in this way is

important, since the well-being of the family influences the well-being and adjustment of its individual members (Walsh, 2003), including the child with a developmental disability.

Family resilience has been found to be influenced by a family's social and cultural background, since this shapes the family's perception of their situation, and influences the available resources. In spite of this, most studies of family resilience have been conducted using Western populations (McCubbin & McCubbin, 1996). There thus is a need for cross-cultural research to identify resilience qualities in families from different cultural backgrounds.

The care of a child with a developmental disability has been found to be a very stressful experience. In spite of this, many families have been found to cope successfully and even thrive. The literature on the impact of a child with a disability on families from different socio-cultural backgrounds is limited, however, as is the literature on family resilience in families from different ethnic and cultural backgrounds. These facts represent the basis of the motivation for the present study.

1.3. Aims of the Study

This study aims to identify factors associated with the successful adaptation of families following the diagnosis of a child with a developmental disability. More specifically, this study aims to examine which strengths and resources facilitate such adaptation in coloured families living in the Western Cape. The term "coloured" is a contentious one, but is still used in South Africa for people of mixed race. This classification is not based on a legal definition but on self-classification; in other words, people of mixed race tend to refer to themselves as "coloured" and the term is thus adopted by the wider population of South Africa (Statistics South Africa, 1999).

Insights gained from this study can be implemented by healthcare professionals, and families, to foster family strengths and guide the acquisition of additional resources, if needed, to facilitate family adaptation and well-being.

1.4. Presentation of the Research

Chapter 2 presents an overview of the theoretical frameworks underlying this study. It contains a detailed explanation of the construct of family resilience and a summary of the main theoretical models guiding resilience research, as well as a description of the difficulties associated with having a child with a developmental disability.

A review of the literature on resilience in families of children with disabilities is presented in Chapter 3.

The methodology used in this study is discussed in Chapter 4, with the results thereof being presented in Chapter 5.

Chapter 6 concludes this document with a discussion of the results obtained in this study, and the subsequent conclusions drawn. It also includes a discussion of the limitations of this study and suggestions for further research.

Chapter 2

Theoretical Frameworks

2.1. Introduction

This chapter provides an overview of the construct of family resilience. It outlines the evolution of family resilience theory and provides a summary of current family resilience models and frameworks. Since this study is aimed at examining the resilience of families with children with developmental disabilities, this chapter also includes a section describing the difficulties faced by such families.

2.2. Family Resilience as a Theoretical Construct

2.2.1. Definition

Resilience has been described or defined in many different ways. All definitions, however, have common elements. They describe resilience as surfacing in the face of hardship or adversity and entailing the ability to “bounce back”, that is, to regain or surpass pre-adversity levels of functioning. Finally, and perhaps most importantly, resilience emphasises the strengths families employ to overcome adversity rather than focusing on deficits (Hawley, 2000).

McCubbin and McCubbin (1988) define family resilience as the “characteristics, dimensions, and properties which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations” (p. 247), while Luthar, Cicchetti and Becker (2000) define family resilience as “a dynamic process encompassing positive adaptation within the context of significant adversity” (p. 543). Hawley and DeHaan (1996) propose a definition that seems to combine these ideas:

Family resilience describes the path a family follows as it adapts and prospers in the face of stress, both in the present and over time. Resilient families positively respond to these

conditions in unique ways, depending on the context, developmental level, the interactive combination of risk and protective factors, and the family's shared outlook. (p. 293)

Family resilience is not a static set of strengths that renders a family resilient, but rather an adaptive pathway, unique to each family and situation. As Walsh (1996) puts it, there is no "blueprint for any singular model of the 'resilient family'" (p. 269). A family's response to a stressor will depend on the unique interaction of risk and protective factors within the family unit, the socio-cultural and developmental context and the family's subjective perception or appraisal of the stressor.

A risk factor or stressor can be defined as a barrier to effective functioning, while a protective factor is a resource that serves to buffer the effects of adversity (Hawley, 2000). Resilience involves achieving a balance between risk and protective factors, that is, minimising risk factors or demands and strengthening protective factors or resources (Hawley, 2000; Patterson, 2002) in order to reduce dysfunction and enhance family functioning and well-being (Luthar et al., 2000).

Risk and protective factors are not static entities, but are rather contextual and changing (Rutter, cited in Hawley & DeHaan, 1996); what constitutes a risk or protective factor varies according to the specific situation and family. A factor that might have been protective in one situation can contribute to family risk in another, just as what serves as a protective factor in one family contributes to risk in another (Hawley, 2000; Hawley & DeHaan, 1996; McCubbin & McCubbin, 1996). Equally, the magnitude and impact of a risk factor can change over time and can vary according to the developmental or life stage the family is at, as well as the concurrent pile-up of other demands (Hawley & DeHaan, 1996; Walsh, 2003). It thus is important for a family resilience framework to combine "ecological and developmental perspectives to view family functioning in relation to its broader sociocultural context and evolution over the multi-generational life-cycle" (Walsh, 2003, p. 3). In other words, it is important to consider the unique

context of the family in assessing its vulnerability and identifying strengths and adaptive pathways that will facilitate resilience both now and in the future.

Resilient families are those that adapt well and are able to regain or surpass their pre-crisis level of functioning in the long run (DeHaan, Hawley, & Deal, 2002).

2.2.2. Evolution of Family Resilience as a Construct

For a long time, psychological research has focused on identifying the causes for adaptive deficits and problems. The past two decades, however, have witnessed a shift in emphasis. Researchers have become interested in identifying why some individuals cope or even thrive in the face of adversity, while others crumble. Antonovsky (1979) terms this a “salutogenic orientation” (p. 2). Rather than studying deficits, which is a pathogenic approach, salutogenesis is concerned with discovering factors or strengths contributing to healthy functioning. The initial focus in these studies was on identifying personal traits accounting for the differences in adaptation following adversity. Resilience, as the ability to overcome adversity became known, was perceived as an innate characteristic held by some individuals (Masten & Garmezy, cited in Luthar et al., 2000; Anthony & Cohler, cited in Walsh, 2003) and not others. In these studies, the family tended to be seen as a risk rather than a protective factor. As research in the field evolved, however, researchers recognised that resilience was often influenced by external factors. Three sets of factors were identified as interacting to contribute to individual resilience, namely characteristics of the individual, aspects of the families and influences from the social environment (Silliman, cited in Hawley & DeHaan, 1996; Werner & Smith, cited in Luthar et al., 2000). The family had thus been identified as both a potential risk and protective factor, and researchers consequently started developing an interest in the factors contributing to healthy family functioning. Resilience became viewed as a systemic quality shared by the family unit (Hawley & DeHaan, 1996). By identifying and fostering family strengths and resilience, the individual’s resilience is bolstered by extension (Walsh, 2003). Working from a family stress

perspective, researchers proposed models and frameworks of family resilience in an effort to understand the factors and processes involved in family resilience (Hawley, 2000). The evolution of these family resilience models will be discussed in detail in Section 2.3.

Olson et al. (1983) define this shift in emphasis from a deficit- to a strength-based approach in the following words: “We have moved from a simple ‘fight versus flight’ notion of coping to the study of the complex processes of acquiring, building, exchanging, and using resources to resist and adjust to the impact of demands.” (p. 136)

2.3. Resiliency Model of Family Stress, Adjustment and Adaptation

2.3.1. Evolution of the Resiliency Model of Family Stress, Adjustment and Adaptation

The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1996) evolved from Reuben Hill’s (1949) ABCX model of family stress and coping. Hill (1949) proposed that a family’s response to stress is influenced by the nature of the stressor (A), the family’s resources (B) and the definition of the stressor (C). These factors interact to determine the family’s response to crisis (X).

This model was expanded on by McCubbin and Patterson (cited in McCubbin & McCubbin, 1996) in their Double ABCX model. They theorised that a family is rarely faced with a single stressor, but rather with a pile-up of demands (AA) placing strain on their resources and capabilities. Since families tend to have more than one resource at their disposal, and the available resources can change over time, the BB factor was introduced. The allocation of resources to meet the demands is influenced by the family’s appraisal of the stressor. This appraisal process involves more than the definition of the stressor (C), but rather an assessment of the total situation, that is, both the demands placed by the stressor and the capabilities or resources available (CC). These factors interact to determine family adaptation (XX), which is the outcome following the crisis.

McCubbin, Dahl, Lester and Ross (cited in McCubbin & McCubbin, 1996) found that adaptation following a crisis is not a static event, but rather involves complex processes, including changes in the family's functioning in order to balance demands and resources. This realisation contributed to the development of McCubbin and Patterson's process-oriented Family Adjustment and Adaptation Response Model (FAAR) (cited in McCubbin & McCubbin, 1996), which attempted to highlight the processes involved in adaptation. This model also introduced a distinction between family adjustment and family adaptation, a distinction that also is central to the Resiliency Model of Family Stress, Adjustment and Adaptation and thus will be discussed in more detail in Section 2.3.2.

Continuing research showed that some families were better able to cope with life's demands than other families faced with similar stressors (Brown-Baatjies, Fouché, & Greeff, 2008). This observation gave rise to the development of McCubbin and McCubbin's Typology Model of Family Adjustment and Adaptation (cited in McCubbin & McCubbin, 1996), which introduced family typology, that is, established patterns of functioning; family vulnerability, as determined by the pile-up of stressors and family life-cycle stages; family problem solving and coping strategies; and family schema as factors influencing adjustment and adaptation (Brown-Baatjies et al., 2008). The family schema refers to a set of beliefs the family holds about "itself in relation to its members and the outside world" (Hawley, 2000, p. 109).

The most recent extension of these models of family resilience is the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1996). This model highlights four domains of family functioning that are critical to restoring or maintaining harmony and balance in the face of adversity, as well as introducing further important levels of family appraisal contributing to recovery, including culture and ethnicity, which had been neglected in previous models (McCubbin & McCubbin, 1996).

According to McCubbin and McCubbin (1996), families faced with crisis situations work to restore order, harmony and balance to the family unit. This process involves changes not only within the family, but also in “the environment, the community and the family’s relationships to the community” (McCubbin & McCubbin, 1996, p. 14). Some families are better able to adapt to adversity and crises than others. The Resiliency Model attempts to identify and explain which factors and processes are involved in the successful recovery of the family following adversity. It distinguishes between two phases, namely the adjustment and the adaptation phase, which will now be discussed in turn.

2.3.2. The Adjustment Phase in Family Resiliency

There are four domains of family functioning that are affected by stressors, namely 1) interpersonal relationships, 2) structure and function, 3) development, well-being and spirituality and 4) community relationships and nature. A family faced with a stressor is required to adjust in order to incorporate the impact of this stressor and to restore harmony and balance in all domains of functioning, that is, to achieve a state of well-being and equilibrium (McCubbin & McCubbin, 1996). This adjustment phase is influenced by several interacting components, and the outcome varies from family to family. Positive adjustment or bonadjustment is characterised by the restoration of harmony and balance using existing resources, with only minimal changes to the established patterns of family functioning. Maladjustment, on the other hand, occurs when demands exceed capabilities, and the family cannot achieve harmony and stability without making changes to the family system, including its roles, values, rules, goals, priorities and patterns of functioning (McCubbin & McCubbin, 1996). This state of maladjustment results in a family crisis, characterised by disharmony, imbalance and disorganisation, the resolution of which demands substantial changes in the family’s patterns of interaction and functioning (McCubbin & McCubbin, 1996). The initiation of these changes marks the beginning of the adaptation phase, which will be discussed in the next section.

Family vulnerability (V): Vulnerability refers to the condition the family unit is in at the time the stressor occurs. It is determined by the “pile-up of demands” (McCubbin & McCubbin, 1996, p. 17) the family has to contend with, which refers to any prior strains and co-occurring stressors and hardships, and the demands associated with the family’s life-cycle stage.

Family typology of established patterns of functioning (T): A family’s typology is defined as a predictable set of behaviours that represents the way the family typically behaves in relation to its environment. These patterns of functioning play an important role in achieving harmony and balance within the family (McCubbin & McCubbin, 1996).

Family resistance resources (B): The family’s resources are those strengths or capabilities that enable the family to address and manage the demands posed by the stressor in order to restore harmony and balance and thus avoid a family crisis and the subsequent major changes to the family’s patterns of functioning. These resources therefore promote family resilience, or the ability to withstand the impact of the stressor. The main resources identified in previous research (as cited in McCubbin & McCubbin, 1996) are social support, economic stability, cohesiveness, flexibility, hardiness, shared spiritual beliefs, open communication, traditions, celebrations, routines and organisation.

Family appraisal of the stressor (C): The family’s appraisal of the stressor refers to the way the family interprets the stressor in terms of its seriousness and the potential impact on the family (McCubbin & McCubbin, 1996).

Family problem solving and coping (PSC): This factor refers to the family’s stress-management techniques. Problem solving entails breaking the stressor down into manageable components and identifying and mobilising resources to address and resolve the issues arising from it. This is facilitated by constructive problem-solving communication within the family. Coping refers to the active and passive coping strategies employed by the family in order to maintain the well-

being of the family unit and its individual members, and to obtain and employ additional resources in order to overcome strains associated with the stressor (McCubbin & McCubbin, 1996).

According to Antonovsky (1979) a stressor causes a state of tension in the family unit that demands a response from the family and calls for “family systems adjustment behaviour” (McCubbin & McCubbin, 1996, p. 21) in order to restore harmony and balance to the family unit. This state of tension is termed family stress in the literature and is characterised by disharmony and imbalance. The level of family stress experienced by the family is determined by the severity of the stressor, its appraisal by the family and the resources available to the family to deal with it, as well as the well-being of the individual family members at the onset of the stressor (McCubbin & McCubbin, 1996). McCubbin and Patterson (cited in McCubbin & McCubbin, 1996) distinguish between two levels of family stress, namely distress and eustress. Distress is a negative state, where the family defines the state of disharmony and imbalance as unpleasant and threatening, while eustress is a positive state, where this state of tension is defined as desirable and a challenge to be overcome in order to emerge stronger.

Most stressors a family is faced with do not result in family distress; they can be dealt with using the family’s established patterns of functioning and available resources and problem-solving and coping strategies, resulting in bonadjustment. Other stressors, for example the birth or diagnosis of a child with disabilities, however, are more severe and require substantial changes to the family system for harmony and balance to be restored. In this case the family experiences maladjustment, which generally results in a family crisis, where the family is called upon to either institute changes to the family system or disintegrate. This stage marks the beginning of the adaptation phase (McCubbin & McCubbin, 1996).

2.3.3. The Adaptation Phase of Family Resiliency

The adaptation phase of the Resiliency Model highlights the factors and resiliency processes involved in the post-crisis recovery of families faced with a major stressor. In other words, it defines the factors that influence family resilience.

A family in crisis finds itself in a state of disharmony, disorganisation and imbalance, caused by the impact of the initial stressor and aggravated by its inadequate patterns of family functioning. This situation is further exacerbated by the concurrent pile-up of other demands (AA). The family is then called upon to institute changes to achieve family adaptation (XX), characterised by the restoration of balance and harmony in the four domains of family functioning, namely the family's interpersonal relations, its structure and function, the development, well-being and spirituality of the family and its members, and the family's relationship to the community and its environment (McCubbin & McCubbin, 1996). The level of adaptation achieved is determined by an interplay of numerous factors, as shown in Figure 2.

The family's typologies, namely established patterns of functioning (T), restored patterns of functioning (T) and newly instituted patterns of functioning (TT), interact with the family's resources, namely internal resources (BB) and social support (BBB), and with the family's appraisal of the situation, as influenced by schema (CCCCC), coherence (CCCC) and paradigms (CCC), which in turn influence appraisal of the situation (CC) and of the stressor (C), to determine perceived impact of the stressor. The patterns of functioning, resources and appraisal then influence and are influenced by the family's problem-solving and coping techniques (PSC).

As is evident from this brief summary, the adaptation phase of the model involves a complex interplay of factors, a number of which were not mentioned in the adjustment phase. These factors and their role in and influence on the process of adaptation will now be discussed in more detail.

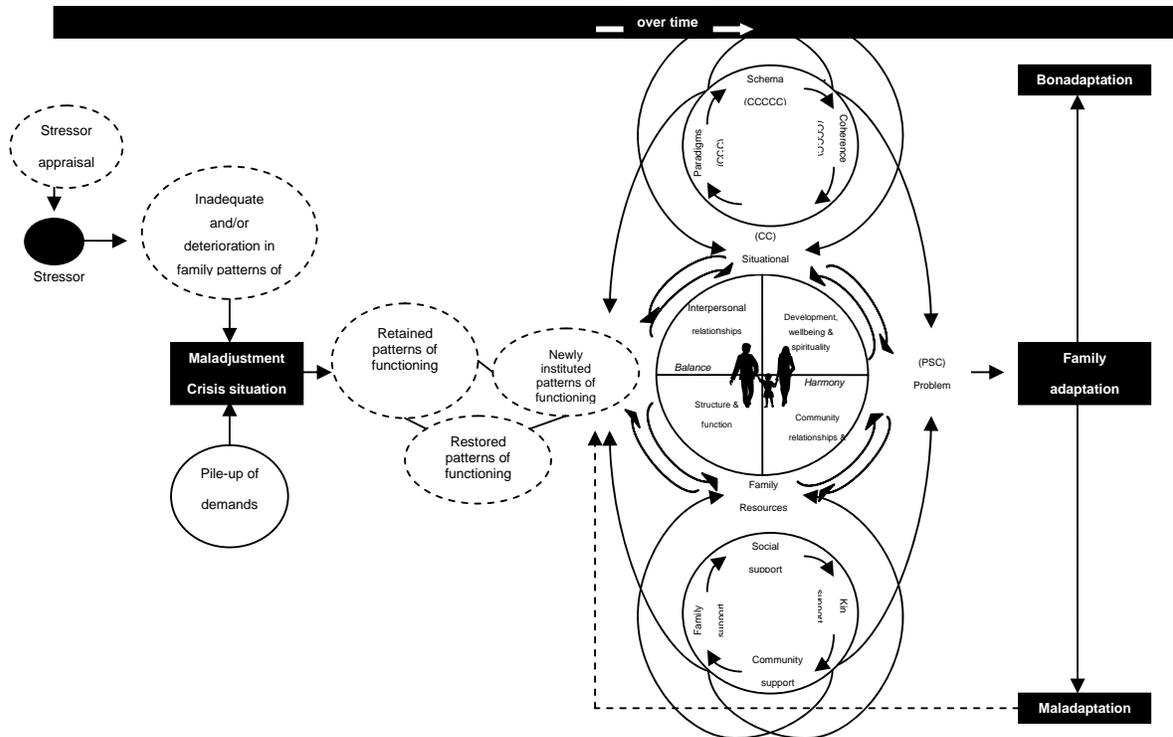


Figure 2.2. The Adaptation Phase of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1996).

2.3.3.1. Pile-up of Demands (AA)

Family adaptation is not a static event occurring at a single moment in time, but rather a process that evolves over time and takes place not in isolation, but within a social and cultural environment. Families are thus rarely faced with a single stressor demanding their attention, but rather have to deal with a whole range of demands and strains, in addition to the stressor that precipitated the crisis. There are seven broad categories of stressors that contribute to this pile-up of demands and thus influence the family's level of vulnerability, including the initial stressor (McCubbin & McCubbin, 1996).

Normative transitions: These refer to the predictable changes the family and its individual members go through over time, for example adolescence, retirement or death. These changes can

occur at the same time as the family struggles to deal with a crisis situation, leading to an overlap of crisis situations, each demanding changes in the family's patterns of functioning (McCubbin & McCubbin, 1996).

Prior strains: Most families are experiencing strains at any given time, either due to previous unresolved problems, for example financial strain, or as a result of family roles, for example parenting responsibilities. These prior strains can become more pronounced in the face of a new stressor and thus contribute to the pile-up of demands (McCubbin & McCubbin, 1996). For example, loss of employment exacerbates the already present financial strain.

Situational demands and contextual difficulties: The family's environment may create additional demands or hinder the family in its attempts to adapt to a crisis, for example the job market might be saturated, making it difficult to find a new job.

Consequences of family efforts to cope: The strategies a family has previously employed to cope with the stressor, leading to a short-term reprieve, are adding to the burden in the long-term, for example one parent staying at home to take care of a sick child leads to increased financial strain.

Intrafamily and social ambiguity: This strain results from the uncertainty associated with instituting changes to the family's patterns of functioning; for example, a family deciding that one parent should stay home with the children cannot be certain how this decision will impact on the family. Also, there are inadequate social guidelines as to what constitutes effective coping and how to achieve it, for example deciding to place a chronically ill family member in a home that provides care might not be considered appropriate by society as a whole.

Newly instituted (TT) versus established (T) patterns of functioning: The resolution of a crisis situation depends on changes in the family's patterns of functioning in an effort to restore

harmony and balance. The initiation of these changes puts additional strain on the family's resources, however, since it calls for a redefinition of previously held roles, beliefs and expectations, which the family might be reluctant to accept (McCubbin & McCubbin, 1996). For example, a mother attempting to cope with the road death of her child may attempt to raise public awareness and bring about legislative change to make the streets safer for children and, in doing so, leave the rest of the family to take up domestic roles, which can lead to tension within the family. The family then has to engage in a process of instituting new patterns of family functioning and appraising their efficacy in managing the stressor and restoring harmony and balance, while also attempting to assimilate these changes into their existing patterns of functioning, values, beliefs and expectations, until they arrive at a level of family functioning that fosters growth, harmony and balance and thus facilitates adaptation (McCubbin & McCubbin, 1996).

2.3.3.2. Family Resources (BB & BBB)

Family resources refer to the strengths and capabilities a family can call upon or create in order to meet the demands that arise from a crisis situation. There are three potential sources of resources, namely the individual family member, the family as a unit and the community. Resilience resources are defined as “a characteristic, trait or competency (...) that facilitates adaptation” (McCubbin & McCubbin, 1996, p. 33).

The following personal resources have been identified in the literature (Antonovsky & Sourani, 1988; McCubbin & McCubbin, 1996; Olson et al., 1983) as contributing to adaptation: intelligence, knowledge and skills; personality traits that facilitate coping; physical, spiritual and emotional health; a sense of mastery; self-esteem; a sense of coherence; and ethnic identity and cultural background. Of these resources, particular emphasis has been placed on sense of mastery, self-esteem, sense of coherence and ethnicity and culture, since these resources facilitate efforts to manage demands and maintain a sense of order during change. Unfortunately,

these are the resources most likely to disintegrate in the face of a crisis (McCubbin & McCubbin, 1996).

In terms of family systems resources, researchers have identified a number of resilience resources that contribute to successful adaptation. The two most prominent resources identified are family cohesion, which refers to the bonds of unity, trust, appreciation, support and respect within the family, and adaptability, or the family's ability to change in order to meet demands. Other relevant family resources are family organisation, communication, family problem-solving styles, family time and routines and family hardiness. Family hardiness refers to the ability to maintain a sense of control, to view change as beneficial and to actively pursue a desired outcome (McCubbin & McCubbin, 1996).

Social Support (BBB) is viewed as one of the primary buffers to stress, thereby facilitating adaptation. It refers to any external resource the family can call upon in a crisis situation to provide support. Social support can be formal, for example medical professionals, or informal, for example the extended family (McCubbin & McCubbin, 1996).

2.3.3.3. Family Appraisal Processes

The family appraisal process as outlined in the Resiliency Model of Family Stress, Adjustment and Adaptation involves five levels: Schema (CCCCC), Coherence (CCCC), Paradigms (CCC), Situational Appraisal (CC) and Stressor Appraisal (C). According to the model, stressor appraisal takes place in the adjustment phase and is carried over into the adaptation phase, where it is expanded upon. The appraisal processes are central to family adaptation and resilience, since they help families to make meaning of stressful life events and play an important role in shaping the family's response. As mentioned previously, the Resiliency Model of Family Stress, Adjustment and Adaptation introduced the concepts of culture and ethnicity as important contributors to family resilience. These factors play an important role in shaping family reactions

to stress, not least because they influence three important levels of family appraisal, namely schema, coherence and paradigms (McCubbin & McCubbin, 1996), which will now be discussed in turn.

Family Schema (CCCCC): A family's schema refers to a set of beliefs, values and expectations the family holds of itself, of the world and of the family in relation to its environment. It includes cultural and ethnic beliefs and serves as a framework for evaluating experiences and shaping responses or behaviour. More specifically, the family schema facilitates meaning making. It allows the family to 'reframe' (Olson et al., 1983) the crisis situation, thereby making it more understandable and manageable and thus enabling the family to formulate an appropriate response geared toward adaptation. The family schema also plays an important role in shaping family patterns of functioning, and problem-solving and coping responses (McCubbin & McCubbin, 1996).

Family Coherence (CCCC): Family coherence refers to the family's perception of the world as comprehensible, manageable and meaningful (Antonovsky, 1979). This perception that their efforts are likely to have an effect provides the family with the confidence needed to mobilise its resources and institute the changes necessary to facilitate coping and adaptation (McCubbin & McCubbin, 1996).

Family Paradigms (CCC): Family paradigms are those rules and expectations the family holds with regard to specific domains of family functioning, for example child rearing. They determine patterns of functioning and are used to interpret situations and guide behaviour. Paradigms are often shaped by a family's cultural and ethnic identity (McCubbin & McCubbin, 1996).

Situational Appraisal (CC): The above-mentioned appraisal processes shape the family's perception of the stressor, its severity and its expected impact on the family patterns of functioning and, by extension, impact on and shape the family's situational appraisal. Situational

appraisal then refers to the family's perception of the demands arising from the stressor relative to the resources available to deal with these demands. Positive appraisal of the situation is positively related to adaptation (McCubbin & McCubbin, 1996).

Stressor Appraisal (C): The family's definition of the stressor and its severity is secondary in the adaptation process, because, following a family crisis, the family is faced with changes in family functioning and a pile-up of subsequent demands, which go beyond the impact of the initial stressor (McCubbin & McCubbin, 1996).

2.3.3.4. Family Problem Solving and Coping (PSC)

Family problem-solving and coping refers to the processes by which families acquire and allocate resources to meet the demands arising from the crisis. More specifically, coping is defined as a specific effort by which the family attempts to reduce the number and intensity of demands, to acquire and employ resources to manage the situation caused by the stressor, and to make meaning of the situation. This appraisal or meaning-making process is facilitated by the family schema and can help the family manage the situation by making it more manageable and acceptable, as well as by fostering a positive outlook. The aim of these coping and problem-solving strategies is to achieve a balance between demands and resources, while reducing stressors or strains (McCubbin & McCubbin, 1996).

Adaptation occurs when a family realises that the demands posed by a stressor outweigh the available resources and that changes in the family's patterns of functioning are necessary to restore stability. It is a dynamic and relational process aimed at restoring harmony and balance, both within the family as well as in the family's relationship to the community and the environment (McCubbin & McCubbin, 1996). Bonadaptation is achieved if new patterns of functioning are instituted and successfully integrated into the family's schema and paradigms, resulting in the desired harmony and balance. However, if the family's attempts at change are

unsuccessful, or if these changes cannot be accepted by family members and incorporated into the family schema, the process results in maladaptation and the family returns to the crisis situation (XX) where the cycle repeats itself (McCubbin & McCubbin, 1996).

In summary, family adjustment involves the resolution of a family stress situation by employing the available resources to restore harmony and balance to the family unit. This involves minor changes to the family system at most. Adaptation, on the other hand, occurs in response to a more severe stressor, the impact of which cannot be buffered or countered with the resources available to the family. This situation then calls for changes to the family system. Families adapt by instituting changes to the patterns of functioning, including roles, values and rules. These changes then need to be legitimated through the family schema, paradigms and the situational appraisal, that is, they need to be incorporated in an effort to achieve stability (McCubbin & McCubbin, 1996).

Another important model of family resilience, namely the Family Resilience Framework, was proposed by Walsh (2003).

2.4. Family Resilience Framework

Drawing on research conducted on family resilience in the past years, Walsh (2003) developed a family resilience framework that provides a summary of factors contributing to family resilience, termed resilience resources, many of which tie in with McCubbin and McCubbin's Resiliency Model of Family Stress, Adjustment and Adaptation (1996). According to Walsh (2003), family resilience involves "key processes over time that foster the ability to "struggle well", [and] surmount obstacles" (p. 1). These key processes enable the family to overcome crises and adapt successfully, emerging stronger and more resourceful. As already outlined in McCubbin and McCubbin's (1996) model, family functioning and resilience have to be viewed within the broader context of society and the environment, as well as within the family's life-cycle stage,

since these contribute to both the perception and severity of the stressor, as well as the family's response. Every family experiences stressors differently, depending on their cultural and ethnic beliefs, experiences, social context and life-cycle stage, and will employ both unique and more typical responses in attempting to overcome the state of distress a stressor has caused. A family resilience framework, then, has to identify common responses to a crisis situation, while also allowing for each family's unique perspectives (Walsh, 2003). Since stressors affect families differently, tend to evolve over time and can be exacerbated further by a concurrent pile-up of demands, no single coping response can explain family adaptation and resilience; resilience rather involves an adaptational pathway (Walsh, 2003), in which numerous resources or strengths are employed and interact over time to facilitate adaptation.

Walsh's (2003) family resilience framework identifies key processes from three domains of family functioning, namely family belief systems, organisational patterns and communication processes, which can facilitate the reduction of stress, foster growth and empower families to overcome adversity, that is, become resilient. These processes will now be discussed in turn.

2.4.1. Family Belief Systems

Family belief systems influence family resilience by helping the family make meaning of adversity, facilitating a positive outlook and offering spiritual guidance and support. They allow the family to reach a shared understanding of their reality and guide their response to the crisis (Walsh, 2003).

A family faced with a family crisis, as determined by a major stressor and the concurrent pile-up of demands, need to make meaning of their situation in order to come to terms with the crisis and select adequate coping behaviours. Families achieve this by attempting to normalise and contextualise their distress. By reframing their feelings and responses as 'normal' and understandable in the light of adversity, and by viewing the situation in the larger context of

society and their environment, that is, looking at the big picture, families feel less overwhelmed and more confident to decide on a shared course of action (Walsh, 2003). This process is facilitated by McCubbin and McCubbin's (1996) family schema, the framework guiding family understanding and behaviour. The desired outcome of the meaning-making process has been termed by Antonovsky and Sourani (1988) as sense of coherence, which is characterised by the perception of a situation as understandable, meaningful and manageable. The meaning-making process is complicated by ambiguity and uncertainty about future outcomes, since these factors make it more difficult to grasp the situation and decide on a suitable course of action (Walsh, cited in Walsh, 2003).

A successful meaning-making process facilitates a positive outlook, another key process identified by Walsh (2003) as influencing family resilience. By reframing a crisis situation as understandable and manageable, the family is able to maintain a sense of control and feel that the struggle to adapt will be successful, or worthwhile in the long run (Hastings & Taunt, 2002). A positive outlook fosters hope, which empowers families to struggle well and rise above adversity. This sense of hope for the future is not to be confused with denial of the severity of the situation; it is rather characterised by a belief that, in spite of the adversity the family is facing, they will make the most of the options available to them (Walsh, 2003). The concept of family hardiness proposed by McCubbin and McCubbin (1996) is related to positive outlook in so far as it enables families to maintain a sense of control, to view change as beneficial and to actively pursue a desired outcome.

Spirituality, religion and culture have also been found to facilitate meaning making and a positive outlook. They provide a framework through which the family can make meaning of the world, as well as allowing the family to seek a deeper understanding of the reasons for their suffering. In perceiving their struggles as having a higher purpose, families are able to accept factors beyond their control, while believing that the ultimate outcome will be positive. They

thus strive to make the most of their situation and emerge stronger. Cultural and religious affiliations also provide important support networks, which help families to avoid feelings of isolation and thus facilitate a positive outlook (Walsh, 2003).

2.4.2. Family Organisational Patterns

The second domain of family functioning vital to family resilience is family organisation. According to McCubbin and McCubbin (1996), adaptation following a crisis is dependent on changes to the family system. The family need to institute major changes to their patterns of functioning, rules and family roles, while at the same time maintaining the integrity of the family unit. This process is facilitated by flexibility, connectedness or cohesion and social and economic resources in the family unit (Walsh, 2003).

Family flexibility refers to the family's ability to adapt following a crisis by instituting and accepting changes to the family structure and functioning. Rather than bouncing back following a crisis, families need to "bounce forward", that is, move toward a new level of functioning (Walsh, cited in Walsh, 2003).

This process is facilitated by family cohesion, defined as the level of emotional closeness, collaboration and support between family members (Olson et al., 1983), while simultaneously putting strain on this cohesion if family members cannot agree on a course of action. Families thus need to agree on a shared course of action that works for the whole family, while being acceptable to its individual members. This allows family members to support each other through adversity and the resulting changes, which in turn makes it less likely for individual family members to feel overwhelmed by the situation (Walsh, 2003).

A family's level of flexibility and cohesion has been found to be indicative of their resilience and adaptation (Hawley & DeHaan, 1996; Patterson, 2002).

As mentioned in the previous section, social support networks are vital in a family's struggle towards adaptation. They offer both emotional and practical support and help counteract feelings of isolation. These networks are made up of the extended family, friends, religious groups and formal institutions. Financial resources are equally important in facilitating family resilience, since the lack thereof adds to the already present pile-up of demands (Walsh, 2003).

2.4.3. Communication and Problem-Solving Processes

The final domain of family functioning contributing to family resilience is communication. Communication processes that encourage open emotional expression help bring clarity to a situation and foster collaborative problem-solving (Walsh, 2003).

Clear and comprehensive information about a situation enables the family to make meaning of it and make an informed decision about an appropriate course of action. As mentioned previously, ambiguity and uncertainty hamper understanding and mastery of a crisis. In striving for resilience it is important that family members are able to communicate openly with each other, both about the realities of their situation and their resulting emotions (Walsh, 2003). This aids a shared understanding of the crisis, allows individuals to feel supported and facilitates collaborative problem-solving.

Collaborative problem-solving allows the family to identify an appropriate course of action for overcoming adversity. This response is unique to the family and is agreed upon by the family as a whole. It takes into account the family's unique resources, values and beliefs, as well as the individual differences and needs of its members and provides family members with a clear idea of what is expected of them and which goal the family is ultimately striving towards (Walsh, 2003).

According to Walsh (2003) there can be no single model or blueprint of successful family functioning and adaptation, since all families are unique and experience or interpret stressors

differently. In addition, every family's response to a stressor or crisis situation will be different, since the resources available to families differ, as does their family structure, including patterns of functioning, schemas and paradigms. There are, however, a number of key processes that are common to high-functioning families and have been found to facilitate resilience. By targeting and strengthening these processes a family can achieve successful adaptation and resilience.

2.5. Summary and Integration of the Two Theories

The concept of family resilience has evolved over time. While family-stress researchers initially focused on family deficits in explaining family stress, the focus shifted towards a strength-based approach, where researchers attempted to explain why some families are better able to cope with stress and adversity than others and often emerge from a crisis stronger and more resourceful. Hill's (1949) ABCX model provided the initial framework within which this research was conducted, but as the knowledge base grew, family stress and resilience models evolved. McCubbin and McCubbin's (1996) Resiliency Model of Family Stress, Adjustment and Adaptation is the most recent extension of family resilience models. It provides a theoretical framework outlining the processes involved in a family's response to a stressor. Family adjustment occurs when a family is able to successfully overcome the impact of a stressor with only minor changes to the family system. In those instances where this adjustment process is unsuccessful due to the severity of the stressor and the family's vulnerability, a family crisis ensues. The family crisis marks the beginning of the adaptation phase, where the family is called upon to institute changes to its patterns of functioning in order to adapt and overcome the adversity it faces.

The key processes of resilience identified by Walsh (2003) can be integrated into and explained through McCubbin and McCubbin's (1996) model. The family belief systems, which facilitate meaning making and positive outlook, correspond to the appraisal processes outlined by McCubbin and McCubbin (1996). The family schema, coherence and paradigms represent the

shared views, rules and expectations the family holds, which shape its meaning-making processes and allows the family to maintain a sense of control and a positive outlook. This sense of control and the perception that adversity is a challenge that can be actively and successfully overcome signify family hardiness, a family resource identified by McCubbin and McCubbin (1996).

The family organisational patterns of flexibility, cohesion and social and economic resources identified by Walsh (2003) are also identified by McCubbin and McCubbin (1996) as resources relevant to adaptation. In addition, flexibility and cohesion are identified as being central to the resilient family typology (McCubbin & McCubbin, 1996).

According to McCubbin and McCubbin (1996), open family communication is a family system resource, as well as an important component in both the appraisal process and the family's problem-solving and coping response. This idea ties in with Walsh's (2003) proposal that clarity and open emotional expression aid meaning making and collaborative problem-solving. In addition, McCubbin and McCubbin (1996) state that any changes to the family's patterns of functioning need to be legitimised or validated through the family schema and paradigms, and should be acceptable to all family members. This statement is mirrored by Walsh (2003), who maintains that any course of action the family decides on has to be acceptable to both the family as a unit as well as to individual family members.

Similar to Walsh's (2003) framework, McCubbin and McCubbin's (1996) model does not represent a rigid model or blueprint against which successful family functioning and resilience are measured, but rather provides a theoretical framework identifying resources central to family resilience and the processes by which these resilience resources shape adaptation.

Since family functioning is a measure of adaptation and family resilience, a resilient family can be defined as a family that adapts successfully following a family crisis and regains or surpasses its original level of functioning (McCubbin & McCubbin, 1996; Walsh, 2003).

Family functioning can be operationalised by family cohesion and flexibility (Hawley & DeHaan, 1996; McCubbin & McCubbin, 1996; Patterson, 2002; Walsh, 2003), since these factors involve achieving a balance between separateness and connectedness and change and stability (Olson et al., 1983). In order to adapt and be resilient, families need to institute changes to their structure and functioning, while maintaining stability and holding on to their core identity. Equally, the family has to work together as a unit, while also allowing for the unique perspectives and needs of its members. A family that can achieve this balance can return to a healthy level of family functioning. For the purpose of this study, flexibility and cohesion have been considered to constitute a measure of family functioning, or adaptation, and will thus be used as the dependent variable (as measured by the Family Attachment and Changeability Index (FACI8)).

2.6. The Experiences of Families with a Child with a Disability

The birth or diagnosis of a child with a developmental disability represents a major and unique stressor to the family unit. The family as a unit, as well as its individual members, has to deal with feelings of shock, grief, guilt, and uncertainty about the future, as well as having to institute major changes to the family's functioning in order to accommodate the unique needs of the child (Beckman, 1991; Gatford, 2007; Quine & Pahl, 1987; Weisner, Beizer, & Stolze, 1991). This process is strongly influenced by the socio-cultural and developmental context the family finds itself in, since these factors influence the family's perception of disability and the resources it has available to cope with care-giving demands and the resulting emotional and also financial strains (Garwick, Kohrman, Titus, Wolam, & Blum, 1999; Walsh, 2003; Xu, 2007). A lot of

research to date has focused on this “negative” impact of disability on the family, and the abovementioned aspects will now be discussed in more detail.

2.6.1. The Social Construct of Disability

As outlined in the discussion on family resilience, the appraisal or meaning-making process is central to family adaptation (McCubbin & McCubbin, 1996; Walsh, 2003). A family’s social and cultural background are core contributors to this appraisal process, since they play a role in shaping a family’s schema and paradigms, or values, beliefs and expectations about itself and the world it exists in. According to Xu (2007), cultural differences play a critical role in how families define disability and in their perceived level of stress, and determine how comfortable they are in seeking help. It is thus important to discuss the cultural constructions of disability, since they shape the family’s perception of its situation and thus its adaptation (Garwick, et al., 1999).

Western culture places a strong emphasis on the value of the individual and his/her contributions to society. In spite of much work in recent years to change this perception, people with disabilities are often still viewed as “deficient” (Gross & Hahn, 2004; Parekh & Jackson, 1997) and as a burden on society (Turnbull & Turnbull, cited in Kearney & Griffin, 2001) and the family (Beckman, 1991; Weisner, et al., 1991). For this reason, the birth of a child with a disability is perceived as devastating (Gatford, 2001). Parents have been found to experience grief at the loss of their “normal” child (Weisner et al., 1991), shock and confusion (Gatford, 2001; Quine & Pahl, 1987), anger (Cunningham & Davis, cited in Gatford, 2001), depression (Blacher et al., cited in Emerson, 2003) and guilt (Gatford, 2001; Masood, Turner, & Baxter, 2007), and it is often assumed that families cannot recover from, and positively adapt to, the birth of a child with a disability (Beckman, 1991; Hartshorne, 2002).

This societal perception of disability and the expected impact a child with a disability will have on the family is evidenced by the reactions families have to contend with, from both medical professionals and their wider social networks. Since the dominant perception of disability is still focused on deficits, the initial diagnosis parents receive regarding their child's condition and the future prognosis is still coloured strongly by negativity (Graungaard & Skov, 2006; Kearney & Griffin, 2001; Retzlaff, 2007). Parents are informed that something is 'wrong' with their child, often without any indication of what to expect from the future and no attention to, or reassurance regarding, the potential for positive development. Such ambiguity and negativity influence the meaning-making process, making it more difficult for the family to reframe the situation and gain a positive outlook in order to work towards adaptation (Taanila, 2002; Walsh, 2003; Woolfson, 2004).

In their wider social network, families may have to contend with prejudice, fear and rejection (Ainbinder et al., 1998; Crabtree, 2007; Retzlaff, 2007; Sari, Baser & Turan, 2006). The stigma attached to disability influences the reactions of others to the family with a child with a disability. Families may feel that their child is not accepted (Crabtree, 2007), is perceived as threatening and repulsive (Crabtree, 2007; Sari et al., 2006), that they are being judged or blamed (Crabtree, 2007; Gatford, 2001), or they might simply feel ashamed (Crabtree, 2007). They will tend to withdraw and attempt to cope on their own rather than dealing with society's prejudices. Since social support networks are an important resource facilitating adaptation (McCubbin & McCubbin, 1996; Walsh, 2003), this isolation increases the strain on the family system and makes it more difficult to cope (Emerson, 2003).

The dominant Western perception then is that the birth of a child with a disability is the 'death knell' for normal, healthy family functioning and that the family is inevitably 'damaged' as a result. Not only is their life expected to be a long struggle, but acceptance of the situation, as

characterised by hope and a positive outlook, is often assumed to be dysfunctional and indicative of denial (Hartshorne, 2002; Helff & Glidden, 1998; Kearney & Griffin, 2001).

This socio-cultural attitude makes adaptation much more difficult for the affected families; not only does it colour their own perceptions and subsequent coping responses, but also has an influence on the resources and support available to them.

Research on perceptions of disability in other cultures is limited, but some studies have found that different cultures place a different emphasis on disability.

Connors (cited in McCubbin & McCubbin, 1996) found that Native American cultures focus not on the deficits of children with disabilities, but rather on the unique function the children can fulfil in their family, or the community, regardless of their level of ability. In spite of their disability they are perceived as fully functioning and valuable members of the community. There is no stigma attached to having a child with a disability and the burden of care is shared by the family and the community, rather than falling on the family alone.

In Nguni cultures, disability is not seen as a generalised deficiency, but is rather seen to affect certain aspects of an otherwise functional and valuable human being. These individuals are wholly integrated into the community (Parekh & Jackson, 1997).

Hinduism explains disability as punishment of the affected individual for sins in a previous life, and the person has to be supported in striving for virtue in order to be redeemed. By being tolerant and supportive of a person with a disability, one can increase the chances of a good or better next life for oneself (Parekh & Jackson, 1997).

Studies conducted by Crabtree (2007) and Masood et al. (2007), however, indicate that social stigma associated with disability is prevalent in Middle Eastern cultures, where the family is often ostracised as a result of having a child with a disability.

As these examples highlight, the perception of disability, its impact and causes differ considerably between cultures. In the words of Parekh and Jackson (1997), “Not only do cultural differences exist in what aspects that specific culture identifies as deficient, but also in how families make sense of why the disability exists and the support they offer as a result” (p. 41).

An additional influence of culture that cannot be disregarded in this discussion is the effect it has on the economic situation of a family. Emerson (2003) found that families from historically disadvantaged groups often had a lower socioeconomic status than other families and subsequently found it more difficult to adapt following the birth of a child with a disability. In South Africa, many families from previously disadvantaged ethnic groups equally have limited external resources available to facilitate adaptation to a child with a developmental disability (Parekh & Jackson, 1997; Statistics South Africa, 2005). For these reasons it is vitally important to take cultural influences into consideration when examining resilience in families of a child with a developmental disability.

2.6.2. Developmental Perspective

Just as the socio-cultural environment of the family influences the impact that the birth or diagnosis of a child with a developmental disability has on the family, so does the family's developmental stage. As mentioned by both Walsh (2003) and McCubbin and McCubbin (1996), the life-cycle stage a family is at determines the pile-up of demands over and above the initial stressor, as well as the resources the family has available. A family that is already faced with an array of other normative and non-normative stressors will find it more difficult to adjust to the birth of a child with a disability, especially if their resources are already depleted. In addition, the

birth of a child with a disability often impedes the family's natural progression through the life-cycle stages. Depending on their level of disability, many of these children will not be able to live independently. The family then does not progress through the launching phase, or experience the empty nest syndrome, but rather has to care for a child into and beyond their retirement stage. This stagnation causes additional stressors for the family (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001).

2.6.3. Difficulties Faced by Families Caring for a Child with a Developmental Disability

On the basis of the previous two sections it is clear that the socio-cultural and developmental context in which the family exists will influence the impact a child with a developmental disability will have on the functioning of the family unit. There are, however, other factors contributing to the difficulty of parenting a child with a disability. This section will discuss these factors, as well as their impact on family functioning.

Following the birth or diagnosis of a child with a developmental disability, parents are forced to re-evaluate their expectations. They are faced with a situation they had not anticipated and might feel ill-equipped to deal with (Gatford, 2001; Graungaard & Skov, 2006; Hartshorne, 2002). In addition to the grief and shock they feel at learning of their child's disability, they face feelings of uncertainty about the future (Taanila et al., 1998). As mentioned in the previous section, the information parents are provided with on diagnosis is generally viewed as insufficient. They cannot yet anticipate the impact their child's disability will have on their family and what the future prognosis for their child will be, or whether they will be able to meet the child's needs (Gatford, 2001; Graungaard & Skov, 2006; Kearney & Griffin, 2001; Quine & Pahl, 1987; Sari et al., 2006). The only thing parents can be sure of is that they will have to redefine their expectations as well as institute changes to their patterns of functioning, including family roles (Cahill & Glidden, 1996; Ellis & Hirsch, 2000). For these reasons, as well as because of the

stigma associated with disability, many parents initially struggle to accept the disability of their child (Ainbinder et al., 1998).

A child with a developmental disability usually has many more care needs than other children, including medical care, feeding, toileting, in addition to providing mental and physical stimulation. These needs place strain on the family's emotional, time and financial resources. Families often find themselves struggling to cope with the demands of daily life (Ellis & Hirsch, 2000) and might even find that one parent has to stay at home, full-time or part-time, to assume the responsibility of care (Parekh & Jackson, 1997; Seltzer et al., 2001). The family thus loses a source of income, which adds to the already increased financial strain (Baker, Blacher, Crnic, & Edelbrock, 2002; Emerson, 2003; Parekh & Jackson, 1997). In addition, the parent having to stay at home might feel frustrated at this role restriction (Pelchat et al., 1998; Sloper & Turner, 1993; Wallander & Varni, 1998) and show increased levels of stress as a result of the difficulties involved in caring for the child (Plant & Saunders, 2006; Sari et al., 2006; Sloper & Turner, 1993). These feelings can foster resentment and lead to interpersonal strain in the family (Catherall & Iphofen, 2006; Ellis & Hirsch, 2000). In addition, due to the demands the child with a disability places on their time, parents might find that they have no time for themselves and become increasingly isolated from their social network, which causes a further increase in stress and places additional strain on family relationships (Catherall & Iphofen, 2006; Crabtree, 2007; Sari et al., 2006; Seltzer et al., 2001; Taanila, Kokkonen, & Järvelin, 1996).

Many young people with disabilities have also been found to exhibit significantly more mental health problems than their non-disabled peers. This is especially true in adolescents with disabilities experiencing the emotional upheaval normally associated with puberty, magnified by their intellectual and/or physical impairments and subsequent dependence (Faust & Scior, 2008). Adolescence is thus often accompanied by an increasing awareness in the child that they are different from their peers and might always need support from others, which can cause an

increase in behavioural problems and depression. This phase in the family life cycle often causes a marked increase in parental stress (Todd & Jones, 2005).

As can be deduced from the abovementioned difficulties associated with caring for a child with disabilities, this can be a very stressful experience. Pelchat et al. (1998) found that the parents of children with a developmental or physical disability showed significantly higher levels of distress than parents of children without disabilities, a finding also reported by Beckman (1991). It is generally assumed that the child's type and level of disability will influence family stress levels and consequently family adjustment and functioning, but the findings on this seem to be conflicting. According to a study by Sloper and Turner (1993), the severity of disability, level of communication difficulties and care-giving demands were positively associated with the level of parental distress and thus influenced the parents' adaptation. Similarly, a study by Hoare, Harris, Jackson, and Kerley (1998) found a positive relationship between the severity of the child's disability and the parents' levels of distress. This was especially true if the child exhibited many behaviour problems and a high level of dependence.

Cahill and Glidden (1996), on the other hand, found no differences in functioning in families of children with Down syndrome compared to families of children with other developmental disabilities. This finding is also reported in a review of studies by Wallander and Varni (1998). In these studies, neither severity nor type of disability was found to affect the mothers' reported adjustment, and neither did the burden or strain of care. They did, however, find that the level of disability-related stress influenced adjustment. A similar finding was reported by Horton and Wallander (2001), who found that actual level of disability did not affect the level of adjustment, while the perception of disability-related stress and care-giving demands did. Baker et al. (2002) conducted a study comparing child behaviour problems and parenting stress in families of children with and without developmental delays. Children with delays were found to exhibit more behaviour problems than children without delays, which in turn contributed to parenting

stress. The level of child behaviour problems contributed more to parenting stress than did level of disability. This contribution of child behaviour problems to parenting stress was also found by Emerson (2003), Plant and Saunders (2006) and Stores, Stores, Fellows and Buckley (1998). Mirroring Horton and Wallander's (2001) finding, Plant and Saunders (2006) also found that the parents' appraisal of the level of disability contributed more to parenting stress than the actual level of functioning. On the basis of these findings it can be concluded that the disability of a child causes an increase in parental stress. This is, however, not associated with the actual level of disability or functioning of the child, but rather with the parents' perceptions thereof, as influenced by behaviour problems and care-giving demands.

In spite of all these demands, many families have been found to adapt positively to their child (Bayat, 2007; Hastings & Taunt, 2002; Kearney & Griffin, 2001; Wallander & Varni, 1998). They learn to cope with their child and develop a 'normal' life (Hartshorne, 2002). Parents report a strong love and admiration for their child and talk about the joy he/she brings and their pride in his/her achievements (Bayat, 2007; Gatford, 2001; Kearney & Griffin, 2001). Many parents go even further, to highlight the positive impact their child has had on them and the family. They feel that they have grown in infinite ways and are proud of their ability to care for and nurture their child in spite of all hardships (Bayat, 2007; Gatford, 2001). Parents report becoming stronger (Kearney & Griffin, 2001), more compassionate, tolerant and understanding, and acquiring new skills as a result of caring for their 'special' child (Bayat, 2007).

2.6.4. Summary

As is evident from the above discussion, the birth or diagnosis of a child with a developmental disability represents a major non-normative stressor for a family. Family members have to deal with feelings of shock, grief and uncertainty about the future, feelings which are often exacerbated by the social prejudice still associated with disability, and with the resulting isolation of the family. In addition to this, the family has to institute major changes to its

established patterns of functioning to incorporate the needs of the child, which further increases the strain on the family unit. In spite of these difficulties associated with the disability of a child, some families adapt well and even thrive in response, while others crumble. The resilience factors and processes outlined in Sections 2.3. and 2.4. are thought to account for this variance.

2.7. Conclusion

This chapter has aimed to outline and explain the central concept of this study, namely family resilience, and to provide an idea of why it is relevant in families of children with a disability. The following chapter will provide a summary of the literature on family resilience and adaptation in families, particularly those with a child with a disability. These studies examine the contribution of the resilience resources, outlined in the abovementioned theories of family resilience, to positive adaptation, or resilience, in families.

Chapter 3

Literature Review

3.1. Introduction

As mentioned in the previous chapter, psychological research in the past has focused mainly on identifying the causes for adaptive deficits and problems, rather than studying strengths contributing to healthy functioning. The past two decades, however, have witnessed a much-needed shift in emphasis towards a salutogenic approach (Antonovsky, 1979).

Seligman (cited in Hawley, 2000) applauds this shift in the following words: “psychology is not just the study of weakness and damage, it is also the study of strength and virtue” (p. 2), and therapists would do well to focus on and amplify strengths rather than try to repair weaknesses.

This approach is underlying in the study of family resilience. Researchers have attempted to identify the factors or strengths contributing to the adaptation of families in the wake of a crisis. The aim of such research is to identify avenues of intervention for therapists working with families in crisis (Luthar et al., 2000). Rather than viewing the family as damaged and focusing on the causes for its difficulties, the focus in therapy or intervention shifts to identifying, amplifying and acquiring resources facilitating adaptation (Walsh, 2003).

Although the study of family resilience is still a comparatively recent concept, there is, however, a growing body of literature describing resilience resources found to be relevant in families. According to Luthar et al. (2000), who conducted a review of resilience literature, similar correlations have been found across multiple different studies. In other words, there are a number of variables that have repeatedly been found to influence family resilience. These resources will now be discussed in turn.

3.2. Family Cohesion and Flexibility

As mentioned in the previous chapter, family cohesion and flexibility are important resilience resources. In order to adapt successfully, families need to institute changes to the family unit while maintaining continuity and stability. During this period of adaptation, family members need to work together and be supportive of each other, while respecting their individual differences and needs (Walsh, 2003). Those families who are able to achieve a balance between change and stability, while maintaining optimal levels of togetherness or cohesion, can return to a healthy level of family functioning (Olson et al., 1983).

According to a study conducted by Bayat (2007), the qualities of flexibility and cohesion in the family unit allow the family to pull together following the birth of a child with a disability. Bayat (2007) conducted a study to examine the factors contributing to family resilience in families of children with autism living in Illinois, USA. A total of 175 primary, biological caregivers, selected by convenience sampling, took part in the study. Of these respondents, 63% were white, 16% were African American, 12% were Hispanic and 3% were Asian American. The majority of the respondents (61%) were of upper socioeconomic status. The study employed both quantitative and qualitative measures. The findings reported here are those obtained from the qualitative measures. The qualitative measure consisted of three questions, asking respondents 1) to describe the positive and/or negative effects of autism on their family life; 2) to describe the positive and/or negative effects of autism on their personal life; and 3) to describe the child. Of the total respondents, 167 responded to these questions. Responses were analysed using thematic content analysis, with Walsh's (2003) framework used for the categorisation of thematic data. This analysis revealed four broad themes corresponding to the resilience resources identified by Walsh (2003), namely 1) pulling resources together, and connectedness, identified by 62% of the respondents; 2) making meaning of adversity (63%); 3) affirmation of strength and becoming more compassionate (39%); and 4) spiritual experience and beliefs (45%). No relationship was found between income or racial background and the perceptions of family members regarding

the effects of autism on their family. As these results indicate, a large percentage (62%) of the respondents identified cohesion as a resilience resource. Family members became closer and worked together to meet the demands of the child and protect it from negative external influences, like social prejudice, when necessary, becoming a stronger unit in the process. This process was facilitated by flexibility and communication within the family (Bayat, 2007).

Similar findings were reported by Retzlaff (2007), who conducted a qualitative study to examine the experience of families living with a child with Rett syndrome and to identify which factors these families perceived as contributing to their adaptation. To this end, six families living in Germany took part in a narrative interview. They were selected by convenience sampling from groups of families identified, in a previous study, as having a low and a high sense of coherence respectively. The data was then analysed in two stages: a qualitative content analysis to categorise the stressors and resources mentioned by the respondents; followed by the construction of narrative types, where the “story” of each family, including their stressors and resources, was examined as a whole and then grouped into story types. This analysis identified six categories of stressors (emotional difficulties, health concerns, uncertainty, social rejection, unavailable or unsupportive experts, and comparison with others), nine categories of resources (economic resources, access to information, personal resources, emotional expression, child characteristics, couple relationship, family relationship, social support, formal support and changes in worldview), and two types of resilience stories (the “story of refund balance”, and the “story of the long tedious walk uphill”, p. 252), each of which had two subtypes. Retzlaff (2007) found that those families with high levels of cohesion were more likely to accept the situation and work together to overcome the hardships associated with the birth of a child with a disability. These families perceived the situation as a challenge they could overcome together by instituting changes to the family system.

Taanila, Järvelin, and Kokkonen (1999) conducted a study to examine how a child's physical or intellectual disability affected family cohesion and parents' social relations, and whether there was an association between family cohesion and social relations. The sample consisted of 89 families (with 88 mothers and 74 fathers responding to the data-collection measures) drawn from the register of a local hospital and welfare organisation in an area of Finland. The respondents completed a questionnaire and took part in an interview, both of which were designed for the purpose of the study. Quantitative data was analysed using the Chi-square test, while qualitative data was coded according to pre-determined categories. These researchers found family cohesion to be the primary coping resource employed by families with a child with a disability. By increasing their levels of cohesion, these families were able to adapt to their situation. This increased family cohesion was not found to influence the parents' social relations, although the child's needs did affect family life and parents' work and leisure activities.

Heiman and Berger (2008) conducted a study comparing the family environment and perceived levels of social support in families of children with Asperger syndrome ($n = 33$), other learning disabilities ($n = 43$), and children without disabilities ($n = 45$) living in Israel. Samples were drawn from families attending a lecture on Asperger syndrome and families attending an after-school leisure and teaching centre. These researchers used two quantitative measures to obtain data from the participating families, namely the Family Environment Scale (FES) and the Multidimensional Scale for Social Support (MSPSS). The FES measures respondents' perceptions of the family climate in three domains, namely relationships, personal growth, and system maintenance. The MSPSS measures perceptions of family, friend and significant other support. Data was analysed using multivariate analyses of variance (MANOVA) to compare differences in family environment between groups; using univariate analyses of variance (ANOVA) to compare perceived social support between groups; and by using a correlation analysis to identify relationships between family environment and social support. The analyses of variance revealed significant differences between groups of families in terms of

expressiveness, family organisation and social support, with family organisation being higher and perceived social support being lower in families of children with Asperger syndrome and learning disabilities compared to families in the control group. The correlations revealed a positive relationship between family cohesion and intra-family support and organisation. According to Heiman and Berger (2008), these findings may emphasise the importance of intra-family support in uniting the family in families of children with a disability.

The abovementioned findings indicate that family cohesion and flexibility are important factors in the adaptation of families of children with a disability. However, in order for the family to work towards achieving optimal levels of cohesion and flexibility, they first have to understand or make meaning of the situation in which they find themselves (Walsh, 2003).

3.3. Making Meaning of Adversity

“Those who have meaning in their lives survive and are healthy” (Frankl, cited in Kearney & Griffin, 2001).

The importance of meaning making for resilience has been highlighted by numerous researchers (Hawley & DeHaan, 1996; McCubbin & McCubbin, 1996; Patterson, 2002; Walsh, 2003). It shapes family functioning by allowing the family to appraise the situation in such a way as to make it understandable and manageable and thus allocate resources to deal with it. Olson et al. (1983) term this process as reframing. Reframing refers to the process by which the family redefines a situation to make it appear more manageable. The family assesses the situation and its ability to tackle the obstacles it is facing and initiates problem-solving strategies. This process influences and is influenced by family hardiness (McCubbin & McCubbin, 1996), that is, the family’s perception that they are in control, that change is beneficial and that they can actively work towards achieving a positive outcome. Reframing facilitates a positive outlook and hope. A vital component of reframing, highlighted by Olson et al. (1983), is the family’s ability to

identify those aspects of a situation that can be influenced, as compared to those that are beyond their control. Those that cannot be influenced are then redefined to make them more acceptable. This is especially relevant to families who have a child with a disability. The family has to accept that it cannot change or 'fix' the disability of its child and that the child might never progress beyond a certain level of functioning, while simultaneously maintaining a sense of hope for the future and believing in their ability to cope with the demands and needs of their child. Hartshorne (2002) terms this the "courageous paradox" (p. 268).

Hastings, Allen, McDermott, and Still (2002) conducted a study aimed at identifying the factors contributing to mothers' positive perceptions of their child with an intellectual disability. To this end, 146 questionnaires were sent home with all children with an intellectual disability attending two local schools in Southern England. Of these questionnaires, 41 were completed by the child's mother and returned. The self-report questionnaires employed in the data collection measured demographic factors, child variables, social support, coping strategies and positive perceptions. Data was analysed using regression analyses to investigate the contribution of the predictor variables to positive perception scores. These analyses revealed that the mothers' positive perceptions of the child were positively associated with reframing coping strategies. By reframing their situation as understandable, manageable and meaningful, the mothers of children with an intellectual disability were more likely to develop more positive perceptions about their child and the child's impact on the family unit.

Various researchers have found that such positive perceptions about the child, the child's influence on the family and the family's ability to cope are important contributors to adaptation in families of children with disabilities (Bayat, 2007; Hastings et al., 2002). According to Folkman (cited in Hastings & Taunt, 2002), positive perceptions can bolster resources, buffer the impact of disability-related stress and protect against depression.

Bayat (2007) found that 63% of families of a child with autism perceived positive reframing of their child's disability as a factor contributing to family adaptation. This meaning-making process allowed families to develop and maintain a positive outlook on life; they were able to take joy in and appreciate every small accomplishment, and focus on lessons learned as a result of caring for a child with autism.

Svavarsdottir and Rayens (2004) conducted a cross-sectional study with families of young children with asthma to examine the effects of the parents' sense of coherence, that is, the perception of life as understandable, predictable and manageable, and the parents' well-being and family hardiness. The study also aimed to assess whether there were any cultural differences in the parents' well-being, sense of coherence and perception of family hardiness. To this end, 76 families of young children with asthma from Iceland, and 61 families from the United States of America, were recruited from health-care facilities where their child received treatment. The participating families were required to complete questionnaires measuring perceived sense of coherence, well-being and family hardiness. Data was analysed using Pearson product-moment correlations to identify relationships between variables. Differences in the parents' well-being, sense of coherence and perception of family hardiness based on nationality were determined using a two-way analysis of covariance. These analyses revealed that sense of coherence and well-being were positively related to perceived family hardiness, and that American families rated their family hardiness more positively than Icelandic families. Positive perceptions about the situation thus facilitated family hardiness in this sample. According to Svavarsdottir and Rayens (2005), high levels of family hardiness made families feel more confident to seek out resources and use them to meet the demands the family was facing. These families felt that they were in control of the situation and that they would be able to find a way to deal with it.

Hassall, Rose and McDonald (2005) conducted a study to examine the influence of parents' cognitions, child characteristics and family support on parenting stress. Participants were

recruited from six special needs schools in Southeast England. To this end, invitations to participate were sent to 202 mothers of children with an intellectual disability. Of these, 46 mothers eventually completed the relevant questionnaires. All the participants were of white European ethnic background and spoke English fluently. The study made use of various quantitative questionnaires for data collection. More specifically, the researchers employed the Vineland Adaptive Behaviour Scale and Maladaptive Behaviour Domain, the Family Support Scale, the Parenting Sense of Competence Scale, the Parental Locus of Control Scale and the Parenting Stress Index. Data was analysed using Pearson's product-moment correlations, partial correlations and a regression analysis. Hassall et al. (2005) reported that those mothers with high parenting self-esteem and a feeling that they were in control of their situation showed lower levels of parenting stress than those who felt they were dependent on external resources to cope.

According to Wallander and Varni (1998), this perception of competence in problem solving increases the likelihood of selecting appropriate coping strategies to facilitate adaptation.

This is similar to the findings reported by Horton and Wallander (2001), who conducted a study to examine the relationship between hope and social support, and parental distress in parents of children with chronic physical conditions. A convenience sample was recruited from mothers attending two local hospitals in Alabama, USA with their children. A total of 111 mothers participated in the study. Data was gathered using quantitative questionnaires designed to measure the perceived severity of the child's disability, hope, social support and maternal distress. Data was analysed using correlation and regression analyses. These researchers found that both hope and social support were negatively associated with maternal distress. In addition, hope moderated the relationship between stress and maladjustment in these mothers of chronically ill children. Those mothers that were able to maintain a sense of hope for the future were better able to cope with the stresses associated with their child's condition and to adapt positively.

Greeff, Vansteenwegen, and DeMot (2006) conducted a study aimed at identifying factors associated with family resilience following divorce. The sample consisted of 68 divorced single parent families from Belgium, with both a parent and a child being required to complete the measuring instruments. The measuring instruments consisted of a biographical questionnaire; five quantitative questionnaires, namely the Family Hardiness Index, the Family Crisis-Oriented Personal Evaluation Scales, the Relative Friend and Support Index, the Social Support Index and the Family Sense of Coherence Scale; as well as an open-ended question. Data was analysed using correlation and regression analyses. These researchers found that positive reframing and family hardiness, or perception of the situation as a manageable challenge, were positively related to family adaptation. Family adaptation was further found to be positively related to communication within the family.

3.3.1. Communication

Communication is an important factor contributing to family adaptation, since it facilitates meaning making as well as fostering collaborative problem-solving (Walsh, 2003). Clear and comprehensive information about a situation allows the family and its individual members to reach an understanding of what to expect, which in turn influences their response. By discussing their situation among themselves, family members are able to reach a shared understanding of the changes that are necessary in order to overcome adversity and of the contribution expected from each member (Bayat, 2007). In addition, open communication within the family ensures that individual family members receive the support they need from the family unit. Communication thus helps families to attain optimal levels of cohesion and flexibility (Patterson, 2002).

Vandsburger, Harrigan, and Biggerstaff (2008) conducted a study aimed at identifying factors related to family coping and adaptation in families living in poverty. To this end, 128 families were recruited from those families whose children attended Youth Centres in Virginia in the

United States of America. The mothers in these families were asked to respond to three open-ended questions aimed at identifying family strengths, challenges and coping responses. The responses were recorded verbatim and the data was then analysed using content analysis. These researchers found that open communication and the resulting mutual support and feelings of closeness were found to play a significant role in family adaptation in times of adversity.

This finding was also reported by Taanila, Syrjälä, Kokkonen, and Järvelin (2002), who found that open expression facilitated coping by increasing feelings of togetherness and cooperation. Taanila et al. (2002) conducted a study to evaluate the coping strategies employed by families of children with intellectual and physical disabilities in northern Finland, and to determine how families coping well differed from those that did not. Families identified as having a child with intellectual and/or physical disabilities in a previous survey were invited to participate in the study. Of 42 eligible families, 27 agreed to take part. These families were then interviewed to determine the impact of the child with a disability on the family and the family's level of functioning. Subsequently, those four families with the highest and lowest scores of family functioning respectively were invited for a second interview. The second interview aimed to identify the coping strategies employed by the participating families. The data thus gathered was analysed using the grounded theory method. The most frequently reported coping strategies were open emotional expression, good family cooperation, social support and information, and acceptance. High-coping families were found to employ more of these strategies than low-coping families, and had a more optimistic attitude about their situation and a positive outlook regarding the future.

3.3.2. First Diagnosis and Information about the Child's Condition

As is evident from the abovementioned findings, open communication within the family has been found to be an important coping resource in the families of children with a disability.

In a study conducted by Kearney and Griffin (2001), it was found that open and positive communication from friends and also medical personnel was equally important for families of children with a disability. Kearney and Griffin (2001) conducted a study to examine the experiences of parents in Western Australia whose child had a developmental disability. Invitations to participate were sent to 12 families with whom the first researcher had previously worked and who had expressed an interest in taking part in future research. Of these families, 10 agreed to take part in the study, whereupon six families were selected to be interviewed and talk about their experiences as parents of a child with a disability. The interviews were transcribed and analysed using Van Manen's (cited in Kearney & Griffin, 2001) phenomenological reflection, interpretation and writing. This analysis revealed that parents experienced feelings of both joy and sorrow with regard to their child's condition. Joy was derived from the parents' relationship with their child, while sorrow was often due to the attitudes of other people. The parents reported that communication from medical professionals and other people was often very negative, which made it more difficult for them to accept their situation, and to develop positive perceptions and an optimistic outlook. Sensitive and positive communication from medical professionals and friends, on the other hand, was reported as fostering hope and a positive outlook. This contribution of communication from external agencies, particularly medical personnel, has also been reported by other researchers (Gatford, 2001; Graungaard & Skov, 2006; Quine & Pahl, 1987; Taanila, 2002).

As mentioned previously, clear and comprehensive information is vital to successful meaning making. For this reason, the first diagnosis of disability is important. It provides the family with the basis from which to work towards understanding the situation facing them and the meaning this will have for their family. According to Taanila (2002), the first diagnosis influences the perception the parents have of their child and his/her future, and their expectations of future family functioning, and thus shapes the problem-solving and coping response. Ambiguity or

negativity from medical personnel can make the birth of a child with disabilities seem overwhelming.

Gatford (2001) conducted a study to examine the experiences of mothers from different cultures following the birth of a child with Down syndrome. Participants were selected by convenience sampling from mothers of a child with Down syndrome living in a South East London inner city borough. This borough comprises a large, multi-ethnic population, and the participants were selected to represent the three largest racial groups, namely white British, African Caribbean and West African. The sample consisted of nine mothers, with three from each racial group. The data was gathered using semi-structured interviews, aimed at recording the experiences of these mothers following the birth of their child. Gatford (2001) found that the mothers found it more difficult to adjust following the birth of a child with a disability if they received only limited and/or negative information about their child's condition. They struggled to make meaning of their child's disability and to perceive ways in which they would be able to cope. This was true for mothers from all ethnic groups.

This is similar to the findings of Quine and Pahl (1987), who conducted a study to examine the impact of the first diagnosis on parents' adjustment to their child with a disability. To this end, a stratified random sample of 200 families was drawn from all families in two districts of South East England whose child had severe intellectual disabilities. Of these families, 10 had to be excluded because the carer had not been present at birth and first diagnosis. The remaining 190 primary carers, all mothers except for one father, were subsequently interviewed and asked about their experiences of and satisfaction with the diagnostic process. Quine and Pahl (1987) found that parents found it more difficult to accept and adapt to their child's disability if the information they received on diagnosis was vague or ambiguous, leaving them feeling uncertain about the implications and expectations for the future.

Kearney and Griffin (2001) found that families had a desperate need for medical professionals to provide them with “a framework of optimism” (p. 289) to facilitate coping. This was also reported by Graungaard and Skov (2006), who found that the emotional reaction of parents to the diagnosis of their child is influenced by the diagnostic process. These researchers conducted a study aimed at investigating parents’ reactions to the diagnosis of their child’s disability, their satisfaction with the delivery thereof and their subsequent coping. The study made use of a qualitative, longitudinal research design. Both parents of eight children with severe mental and physical disabilities were interviewed about their experiences, shortly after the first diagnosis, and then again two years later. Participants were recruited from the patient register of a hospital in Copenhagen, Denmark. All 11 families of children with severe disabilities registered at the hospital were invited to participate, but only eight families agreed to take part in the interviews. The participating parents were interviewed separately. The interviews were transcribed verbatim and analysed using a grounded theory analysis. The results thus obtained indicate that those parents who were provided with clear information about the condition of their child and of what to expect found it easier to adapt to the situation. This was particularly so if medical professionals adopted an empathic approach and were able to give parents hope for the future, focussing not only on the ‘deficits’ of the child, but also on the child’s potential for development. Adaptation was further facilitated if the parents were provided with guidelines on how they could support their child, since this helped them maintain a sense of control over the situation.

Clear guidelines concerning the care for and support of the child with a disability were also found to be helpful in a study conducted by Taanila et al. (1998). These researchers conducted a study aimed at identifying whether the quality of the diagnostic process had improved in Finland over a course of 10 years, and whether the quality of information received affected parents’ adjustment and coping. They compared the experience of the diagnostic process and consequent adjustment among parents whose children had been diagnosed with an intellectual and/or physical disability in the late 1970s (n = 58) with that of those parents whose children had been

diagnosed between 1985 and 1986 ($n = 27$). All parents of children with a disability who had been born and diagnosed in Northern Finland during these times were invited to participate in the study. Of the families thus invited, 15 refused to participate, leaving a sample of 85 participants. Data was collected using a biographical questionnaire and an interview aimed at examining the experiences of the parents. Taanila et al. (1998) found that the information and advice received upon diagnosis by the parents of younger children was better than that received by parents whose child had been diagnosed in the late 1970s. The parents of the younger children reported that they had felt better prepared to care for their child than had the parents of the older children. More specifically, those parents who had received limited and/or negative information had felt more insecure and helpless than those who were satisfied with the information received. According to Taanila et al. (1998), information and advice not only facilitated the parents' adjustment to the disability of their child and their positive outlook, but also carried the added benefit of preventing disagreement within the family regarding the child's care and the family's coping response.

For the same reasons, parents who actively sought further information about their child's disability and additional resources were found to adapt better. Taanila et al. (2002) found that high-coping families reported that the first diagnosis of their child's disability had been delivered well and that they had also actively sought out further information. These families felt that the knowledge thus gained had facilitated their understanding and acceptance of the situation and enabled them to maintain a positive outlook for the future.

Retzlaff (2007) also found that those families who actively sought to learn more about their child's condition perceived the situation as more manageable, showed increased family cohesion and adapted better.

3.3.3. Spirituality and Religion

According to Walsh (2003), the meaning-making process is influenced by religion and spirituality. Weisner et al. (1991) conducted a study to assess the impact of religion on adjustment in families of children with developmental delays. To this end, 102 families of children aged between three and five years with a developmental delay of unknown origin were asked to complete a biographical questionnaire and take part in a semi-structured interview. Data obtained from the questionnaire and interview was used to determine a religiosity score for each participating family. Chi-square tests were used to identify any association between religiosity and family beliefs, support, sense of meaning and adjustment to the child. The interview data was further analysed using qualitative data analysis to identify any religious philosophy or themes influencing family adaptation. Weisner et al. (1991) found that religion helped parents to make meaning of having a child with a disability, helping them view the situation as an opportunity for personal growth, as well as fostering their acceptance of the child. There were however no differences in overall emotional adjustment between religious and non-religious families.

This spiritual meaning making was also reported by Bayat (2007), who found that many parents accepted that they had been chosen by God to take care of this 'special' child. These religious or spiritual families were found in both studies to be more likely than their non-religious counterparts to highlight the importance of the family unit and of working together. They were found to engage in more joint activities, which foster family cohesion. In addition, religious families were found to have more people providing support and to participate in more social activities than non-religious families.

Greeff and Loubser (2008) reported similar findings concerning the importance of spirituality in family resilience. These researchers conducted a study aimed at examining the importance of spirituality as a resilience resource in Xhosa-speaking families in South Africa. To this end,

Xhosa-speaking families living in a rural area of the Eastern Cape who had experienced the death of a child or a major financial setback were identified and approached about their willingness to participate in the study. Of the families thus approached, 51 agreed to take part in the study. One parent (n = 51), and in some cases also one adolescent (n = 26), were interviewed and asked about their family and the importance of the family unit, and were asked to identify any strengths that had helped the family cope during the recent crisis. Interviews were recorded and transcribed, after which the raw data set was analysed using grounded theory. This analysis revealed that spirituality was an important factor contributing to family resilience in these families. It was found to facilitate meaning making and provide encouragement and hope for the future, as well as influence the value placed on the family unit and the resulting support family members extended to each other.

Findings reported in the previously mentioned study by Vandsburger et al. (2008) indicate that, in addition to helping families make meaning of adversity, religion provides guidance and inspiration regarding the changes necessary to overcome hardship.

Crabtree (2007) reported interesting findings regarding the influence of religion on adaptation following the birth of a child with a disability in Middle Eastern families. She conducted a study examining the experiences of mothers of children with developmental disabilities in the United Arab Emirates (UAE). Parents whose children attended one of three day-care centres for children with a developmental disability in Sharjah (UAE) were invited to attend one of three meetings where the proposed study was discussed. Participants were recruited from the families attending, and 15 mothers attending these meetings agreed to participate in the study. Data was collected using several in-depth interviews conducted over a period of 10 months and subsequently coded into main themes. The findings indicate that social stigma is prevalent in this society and that it affects the child with a disability, the mother and the family. Religion was found to have a mediating influence on the acceptance of the child's disability and the family's subsequent

adaptation. Crabtree (2007) reported that those families who perceived the disability of their child as 'Allah's will' often interpreted this event as being indicative of a divine plan, which consequently bestowed blessings on the family. These families were able to accept the child and its disability and adapt well to the situation. Other families, however, were found to view the birth of a child with a disability as a punishment from Allah. This perception led to feelings of depression and often the emotional rejection of the child, which impeded adaptation.

3.4. Social Support

Social support has been found to facilitate adaptation in families of children with disabilities, since it acts as an emotional buffer in times of crisis (McCubbin & McCubbin, 1996).

3.4.1. Support from Similar Others

As mentioned previously, Taanila et al. (1999) conducted a study to examine how a child's physical or intellectual disability affected family cohesion and the parents' social relations. They found that parents considered social support as an important coping resource, with support from families with a child with a similar disability being perceived as the most valuable form of social support.

Olson et al. (1983) provide the following explanation for the perceived value of this form of support. They maintain that social support is based on reciprocity and mutual respect and understanding. Families are more likely to ask for help if they feel that they are equal to the other party and can offer something in return. This is also reflected in the findings of Hartshorne (2002) and Ainbinder et al. (1998).

Hartshorne (2002) conducted a review of the literature on family stress and coping in relation to families of children with a disability, and found that contact with other families in the same situation is important, since it allows families to share information about their child's disability and about their experiences, as well discussing coping responses they have found to be helpful.

Ainbinder et al. (1998) conducted a study aimed specifically at identifying the value of support from similar others for families of a child with a disability. Participants for the study were selected by stratified random sampling from 340 families taking part in a Parent to Parent support programme in five states of the eastern United States of America. A total of 38 families were invited to participate in the study, with 24 families agreeing to be interviewed. The semi-structured interviews were conducted telephonically and recorded and transcribed. The data thus gained was analysed and coded for emerging themes using constant-comparative procedures (Lincoln & Guba, cited in Ainbinder et al., 1998). Ainbinder et al. (1998) found that parents perceived contact with similar others to be empowering. It provided them with an opportunity to talk to people who had an understanding of their situation and the concomitant difficulties, and with whom they could share their experiences, hopes and fears. In these interactions they felt that they were able to express their feelings without fear of judgement, since the other party could relate to their situation and often mirrored their feelings. In addition, this contact allowed families to share their ideas and problem-solving strategies, and jointly work towards improving them. This reciprocity or sharing of thoughts and feelings was found to be the key element of these interactions. Families perceived their ability to share their knowledge and help another family as empowering and satisfying, while simultaneously benefiting from the experiences of their counterpart.

The importance of contact with similar others was also reported by Gatford (2001) and Taanila et al. (2002), the latter of whom also found that, while this form of social support was helpful, families still depended heavily on support from friends and relatives.

3.4.2. Support from Friends and Relatives

As mentioned previously, Hastings et al. (2002) conducted a study aimed at investigating the factors contributing to mothers' positive perceptions of their child with an intellectual disability. These researchers found that the availability of support from friends and family facilitated

positive perceptions. Families felt that they had external resources they could depend on to cope with the situation, either in terms of practical help or emotional support.

Retzlaff (2007), as mentioned previously, found that the availability of social resources helped families to reframe the situation. Rather than being overwhelming, it appeared manageable and families could focus on the positive aspects thereof. According to Greeff et al. (2006), social support also provides families with a sense of worth and integration.

In the study conducted by Horton and Wallander (2001) it was found that families with more social support available to them showed lower levels of distress than families with less external support.

Plant and Saunders (2007) conducted a study aimed at examining factors influencing parent stress in families of a pre-school child with a developmental disability. The participants were recruited from families in South Eastern Australia whose children were receiving early intervention services due to a developmental disability. All families invited to participate in the study agreed to take part (n = 105). The participants were required to complete several quantitative instruments measuring level of parent stress, difficulty and stressfulness of care-giving tasks, child behaviour problems, perceived level of disability, social support and coping strategies. Data was analysed using Pearson product-moment correlations and regression analyses. Plant and Saunders (2007) found that the difficulty of care-giving tasks, child behaviour problems and perceived level of disability were significant predictors of parent stress. Social support was found to have a moderating effect on the relationships between the independent variables and parent stress. More specifically, these researchers found that support from friends decreased the stress associated with child behaviour problems during care-giving tasks, while support from professionals decreased the stress associated with overall child behaviour problems.

In a study highlighting the socio-cultural influence of disability, Heiman and Berger (2008), as mentioned previously, found that families of children with disabilities had less social support available to them than families of other children. Those that did have social support available were found to have a more positive perception of their situation.

These findings mirror those of Catherall and Iphofen (2006), who also found that families of children with a severe intellectual disability reported a decrease in social support over the years, yet relied on the support still remaining, since it provided the hope and additional resources necessary to cope. Catherall and Iphofen (2006) conducted a qualitative study aimed at examining the experiences of parents of a child with a severe intellectual disability. Invitations to participate in the study were sent to 20 families whose child attended a special needs school in Wales, United Kingdom. Of these families, seven agreed to participate. The mothers and the fathers were interviewed separately ($n = 14$). An initial unstructured interview was followed by a more specific, semi-structured interview aimed at gaining an in-depth understanding of the parents' experiences. Data was analysed using the QSR NUD8IST/NVivo qualitative software (Richards, cited in Catherall & Iphofen, 2006) and thematic coding processes. The findings revealed that parents perceived their situation as challenging and stressful. They depended on social support, family routines, intra-family support, working together and maintaining a positive outlook to facilitate coping.

Sari et al. (2006) conducted a study aimed at exploring the experiences of mothers of children with Down syndrome in Turkey. Participants were selected from a group of 60 mothers whose child attended a training and rehabilitation centre for children with Down syndrome in Izmir, Turkey. Mothers of children from four different age groups (1 to 3 years; 4 to 6 years; 7 to 12 years; and 13 to 18 years) were invited to participate. The sample eventually consisted of three mothers of children from each age group ($n = 12$). Data was collected using in-depth semi-structured interviews. Responses were recorded and transcribed, and the raw data set was then

analysed to identify themes. Sari et al. (2006) found that the families of a child with Down syndrome had few social contacts outside the family, especially those families of children aged one to three years. Mothers reported that they faced a lot of social prejudice and rejection, even among their extended family, which caused them to avoid social interaction as far as possible.

Gatford (2001), mentioned previously, found that the amount of supportive friends and family available to families after the birth of a child with a disability was influenced by cultural affiliation. She compared the experiences of white, African Caribbean and West African mothers and found that only West African mothers reported a decrease in social support, due to a lack of understanding and acceptance among their peers. These mothers were found to rely more on formal support.

The abovementioned relationship between social support, hope and adaptation was also reported on by Wallander and Varni (1998). These researchers conducted a review of the literature on the psychosocial effects of disability on families and found that social support was positively related to family adaptation, since it facilitated a positive outlook, which in turn served to buffer stress. In addition, social support was found to be a mediating factor between adaptation and the parents' perceived role restrictions. This finding ties in with the finding, reported by Greeff et al. (2006), that social support provides family members with a sense of worth, over and above their role in the family.

3.4.3. Formal Support

As indicated in Section 3.3.2., the families of children with disabilities depend on formal support for information and advice. In addition, the availability of respite care and appropriate educational facilities for children with disabilities has been found to be a valuable coping resource. Catherall and Iphofen (2006) found that families whose children received regular respite care were found to cope better, since they had occasional breaks from the care-giving

burden. Sari et al. (2006) reported that those parents who were able to find educational and therapy programmes for their children showed decreased levels of parenting stress, but that these resources were very limited in Turkey; while Crabtree (2007) found that the lack of such resources was perceived as stressful by parents in the United Arab Emirates.

3.5. Economic Resources

As mentioned previously, social support is valuable not only for the emotional support it offers, but also because it provides families with additional resources of time and money. The importance of financial security cannot be neglected in the adaptation of families following the birth of a child with a disability. As indicated in the previous chapter, caring for such a child places unique strains on family finances (Baker et al., 2002; Emerson, 2003), which can contribute to the pile-up of demands faced by the family.

Sloper and Turner (1993) conducted a study examining the risk and resilience factors in families of children with a severe physical disability. A convenience sample of 176 families of children with a severe physical disability in greater Manchester, England was drawn from the patient register of local hospitals and paediatricians, as well as children attending local special needs schools. Of the families thus selected and invited to participate, 107 families subsequently took part in the study. Mothers ($n = 98$) and fathers ($n = 72$) were asked to complete a number of self-report questionnaires measuring parental distress, life satisfaction and adaptation, as well as child characteristics, parental and family resources and coping strategies. The mothers participating in the study were also asked to take part in an interview to further illuminate the findings from the quantitative measures. Data was analysed using correlation and multiple regression analyses. Sloper and Turner (1993) found that the parents, particularly the mothers, showed high levels of distress. The level of distress exhibited by parents of both genders appeared to be positively related to neuroticism scores, and inversely related to socioeconomic resources. In other words,

the findings indicated that adequate social and financial resources were significant in the adaptation of parents with a child with a disability.

A similar finding was reported by Emerson (2003), who found that socioeconomic status was related positively to adaptation in such families. Emerson (2003) conducted a study aimed at examining differences in socioeconomic status among mothers of children with and without an intellectual disability, as well as assessing the impact a child with an intellectual disability has on the mothers' psychological well-being. To this end, Emerson (2003) conducted a secondary analysis of data collected by the Office for National Statistics in a survey of the Mental Health of Children and Adolescents in Britain (Meltzer et al., cited in Emerson, 2003). In this survey, data was collected from 9 726 families with children aged between five and 15 years, across England, Wales and Scotland. Of these families, 245 had a child diagnosed with an intellectual disability. Information about the family demographics, the social functioning of the family, the strengths and difficulties of the child, and the psychological well-being of the parents was gathered using in-depth interviews with the mothers of the participating families. The secondary analysis, by Emerson (2003), of the data collected in the survey revealed that those families supporting a child with an intellectual disability were significantly economically disadvantaged as compared to those families whose child did not have an intellectual disability. Socioeconomic disadvantage was found to be positively related to psychological distress in family members. Emerson (2003) also found that the mothers of children with an intellectual disability reported higher levels of psychological distress due to social deprivation than did mothers of children without a disability.

According to the findings of Sari et al. (2006), Crabtree (2007) and Taanila et al. (2002), sufficient economic resources are important not only in facilitating coping in the present, but also serve to offer parents peace of mind for the future, since they feel confident that their child will be provided for once they are no longer there to take care of the child.

3.6. Family Routines and Rituals

Shared family activities, or routines and rituals, strengthen family cohesion and flexibility in numerous ways. They serve to reinforce the identity of the family, reflecting the core values and beliefs it adheres to. Family members thus gain a sense of continuity and stability, as well as a sense of togetherness in times of crisis (Walsh, 2003). Spending family time together also provides the family with a context in which they can communicate about their situation. This enables the family to reach a shared understanding and decide on a joint course of action that takes the needs of all family members into consideration. Finally, routines and rituals provide family members with guidelines on what is expected of them within the family unit and how they can contribute to sharing the burden.

According to Hutchinson, Afifi, and Krause (2007), family time provides the context in which Walsh's (2003) key processes are operationalised, that is, family time provides the context in which families define their belief systems and organisational patterns and engage in communication and problem-solving. These researchers conducted a study to examine the value of family time in facilitating family resilience following divorce. Participants in the study were recruited using different strategies, including advertisements, flyers, the attendance of local divorce support groups and network sampling. A sample consisting of 51 families was thus obtained. Data was collected by interviewing both parents of the family, an adolescent from each participating family, as well as any stepparents, with a total of 163 individuals being interviewed. Participating family members were interviewed first as a group and then individually. The interviews were recorded and transcribed before being analysed using a grounded theory approach. The results of these analyses indicate that families who engaged in shared activities showed more positive emotions and adapted better than those who allowed their members to go their separate ways. The shared family time allowed family members to support each other in the coping process, maintain their relationships and rebuild a sense of family following the changes to the family structure.

A similar finding was reported by Taanila et al. (2002), who found that family time and activities increased feelings of togetherness and cooperation and thus facilitated coping.

The findings of Catherall and Iphofen (2006) highlight further aspects of the importance of family routines. They found that these routines made life predictable and thus more manageable, especially since it provided stability for the child with disabilities, who might otherwise demonstrate challenging behaviour. In addition, these routines ensured that the burden of care was shared between the family members, thus facilitating coping.

3.7. Problem-Solving and Coping Behaviours

Problem-solving and coping behaviours are those processes instituted by the family in an attempt to reduce demands, acquire additional resources and strengthen existing ones, and appraise the situation in such a way as to make it manageable (McCubbin & McCubbin, 1996).

Taanila et al. (2002), as mentioned previously, found that high-coping families had more resources available and engaged in a broader array of coping responses than low-coping families. These families were found to focus on their strengths rather than on the presenting problems, as low-coping families were likely to do. Low-coping families were more likely to struggle with an accumulation of problems or demands.

A similar finding was reported by Graungaard and Skov (2006), who found that families engaged in active coping strategies aimed at reducing demands and strengthening resources adapted better than families engaged in passive or avoidant coping. According to Woolfson (2004), an active approach focussing on the positive aspects of a situation is vital in the process of adaptation.

3.8. Conclusion

As this review of the literature on resilience factors in families of children with disabilities indicates, the resilience resources and processes identified by McCubbin and McCubbin (1996) and Walsh (2003) have been found to contribute to adaptation, and consequently to family resilience in these families. Family resilience is dependent on the attainment of optimal levels of cohesion and flexibility. Meaning making and maintaining a positive outlook seem to be central to this process and are facilitated by family hardiness, clear and open communication, information, spirituality or religion, and social support. Communication has also been found to contribute to family cohesion and flexibility, as do family routines and rituals. Those families who employed more of these resilience resources were found to adapt better than families who employed fewer resilience resources.

The following chapter outlines the methodology of this study. It includes information about the sampling procedures and participants, a description of the measuring instruments used, as well as the procedures employed during data gathering. In addition, the chapter will detail the statistical and qualitative techniques used to analyse the data.

Chapter 4

Methodology

4.1. Introduction

This chapter describes the methodology used in this study. It includes the problem statement, a description of the research design and of the participants, as well as of the procedures used during data collection. The chapter will outline the measuring instruments used, including a brief description of what they entail and their statistical validity and reliability, as well as detailing the analyses performed on the data thus collected.

4.2. Problem Statement

As mentioned in Chapter 1, in South Africa approximately 2.1% of children aged 0 to 9 and 3% of children aged 10 to 19 live with a disability. It is evident from these figures that disability affects a large number of families in South Africa. As outlined in Section 2.6, the birth of a child with a disability represents a major stressor for the family; it places a high strain on a family's resources, and many families might find it difficult to adapt following this event.

The study of family resilience, by definition, involves an attempt to identify those strengths within the family unit that allow it to reduce the demands represented by a stressor, acquire and use additional resources, and thus regain a healthy level of family functioning.

A number of studies have been conducted to identify the factors contributing to successful family adaptation following the birth of a child with a disability (see Chapter 3). These studies have for the most part focussed on examining the influence of one or two factors, rather than investigating an array of factors and their interplay (Emerson, 2003). Since family resilience depends on complex adaptation processes involving a number of factors, it would be beneficial to conduct a study examining the influence and interplay of numerous factors. In addition,

studies of family resilience have for the most part been conducted using Western populations. Since the socio-cultural context of a family has been found to influence its response to a stressor and its subsequent adaptation (Walsh, 2003), family resilience also needs to be studied using other population groups.

This study then aims to examine which resilience resources identified by Walsh (2003) and McCubbin and McCubbin (1996) contribute to the successful adaptation of coloured families in South Africa who have a child with a developmental disability, and to what extent each of these factors accounts for the variance in family adaptation. The research question can thus be stated as follows: What are the family characteristics and resources that are associated with family adaptation in coloured families of children with developmental disabilities?

4.3. Research Design

This study was conducted using a cross-sectional research design. This method involves the collection of data from study participants only once and yields a measurement of the characteristics of interest at that point in time (Graziano & Raulin, 2000). In an effort to gain as comprehensive a data set as possible, both quantitative and qualitative methods were used. One parent from each participating family was required to complete the measuring instruments. Quantitative data was collected using a number of established measuring instruments based on the theoretical models discussed in Chapter 2, while qualitative data was gathered by asking the participating parent to answer an open-ended question.

A detailed description of these measuring instruments will follow in Section 4.5.

4.4. Participants

The participants for this study were recruited from a school for children and adolescents with developmental disabilities in the Boland region, Western Cape, South Africa. Children are referred to this school if they have developmental delays that render them unable to follow the

progress in a regular school. Permission to conduct the study was obtained from the Department of Education and the principal of the school. Upon approval of the study, the principal was asked for a list of eligible families. The families were required to meet the following requirements in order to qualify for the study:

- 1) Two parents (not necessarily the biological parents of the child with a disability) were required to head the family.
- 2) The family should be from a previously disadvantaged ethnic group.
- 3) The child with a disability was required to be enrolled at this particular school at the time of the study.

From the families thus identified, 80 were selected by simple random sampling and invited to participate in the study. A letter to this effect was sent home with the child (see Addendum B). The letter included information about the purpose and aims of the study, and outlined what participation in the study involved. In it, the parents were assured of the confidentiality and anonymity, as far as possible, of their responses if they should choose to participate. The parents that returned the letter providing their contact details were seen to have given informed consent to participate in the study and were subsequently contacted telephonically by the researcher to arrange a time and place to meet in order to proceed with data collection. During this telephone conversation, the parents were given the opportunity to ask any questions they might have and to withdraw from the study, without any negative consequences to themselves or their child, should they desire to do so.

The letter was returned by 46 families (58%), all of whom subsequently agreed to meet the researcher. Of the 46 collected data sets, six had to be excluded from analysis due to the family failing to meet one of the selection criteria, or failing to complete all the questionnaires. The data from 40 participating families was thus used for the analyses in this study.

The majority of the participants in this study were female ($n = 37$; 93%). The participants were aged between 29 and 54, with a mean age of 39.8 ($SD = 5.3$). Their partners were aged between 30 and 61, with a mean age of 41.9 ($SD = 6.4$). The mean length of the couple's relationship was 14.55 years ($SD = 7.74$), ranging from 1 to 33 years. The majority of the children with disabilities were male ($n = 28$; 70%) as compared to female ($n = 12$; 30%). The children's ages ranged from 8 to 18, with a mean age of 12.8 ($SD = 2.91$). The mean number of years since diagnosis was 7.03 ($SD = 4.15$), with two years being the most recent and 17 years the longest. Of the families represented in the study, 13 had one other child, 19 had two other children and five had three other children, while three families had no other children. In terms of socioeconomic status, 15 families were of lower socioeconomic status, 17 of middle socioeconomic status and eight of upper socioeconomic status. All families participating in this study were coloured.

4.5. Measuring Instruments

As mentioned previously, both quantitative and qualitative measuring instruments were used in this study. A biographical questionnaire was also administered to determine the composition of the family, the marital status of the parents, the length of time since diagnosis and the socioeconomic status of the family (see Addendum C).

The family's socioeconomic status was determined using a composite index derived by Riordan (cited in Tennant, 1996). According to this index (see Addendum A), the occupation of the primary breadwinner and their educational level can be used to determine a family's socioeconomic status. To this end, Riordan derived an occupation classification, rated on a nine-point scale, and an education classification, rated on a seven-point scale. The total score, derived by adding the score on the occupation classification to the score on the education classification, provides the socioeconomic index. Since different ethnic groups in South Africa have historically not been represented equally in occupational, educational and income categories,

Riordan assigned different cut-off points for determining socioeconomic status, depending on ethnic affiliation. According to this classification, scores between 2 and 6 indicate lower socioeconomic status, scores between 7 and 10 indicate middle socioeconomic status, and scores between 11 and 16 indicate upper socioeconomic status for coloured families.

4.5.1. Quantitative Measuring Instruments

The measuring instruments detailed below were used to measure the dependent variable, family adaptation, as well as potential resilience resources identified in previous research and outlined in the abovementioned theoretical frameworks.

4.5.1.1. The Family Attachment and Changeability Index 8

The dependent variable in this study, namely family adaptation, was measured using the Family Attachment and Changeability Index (FACI8). This index is an ethnically sensitive measure of family adaptation and functioning, adapted from the Family Adaptability and Cohesion Evaluation Scales (FACES), by McCubbin, Thompson, and Elver (1996). The FACI8 consists of two subscales, namely the attachment and the changeability subscales, which measure the levels of family cohesion and family flexibility. More specifically, the attachment subscale measures the strength of the family members' attachment to one another, while the changeability subscale determines the degree to which family members are flexible in their relationships with each other (McCubbin, Thompson, and Elver, 1996). The scale consists of 16 statements that respondents are required to rate on two five-point Likert scales, indicating to what extent the statement is now true for their family, and what they would like the response to be. Responses on these scales range from Never = 1 to Always = 5. The total score of the FACI8 represents a measure of family adaptation.

The internal reliability of this scale and the subscales (Cronbach's alpha) varies between .73 and .80 (McCubbin, Thompson, and Elver, 1996). In this study, the FACI8 obtained an overall

internal reliability (Cronbach's alpha) of .49, with the attachment and changeability subscales obtaining an internal reliability of .75 and .58 respectively.

4.5.1.2. The Family Hardiness Index

The Family Hardiness Index (FHI) was developed by McCubbin, McCubbin, and Thompson (1996b). The FHI measures internal strength and durability in the family unit, as characterised by a sense of control over the outcome of stressful situations, a view of change as beneficial and an active approach to overcoming adversity (McCubbin, McCubbin, and Thompson, 1996b).

The FHI consists of 20 items measuring the responses families employ when faced with a stressor. Respondents have to indicate whether and to which extent the statement is applicable to their family, using a five-point Likert scale (False = 0, Mostly false = 1, Mostly true = 2, True = 3, Not applicable = 0). The FHI is divided into three subscales, namely family commitment, challenge, and control. The commitment subscale measures the family's sense of dependability, their internal strengths and their ability to work together. The challenge subscale assesses the family's willingness to engage in new experiences, use an active and innovative approach and to learn from their experiences, while the control subscale measures the family's perception of being in control of their family life, as opposed to being shaped by outside events and circumstances (McCubbin, McCubbin, and Thompson, 1996b).

The overall internal reliability (Cronbach's alpha) of this scale is .82, with the commitment, challenge and control subscales having an internal reliability of .81, .80, and .65 respectively. This scale has a validity coefficient of between .20 and .23 when correlated with measures of family satisfaction, time, routine and adaptability (McCubbin, McCubbin, and Thompson, 1996b). In this study the FHI obtained an overall internal reliability (Cronbach's alpha) of .59, with an internal reliability of .62 for the commitment subscale, .58 for the challenge subscale and .74 for the control subscale.

4.5.1.3. The Social Support Index

The Social Support Index (SSI) was developed by McCubbin, Patterson, and Glynn (1996). It aims to determine the extent to which the family is integrated into the community it lives in, and the level of support provided by this community. The scale identifies whether the family perceives the community as a source of social, emotional and esteem support. The SSI consists of 17 items rated on a five-point Likert scale, with responses ranging from Strongly disagree = 0 to Strongly agree = 4.

The SSI has an internal reliability (Cronbach's alpha) of .82, and a test-retest reliability of .83. It has a validity coefficient of .40 when correlated with a measure of family well-being (McCubbin, Patterson, and Glynn, 1996). The SSI obtained an internal reliability (Cronbach's alpha) of .76 in this study.

4.5.1.4. The Relative and Friend Support Index

The Relative and Friend Support Index (RFS) was developed by McCubbin, Larson and Olson (1982). It measures the extent to which family members use the support of friends and family as a coping strategy in the face of stressors. The scale consists of eight items asking respondents to rate, on a five-point Likert scale, the extent to which the family shares problems and asks for advice from friends and relatives. Possible answers range from Strongly disagree to Strongly agree. The RFS has an internal reliability (Cronbach's alpha) of .82 and a validity coefficient (as determined by correlation with the original F-COPES) of .99 (McCubbin et al., 1982). The internal reliability (Cronbach's alpha) of the RFS in this study was .80.

4.5.1.5. The Family Crisis-Oriented Personal Evaluation Scales

The Family Crisis-Oriented Personal Evaluation Scales (F-COPES) was developed by McCubbin, Olson, and Larson (1996). It measures the problem-solving and coping behaviours employed by a family in times of adversity. Modelled on the coping processes outlined in the

Resiliency Model of Family Stress, Adjustment and Adaptation, this scale examines the influence of the pile-up of demands, the family resources and the meaning making or appraisal process on coping (McCubbin, Olson, & Larson, 1996). The F-COPES examines the influence of five different coping strategies in dealing with stressors that a) arise within the family, that is, problems between family members, and b) arise outside the family unit but have an influence on the family. It is assumed that families that employ coping behaviours that focus on resolving both internal and external problems will adapt more successfully in crisis situations. The F-COPES consists of 30 statements rated on a five-point Likert scale, with responses ranging from Never = 1 to Always = 5. It is divided into five subscales, each examining a different coping strategy. These strategies are divided into internal and external coping strategies. Internal coping strategies are those strategies based on resources within the family unit. They are 1) reframing the situation to make it meaningful and manageable (Cronbach's alpha .64), and 2) passive appraisal, that is passively accepting the situation without doing anything to change it (Cronbach's alpha = .66). External coping strategies are those behaviours the family engages in to acquire resources from outside the family unit. They are 1) the family's ability to obtain support from friends (Cronbach's alpha = .74), family (Cronbach's alpha = .86) and neighbours (Cronbach's alpha = .79), 2) the search for and use of spiritual and religious support (Cronbach's alpha = .87), and 3) the mobilisation of family members to seek and accept help from others (Cronbach's alpha = .70) (McCubbin, Olson, & Larson, 1996).

A high total score on the F-COPES indicates that the family has a varied repertoire of coping strategies available. The scale has an overall internal reliability (Cronbach's alpha) of .77 and a test-retest reliability of .71 (McCubbin, Olson, & Larson, 1996). In this study, the F-COPES obtained an internal reliability (Cronbach's alpha) of .63 on the reframing subscale, .61 on the passive appraisal subscale, .76 on the social support subscale, .52 on the religion and spirituality subscale and .60 on the mobilisation subscale.

4.5.1.6. The Family Time and Routine Index

The Family Time and Routine Index (FTRI) was developed by McCubbin, McCubbin, and Thompson (1996a). It is used to determine which routines and activities the family engages in and what value they attribute to these. Family time and routines are relatively reliable indicators of family stability and integration, both of which are important in dealing with normative problems and family crises (McCubbin, McCubbin, and Thompson, 1996a).

The FTRI consists of eight subscales and 32 questions in total. Respondents are required to indicate, on two four-point Likert scales, firstly the extent to which the statement is applicable to the family, with responses ranging from False = 0 to True = 3. Secondly, they have to indicate how important the routine is to the family, with responses ranging from Not important = 0 to Very important = 2, with Not applicable = 0 being the fourth option.

The subscales of the FTRI are: Parent-child togetherness - the family's emphasis on predictable communication between parents and children; Couple togetherness - the family's emphasis on creating routines to encourage communication between spouses; Child routines - the family's emphasis on creating predictable routines to promote children's sense of independence and order; Meals together; and Family time together - the family's emphasis on predictable routines to encourage togetherness; Family chores routines - the family's emphasis on establishing predictable routines to encourage children's responsibilities in the home; Relatives connection routines - the family's attempts to create predictable routines to encourage a meaningful connection with relatives; and Family management routines - the family's attempts to create predictable routines to promote an atmosphere of family organisation and the accountability necessary to uphold family order in the home (McCubbin, McCubbin, and Thompson, 1996a).

The FTRI has an overall internal reliability (Cronbach's alpha) of .88, with validity coefficients ranging from .24 to .34 when correlated with measures of family bonding, family satisfaction,

marital satisfaction, family celebrations and family coherence (McCubbin, McCubbin, and Thompson, 1996a). In this study, the FTRI obtained an internal reliability (Cronbach's alpha) of .85 on the total Family Routines scale and .88 on the total Importance scale. The internal reliability (Cronbach's alpha) obtained on the subscales was .33 for Child routines, .65 for Couple togetherness, .43 for Meals together, .55 for Parent-child togetherness, .63 for Family togetherness, .65 for Relatives connection routines, .56 for Family chores routines and .38 for Family management routines.

4.5.1.7. The Family Problem-Solving and Communication Scale

The Family Problem-Solving and Communication Scale (FPSC) was developed by McCubbin, McCubbin, Thompson and Elver (1996). It is used to evaluate the positive and negative patterns of family communication that influence problem-solving and coping. It is assumed that the quality of communication within the family is indicative of the extent to which the family is able to manage stressors and regain an adequate level of family functioning or adaptation (McCubbin, McCubbin, Thompson, & Elver, 1996). The FPSC consists of 10 statements rated on a four-point Likert scale. Responses range from False = 0 to True = 3. The scale is divided into two subscales measuring incendiary and affirming communication respectively. Incendiary communication is provocative and tends to intensify a situation, while affirming communication is supportive and serves to calm a situation (McCubbin, McCubbin, Thompson, & Elver, 1996).

The FPSC has an overall internal reliability (Cronbach's alpha) of .88. The incendiary communication subscale has an internal reliability of .78, while the affirming communication subscale has an internal reliability of .86 (McCubbin, McCubbin, Thompson, & Elver, 1996). The FPSC has a test-retest reliability of .86. In this study the overall internal reliability (Cronbach's alpha) obtained was .79, while the internal reliability for the incendiary and affirming communication subscales was .65 and .90 respectively.

4.5.2. Qualitative Measure

The qualitative measure in this study comprised an open-ended question asking respondents to indicate which factors and family characteristics helped them to adapt to the experience of having a child with a developmental disability (see Addendum D). This measure was employed in an effort to more fully understand the family's experiences and the factors they perceived as important contributors to their family's adaptation. The question put to the participants was phrased as follows: "In your own words, which are the most important factors, or family strengths, that have helped your family adapt to having a child with a developmental disability?"

4.6. Procedure

4.6.1. Data Collection

Following the return of the informed consent form to the school, the parents were contacted telephonically by the researcher. During this conversation, the parents were given the opportunity to ask any additional questions they might have about the study and to clarify what would be expected of them. They were then asked whether they were still willing to participate in the study. Upon agreement, the researcher arranged an appointment with the respondents, at a time and place convenient to them. All the participants asked the researcher to visit them at their homes, except for one, who wanted to meet at her place of work.

Upon meeting the participants, the researcher greeted them and thanked them for agreeing to participate in the study. The voluntary nature of participation was again highlighted and the participants were assured that they could withdraw from the study at any point during the data collection without having to fear any negative repercussions for themselves and their child. The researcher explained how the participant's confidentiality and anonymity would be safeguarded as far as possible, and that no identifying information would be recorded on any of the measuring instruments.

The biographical questionnaire was administered first, followed by the qualitative measure. The open-ended question was posed before the quantitative measures were administered in order to avoid responses being influenced by the topics addressed in the quantitative measuring instruments. The participants were given the option of writing down their response to the open-ended question on the space available on the questionnaire, or of responding verbally. Of the participants whose data was used for analysis ($n = 40$), 15 (38%) responded to the open-ended question in writing, while the remainder ($n = 25$, 63%) responded verbally. Those participants who chose to respond verbally were asked whether they would mind if the response was recorded using a Dictaphone. All the participants agreed to the recording. The responses to the qualitative measure were generally brief, consisting of only a few sentences.

Once the participants had responded to the open-ended question and completed the biographical questionnaire, they were asked to complete the seven quantitative measuring instruments discussed in Section 4.5.1. These questionnaires were originally designed to be completed by the participants themselves. However, the majority of the participants in this study preferred the questions to be read out to them and to answer verbally, with many statements requiring clarification before the participants were able to answer. The potential implications of this will be addressed in the Discussion in Chapter 6. In spite of the researcher being available to provide clarification, some participants felt unable to answer some of the questions. The data collection procedure lasted between one and two hours, depending on the participant, with the majority taking approximately one and a half hours. Upon completing the questionnaires, most of the participants chatted to the researcher about the study, about their experiences and feelings regarding their child, and insisted on the researcher meeting the child. The participants were thanked sincerely for their participation in the study.

4.6.2. Scoring of Questionnaires

Upon completion of the data collection, all the questionnaires were checked for completion. Responses to the biographical questionnaire were assigned a numerical value. This was done in order to facilitate the data entry and subsequent statistical analyses. Those data sets with incomplete questionnaires were excluded from the data analysis. Data was then entered into a Microsoft Excel spreadsheet.

The responses provided to the quantitative measures were scored according to established formulae. The responses on the Family Time and Routine Index, the Family Hardiness Index and the Family Problem Solving and Communication Scale were entered into the data file by allocating a number between zero and three to each response. The Social Support Index required a number between zero and four to be allocated to each response, while the Relative and Friend Support Index, the Family Crisis Oriented Personal Evaluation Scales and the Family Attachment and Changeability Index all required the allocation of a score between one and five. In some cases the scores had to be reversed, but this was done automatically by the Excel spreadsheet.

Once all the data had been entered into the Microsoft Excel spreadsheet, the statistical analyses could be undertaken.

4.7. Data Analysis

4.7.1. Qualitative Data Analysis

The qualitative data in this study was analysed through thematic content analysis. Content analysis refers to “the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (Hsieh & Shannon, 2005, p. 1278). It was used in this study because it allows for the re-examination of existing theory, and

also allows the identification of behaviours or factors not mentioned previously, which may stimulate hypotheses for future studies (White & Marsh, 2006).

Since this study aimed to investigate the contribution of specific resilience resources to family adaptation, the main analytic categories, or “master codes” (Woods, Priest & Roberts, 2002, p. 47) were known. More specifically, the main analytic categories in this analysis were represented by the resilience resources identified in the models of McCubbin and McCubbin (1996) and Walsh (2003). This form of coding is also known as *a priori* coding.

With the main analytic categories having thus been established, the data was examined to identify themes representing each main category. Themes can be words, phrases, sentences or paragraphs that embody ideas about the topic under investigation (Woods et al., 2002). During this process, the researcher is called upon to note and record not only those themes corresponding to the previously identified categories, but also to look for alternative perspectives and ideas that are unexpected, but seem important (White & Marsh, 2006). In this instance, this led to the inclusion of further categories not identified by the theoretical frameworks.

The categories were revised if necessary, to ensure maximum mutual exclusivity and exhaustiveness, that is, to ensure that all themes corresponding to a main category were included in that category without replication between categories (Weber, 1990). The data was then coded according to the themes identified, that is, the occurrence of each theme in the data was identified and recorded. The raw data was thus reduced to a data set representing the factors identified as contributing to family resilience and the frequency with which they were mentioned, that is their relative importance.

4.7.2. Quantitative Data Analysis

The quantitative data was analysed using Statistica (StatSoft, 2003). An analysis of variance (ANOVA) was carried out to test for statistically significant mean differences among groups

(Graziano & Raulin, 2000), as determined by biographical variables. In other words, the ANOVA was carried out to determine whether families from different groups differed significantly in terms of their level of adaptation, as measured by the Family Attachment and Changeability Index (FACI8). The variables included in this analysis were gender of the child with a disability, socioeconomic status and other people living in the household.

Pearson's product-moment correlation coefficients were calculated to determine the correlations between the independent variables and the dependent variable. The Pearson product-moment correlation is an index of the linear relationship between two variables; it provides a measure of the degree and direction of association between them (Graziano & Raulin, 2000). Scatter plots were drawn to visually depict the relationship between the measured variables.

Finally, a multiple regression analysis was conducted to determine which combination of independent variables best predicts the value of the dependent variable, or which combination of independent variables best accounts for the variance in family adaptation (Field, 2000). A best-subsets regression analysis was used to determine which independent variables should be included in the multiple regression model. To this end, all possible combinations of the independent variables were included in the regression model and their relative contribution to the value of the dependent variable was calculated. Those variables that did not contribute significantly to predicting the outcome variable were excluded and the regression model was recalculated. The aim of this analysis was to identify the combination of family resilience qualities best able to predict family adaptation. The results of the abovementioned data analyses will be presented in Chapter 5.

4.8. Ethical Considerations

The participants in this study were informed of the aims of the study, and were informed about what participation in the study would entail. Those families that indicated an interest in

participating in the study were subsequently contacted telephonically by the researcher and any remaining uncertainties were eliminated in this conversation. The participating families thus all gave informed consent to take part in the study. Upon meeting with the researcher, the participants were assured that they could still withdraw from the study at any point during the data collection procedure if they felt uncomfortable with the topics under discussion. It was reiterated that withdrawal from the study would not have any negative repercussions for themselves or their children.

All the participants were assured of confidentiality and anonymity, as far as this was practicable. The families meeting the inclusion criteria were identified by the principal, and the families were invited to participate in the study via the school. The families invited to participate in the study were selected randomly. An invitation was addressed to the family as soon as the number corresponding to that family was drawn. No records were kept regarding the families thus selected. For logistical reasons, those families wishing to participate in the study returned their completed consent forms to the school, where they were collected by the researcher at regular intervals. The importance of confidentiality regarding the returned forms was agreed upon by the researcher and the principal, and the returned forms were locked away until collection by the researcher. Neither the principal nor any other member of staff at the school was provided with information about which families ultimately agreed to participate in the study; this information was known only to the researcher.

Absolute anonymity was not possible in this study, since the data was collected during a face-to-face meeting between the researcher and the participants. However, in an effort to maintain anonymity and confidentiality, no information that would later serve to identify the respondent was recorded on any of the measuring instruments. The participants were rather randomly assigned a number, which was then written on all the measuring instruments completed by that participant. In those instances where participants responded to the open-ended question verbally,

the number was marked on the tape. No record was kept of the names corresponding to the numbers.

The data collected was treated as confidential and not shared with any external agencies. All questionnaires and answers given in response to the open-ended question were scored and coded by the researcher. The completed measuring instruments and tapes were stored in a locked drawer only accessible to the researcher; while the electronic files into which data was inputted were saved on the researcher's personal computer and protected by a password.

Chapter 5

Results

5.1. Introduction

This chapter will outline the results obtained from the data collected using the analyses described in Section 4.7. It will reflect which factors were found to be associated with the family adaptation or family resilience of families with children with developmental disabilities. The results obtained from the quantitative measures will be reported first, with the results from the qualitative measure concluding the chapter.

As concerns the quantitative data, the findings from the analyses of variance, which compared differences between groups, will be reported first, followed by a description of the relationships found between the independent and dependent variables using the Pearson product-moment correlation. The combination of factors found to best predict the variance in family adaptation, as calculated by a best-subsets regression, will be reported last.

Results are regarded as statistically significant at a probability level of 5% ($p \leq .05$); the lower the p-value, the more significant the finding.

5.2. Analysis of Variance

Analyses of variance (ANOVAS) were calculated to compare any differences in level of family adaptation between families of different groups, as determined by socioeconomic status (families of lower, middle and upper socioeconomic status), the gender of the child with a disability and people other than immediate family members living with the family. The comparison of mean differences between groups of families differing on these biographical variables did not yield any statistically significant findings in this study. More specifically, no significant differences in level of family adaptation, as measured by the Family Attachment and Changeability Index

(FACI8), were found between groups of families differing in the indicated demographic variables.

5.3. Pearson Product-Moment Correlations

Pearson product-moment correlations were calculated to determine which independent variables showed a correlation with the dependent variable, family adaptation (as measured by FACI8).

Table 5.1 provides a summary of these correlation coefficients, with their corresponding significance values (p-values).

As can be seen from Table 5.1, eight of the correlations calculated were found to be statistically significant. These correlations will be explained in more detail and illustrated graphically in the next section.

Table 5.1

Summary of the Correlations Found Between the Independent Variables and the Level of Family Adaptation as Measured by the FACI8 (N = 40)

Variable	r-value	p-value
Length of parental relationship	-.02	.92
Age of participant	.08	.63
Age of partner	.11	.49
Age of child ^a	-.42**	.008
Number of other children in family	-.12	.46
Years since diagnosis	-.09	.55
Relative and Friend Support Index (RFS)	-.15	.36
Family Problem Solving and Communication Scale (FPSC)	.54**	< .01
Affirming, or supportive communication	.53**	< .01
Incendiary, or provocative communication	-.46**	< .01
Family Hardiness Index (FHI)	.51**	< .01
Commitment (internal strength, ability to work together)	.43**	< .01
Challenge (engage in & learn from new experiences)	.65**	< .01
Control (perception of control over family life)	.16	.32
Family Crisis Oriented Personal Evaluation Scales (F-COPES)		
Social Support (ability to obtain friend & family support)	-.14	.37
Spiritual Support (use of spiritual support)	.14	.39
Mobilising Community Resources (seek & accept help)	-.07	.66
Reframing (recast situation as meaningful & manageable)	.25	.11
Passive Appraisal (accept the situation as it is)	.34*	.03

(Table continues)

(Table 5.1. continued)

Variable	r-value	p-value
Social Support Index (integration into & support from community)	.26	.11
Family Time and Routine Index (FTRI): Family Total	.07	.67
Importance attributed to family time and routines	.09	.55
Child Routines	.01	.94
Couple Togetherness	-.02	.87
Parent-Child Togetherness	.12	.45
Family Time Together	.08	.64
Meals Together	-.01	.95
Family Chores Routines	-.06	.73
Relatives Connection Routines	.05	.77
Family Management Routines	.25	.12

Note. ^a n = 39: The correlation between age of the child with a disability and family adaptation was initially not significant statistically due to an outlier value. The correlation was recalculated excluding the outlier value, which yielded a statistically significant correlation.

* $p \leq .05$

** $p \leq .01$

5.4. Scatter Plots

Scatter plots show the relationship between two variables by displaying data points on a two-dimensional graph. The independent variable is plotted on the x axis, and the dependent variable is plotted on the y axis. A correlation between the variables results in the clustering of data points along a line, known as the regression line or line of best fit (Graziano & Raulin, 2000).

The Pearson product-moment correlation between family adaptation, as measured by the FACI8, and the age of the child with a developmental disability was initially found to be statistically insignificant ($r = -.29$, $p = .07$), due to an outlier. However, the Spearman's rho correlation, which is not that sensitive to the effect of outliers, showed the correlation to be significant at $r =$

-.32, $p = .05$. The Pearson product-moment correlation was recalculated excluding the outlier, which resulted in a significant negative correlation ($r = -.42, p \leq .01$).

Figures 5.1a and 5.1b illustrate the relationship between family adaptation and the age of the child, with the outlier included and excluded respectively. As can be seen from the regression line, the relationship is influenced considerably by the outlier.

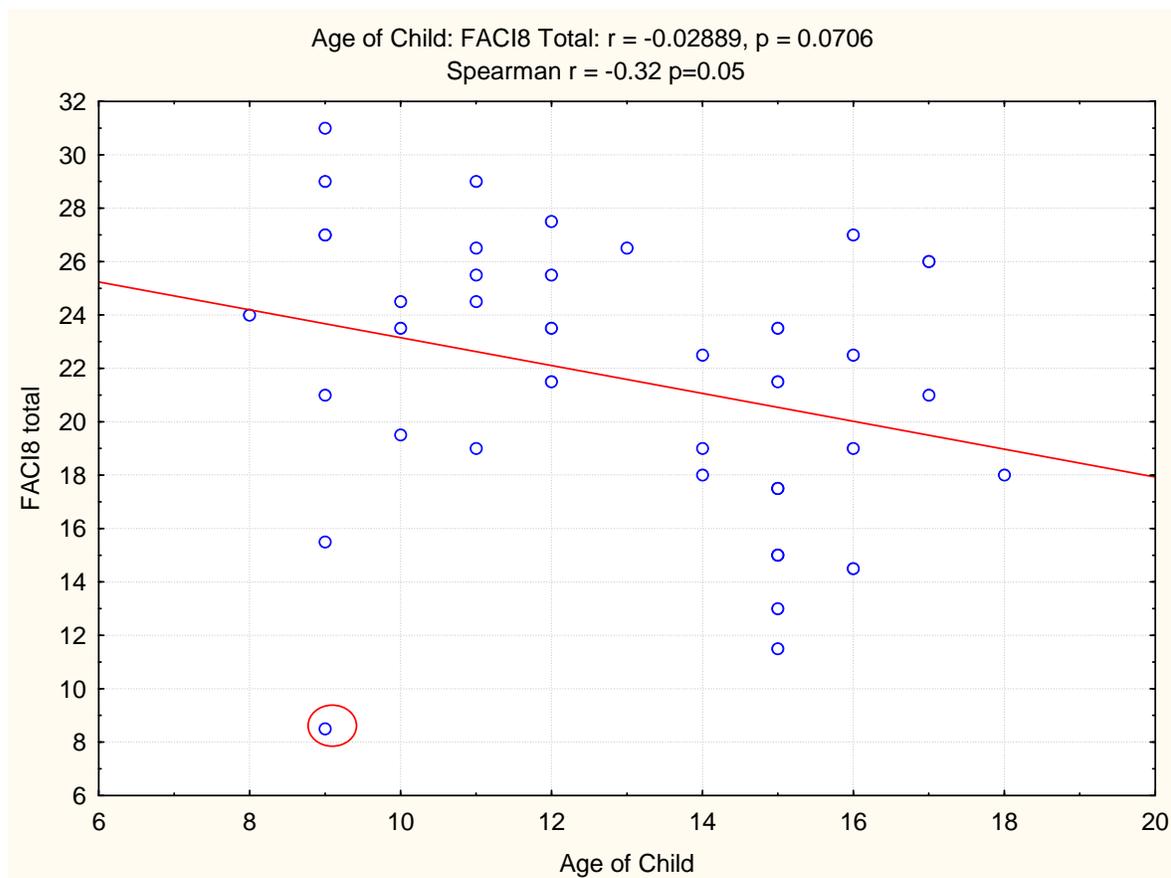


Figure 5.1a. Scatter plot showing the correlation between family adaptation (FACI8 score) and age of the child with a developmental disability, including the outlier.

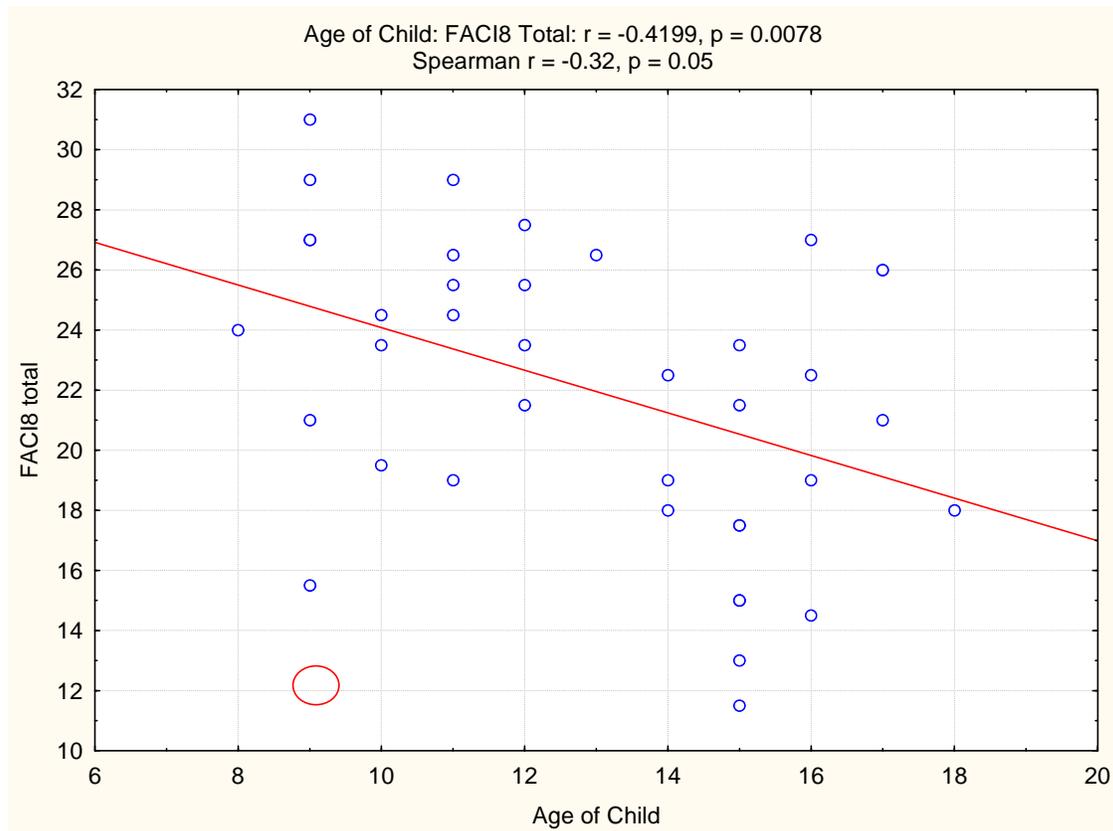


Figure 5.1b. Scatter plot showing the correlation between family adaptation (FACI8 score) and age of the child with a developmental disability, excluding outlier.

This significant negative correlation between family adaptation (FACI8 scores) and age of the child with a developmental disability suggests that family adaptation is lower the older the child.

Significant correlations were also found between family adaptation and the patterns of communication used by the family, as measured by the Family Problem-Solving and Communication Scale (FPSC). Figures 5.2a, 5.2b and 5.2c, to follow, illustrate these correlations.

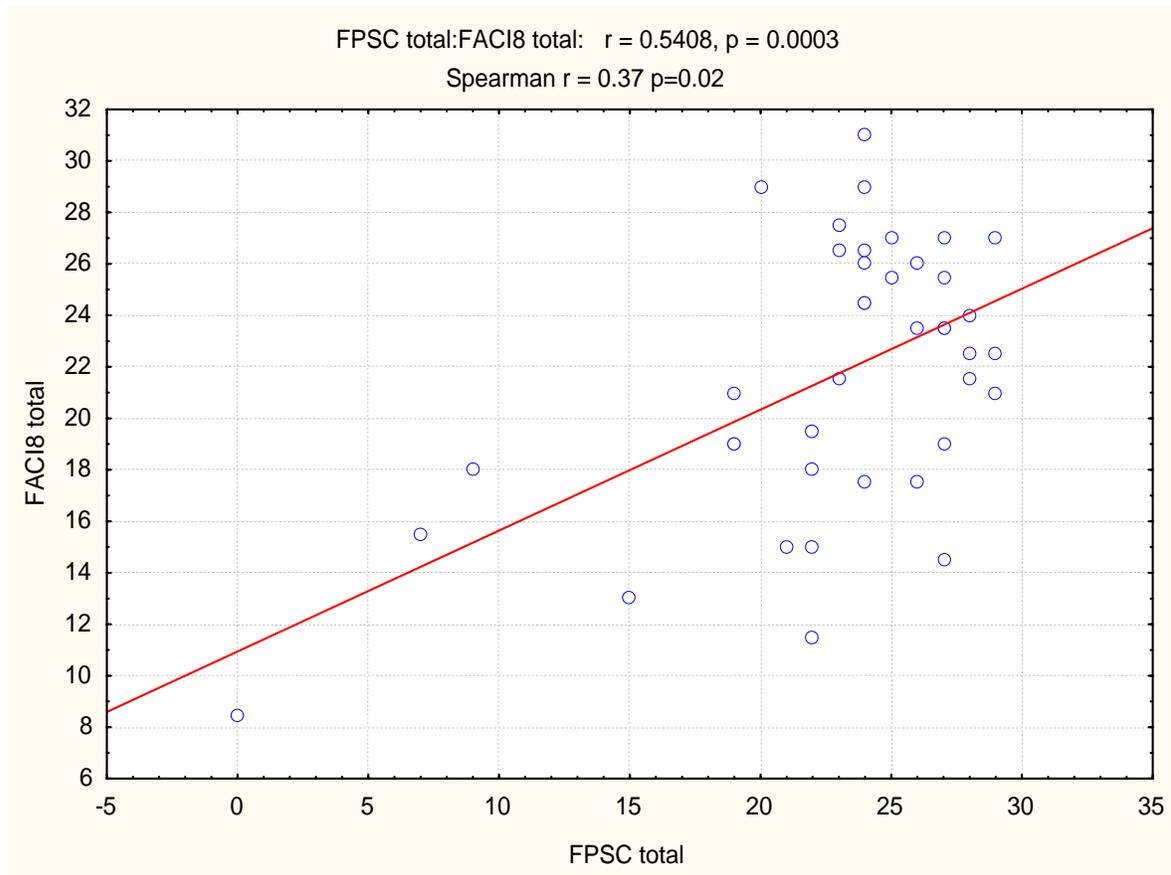


Figure 5.2a. Scatter plot showing the correlation between family adaptation (FACI8 score) and the quality of family communication (as measured by the FPSC Total).

As can be seen from Figure 5.2a, a significant positive correlation ($r = .54$, $p \leq .01$) was found between family adaptation and family communication. This would indicate that the better the quality of communication within the family, as evidenced by positive compared to negative patterns of communication, the better the family adaptation.

Figure 5.2b shows the relationship between affirming or positive patterns of communication and family adaptation.

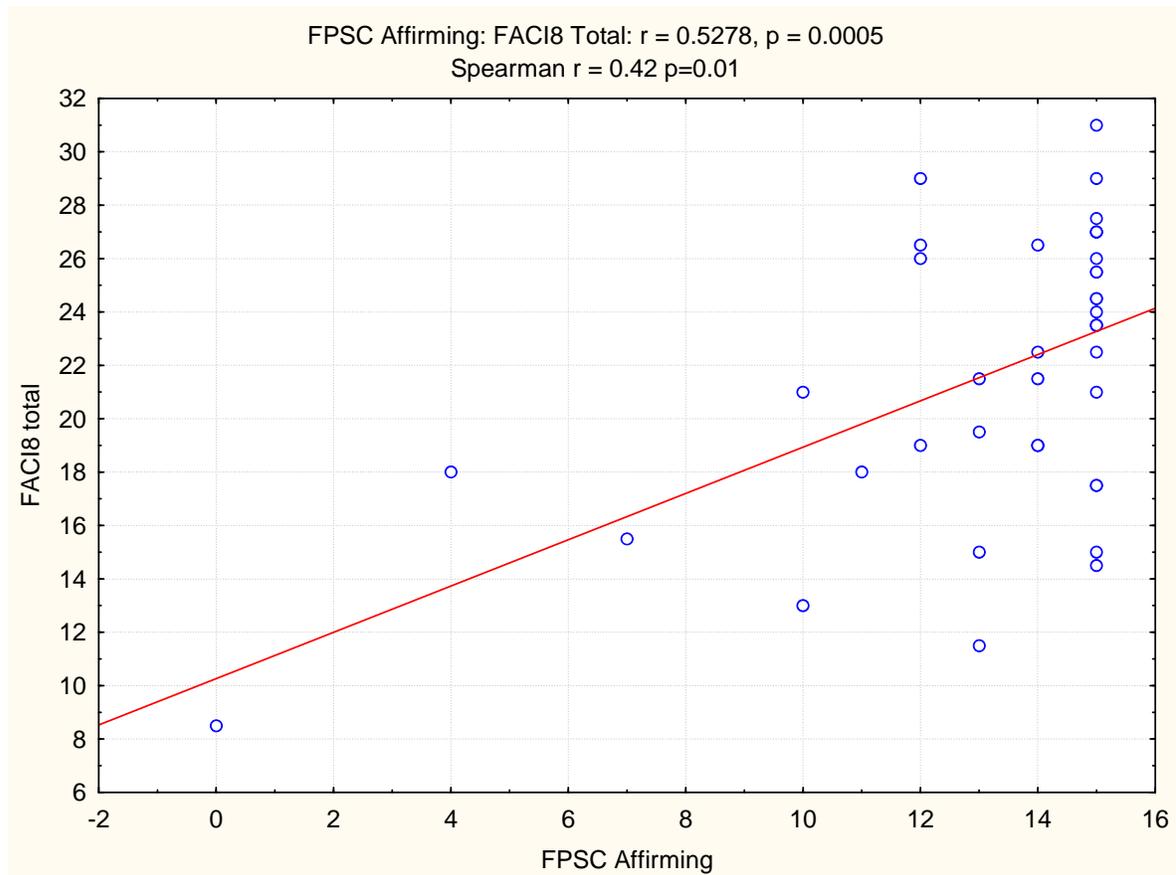


Figure 5.2b. Scatter plot showing the correlation between family adaptation (FACI8 score) and affirming patterns of communication within the family (as measured by the FPSC Affirming Communication Subscale).

Figure 5.2b shows a significant positive correlation ($r = .53$, $p \leq .01$) between family adaptation and affirming patterns of communication within the family. This would indicate that family adaptation is better the higher the levels of such communication in the family unit.

The relationship between family adaptation and incendiary or provocative patterns of family communication is represented in Figure 5.2c.

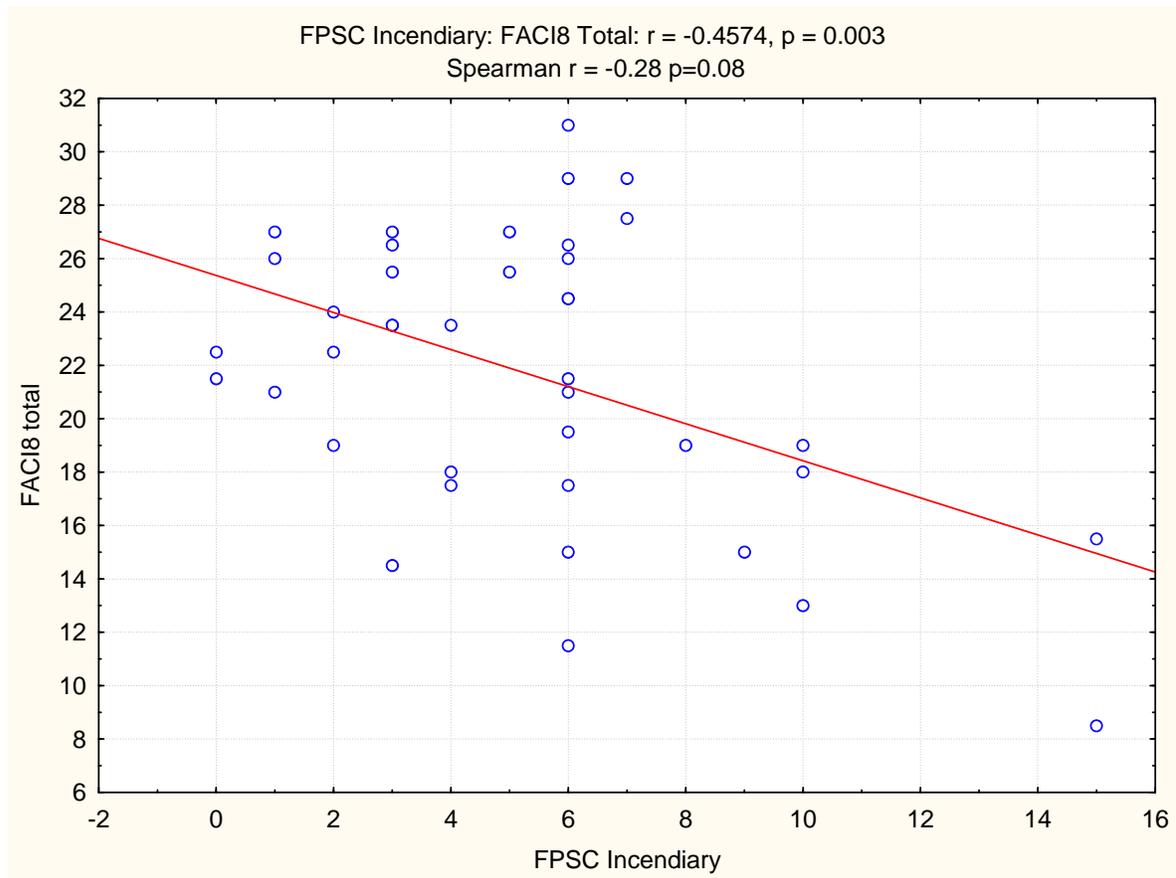


Figure 5.2c. Scatter plot showing the correlation between family adaptation (FACI8 score) and incendiary patterns of communication (as measured by the FPSC Incendiary Communication Subscale).

As is evident from Figure 5.2c, a significant negative relationship ($r = -.46$, $p \leq .01$) was found between family adaptation and incendiary family communication. This finding would indicate that family adaptation is worse the more incendiary or provocative the patterns of communication within the family are.

Significant correlations were further found between measures of family hardiness, as determined by the Family Hardiness Index (FHI), and family adaptation. These relationships will be illustrated in Figures 5.3a, 5.3b and 5.3c.

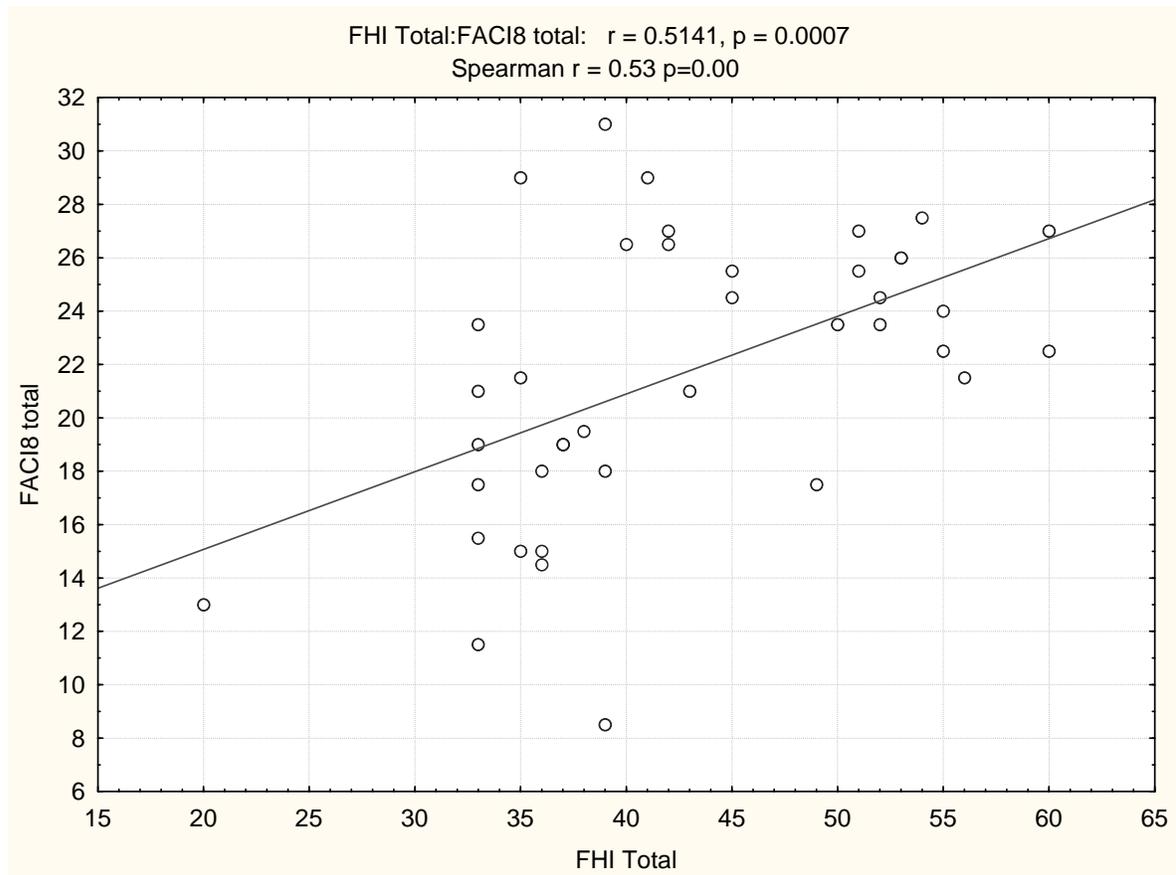


Figure 5.3a. Scatter plot showing the correlation between family adaptation (FACI8 score) and the internal strength and durability in the family unit measured by the Family Hardiness Index (FHI Total).

As Figure 5.3a illustrates, a significant positive relationship ($r = .51$, $p \leq .01$) was found between family adaptation and the total level of family hardiness, or the internal strength and durability of the family unit. This would indicate that family adaptation is better the higher the level of family hardiness.

Figure 5.3b, to follow, represents the correlation between family adaptation and scores obtained on the commitment subscale of the FHI.

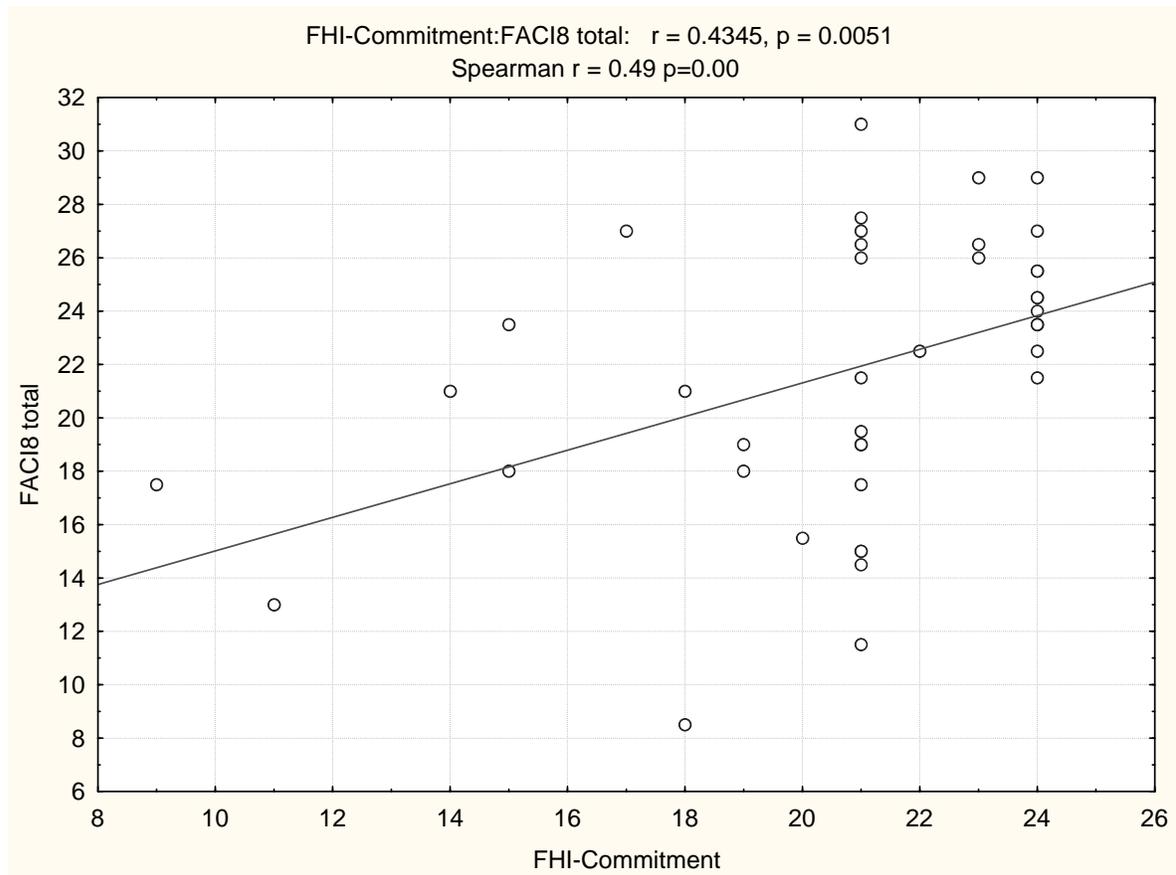


Figure 5.3b. Scatter plot showing the correlation between family adaptation (FACI8 score) and scores obtained on the commitment subscale of the FHI.

Figure 5.3b shows a significant positive correlation ($r = .43$, $p \leq .01$) between family adaptation and the family's internal strength, dependability and ability to work together, as measured by the commitment subscale of the FHI. This finding would indicate that family adaptation is better in families that are able to work together and depend on each other.

The relationship between scores obtained on the challenge subscale of the FHI and family adaptation is illustrated in Figure 5.3c.

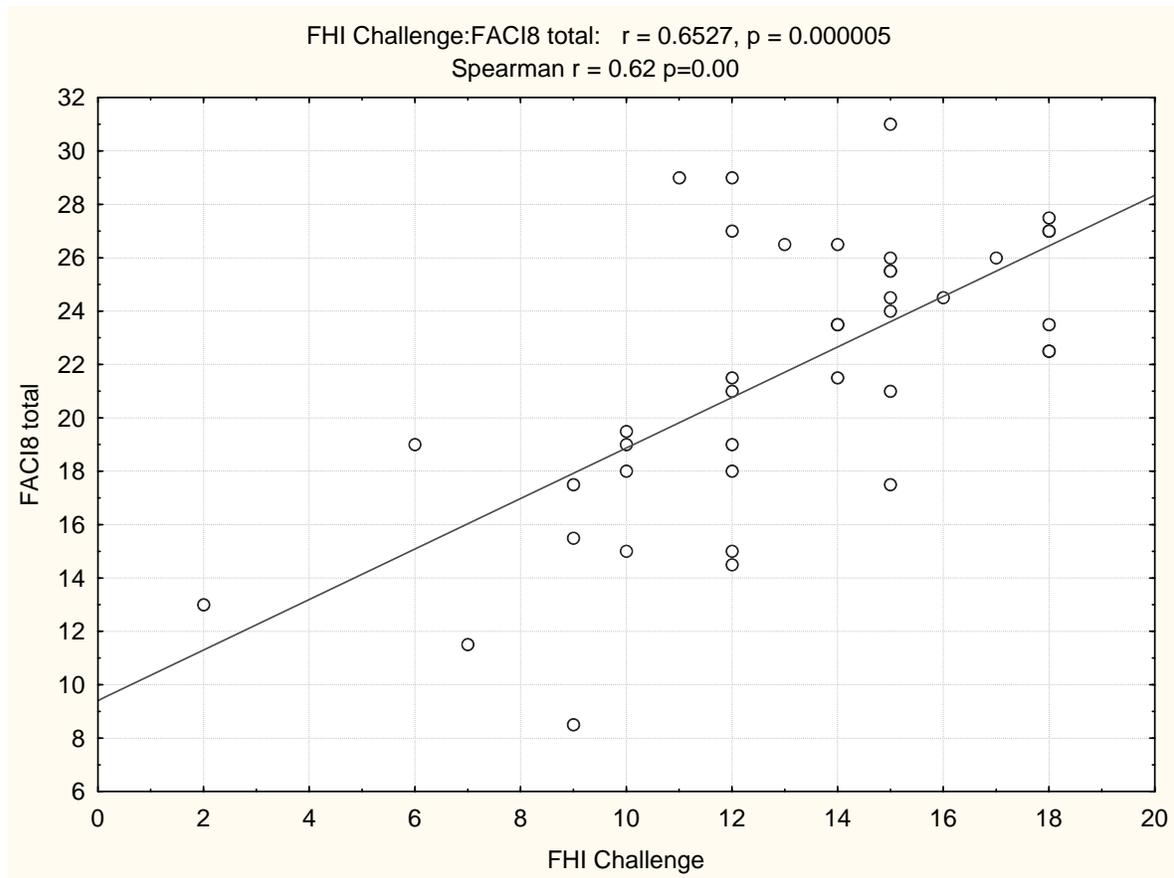


Figure 5.3c. Scatter plot showing the correlation between family adaptation (FACI8 score) and scores obtained on the challenge subscale of the FHI.

As Figure 5.3c shows, a significant positive relationship ($r = .65$, $p \leq .01$) was found between family adaptation and a family's willingness to engage in new experiences, use an active approach to problem-solving and learn from their experiences, as measured by the challenge subscale of the FHI. This finding would indicate that family adaptation is better the better the family's scores on the challenge subscale of the FHI.

The final statistically significant correlation in this study was found between family adaptation and the problem-solving and coping behaviour of passive appraisal, as measured by the passive evaluation subscale of the Family Crisis-Oriented Personal Evaluation Scales (F-COPES). This relationship is illustrated in Figure 5.4.

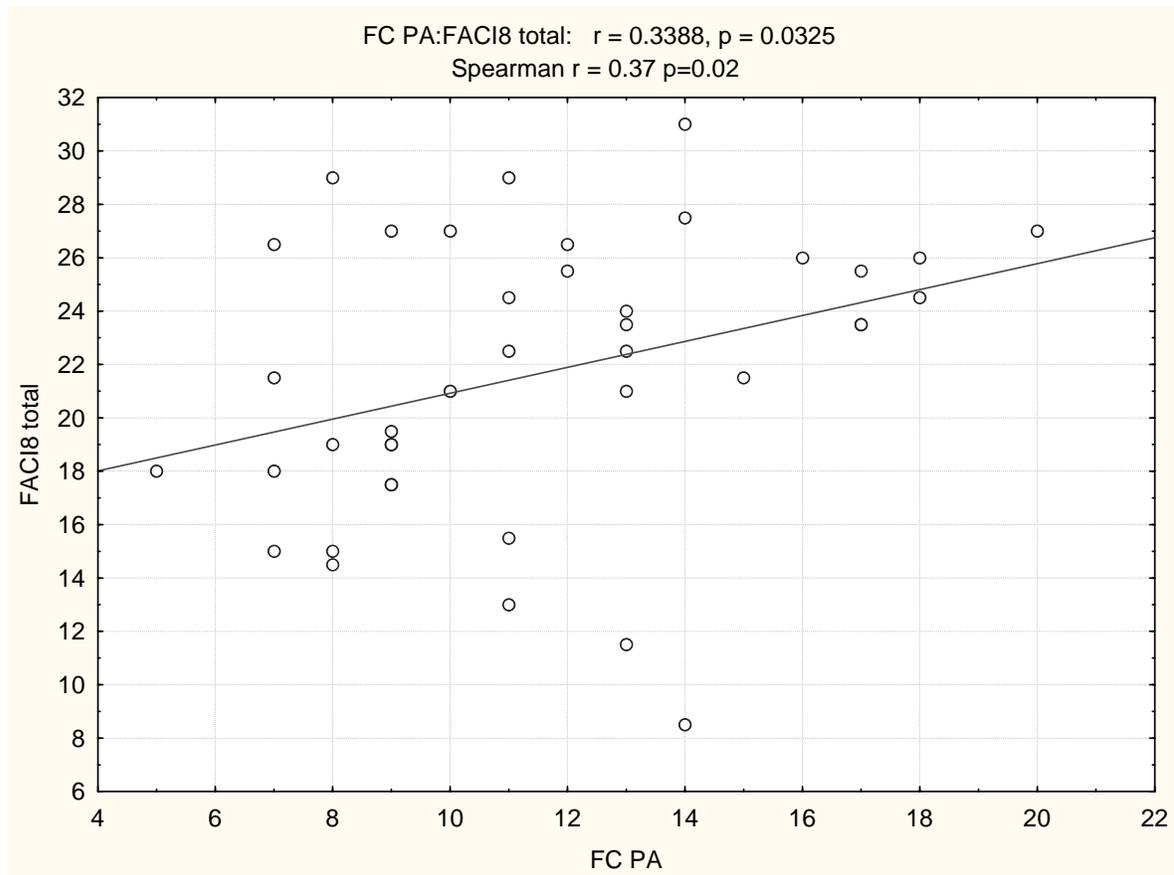


Figure 5.4 Scatter plot showing the correlation between family adaptation (FACI8 score) and scores obtained on the passive evaluation subscale of the F-COPES.

As Figure 5.4 illustrates, a significant positive relationship ($r = .34$, $p \leq .05$) was found between scores obtained on the passive evaluation subscale of the F-COPES and family adaptation. This relationship would seem to indicate that those families who passively accept the situation without doing anything to change it adapt better than those who do not.

Significant correlations were thus found between family adaptation and age of the child with a disability, three measures of family hardiness, three measures of family communication, and passive appraisal as a coping style. All but two (age of the child and incendiary communication) of these correlations were positive.

5.5. Regression Analysis

A multiple regression analysis was carried out in an effort to determine which combination of independent variables would best predict the level of family adaptation, the dependent variable in this study. As mentioned previously, a best-subsets regression was used to determine which independent variables should be included in the multiple regression model. This method involves examining all of the models created from all possible combinations of independent variables. Best subsets regression uses R^2 to check for the best model (Field, 2000).

Table 5.2. provides a summary of the results of the multiple regression analysis.

Table 5.2

Multiple Regression Analysis: The Best Combination of Predictor Variables for Family Adaptation (N = 40)

Variable	B	t(34)	p-value
FTRI Importance Total	-.09	-1.01	.32
F-COPES Reframing	.42	2.06	.05
F-COPES Spiritual Support	.38	.96	.34
F-COPES Passive Appraisal	.42	2.2	.03
FPSC Total	.47	4.01	.01

As can be seen in Table 5.2, the multiple regression analysis revealed the following combination of independent variables to be the best predictor of family adaptation: The importance families associate with family time and routines (Total FTRI Importance), the problem-solving and coping strategies of reframing the situation, passive appraisal and the search for and utilisation of spiritual support (as measured by the relevant subscales of the F-COPES) and the level of total family communication (FPSC Total). Family communication (as measured by the FPSC Total) was found to be the most significant contributor to the variation in family adaptation.

Table 5.3. provides a summary of the relevant statistics of this multiple regression model.

Table 5.3

Regression Summary for the Dependent Variable (FACI8 Total score)

Statistic	Value
Multiple R	.69
Multiple R ²	.48
Adjusted R ²	.40
F (5,34)	6.25
p	.0003
Std. error of estimate	4.07

From the R value ($R = .69$, $F(3,34) = 6.25$, $p < .01$) in Table 5.3 it is clear that a significant positive correlation exists between the true FACI8 scores and the estimated FACI8 scores as predicted by the independent variables listed in Table 5.2. The R² value (.48) reflected in Table 5.3 indicates that the independent variables listed in Table 5.2 account for 48% of the variation in the FACI8 scores obtained in this study. The adjusted R² value, R² adjusted for degrees of freedom, indicates that this model accounts for 40% of variation in the general population. The p-values listed in Table 5.2 show that the B values of the independent variables, measured by the F-COPES Reframing, F-COPES Passive Appraisal and FPSC Total, used to describe this model differ significantly from zero ($p \leq 0.05$). This indicates the significant contribution of these independent variables to predicting the dependent variable, namely family adaptation. Although the B values associated with the independent variables measured by F-COPES Spiritual Support and FTRI Importance Total do not differ significantly from zero, they were nonetheless included, since they were identified by the best-subsets regression as contributing to the variation in family adaptation.

5.6. Qualitative Data

The qualitative data was collected by asking respondents the following question: “In your own words, which are the most important factors, or family strengths, that have helped your family adapt to having a child with a developmental disability?” All 40 participants responded to the question. The data thus gathered was analysed using thematic content analysis, in which the data was examined and coded to reveal themes expressed by the respondents. Themes were grouped into categories based on the theoretical models of family resilience and on categories that emerged during data analysis.

Table 5.4. presents a summary of the identified themes and their prevalence.

Table 5.4

Summary of Resilience Factors Identified by Respondents in Response to the Qualitative Measure (N = 40)

Categories and Themes	Frequency	%
Make meaning of adversity		
Belief that there is a reason for having a child with a disability (personal growth, uniting the family)	10	25
Attitude of acceptance, realising that there is nothing that can be done to change the situation and it has to be accepted	27	68
Regardless of any associated difficulties, he/she is our child and we have to love him/her	23	58
Maintain Hope and a Positive Outlook		
Belief that, in spite of the difficulties of the situation, everything would work out for the best in terms of the future of the child and the family	2	5
Belief that the family is a strong unit and can cope with any difficulties it faces, without disintegrating	5	13

(Table continues)

(Table continued)

Categories and Themes	Frequency	%
Spirituality and Religion		
Belief that it was God's will that the family should care for a child with a disability	8	20
Belief that God gives the family and its members the strength needed to cope with the difficulties associated with a child with a disability	10	25
Flexibility		
Belief that adaptation was facilitated by changing the family's routines to incorporate the needs of the child and work around the child	8	20
Belief that the integration of the child into family life is important. Like any other member of the family, the child performs chores and contributes	11	28
Family rules and routines provide stability, there is a set timetable and everybody knows what is expected of them	5	13
Social and Economic Resources		
Belief that support from friends is important; having someone to talk to, who can also sometimes watch the children	17	43
Support from doctors, psychologists and the school is important for family adaptation, it provides information, relieves the care burden and gives respite	18	45
Belief that it helps to be able to afford good doctors who can help with the medical care of the child and provide peace of mind	2	5
Family Communication		
It is important to talk to each other about feelings, especially when feeling sad or if someone does something you do not like	16	40
Belief that it helps if family members make decisions together, then everyone agrees about what is decided and knows what to do	12	30
It is important to be able to ask the other children and partner for help if there is too much to do	3	8
Connectedness and Mutual Support		
All members of the family contribute to household chores and child care, the burden of care is shared	12	30
It is important to take time for the other children in the family and ensure that their needs are met too	2	5
Belief that the family is strengthened by spending quality time together and doing things as a family	4	10
Belief that the family is able to cope with their situation due to the love, affection and mutual support among family members	5	13

(Table continues)

(Table continued)

Categories and themes	Frequency	%
Resignation *		
Nothing helps, life is just very difficult	1	3
Social acceptance of the child *		
Belief that it is easier to accept the disability of the child if nobody gives the child funny looks	2	5
Family adaptation is facilitated if the child is treated like any other by the community, integrated into daily life and plays with other children	4	10
Contact with similar others *		
Helps to talk to other people with a child with a disability, they can understand the situation and can give advice about what to do	5	13
Focus on nurturing the child *		
Important to spend a lot of time with the child, to support his/her development and show him/her that we love him/her, this also helps to avoid bad behaviour	14	35
Teach the child to become independent, so he/she can do things for him/herself and take care of him/herself in the future	5	13
Teach the child new skills, it makes me happy if he/she learns something new which he/she was not able to do before	8	20
Strong marital relationship *		
I couldn't do it without my partner	1	3
Joy brought by the child *		
He/she brings joy to the family, he/she is such a special person, is always happy and laughs at little things, he/she makes us laugh too	10	25
He/she cannot do many things but keeps learning. Many things he/she learns are unexpected and it makes me proud of him/her and of my family	5	13
Characteristics of the child *		
He is very easy-going and loving. He gives me less trouble than the other children	2	5

Note. *categories identified during the coding process

As can be seen from Table 5.3, the factors most often reported by the participants as contributing to family adaptation were acceptance and love of the child (68% and 58% respectively). The value of formal and friend support was also mentioned frequently, with formal support being perceived as marginally more valuable (45% and 43% respectively). Family communication (40%), spending a lot of time with the child (35%), working together as a family (30%), making decisions together (30%) and integrating the child into family life (28%) were also among the factors frequently mentioned as contributing to family adaptation in families of children with developmental disabilities. Of the participants, 25% also mentioned that God gave them the strength to cope and that adaptation was facilitated by the joy the child brought to the family. Instituting changes to the family's routines in order to incorporate the needs of the child was rated as an adaptation resource by 20% of the participants in this study.

The following chapter contains a discussion of the results of this study, with reference to the theories and literature presented in Chapter 2 and 3. It will include the conclusions of this study, a discussion of the limitations, as well as suggestions for future research.

Chapter 6

Discussion, Conclusions, Limitations and Recommendations

6.1. Introduction

The aim of this study was to identify strengths and resources associated with the successful adaptation of coloured families living in the Western Cape following the diagnosis of a child with a developmental disability. Family resilience, indicated by successful adaptation, is characterised by the family's ability to "bounce forward" following a period of hardship or a family crisis (Walsh, 2003, p. 10), that is, to regain or exceed their pre-crisis level of family functioning. Family resilience involves more than merely coping with a situation and the associated stressors, but rather entails change, transformation and growth within the family unit (McCubbin & McCubbin, 1996; Walsh, 2003).

The results presented in the previous chapter will now be discussed with reference to the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1996) and the Family Resilience Framework (Walsh, 2003) outlined in Chapter 2, and the literature on adaptation in families of children with developmental disabilities presented in Chapter 3.

A discussion of the conclusions drawn from this study will follow, with the limitations of the study and suggestions for further research concluding this chapter.

6.2. Discussion

6.2.1. Age of the Child with a Developmental Disability

As mentioned in Chapter 5, a significant negative correlation was found between the age of the child with a developmental disability and family adaptation (as measured by the Family Attachment and Changeability Index (FACI8)). This finding indicates that family adaptation is lower in families of an older child than in those with younger children. A possible explanation

for this is presented by Faust and Scior (2008). These researchers reported that children and adolescents with developmental disabilities are at increased risk of developing mental health problems, such as challenging behaviour and depression. This is especially true for adolescents with disabilities, since these individuals experience the emotional upheaval normally associated with the onset of puberty, but it is magnified by their perception of their intellectual and physical impairments and subsequent dependence on support. This increasing awareness that they are different from their peers can lead to an increase in behaviour problems, depression and anxiety, which in turn increases the care strain on the family. This finding is mirrored by Todd and Jones (2005), who found that this stage of the family life-cycle, the middle years, is often marked by an increase in parental stress due to an increase in care strain and increased worries about the future.

According to Sari et al. (2006), Crabtree (2007) and Taanila et al. (2002), these worries about the future of the child with disabilities can be partly ameliorated by sufficient financial resources. These resources allow families to feel secure in the knowledge that their child will be provided for even after the parents' retirement and, ultimately, their death. According to McCubbin and McCubbin (1996) and Walsh (2003), economic resources are an important contributing factor to family resilience, since the lack thereof adds to the pile-up of demands faced by the family and consequently makes adaptation more difficult.

6.2.2. Socioeconomic Status

An analysis of variance was conducted to determine whether there were differences in family adaptation based on the socioeconomic status of the families participating in this study. Interestingly, while families of middle ($n = 17$, 43%) and upper ($n = 8$, 20%) socioeconomic status showed marginally higher scores on the family adaptation measure (FACI8) than did families of lower socioeconomic status ($n = 15$, 38%), this difference did not approach statistical significance. This finding indicates that, in this sample, the socioeconomic status of a family was not associated with the level of family adaptation. This contradicts the results reported by other

researchers, who identified socioeconomic status and financial security as resources facilitating adaptation (Emerson, 2003; Sloper & Turner, 1993).

6.2.3. Making Meaning of Adversity

According to McCubbin and McCubbin (1996) and Walsh (2003), the appraisal or meaning-making process is central to positive adaptation, since it defines the family's perception of their situation and subsequently influences the coping response and the changes instituted. According to these researchers, families who are unable to make meaning of their situation and reframe it as understandable and manageable are likely to be overwhelmed and fail to make the necessary changes needed to adapt. This appraisal process is influenced by the family's values and beliefs about itself and the environment it exists in, that is the family schema, by the family's paradigms, or rules and expectations (McCubbin & McCubbin, 1996), as well as by the family's religious or spiritual beliefs (Walsh, 2003).

The multiple regression analysis conducted on the quantitative data collected in this study revealed that meaning-making processes contributed significantly to family adaptation in this sample. More specifically, this analysis showed that the coping strategies of reframing and passive appraisal (as measured by the relevant Family Crisis-Oriented Personal Evaluation Scales (F-COPES) subscales) were strong predictors of family adaptation scores, with the latter making the more significant contribution (see Table 5.2). In addition, the search for and use of spiritual support (as measured by the spiritual support subscale of the F-COPES) was found to be a predictor of family adaptation, albeit an insignificant one.

These results indicate that those families who are able to make meaning of and accept their situation are better able to adapt than those who are not able to do so, and that spiritual resources are helpful in this process. This observation is partly confirmed by the results of the Pearson product-moment correlations (see Table 5.1). Although the relationship between the coping

strategies of reframing and seeking spiritual support (as measured by the relevant F-COPES subscales) and family adaptation (FACI8 scores) was insignificant, a significant positive correlation was found between the coping strategy of passive appraisal (F-COPES scores) and family adaptation.

These results would seem to indicate that the families participating in this study relied less on reframing their situation, or trying to understand the reasons for the disability of their child, but rather took the position that there was nothing they could do to change the situation and they thus had to accept it and make the most of it. According to Olson et al. (1983), this acceptance is a key feature of successful reframing or meaning making. It allows the family to accept what cannot be changed and rather to focus their efforts on those aspects of life they can control. According to Hartshorne (2002), this process is especially relevant in families of children with disabilities, since they have to accept the reality of their child's disability while maintaining a positive outlook for the future.

The findings obtained from the analysis of the quantitative data in this study were also reflected in the responses given by the participants in response to the qualitative measure, that is, the open-ended question (see Table 5.4). Of the participants, 68% stated that there was nothing they could do about the disability of their child, they therefore just had to accept it, while 58% of the participants stated that it was their child and they had to love him/her regardless of the associated difficulties. Only 25% and 20% of the participants stated that they had been given the child for a reason, or that it was the will of God, respectively. Some families (25%) did, however, report that they felt that God gave them the strength to cope with their situation, a response that corresponds to Vandsburger et al.'s (2008) finding that religion or spirituality has been found to offer guidance in times of adversity.

Nonetheless, these findings are slightly different from those reported by Weisner et al. (1991) and Bayat (2007), who found that religion or spirituality was a key contributor to meaning making and adaptation, and facilitated the acceptance of the child. The families in this study were found to show high levels of acceptance of their situation and the child, but seemed to rely less on spiritual explanations and meaning making in the process.

The insignificant relationship between reframing (as measured by the reframing subscale of the F-COPES) and family adaptation (as measured by the FACI8) obtained in this study is contrary to the findings of Bayat (2007) and Hastings et al. (2002), who found reframing and the ability to make meaning of having a child with a disability to be key adaptation resources in these families.

According to Hastings et al. (2002), families who are able to reframe their situation as understandable, manageable and meaningful show higher levels of family hardiness and consequently a more positive outlook. Although the relationship between reframing and family adaptation was insignificant in this study, a strong positive correlation was found between family adaptation and family hardiness.

6.2.4. Family Hardiness and Maintaining a Positive Outlook

Family hardiness, that is the family's sense of control over the outcome of stressful situations, a view of change as beneficial and an active approach to overcoming adversity by working together, was identified as a key resilience resource by McCubbin and McCubbin (1996). Walsh (2003) also found that a family's ability to embrace and adapt to new challenges by working together was a key process in family resilience.

According to Bayat (2007), family hardiness, or positive perceptions about a situation, serves as a buffer for the stresses associated with caring for a child with disabilities, since families can still hold on to the belief that, in spite of the difficulties they are facing, the situation can be mastered and will ultimately serve to strengthen the family unit.

In this study, the internal strength and durability of the family unit, as measured by the total score obtained on the Family Hardiness Index, was found to have a significant positive relationship with family adaptation (as measured by the FACI8). A significant positive correlation was also found between family adaptation (as measured by the FACI8) and the scores obtained on the commitment and challenge subscales of the Family Hardiness Index (FHI) (see Table 5.1). These findings suggest that those families in which family members feel they can depend on each other and work together to overcome a period of adversity adapt better than those families scoring low on the commitment subscale. The positive correlation between scores on the challenge subscale and family adaptation further indicate that those families who perceive change as an opportunity for growth, and who are willing to engage in new experiences, adapt better than those who do not.

These findings mirror those reported by Bayat (2007), Retzlaff (2007) and Taanila et al. (1999), who found that families who were able to accept the diagnosis of disability and work together to overcome the associated hardships and maintain the integrity of the family unit adapted better than those who did not. These families perceived the situation they were faced with as a challenge they could overcome together, as did the families in this study.

Interestingly, the relationship between family adaptation and a sense of control over the situation, as measured by the FHI Control subscale, was found to be statistically insignificant in this study (see Table 5.1). This would seem to indicate that the families' sense of control over their situation and the outcomes thereof did not affect their level of family adaptation. This finding, in combination with the positive relationship found between family adaptation and passive appraisal, might indicate that the families participating in this study perceived the events affecting their family as being beyond their control, and thus worked towards accepting their situation as it was.

The significant positive correlations found between family adaptation scores and overall family hardiness scores, as well as the positive correlations between family adaptation scores and scores obtained on the commitment and challenge subscales of the FHI, further indicate that, in spite of this perception that life's events are outside their control, the participating families seemed to maintain a positive outlook and a belief that challenges and change can be mastered by working together.

Interestingly, this family hardiness was less pronounced in the results obtained from the qualitative data (see Table 5.4). Families reported on the importance of working together (30%), but only 13% of the families reported that they perceived themselves as a strong family able to overcome adversity, with a mere 5% confessing to a belief that everything would work out for the best. This might indicate that the assumption that they were doing the best they could is inherent, that is, families perceive their attempts to make the best of the situation as a given and do not think of this attitude as a particular strength or coping resource.

As mentioned previously, 58% of the families said that they loved their child regardless of any disability and the associated stresses, while 25% went further to say that the child brought a lot of joy to the family. Many families (35%) reported that they spent a lot of time with the child and aimed to teach the child new skills (20%), and to support it to become as independent as possible (13%). These responses indicate that, in spite of the fact that it was not overtly stated, many families maintained a positive outlook and hope for the future.

Hutchinson et al. (2007) and Taanila et al. (2000) reported that family hardiness is facilitated by family time and routines, since these provide family members with an opportunity to spend time together and discuss their situation, as well as providing a sense of stability and continuity in times of adversity.

In this study, the importance attributed by the family to family time and routines, as measured by the Family Time and Routines Index (FTRI) (Importance subscale), was found in the multiple regression analysis to be a significant predictor of family adaptation (see Table 5.2).

This finding is confirmed in the responses given to the open-ended question (see Table 5.4). Of the participants, 28% and 20% respectively reported that they had changed their routines to integrate the child into the family and to incorporate its needs into their daily routine. Another 13% of the participants highlighted that these routines provided a much-needed stability to the family unit, while 10% said that spending time together as a family was an important resilience resource.

These results correspond with the findings of other researchers mentioned previously. The correlations between scores on the FTRI and family adaptation (FACI8 scores) were statistically insignificant (see Table 5.1), however, which indicates that the contribution of family time and routines to family adaptation was, at most, minor in this sample.

According to Greeff et al. (2006), family hardiness is also facilitated by communication within the family. This resource was also found to be significantly associated with family adaptation in this study.

6.2.5. Communication

According to the Family Resilience Framework proposed by Walsh (2003), communication is a key resilience resource, since it facilitates the meaning-making process and fosters collaborative problem-solving. It was also identified by McCubbin and McCubbin (1996) as a resistance resource employed by families to manage the demands they are facing.

In this study, a significant positive correlation was found between the quality of family communication (as measured by the Family Problem-Solving and Communication Scale

(FPSC)) and family adaptation (as measured by the FACI8). A further significant positive correlation was found between affirming patterns of communication and family adaptation, with a significant negative correlation found between incendiary communication and the dependent variable (see Table 5.1), as measured by the relevant subscales of the FPSC and the FACI8. These findings suggest that those families who communicate openly and honestly about their situation, with a focus on supporting individual members and calming the situation, adapt more successfully than those who do not. More specifically, those families found to engage in provocative or confrontational patterns of communication were found to adapt less well than those whose patterns of communication were supportive and affirming.

These results are further supported by the findings obtained from the multiple regression analysis (see Table 5.2). The quality of family patterns of communication (as indicated by the FPSC Total score) was found to be the most significant predictor of family adaptation scores.

A pattern of communication that emphasises and encourages open communication allows family members to reach a shared understanding of their situation and of the changes necessary to adapt successfully. It ensures that all family members are aware of the contribution expected from them in this process, while also giving them the opportunity to voice any support needs they themselves might have (Bayat, 2007). Vandsburger et al. (2008) found that open communication, and the resulting mutual support and feelings of closeness, were found to play a significant role in family adaptation in times of adversity, a finding supported by the results of this study.

The responses obtained on the qualitative measure further underline the importance of family communication in the coping and adaptation process. Of the participants, 40% reported that it helped them to talk about their feelings within the family, while 30% stated that they discussed their situation and made decisions as a family unit (see Table 5.4). Family communication,

particularly affirming and supportive patterns of communication, thus facilitates family hardiness and was found to have a significant positive relationship with family adaptation in this study.

According to Svavarsdottir and Rayens (2004), family hardiness, or positive perceptions about the situation and the expected outcome, makes families more confident to seek out resources and use them to meet the demands placed on the family. The findings relating to this search for resources will be discussed in the next section.

6.2.6. Social Support

Interestingly, the Pearson product-moment correlations calculated from the quantitative data showed no significant correlations between the family's motivation to seek and mobilise external resources (as measured by the Mobilisation subscale of the F-COPES) and family adaptation (FACI8 scores) (see Table 5.1). This seems to indicate that the families adopted a passive approach in terms of the resources available to them, only using those they already had available.

This finding is further supported by the lack of significant correlations between community support (as measured by the Social Support Index (SSI)), relative and friend support (as measured by the Relative and Friend Support Index (RFS)) and family adaptation (FACI8 scores). The families taking part in this study seemed to rely on their family unit to cope with the situation independently, without mobilising support from the community, relatives and friends.

These results are unusual, since social support has previously been found to be a key resilience resource and is mentioned in the resilience models of both Walsh (2003) and McCubbin and McCubbin (1996). These researchers suggest that social support networks offer practical and emotional support in times of adversity and serve as a buffer for the stress associated with adversity and family crises. This theory has received a lot of support in the literature on coping in families of children with disabilities. Hastings et al. (2002) reported that the availability of support from friends and family facilitated positive perceptions, since families felt that they had

external resources they could depend on to cope with their situation. Hastings et al. (2002) and other researchers (Hoare et al., 1998; Horton & Wallander, 2001; Plant & Saunders, 2007) found that those families with more social support showed lower levels of distress than those with less social support.

According to the findings obtained from the quantitative data in this study, the level of social support available to the participating families did not affect their level of family adaptation, nor did the families' attempts to mobilise external resources. These findings might indicate that the families participating in this study relied on internal family resources to facilitate coping rather than attempting to acquire additional, external resources. A possible explanation for this can be found in the qualitative data. The families mentioned that it was important for their coping and adaptation that the child was accepted by the people around them. Of the participants, 5% mentioned that it was important that the child did not receive funny looks, while 10% said that they needed the child to be treated like any other in the community (see Table 5.4). These responses might be seen to imply that social prejudice is still prevalent in these communities and that the families thus isolate themselves to protect both the child and the family itself.

This idea is supported by findings reported by other researchers. Crabtree (2007) and Sari et al. (2006) reported that families often felt socially isolated, since their child was not accepted by their community and even perceived as being threatening or repulsive. Similar results were also reported by Heiman and Berger (2008) and Catherall and Iphofen (2006), who found that families with children with disabilities had less social support available to them than the families of other children. As mentioned in Chapter 2, the amount of social support available to a family with a child with a disability is often influenced by the sociocultural context of the family.

According to Chinkanda (cited in Parekh & Jackson, 1997), families who have a child with a disability in South Africa derive minimal support from social networks. This might be due to the

above-mentioned social prejudice against people with disabilities, or might be the result of the life demands faced by peers in the community. According to Philpott (cited in Parekh & Jackson, 1997), working-class, poor women are not likely to offer support to others, since they have neither the time nor the energy, for example, to help with the care of another family's child with disabilities. Since a large percentage of the families participating in this study were of lower and middle socioeconomic status, this factor might also play a role in the limited social support these families seem to have available and their reliance on immediate family members to facilitate coping in the family unit.

Contrary to the not significant relationship between family adaptation and social support implied by the results of the Pearson product-moment correlations, (see Table 5.1), a large percentage of families reported that they depended on social support in response to the open-ended question (see Table 5.4). More specifically, 43% of the families reported that they relied on support from friends and relatives, while 45% mentioned the importance of support from doctors, psychologists and the school.

The finding that formal support was mentioned as a coping resource more frequently (45%) than social support (43%) resembles a finding reported by Gatford (2001). She found that those families who did not have an adequate social support network, due to social misconceptions, relied more on formal support to facilitate coping. This form of support has also been found to be valuable by other researchers. Graungaard and Skov (2006) found that formal support was helpful in providing information and guidelines for families of children with disabilities. Families who were given an idea of what to expect and provided with recommendations regarding the care of the child were found to adapt more positively than those who were not. Similar findings were also reported by Kearney and Griffin (2001) and Taanila et al. (1998; 2002).

Gatford (2001) and Taanila et al. (2002) also reported that formal support had the added advantage of putting families in touch with other families of children with disabilities. They found that families perceived contact with other families in the same situation as helpful. The value of this support was investigated in detail by Ainbinder et al. (1998), who found that support from similar others was perceived as empowering by the families of children with disabilities, since it allowed them the opportunity to talk with people who had the same experiences as them and would therefore be less judgmental. In addition, these support networks allowed for the exchange of ideas about caring for the child and addressing the associated difficulties, which was regarded as helpful by the participating families. A number of families (13%) in this study also mentioned that they found contact with and support from other families with children with disabilities to be a resource facilitating adaptation, because it allowed them to share their experiences with somebody who could understand them (see Table 5.4).

6.3 Summary of Results

A number of interesting relationships were identified in this study and will now be summarised, followed by the conclusions that can be drawn from this study.

According to the multiple regression analysis performed to determine which independent variables were the best predictors of the outcome variable, or family adaptation, the strongest predictor of family adaptation (as measured by the FACI8) was the level of family communication (as indicated by the FPSC Total score), followed by the coping strategies of passive appraisal and reframing (as measured by the relevant F-COPES subscales). The importance attributed to family time and routines by the family (as measured by the FTRI Importance subscale), and the coping strategy of seeking and using spiritual support (as measured by the relevant subscale of the F-COPES), were also found to be predictors of family adaptation, although their contribution was largely insignificant.

These findings are also reflected partly in the results obtained from the Pearson product-moment correlations conducted to determine the nature of the relationships between the independent variables measured by the quantitative measuring instruments and the dependent variable, family adaptation (measured by the FACI8). Significant positive correlations were found between family adaptation and family communication (both the total quality of family communication (FPSC Total) and the scores obtained on the affirming communication subscale of the FPSC); family adaptation and family hardiness (the total score and scores obtained on the commitment and challenge subscales of the FHI); and family adaptation and the coping strategy of passive appraisal (as measured by the relevant F-COPES subscale). A significant negative or inverse relationship was found between family adaptation and the scores obtained on the incendiary communication subscale of the FPSC; and between family adaptation and age of the child with developmental disabilities.

No significant relationships were found between social support (as measured by the Social Support Index, and Relative and Friend Support scale) and family adaptation (as measured by the FACI8).

According to both Walsh (2003) and McCubbin and McCubbin (1996), the appraisal or meaning-making process is central to family adaptation, since it influences the family's perception of and subsequent response to the stressor. This theory seems to be borne out by the results of this study. The variables relating to meaning making, namely reframing, passive appraisal and spiritual support, were found by the multiple regression analysis to be significant predictors of family adaptation in this sample of families. Interestingly, passive appraisal, or the passive acceptance of the situation, was found to be the most significant meaning-making and coping response, a finding supported by the significant positive relationship between this variable and family adaptation identified by the Pearson product-moment correlations. This is unusual, because although the acceptance of that which cannot be changed is central to meaning

making or reframing, the majority of previous studies have found that families adapted better if they could make meaning of, or find a reason for, having a child with a developmental disability and could believe that the outcome of the situation would ultimately benefit their family (Bayat, 2007; Hastings et al., 2002). The families in this study, however, seemed to focus more on acceptance of the situation as something they could not change and thus had to deal with, without dwelling on trying to understand the reasons for it. This attitude was also observed by the researcher during the data collection procedure and in the responses given by participants answering the qualitative question. When asked which strengths helped them to cope with having a child with a developmental disability, many participants initially just shrugged and stated that they did not dwell on it, and just got on with their lives.

The weak correlation between the family adaptation scores (as measured by the FACI8) and a sense of control over the outcomes of life (as measured by the FHI control subscale) found in this study seems to underline this finding. The participating families' adaptation did not seem to be influenced by their perceived level of control over their situation and the outcomes thereof.

The results obtained in this study also indicate that the participating families relied heavily on the resources available within the family unit to cope with the demands of caring for a child with a developmental disability, rather than relying on external support and resources. The positive relationships found between family adaptation (FACI8 scores) and the family hardiness scores (total scale) and the scores obtained on the commitment and challenge subscales of the FHI, indicate that these families' adaptation and coping was facilitated by their ability to work together and by the support individual family members provided to each other in trying to overcome the hardships associated with having a child with a developmental disability.

The positive correlations between family adaptation (FACI8 scores) and family communication (as measured by the FPSC) identified in this study indicate that this working together was

facilitated by family communication, more specifically by supportive and positive communication aimed at jointly identifying and implementing problem-solving and coping strategies. Incendiary or provocative communication, on the other hand, was found to be negatively related to family adaptation.

Interestingly, no relationship was found between family adaptation (FACI8 scores) and the availability of social support (as measured by the SSI and RFS) in this study. Both Walsh (2003) and McCubbin and McCubbin (1996) identified social support as an important adaptation or resilience resource, since it facilitates hope and acts as a buffer to stress, a proposal borne out in studies conducted by other researchers (Horton & Wallander, 2001; Plant & Saunders, 2007).

In this study, however, the availability of social support did not seem to be associated with the adaptation of the participating families. Heiman and Berger (2008) and Catherall and Iphofen (2006) found that families of children with disabilities frequently reported a decrease in social support structures. It is possible that the families participating in this study also had limited social support available and thus had to depend on the family members to cope independently. This decrease in social support could be due to societal misconceptions and prejudice about disability, or might be a result of the excessive demands already faced by other families in the community, leaving them unable to offer support to their peers (Philpott, cited in Parekh & Jackson, 1997).

The findings of this study would indicate that an acceptance of the situation, positive patterns of communication, commitment to the family unit and a positive attitude towards new experiences and challenges facilitate family adaptation, while incendiary communication and the age of the child were found to be inversely related to family adaptation.

6.4 Conclusion

As is evident from the above discussion, a number of variables identified as contributing to family resilience in the theoretical frameworks of McCubbin and McCubbin (1996) and Walsh (2003), outlined in Chapter 2, were also found to be related to family adaptation in this study. Somewhat surprisingly, however, other variables that had been identified as relevant by these and other researchers were not found to be related to family adaptation in this study.

As mentioned previously, the quantitative measures used in this study were designed to be completed by the participant him/herself. However, many participants in this study preferred the researcher to administer the questionnaires and measuring instruments verbally. During this process, many statements needed clarification by the researcher before the participants felt confident to answer. Care was taken to circumscribe the exact content and meaning of the statement in question into a statement the participant could understand. Nonetheless, the participants frequently seemed to struggle to understand what was being asked, or struggled to relate the question or statement to their own life. This limited understanding of the measuring instruments might serve to explain the low reliability scores obtained on some measures during this study, and raises the question whether these instruments were suitable for this study population. It is possible that the results obtained in this study would have been different if other, more applicable, measuring instruments had been used.

The findings suggest some possible avenues of intervention to support the adaptation of families in South Africa who have a child with a developmental disability. Firstly, more attention and support need to be offered to families of older children, since these families seem to find adaptation and coping more difficult than those with younger children.

Secondly, families can be supported in their acceptance of their child's diagnosis and of the resulting situation. Previous studies (Graungaard & Skov, 2008; Kearney & Griffin, 2001;

Taanila et al., 2002) have found that acceptance and meaning making in families of children with disabilities is facilitated by information about the condition and expectations for the future. Since acceptance was found to be central to adaptation in this study, families might benefit from facilities where they can find additional information about their child's condition and guidelines for caring for this child. In addition, it might be useful for families of children with disabilities to have the opportunity to meet and interact with other families in the same situation. The value of such contact was found in previous studies (Ainbinder et al., 1998; Taanila et al., 1999), and also mentioned in response to the open-ended question by a few participants in this study. This might be especially useful, since families of children with disabilities in South Africa seem to have limited social support networks, as reported by Parekh and Jackson (1997) and found in this study.

Finally, these findings suggest that families can be supported in their adaptation following the diagnosis of a child with a disability by implementing programmes designed to facilitate positive communication and problem-solving strategies within the family, which would enable the family members to work together and support each other more effectively. This would allow them to feel more confident in their ability to cope with the situation and the associated demands.

This study has yielded some interesting findings. There are, however, a few limitations to this research, which will be discussed in the following section.

6.5 Limitations

A major drawback of this study is the lack of comparative data examining the influence of the child's level of disability and concurrent behaviour problems on family adaptation. As mentioned in Chapter 2, the findings regarding the influence of the severity of the child's disability on family adaptation are contradictory, but the majority of studies suggest that family adaptation is influenced by the carers' perceptions of their child's disability and care needs,

rather than by the actual level of disability. The literature further suggests that behaviour problems lead to a more negative perception of the child's level of disability and needs, and thus affects adaptation. All but three families participating in this study stated that their child had many needs and was often very difficult, that is, presented with challenging behaviour. Unfortunately, no measuring instrument was used to gather more specific information about the perceptions the participants had of their child's level of disability and the level of behaviour problems the child presented. There are thus no analyses investigating the impact of these perceptions on family adaptation. A possible alternative to measuring the carers' perceptions would have been to compare family adaptation according to the severity of disability as determined by the school. Since the questionnaires were completed without any identifying information in order to maintain the participants' anonymity, it would, however, not have been possible to match this information to the relevant set of measuring instruments.

A second limitation of this study is the fact that it assumes the responses of one family member to be representative of the opinions of the entire family unit. It would have been more illuminating if data could have been gathered from other family members as well, including other children in the family, to obtain more detailed information about the variables of interest. This was not possible, however, due to the small study population available for this study.

Finally, this study only measures family adaptation at a single point in time. It does not contain any information on the families' levels of adaptation before the diagnosis of a developmental disability in their child, and thus operates on the assumption that the families' adaptation was indeed affected by the diagnosis and that they have since instituted changes and employed resources to recover. A longitudinal study comparing family adaptation both pre- and post-diagnosis, as well as a few years later, would have been more informative, especially in light of the fact that family adaptation was found to be inversely related to the age of the child.

6.6 Suggestions for Future Research

In light of these limitations it would be useful to conduct another study of family adaptation in families of children with disabilities that includes comparative data regarding the influence of the child's level of disability and behaviour problems on family adaptation. Such a study should also include the responses of more than one family member in the analyses. In addition, based on the question raised earlier regarding the applicability of the measuring instruments used in this study in a South African context, a study specifically examining this applicability would be useful.

This study aimed to compare the resilience resources employed by coloured families with a child with developmental disabilities living in South Africa to those employed by the mainly Caucasian families living in America or Europe who participated in previous research on resilience in families of children with disabilities. Some of the variables identified as being resilience resources in this prior research were also identified in this study, while others were not. It would be interesting to conduct a study using a more heterogeneous sample of South African families, that is, coloured, black, white and Indian families, to compare the resilience resources used by each and thus identify any cultural differences, especially in terms of the social support available to these families.

Finally, based on the fact that passive acceptance was one of the main contributors to adaptation in the families participating in this study, it would be useful to conduct a study measuring family adaptation in families both before and after the diagnosis of a developmental disability to determine whether the diagnosis does in fact affect adaptation, or whether it is just accepted as part of an already difficult life, especially in families of lower socioeconomic status.

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ADDENDUM A

Socio-Economic Status (Riordan, cited in Tennant, 1996)

Classification of Breadwinner's Occupation

Occupation Classification	Score
Top professional, executive, administrative and technical occupations	9
Professional, administrative and managerial workers	8
Independent commercial	7
Lower grade administrative, technical and clerical with limited supervisory and	6
Artisans and skilled workers with trade qualifications	5
Routine clerical and administrative workers, service and sales workers	4
Semi-skilled production and manual workers	3
Unskilled production and manual workers	2
Not economically active or productive	1
No response	0

Classification of Breadwinner's Education

Father's Education	Score
University attendance	7
Post-Matric training (not university)	6
Matric	5
Apprenticeship	4
Junior Certificate	3
Primary School	2
None at all	1
No response	0

Classification of Socio-Economic Status

	Lower	Middle	Upper
White	2 – 10	11 – 13	14 – 16
Coloured	2 – 6	7 – 10	11 – 16
Indian	2 – 6	7 – 10	11 – 16
Black	2 – 5	6 – 10	11 – 16

ADDENDUM B

Naam van kind: _____

Geagte Ouer

Mej. Claudia Nolting het my genader om 'n ondersoek by ons skool te doen. Die Departement van Onderwys en ek glo dat die studie belangrik is en het du sons toestemming daarvoor gegee. Mej. Nolting geniet my volle ondersteuning en u samewerking sal waardeer word.

Vriendelik die uwe

Mnr. Davis

Geagte Ouer

My naam is Claudia Nolting. Ek is 'n MA student in die Departement Sielkunde by die Universiteit van Stellenbosch. Ek is tans besig met 'n ondersoek wat kyk na die sterktes in gesinne met kinder swat 'n leertekort het, d.w.s. ek wil graag uitvind watter faktore so 'n gesin help om by die situasie aan te pas.

Vir die doel het ek 'n paar vraelyste wat deur een ouer van die kind met 'n leertekort ingevul moet word. Hierdie vraelyste prober bepaal watter metodes en van watter ondersteuning gesinne gebruik maak om by hulle kind aan te pas. Dit neem omtrent 30 tot 45 minute om die vraelyste in te vul. Al die antwoorde op die vraelyste is heeltemal anoniem en vertroulik, d.w.s. niemand sal weet wie watter antwoorde gegee het nie. As u inwillig om aan die ondersoek deel te neem wil ek graag 'n afspraak met u maak om u te ontmoet wanneer en waar dit u sou pas.

Ek glo dat hierdie ondersoek belangrik is, omdat dit vir ons 'n idée kan gee watter ondersteuning gesinne met 'n kind wat 'n leertekort het, nodig het.

As u belangstel om aan die ondersoek deel te neem, vul asseblief u kontakbesonderhede onder aan die bladsy in en stuur die bladsy voor donderdag (26/08) terug na die skool. Ek sal u dan binnekort kontak en 'n afspraak met u maak.

U samewerking sal opreg waardeer word.

Vriendelik die uwe

Claudia Nolting

Dr. A.P. Greeff

Supervisor

Naam: _____

Telefoonnommer by die huis: _____

Telefoonnommer by die werk: _____

ADDENDUM C
BIOGRAPHICAL INFORMATION

All the information provided in this questionnaire will be treated as strictly confidential and you will remain anonymous.

Please tick the appropriate block, or supply the required information.

1. **Residing in** (suburb or town)
2. **Marital status:** Are you currently married or in a long-term relationship? No Yes
How long have you been in the relationship? (months or years)

3. Family Composition:

	Self	Partner	Child at Dorothea School	Child 2	Child 3	Child 4
Age						
Gender						

Is there anybody else currently living with you? No Yes

Please explain

.....

How long ago was your child diagnosed with having mental disabilities? Years

4. Occupation and Education of the Primary Breadwinner

- Highly qualified professional, executive, technical and administrative occupation
- Professional worker, administrative worker and manager
- Commercially independent
- Less qualified administrative, technical and clerical occupation with limited supervisory responsibility
- Skilled worker and artisan with commercial qualification
- Routine clerical, administrative, maintenance and sales worker
- Semi-skilled production and manual labourer
- Unskilled production and manual labourer
- Not economically active or productive
- No comment

Education of Breadwinner

- University Education
- Other tertiary education
- Matric
- Artisan
- Junior Certificate (Std. 8)
- Primary school
- No education
- No comment

