RESILIENCE IN FAMILIES WITH A CHILD LIVING WITH AUTISM SPECTRUM DISORDER

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Abstract

In recent years the number of studies on resilience emerging within the field of positive psychology has increased. However, such studies are limited within the South African context and so the proposed study aims to explore and describe the factors that facilitate adjustment and adaptation in South African families living with Autism Spectrum Disorder. McCubbin, McCubbin and Thompson (2001) developed the Resiliency Model of Family Stress, Adjustment and Adaptation which were used to conceptualise the family’s adaptation.

 Mothers (n = 19) from 19 families participated in the study. The families consisted of at least three members, of which two are parents and one a child younger than 18 years of age that has been diagnosed with Autistic Spectrum Disorder. A combination of non-probability purposive sampling and snowball sampling was used to select participants.

The study had an exploratory and descriptive aim and employed triangulation of method, including both qualitative and quantitative data collection procedures. A biographical questionnaire and the following seven structured paper-and-pencil questionnaires were used: the Family Attachment and Changeability Index 8 (FACI8), the Family Crisis-oriented Personal Evaluation Scales (F-COPES), the Family Hardiness Index (FHI), the Family Problem-solving Communication (FPSC), the Family Time and Routine Index (FTRI), the Relative and Friend Support (RFS), and the Social Support Index (SSI). Descriptive statistics were used to describe the biographical information. Qualitative data were analysed by means of content analysis. Quantitative data were manipulated by means of correlation and regression analysis.

The results from the quantitative analysis indicate three significant positive correlations with the FACI8. These variables were the family hardiness (measured by FHI), family problem-solving communication (measured by the FPSC), and family time and routines (measured by the FTRI). The findings from the qualitative analysis point out that social support, the spousal relationship and family time, togetherness and routines are the most important strength factors that contribute to the family’s adjustment and adaptation.
Even though this study had a small sample size and several other limitations, the findings of this study could still assist in guiding specialised institutions toward providing more comprehensive information and support to families living with a child diagnosed with Autism Spectrum Disorder. This study also contributes to the studies on family resilience within a South African context.

Key concepts: Autism Spectrum Disorder, family resilience; Resiliency Model of Stress, Adjustment and Adaptation
Chapter 1: Introduction and Motivation for This Study

1.1 Introduction

Chapter one introduces the present research on resilience in families living with a child diagnosed with Autism Spectrum Disorder (ASD). Attention is given to the context of the research and the theory within which this study is embedded. The motivation and aim of the study is clearly stated. The chapter concludes with a delineation of the chapters to follow.

1.2 Context of the Research

This section focuses on the context of the research and presents a literature overview on families living with ASD and resilience. This study is embedded within positive psychology, and this paradigm is briefly discussed.

1.2.1 Families Living with Autism Spectrum Disorder (ASD)

In South Africa the prevalence of autism alone is 88,896 in an estimated population of 44.5 million people, with an incidence of 490 new cases being diagnosed every year (Adviware Pty Ltd., 2006). Latest studies suggest that as much as one out of 150 children is diagnosed with ASDs. This makes ASD five times more common than Down syndrome and three times more prevalent than juvenile diabetes (Nash, 2002).

The birth of a child with ASD presents many challenges and difficulties to the parents and other family members as this pervasive disability affects almost every area of family functioning. The uniqueness of every child (Deverell & Ross, 2004; Freeman, 1993; Mash & Wolve, 2002) brings about unique stressors which the family needs to cope with and the family is faced with changes to their routine, relationships, and patterns of communication. A diagnosis of ASD presents unique challenges in areas such as communication, bonding, coping with unpredictable behaviour and family routine which forces the family to adjust (Drew & Norton, 1994) in order to incorporate the needs of
both the ASD child and the family as a unit. Schall (2000) emphasised that ASD is a pervasive disorder and should be regarded as a family problem and not only the problem of the ASD individual.

Extensive research has been conducted with regards to describing the genetic factor in families with a child with ASD, including studies which found neuropsychological disorders such as depression, bipolar disorder, obsessive compulsive disorder, alcoholism, substance abuse, social phobia, anxiety disorders and motor tics to cluster in families with ASDs (Arndt, Childress, Jacobi, Palmer & Piven, 1997; Bolton, Murphy, Pickles & Rutt, 1998; Bristol, Cohen & Costello, 1996; Haber, Hadden, Miles & Takahashi, 2003; McCracken, Smalley & Tanguay, 1995; NIMH Genetics Workgroup, 1998). Various researchers also investigated educational interventions aimed to increase social communication and behaviour of children with ASD (Bimbela, Koegel & Schreibman, 1996; Chan, Iacono & Waring, 1998; McEachin, Smith & Lovaas, 1993; Symon, 2005). Research studies on the effects of any disability on the family unit are very limited, and even more so in the field of ASD (Drew & Norton, 1994).

A diagnosis of ASD is often postponed and because being undiagnosed leaves children excluded from specialised education, early intervention is desirable (Drew & Norton, 1994; Lord & Risi, 2000). This time of uncertainty is an emotionally trying period for the family. Often their feelings of loss and grief are repressed to be fully experienced and managed only after their persistent requests for assistance and assessment toward a diagnosis and intervention have been responded to (Sicile-Kira, 2003). Living through the experience of grief usually orients the family toward developing and implementing coping strategies to deal with their situation (Drew & Norton, 1994).

Research suggests that the family power structure alters as older siblings tend to assume more power and authority because parents are focused on the needs of the child with disabilities (Drew, Egan, Hardman & Wolf, 1993; Drew & Norton, 1994). Non-disabled, older, female siblings often take on additional childcare responsibilities and could even develop negative attitudes towards the changes in the family system. In situations where positive adaptation took place, the siblings appeared to benefit from the experience as they displayed increased awareness and tolerance of individual differences in others (Darling & Seligman, 1997; Drew & Norton, 1994).
There is discordance in the literature regarding the effects that having a child with ASD has on the parents’ marriage. Featherstone (1980) described the child with ASD as “a symbol of shared failure” (p. 72) and stated that the situation can evoke strong emotions from both partners resulting in extreme marital conflict. On the other hand, Cobb (1987) claimed that the diagnosis of a disability can draw couples closer together. Darling and Seligman (1997) has found that these marriages do not experience more stress, but that parents of children with ASD often experience most stress when attention is drawn to the family because of their ASD child’s behaviour.

The psychological well-being of the caretakers of a child with ASD is also taken into consideration within the literature (Gordon, Gowar & Ramcharan, 2003). While some researchers indicate that primary caretakers of children with disabilities do not suffer from serious emotional problems (Carr, Horner, Reed, Strain & Todd, 2002), others have found caretakers, especially mothers, to be more vulnerable to serious emotional problems such as sensitivity to guilt and criticism (Drew & Norton, 1994; Featherstone, 1980).

McCubbin and Patterson (1983b) confirmed that families of children with disabilities deal with several challenges such as strained relationships, changed priorities, increased financial expenses, social isolation, medical problems, special schooling or remedial teaching, and grief for the limited opportunities of the impaired child. Literature indicates that families are unique in their response to the arrival of a child with disabilities and that the outcome could be either a weakened family system or unification of the family (Jeppson, Johnson & Shelton, 1987). All of these studies focused on subsystems within the family. Literature concerning the family system and how the system copes with and adjusts to an ASD child in the family, is sparse.

1.2.2 Positive Psychology and Resilience

In recent years, a general move occurred within the social sciences from the problem-oriented pathogenic model of disease and illness toward health-oriented positive psychology and the understanding of what contributes to the growth, development, and general wellness of individuals. Aaron Antonovsky theorised that a pathogenic orientation views stressors and adversity as risks and
that dealing with these stressors simply returns one to a state of homeostasis without developing and enhancing active coping strategies for the future (Compton, 2005).

Antonovsky (1979; 1987; 1996) developed the salutogenetic paradigm which focuses on the strengths and positive characteristics which cultivates growth and hardiness within individuals. His theory of wellness suggests that a health-ease versus dis-ease (rather than disease) model should be used which is essentially strengths-based and focuses on what enables individuals to stay healthy (Sarafino, 2006). Antonovsky preferred a continuum approach to health as apposed to a dichotomous classification which labels people as being either diseased or healthy (Antonovsky, 1979; 1987; 1996). This enabled him to enquire into general factors relevant to all diseases as well as explaining what facilitates movement toward the most salutary end of the continuum without narrowing one’s search to specific, disease-relevant factors (Antonovsky, 1979; 1987; 1996). Antonovsky has found that one such factor, a sense of coherence, fosters health (Sarafino, 2006). Various approaches were developed from Antonovsky’s theory of the sense of coherence (also referred to as positive coping) (Comptom, 2005), including that of resilience.

Resilience refers to the presence of self-esteem, personal control, and optimism. Resilient individuals demonstrate hardiness by appraising stressful events as less stressful and by bouncing back from hardships and misfortunes (Sarafino, 2006). Resilience research generally focused on the resilience of individuals, with special attention to children at risk to adverse developmental outcomes (Allen, Han, McCubbin, McCubbin, Thompson, 1997). Research has shown that the broader context within which children find themselves, the family milieu being a generic factor, could be a protective factor in fostering resilience through hardship (Walsh, 2003). Longitudinal research of individual resiliency traits progressed towards studies with the family as their primary focus (Richardson, 2002).

Family resilience frameworks are embedded in the movement of positive psychology and move away from the search for deficits or pathology in families (Csikszentmihalyi & Seligman, 2000; Seligman, 1998). Family resilience seeks to discover the family’s strengths and coping skills in an attempt to develop their potential, to increase family functioning and individual well-being, as well as to understand how the family endures and adapts in the face of adversity (Allen et al., 1997; Goldenberg
& Goldenberg, 2004; McCubbin and McCubbin, 1988; Walsh, 1993; 2003). Walsh (1993) stated that all families have the potential for growth and repair in response to distress, adversity or crises, and even though the family unit or one of its members manifests dysfunctional behaviour during transition periods, one need not conclude that the family is without resources and strengths (Goldenberg & Goldenberg, 2004; Walsh, 2003). The family serves as a valuable buffer against hardship as the family fosters both protective and recovery factors to shield its members against hardship and to enable them to bounce back from adversity (called resiliency factors). General resiliency factors include family problem-solving communication, family hardiness, family time and routine, equality, spirituality, flexibility, truthfulness, hope, social support, and health (Allen et al., 1997). The literature suggests that a focus on what makes families strong in the face of adversity could be beneficial to the family (Hawley, 2000; McCubbin, McCubbin & Thompson, 2001; Ryff & Singer, 2003; Walsh, 2003). Cohesion and adaptability are important family resources with regard to stress management in times of crisis or transition (McKenry & Price, 1994). Families with a strong sense of coherence and a belief that hardships will eventually work out favourably (Antonovsky, 1979; 1987; 1996) have been found to be quite capable of enduring stress, crises, and adversity, and even manifest immense growth throughout difficult circumstances (Hawley, 2000).

The concept of individual resilience, especially with children, has been thoroughly researched through the years; but research with regard to resilience in the family as a primary unit is lacking, especially in South Africa where family resiliency research is scarce. Limited published studies on family resilience in South Africa include that of Der Kinderen and Greeff (2003) who identified and described resilience factors in families in which a parent accepted a voluntary retrenchment package; Greeff and Aspeling (2004) who focused on single-parent families; Greeff and Human (2004) who studied families where a parent had died; and Greeff and Van der Merwe (2004) who studied divorced families. The present research forms part of resilience research funded by the South Africa Netherlands Research Programme on Alternatives in Development (SANPAD). These research endeavours focus on the impact of normative and non-normative crises on the family.
In a post-modern society with its increasing options, blurred gender roles and shifting values, the family is in a critical position. Its traditional assumptions and conceptualisations are being challenged within a changing environment, which contributes greatly to the stressors facing the family system (Allen et al., 1997; McKenry & Price, 1994). Despite these modern-day challenges, the family of a child diagnosed with ASD also needs to cope with and adapt to the added stressors presented by the diagnosis. In addition to this, the prevalence rates of the disorder are increasing, placing more and more families in a position where they are in need of resilience to adjust and adapt to such a diagnosis and the challenges it presents. The main focus of previous research studies on families with a child with ASD, was to explore the various stressors faced by these families (Richardson, 2002). Limited research studies have been conducted on family coping strategies associated with ASD (Cutler, Domingue, & McTarnaghan, 2000; Drew & Norton, 1994; Hauch & Trute, 1988; Jones & Passey, 2005), as well as on the process of resilience within these families, making use of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin, McCubbin & Thompson, 2001).

The abovementioned literature introduced the two-fold motivation for this study: growing concern for the potentially adverse effects the disorder may have on family functioning and the lack of South African research on family resilience, particularly in relation to families with a child diagnosed with ASD. The findings of this study could lend itself to an improved understanding and an in-depth exploration of the factors which contribute to the resiliency of these families and could assist in guiding specialised institutions toward providing more comprehensive information and support to these families than was available before.

1.3 Primary Aim of the Research

The primary aim of this research was to explore and describe the resilience factors that facilitate adjustment and adaptation in a family with a child that has been diagnosed with ASD.
1.4 Delineation of Chapters

Chapter one introduced the present study. This chapter explained the context of the research and the theory within which this study is embedded. The motivation and aim for the study are also stated.

Chapter two focuses on resilience and provides an overview of the progression in studies of resilience from a personality trait to a family level construct. A detailed discussion of McCubbin, McCubbin and Thompson’s (2001) conceptual model for family adjustment and adaptation are provided.

Chapter three describes the family’s experience of ASD. This chapter focuses on the characteristics of the diagnosis and the psychosocial impact it has on the family in its attempt to cope with and adapt to this lifestyle.

Chapter four describes the research design and method used to obtain the data for this study. The chapter provides an outline of the sampling procedure and the various instruments that were used. This is followed by an explanation of the data analysis methods that were used. The chapter concludes with the ethical considerations of this study.

Chapter five discusses the research results obtained from the data analysis. These results are interpreted in terms of the literature presented in chapters two and three.

Chapter six discusses the conclusions of the study based on the research results and theories. Attention is given to the limitations of the study and recommendations are made for future studies on this topic. The chapter concludes with notes for the attention of policy makers, institutions and professionals, based on the researcher’s observations of the studied sample.

1.5 Conclusion

Chapter one provided an outline for the current study. It was stated that families living with a child diagnosed with ASD are faced with a myriads of challenges and need to cope with their circumstances and with increasing prevalence rates, more families will share this experience. These families are in need of resilience in an attempt to adjust and adapt to this crisis. The construct of
resilience has been receiving increased attention among researchers. The motivation for this study was discussed and the aim of the study was stated. The chapter concluded with a delineation of the chapters to follow.
Chapter 2: Family Resilience

2.1 Introduction

The construct of resilience has long been studied as a personality trait within individuals. Special attention has been given to studies on individual resilience in children of mentally ill parents, children in dysfunctional families and children exposed to poverty and other extraordinary circumstances. These studies have focused on individual resilience as a protective factor and isolated the child from the system in which children find themselves to be. Longitudinal research of individual resiliency traits progressed towards studies with the family as their primary focus. Studying the child within his family milieu contributed to information about the family’s role in fostering resilience through hardship, ultimately resulting in studies on family resilience.

Chapter two gives an overview of the progression in studies of resilience from a personality trait to a family level construct. A discussion on McCubbin and Mc Cubbin’s Resiliency Model of Family Stress, Adjustment and Adaptation and its processes will follow. Special attention will be given to the Adaptation phase of this model, seeing as this phase is the focus of this study. Lastly, the chapter will discuss research on the resilience of families coping with a child with Autism Spectrum Disorder (ASD).

2.2 Historical Overview of the Concept of Resilience

The term resilience emerged from a remarkable forty year longitudinal study conducted by Emmy Werner and Ruth Smith starting from the 1950s. Werner and Smith tracked almost 700 children’s development far into adulthood on the Island of Kauai and assessed the long-term consequences of peri- and prenatal complications, rearing conditions, development and adaptation using various biological and psychosocial variables (Johnson & Wiechelt, 2004; Richardson, 2002; Walsh, 2003). All the children grew up in immense poverty and a chaotic family environment, including alcoholism, mental illness and parental divorce. Despite similar environments, two thirds of
the children developed serious problems into adulthood whereas one third developed into caring and well-adjusted adults. This result begged the question as to what caused the different outcomes.

Werner and Smith’s research paved the way for psychologists to start thinking about “developmental assets” (Richardson, 2002, p. 309) of individuals and “nurturing personal strengths” (Richardson, 2002, p. 310) that would assist them to rise above the hardship, rather than the risk factors – the predictors of poor outcomes to adversity and trauma. These developmental assets were seen as the individual’s protective factors which lead to resilience (Johnson & Wiechelt, 2004). In her research, Werner described four main protective factors prevalent in resilient adults: to have developed at least one personal, healthy relationship within infancy and childhood; to be responsive, affectionate and good-natured as an infant and child; to have had friends during their school years and to participate in various school events and youth groups; and to have good language and reasoning skills in relation to their peers during their school years (Johnson & Wiechelt, 2004). British psychiatrist Michael Rutter conducted various studies on inner-city London youth and echoed Werner’s work. This researcher contributed to the list of protective factors and included attributes such as self-efficacy, self-mastery and planning skills (Rutter, 1979; 1985). In 1984 Norman Garmezy and colleagues conducted the Minnesota Risk Research Project. Norman Garmezy’s research included children of schizophrenic parents and this researcher developed a “triad of resilience” (Garmezy, 1993; Hawley, 2000; Richardson, 2002, p. 309) which includes a personality disposition, a supportive family environment and an external support system. In several research studies throughout the fifties up until the nineties, researchers identified several protective factors which aided children and adults alike to bounce back from adversity and to develop into confident, caring and coping adults. In recent years, resilience qualities have been identified within the emerging field of positive psychology which concentrates on strengths, virtues and characteristics indicative of mental health (Csikszentmihalyi & Seligman, 2000; Seligman, 1998). Some of these qualities include happiness, creativity, optimism, wisdom, excellence, self-determination, forgiveness, hope and humility (Allen, Han, McCubbin, McCubbin & Thompson, 1997; Csikszentmihalyi & Seligman, 2000; Richardson, 2002).
Studies that aim to identify and describe protective factors within individuals are known as the first wave of resiliency inquiry. The first wave is characterised by a shift from looking at risk factors to focusing on protective factors and adjustment (Richardson, 2002). The second wave of resilience inquiry recognises that resilience is a dynamic process, an interplay between the environment, the individual and event, and aims to develop the theory behind the construct and to discover the process of attaining resilience qualities. Resilience became more than just a list of protective factors, but rather a process of coping and adjustment, using one’s own resources and enriching or developing your existing resilient qualities. The potential to develop and enhance resilience is therefore something that happens across the life course of individuals (Walsh, 2003).

Walsh (2003) commented that many authors acknowledge the role of mentors, coaches and significant family members, but they do not recognise the role of families within the process of resilience. Instead of seeing families as protective factors, they are most often described as contributors to the risk factors of individuals. Walsh took a systems-oriented view of resilience, describing families as “challenged in the face of adversity” (p. 2) rather than “damaged beyond repair” (p. 2) – a conceptualisation which is core to positive psychology (Csikszentmihalyi & Seligman, 2000; Walsh, 1993; 2003). In her research on resilience, Walsh makes use of a family framework and attempts to identify the strengths and potentials that families hold to help them cope with life’s demands and stressors. The advantages of a family resilience framework is its focus on strengths, acknowledging the uniqueness of each family and viewing processes for optimal functioning as varying across the life cycle requiring collaborative effort from the whole family to overcome crises (Walsh, 2003). De Haan and Hawley (1996), and Yates and Masten (2004) also commented on the uniqueness of the family’s response in that resilience is a process, rather than a fixed set of traits that allows the family to change and adjust to the stressors and to develop and grow through this process. A systems-oriented view of resilience brought the family to the forefront of research and the study of resilience became increasingly viewed as a family level construct.
2.3 Family Resilience

Family resilience literally means the ability to bounce back. McCubbin, McCubbin and Thompson (2001) defined resiliency as

…the positive behavioural patterns and functional competence individuals and the family unit demonstrate under stressful or adverse circumstances, which determine the family’s ability to recover by maintaining its integrity as a unit while insuring, and where necessary restoring, the well-being of family members and the family unity as a whole (p. 5).

In other words, resiliency is the family’s ability to cultivate strengths that enable them to meet the challenges of life and yet return to previous levels of functioning following a challenge or crisis (Allen et al., 1997). Families occur in a diversity of forms, which must be considered as a social system with an evolved set of rules, boundaries and a shared history. Traditionally, entrance to a family was considered to be via birth, marriage or adoption. In post-modern times, as membership is also obtained via a committed relationship, it is important to also consider cohabiting families or children who have permanent living arrangements with family members or siblings as a family (Goldenberg & Goldenberg, 2004; Walsh, 1993). For the purpose of this study, a family is defined as a group of people who are bound together by a set of rules and boundaries and who have gained access to the group via birth, marriage, adoption or a committed relationship.

Walsh (1998; 2003) identified three key family processes in resilience: 1) a positive belief system, 2) the family’s organisational processes, and 3) the family’s communication processes. An affirming belief system provides the family with a shared set of guidelines to behaviour based on shared morals, values and a bigger purpose. The family’s belief system must speak of hope, optimism and encouragement from which they can draw strength. To develop a sense of coherence or togetherness, the family needs to be able to normalise and contextualise their experience and to construct meaning from it (Bates, Baxter, King, King, Rosenbaum & Zwaigenbaum, 2006; Walsh, 2003). Organisational processes refer to the family’s ability to organise itself and to experience a sense of control when difficulties cross their path. Leadership and authority should be negotiated and established in an effort to create/maintain boundaries and provide guidance within a nurturing,
protective family environment. Organisation patterns includes flexibility, but stability in the course of disruption, a sense of connectedness gained through support, commitment and collaboration and the ability to mobilise resources, delegating tasks and sharing responsibility (McCubbin, McCubbin & Thompson, 2001; Whitman, 2004). Communication within the family needs to be clear, consistent and congruent to strengthen trust and openness among its members (Walsh, 2003). Communication patterns include collaborative problem-solving where the family shares the decision making responsibility and engages in constructive conflict resolution (Allen et al., 1997). These three processes largely predict how the family will be able to recover from misfortune (Walsh, 1998; 2003).

Within a family resilience framework, resilience is viewed as two different but interconnected processes: 1) adjustment, which is concerned with the protective factors which enable the family to fulfil their developmental tasks, to continue functioning and maintain integrity despite facing hardship and/or crises, and 2) adaptation, which entails the recovery factors which promote the family’s hardiness and ability to adapt to the crisis situation (Allen et al., 1997). The following section provides an overview of family resilience research within the South African context.

2.4 Family Resilience Research in the South African Context

South Africa mirrored the same trend with regards to resilience research, than was apparent in the rest of the world. Strümpher (1993, 2005), a researcher from the University of Cape Town, and Wissing (1996), from the University of Potchefstroom, conducted various studies on individual resilience. As interest in the field of positive psychology gained momentum, South African research into individual resilience progressed to investigations into the concept of family resilience (Greeff, 2004). Greeff (2004), from the University of Stellenbosch, made a considerable contribution to South African research publications on the topic of family resilience, including various vulnerable family populations like: families in which a parent accepted a voluntary retrenchment package (Der Kinderen & Greeff, 2003), single-parent families (Greeff & Aspeling, 2004; Greeff & Ritman, 2005), families in which a parent has died (Greeff & Human, 2004), and divorced families (Greeff & Van der Merwe, 2004). The results of these studies indicate that social, emotional and practical support from extended
family and friends (Greeff & Human, 2004; Greeff & Van der Merwe, 2004) contributes greatly to the family’s resilience. The researchers also found that the family’s hardiness plays a considerable role in its adaptation to crises. Hardiness can be described as a family’s internal strengths, their ability to work together and to depend on each other (Greeff & Human, 2004).

The aforementioned studies as well as the present study forms part of research collaboration between South Africa and the Netherlands. This family resilience project is funded by the South Africa Netherlands Research Programme on Alternatives in Development (i.e. SANPAD). As part of the family resilience project, the University of Stellenbosch is currently conducting research into the characteristics of African families affected by normative or non-normative crises.

Overall, it is apparent that even though South African research on family resilience is limited, the interest into the field is growing and contributing to the existing knowledge of family life in South Africa. From the available South African studies, it has been concluded that South African families do have the capacity to preserve family stability and harmony and have the capacity to restore the family’s functioning following crises. This indicates that South African families are resilient (Greeff, 2004; Greeff & Human, 2004; Greeff & Van der Merwe, 2004). A discussion of the conceptual framework used in the SANPAD funded resilience project, and thus in the present study, follows.

2.5 Conceptual Framework

McCubbin and McCubbin (1996) made a significant contribution to the development of family resilience research. These researchers expanded on Hill’s (1958) ABCX model which focused on pre-crisis factors in the family; McCubbin and Patterson’s (1983) double ABCX model and its extension; the Family Adjustment and Adaptation Response Model (FAAR) which incorporates both pre- and post-crisis factors, and suggested the Resiliency Model (McCubbin & McCubbin, 1996). This model is embedded in family stress theory and suggests that various factors can predict a family’s adaptation to stressors, including the familial resources, their appraisal of the stressor, hardiness, problem-solving skills and coping skills (Hawley, 2000; McCubbin, 1995; McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001).
Research based on the family Resiliency Model of Family Stress, Adjustment and Adaptation (hereafter referred to as the Resiliency Model) has a post-crisis focus. This model studies family strengths, resources and coping in an effort to understand and explain why some families are able to adjust to change and recover from a crisis-state, illustrating problem-solving skills, a directedness towards goals and life satisfaction and being more flexible and able to adjust to conditions of flux (Deal, De Haan & Hawley, 2002; McCubbin & McCubbin, 1988; McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001; Walsh, 1993; 2003). On the other end of the spectrum, this model also aims to understand why other families seem to deteriorate and remain at risk when exposed to similar situations (McCubbin & McCubbin, 1988; McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001; Walsh, 1993). A crisis-state for the family is a time when the family is not functioning adequately, boundaries disintegrate, roles neglected, and its members' physical and psychological functioning is not at an optimum level (McKenry & Price, 1994). Allen, Han, McCubbin, McCubbin and Thompson (1997) described family crises as a state of disequilibrium which
denotes the family susceptibility to continued instability, disorganization and
dysfunction. Crisis producing events are those normative and non-normative life events that
disrupt the family system and that precipitate changes in, or the necessity for changes in,
the family’s patterns of functioning, thus placing the family system at risk for continued
decline in functioning leading to dysfunction (p. 6-7).

The Resiliency Model is based on five assumptions (McCubbin & McCubbin, 1996; McCubbin,
McCubbin & Thompson, 2001). Firstly, crisis, hardship and changes are a natural and predictable
aspect of family life which all families undergo at some stage or another. Secondly, families develop
and acquire skills, patterns of functioning and competencies which protects them from these changes
and hardship and help them to grow and develop as a family. It follows that families develop and
acquire skills, patterns of functioning and competencies to protect them from stressors and trauma
and to foster the family’s recovery following the hardship and transition. In the fourth place, families
make use of and contribute to social networks and resources within the community especially during
times of crisis and stress. Lastly the model is based on the assumption that when in crisis, families
need to make changes in their functioning in order to return to a state of equilibrium, and that these changes occur during their experience of the stressors and crisis (McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001).

Investigation into family resiliency is based on two interrelated processes: in the face of stressors, adversity or crisis, families utilise and create resources to protect the family system from breakdown and/or deterioration to promote 1) adjustment and 2) adaptation to the situation (Allen et al., 1997; Deal, De Haan & Hawley, 2002; McCubbin & McCubbin, 1988; McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001). These two processes are now discussed in detail.

2.5.1 Adjustment

The first process, adjustment, refers to the protective factors that interact and in turn affect the family’s ability to withstand times of adversity (McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001). A stressor is a demand placed on the family and produces change, or has the potential to produce change within the family system. When a family is faced by a stressor (A), several factors interact that will determine the outcome of the situation. Firstly the stressor has an impact on the family’s vulnerability (V), which is shaped by the pile-up of stressors at that particular time. A family’s vulnerability is determined by other demands placed on the family at that particular point in time such as being overworked and stressed or in financial debt, as well as the everyday difficulties associated with the particular developmental stage the family finds themselves in. The vulnerability of the family will interact with the family’s current and established patterns of functioning or typology (T). A family’s typology refers to a “set of attributes or cluster of behaviours that explain how the family system typically operates or behaves” (McCubbin, McCubbin & Thompson, 2001, p. 18). These factors now interact with the family’s resistance resources (B) in a reciprocal fashion. The resistance resources are the family’s abilities and capabilities to manage the stressor and the demands on the family in such a way that it will prevent deterioration or a break-down of the family system and patterns of functioning in an effort to maintain balance and harmony within the family system – the ultimate goal of the adjustment process. The resistance resources in turn interact with
the shared definition the family attaches to the stressor or the family appraisal of the stressor (C). The family’s interpretation of the seriousness of the stressor and its related complications can range between defining the stressor as something minor that is a challenge and can be overcome, or as insurmountable odds which are overwhelming. All the previous factors interact with the family’s problem-solving and coping abilities (PSC). Here the family’s ability and skill to organise, manage and possibly eliminate the stressor are being put to the test. The family is challenged to generate alternative patterns of functioning, to execute a viable option and encourage positive problem-solving communication. This is done in an effort to maintain or restore emotional stability and well-being and to strengthen the family as a unit (Allen et al., 1997; McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001).

The outcome of the adjustment phase varies along a continuum which ranges from being well adjusted and maintaining established patterns of functioning (bonajustment) to a family crisis (X) (maladjustment). Maladjustment demands of the family to enter the next stage of change (the adaptation cycle) in order to achieve equilibrium, i.e. harmony and balance (McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001).

2.5.2 Adaptation

Adaptation is concerned with the recovery factors which promote the family’s hardiness and ability to bounce back after a time of crisis or hardship (McCubbin & McCubbin, 1988; 1996; McCubbin, McCubbin & Thompson, 2001). The adaptation process is the phase of concern in this study and accordingly this process is discussed in detail. Figure 1 provides a diagrammatical representation of the adaptation phase of the Resiliency Model.
Figure 1: The Adaptation Phase of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin, McCubbin & Thompson, 2001, p. 25)
Two factors exacerbate a family crisis – the accumulated demands (AA) that a stressor (A) places on a family as well as the inadequate patterns of functioning (T) employed by the family. The family continually evaluates, interprets and ascribes meaning to their experiences with regard to their existing (T) and newly acquired patterns of functioning (TT) in an effort to make the situation more manageable and controllable. This family appraisal is performed in terms of various factors: their family schema (CCCCC) which constitutes their shared values and beliefs, their sense of coherence (CCCC), their paradigms on family functioning (CCC), their situational appraisal (CC) on the goodness of fit between the familial resources and the demands the stressor has imposed on the family and lastly, stressor appraisal (C) (McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001). In order for the family to cope and regain stability and harmony, they need to apply their problem-solving and coping skills (PSC), employ existing and innovative psychological, social and familial resources (BB), and activate support from the community (BBB). These factors culminate in the family reaching the crisis response or adaptation (XX). The outcome of the family’s adaptation over time can move them to either point of the continuum: bonadaptation or maladaptation (McCubbin & Patterson, 1983). Bonadaptation implies the maintenance of family patterns, the promotion of individual well-being of the family’s individual members as well as a sense of cohesion within the family. Maladaptation refers to an unsatisfactory level of adaptation that has been reached, causing the family to revert to a crisis situation from which the cycle will repeat itself (Hawley, 2000; McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001).

Overall, the adaptation phase aims to restore harmony and balance to the family system, with specific reference to its interpersonal relationships, the development, well-being and spirituality of the unit and its individual members, the family’s structure and function and lastly within its relationship with the community and nature (McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001). Following is a more detailed description of the various interacting components within the adaptation phase.
2.5.2.1 The Pile-up of Demands and Stressors (AA)

The family is in a continuous cycle of development and is part of an ever changing social context. The family is therefore never faced with a single precipitating stressor, but rather a pile-up of demands stemming from various changes within the family system. McCubbin, McCubbin and Thompson (2001) identified nine broad categories of stressors and strains which contribute to the pile-up of family stressors:

*The initial stressor and related hardships which developed over time:* All stressors are accompanied by related hardships which places additional burdens on the family. Such hardships might include marital discord, sibling rivalry, financial strain and depleted emotional resources.

*Normative transitions:* As stated by the assumptions made by the model, families experience normal and predictable transitions associated with the developmental stage and normal growth of the family and its individual members. These transitions (from the family, its members and extended family and friends) contribute to the added stressors that the family experience and add to the uniqueness of the family’s experience (De Haan and Hawley, 1996; Walsh, 1998; 2003).

*Prior family strains accumulated over time:* Prior strains can stem from earlier crises, hardships or transitions that have not been properly resolved and are now exacerbated in the face of a new stressor. This could mean that the pressured family will not be able to ignore the traces of prior strains, which now adds to the pile-up.

*Situational demands and contextual difficulties:* McCubbin, McCubbin and Thompson (2001) explained that the family’s community or greater society contributes to the pile-up of stressors as it influences the family’s struggle to adapt to their crisis situation. Government policies (such as affirmative action or closing down facilities for special schooling), social tendencies (for example crime waves), the economy (for example rising inflation rates, or price increases on consumer products), and neighbourhood responsibilities (such as the extra load of neighbourhood watch or a financial burden of employing neighbourhood security) can all impact on the coping strategies the family uses to adapt, and the success thereof, therefore adding to the stressor pile-up.
**Consequences of family efforts to cope:** Families employ various coping strategies in the adjustment phase to help them cope for that moment in time. The long-term results of these strategies (for example suppressing feelings of frustration, turning a blind-eye or burying one’s self under work) might indicate that these coping patterns are not as beneficial to the family or its functioning during the adaptation phase than it was before. McCubbin, McCubbin and Thompson (2001) explained that the consequences of these earlier coping efforts add to the family’s stressors and the current crisis situation might call for a problem-solving effort that will have advantageous longer-term effects.

**Intrafamily and social ambiguity:** The family often expect society to provide guidelines to cope with a crisis, especially since changes in structure, rules, roles and responsibilities can be daunting. McCubbin, McCubbin and Thompson (2001) explained that the social instructions are often absent, not supportive or are in contrast with the family’s coping strategies. For example, the institutionalisation of a child with disabilities might seem to be the least taxing option for an already strained family, but might be condemned by community groups, religious leaders or specific family members. Stress derived from such choices adds to the family’s pile-up of stressors.

**Newly instituted patterns of functioning which demand changes in the family functioning or which are not in line with the family’s schema or paradigms:** A family’s values, beliefs, rules and expectations are an integral part of the unit, and each individual member. Newly instituted patterns of functioning could be clashing with their schemas and paradigms causing further distress which adds to the pile-up of stressors (Walsh, 2003). Although changes in the family’s patterns of functioning may in the long run provide for greater harmony and balance, it could be met with resistance from family members and the immediate effect could be disharmony which could even prolong the crisis situation.

**Established patterns of functioning:** Routines and established ways of doing things are some of the most difficult behaviours to change. Even if new patterns of functioning might be very necessary, they are often in conflict with established patterns that provided stability and harmony at some stage in the family’s functioning. All patterns of functioning, whether established, new or altered, will be
legitimised and measured against the family’s values, beliefs, expectations and rules – the family’s appraisal.

2.5.2.2 The Family Resources (BB) – Strengths and Capabilities

The Resiliency Model defines family capabilities as “a potential the family can call upon or can create to meet the demands it faces in a crisis situation, if it chooses to do so” (McCubbin, McCubbin & Thompson, 2001, p. 32). The family’s capabilities need to meet the demands of its individual members, or the family as a unit, as well as the community it finds itself in. However, these sources of demand also serve as potential resources from which the family can draw during a time of crisis. A resiliency resource will therefore be defined as a “characteristic, trait, or competency of one of these systems that facilitate adaptation” (McCubbin, McCubbin & Thompson, 2001, p. 33). An overview of the crucial resiliency resources from all three systems (the individual member, the family system and the community) are now briefly discussed.

There are eight important personal resources a family can draw on to facilitate adaptation and to achieve harmony and balance within the family during a crisis and associated hardships. A crisis is taxing on all the members of the family. The physical, spiritual and emotional health of individual members is therefore vital to ensure that the family is able to meet the demands placed upon them. Certain personality traits such as hardiness, a healthy self-esteem and perseverance (Whitman, 2004) can assist some individuals to persist throughout the adaptation phase and move towards harmony and stability. Other personal traits such as being positive or having a sense of humour can bring relief to the individual and other family members and add to the bond among family members which is needed to achieve a good outcome (Whitman, 2004).

During the adaptation phase, the family will be faced with a myriad of new tasks, changes in functioning and a demand for creative problem solving. Intellectual intelligence of family members as well as knowledge and skills gained from prior experience, education and training could assist the family to master their situation. Intellect will most certainly add to greater awareness and
comprehension of the situation, whereas expertise will greatly assist in helping the family to perform tasks with greater efficiency and ease.

Many authors agree that a sense of mastery (Bayat, 2007), a healthy self-esteem and a worldview embedded within the family’s ethnic identity and cultural background are some of the most important factors in personal resilience resources. Lastly, a sense of coherence is another critical factor to the family’s adaptation process. Antonovksy (1987) defined sense of coherence as the extent to which the individual believes that stimuli from internal and external environments are predictable and understandable, that resources are available to meet the demands of the stimuli and that these stimuli are challenges worthy of engagement rather than risks. These factors are essential in the adaptation process, because it assists the individual to manage the situation while maintaining a sense or order during the family’s time of transition and change.

The second system which is a source of resiliency resources is the family system: Cohesion (the bonds that tie a family together which includes aspects such as trust, support and respect) and adaptability (the ability to change course when confronted with obstacles) are regarded as two of the most prominent family resilience resources (Bates et al., 2006; Bayat, 2007). The family’s organisational processes are another resilience factor (Jones & Passey, 2005; McCubbin, McCubbin & Thompson, 2001; Walsh, 1998; 2003; Whitman, 2004). Such processes include shared parental leadership and generational boundaries, as well as agreement, clarity and consistency with regard to roles, structure and responsibilities within the family. Clear, congruent and consistent communication is of utmost importance (McCubbin, McCubbin & Thompson, 2001; Walsh, 1998; 2003) for the family in their attempts to adapt. Opportunities for healthy expression are a vehicle for openness and builds trust among its members. This feeling of collaboration contributes to the family’s problem-solving abilities – another family resilience factor (McCubbin, McCubbin & Thompson, 2001; Walsh, 1998; 2003). Problem-solving and conflict resolution styles employed by the family should be strength-focused and provide an opportunity for growth and affirmation rather than criticism and decay (Hawley, 2000; McCubbin, 1995; McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001). Amidst all these ongoing changes within the family structure, a sense of continuation and stability is
needed for the family to persevere throughout the course of the adaptation phase. Family time and routines are an important resilience factor in this regard. A continuation of established family time, routines and traditions, can add that sense of familiarity, harmony and balance while introducing changes. The last significant family resilience resource is family hardiness (Hawley, 2000; McCubbin, 1995; McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001; Whitman, 2004). McCubbin, McCubbin and Thompson (2001) explained that hardiness is “characterised by a sense of control over the outcome of life events and hardships, a view of change as beneficial and growth producing, and an active orientation in responding to stressful situations” (p. 34). Family hardiness safeguards the family against the impact of the stressor and associated hardships and also serves as a stabilising factor in the changing family context.

The third system is the community. Social support (BBB) stems from all community resources and can be classified as formal or informal resources. Formal resources that can be drawn on to assist in managing the demand are mainly medical, educational and social services (Bates et al., 2006; Bayat, 2007; Connolly, Novak & Twoy, 2007; Jones & Passey, 2005). These services include those of medical professionals, such as doctors and paediatricians, medical helping professions, such as psychologists, speech and language therapists or occupational therapists, school teachers, remedial teachers, respite care-givers, day-care volunteers and social workers. A family’s relationships within their community system might add other formal resources to their repertoire such as employers, churches or religious groups. Informal resources refer to support from family members, extended family, friends and mentors (Walsh, 2003). The importance of support is immeasurable. Emotional, esteem and network support leads the family to feel loved, respected and nurtured and includes them in a network involving mutual support and understanding (Connolly, Novak & Twoy, 2007; Jones & Passey, 2005).
2.5.2.3 Family Problem Solving and Coping (PSC)

The family problem solving and coping component of the adaptation phase can be described as the part of the process where appropriate resources are sought, allocated and utilised in order to meet the demands of the family and its individual members (McCubbin, McCubbin & Thompson, 2001). Family coping can be viewed as problem solving behaviour which involves the whole family, or as the efforts of the individual members to fit together as a whole. Coping adds to adaptation by bringing about a balance between the demand and the resources, which in turn, minimises stressors and struggles. McCubbin, McCubbin and Thompson (2001) identified four ways in which coping facilitates adaptation:

To reduce the amount or intensity of demands: Problem solving and coping might involve actions that will eradicate or reduce the demands of the stressor placed on the family. An example of this is a family who decides to institutionalise their disabled child as they struggle to cope with the stressors and responsibilities of dealing with a disabled child on a day to day basis. By doing this, the family can lessen their burdens and reduce the demands placed on them.

To acquire additional resources: Some situations demand more resources than what is available to the family at that moment in time. For efficient coping and problem solving the family might need to acquire additional resources, such as when a family is confronted with their child’s diagnosis of ASD. For many parents, this is just a diagnosis and they need to improve their knowledge on the subject and acquire skills to assist the child with language and social development in order to meet the demands of the child with ASD and the family (Connolly, Novak & Twoy, 2007).

To manage tension: During a period of crisis, the family are caught up in a situation of ongoing strains which is emotionally and physically tiring. However, it is important for the family to maintain emotional, physical and spiritual health from which they can draw energy and reserves when needed. McCubbin, McCubbin and Thompson (2001) noted that coping may involve efforts to manage and reduce stress during such periods. Organising respite-care can offer many care givers an opportunity to reload and to get in touch with themselves again (Sicile-Kira, 2003). Fun family activities also
provide an opportunity for the family to relax together and to share in one another’s joy (Connolly, Novak & Twoy, 2007).

To create, shape and evaluate meaning: This level of coping interacts directly with the family’s appraisal process, specifically the family schema, where the family needs to create, shape or evaluate the meaning they attach to a situation in order to make the situation bearable, manageable and acceptable. In the process where the family alters the family schema to cope, the family needs to attain a positive appraisal of the situation. The playroom of the child with ASD might be the root of jealousy for rival siblings. Positive appraisal could lead the siblings to interpret the playroom as a classroom within which learning takes place (Bates et al., 2006).

2.5.2.4 Family Appraisal Processes (C)

The family appraisal processes is a well integrated process within the adaptation phase and involves the individual members, the family unit and their community system. The appraisal process entails five fundamental levels: schema (CCCCC), coherence (CCCC), paradigms (CC), situational appraisal (CC) and stressor appraisal (C) (McCubbin, McCubbin & Thompson, 2001). Stressor appraisal forms part of the processes in the adjustment phase of the Resiliency Model. Schema, coherence, paradigms and situational appraisal is the focus of the adaptation phase and is discussed in more detail.

A recent trend in resilience research is to investigate the role that culture and ethnicity plays in family appraisal (Deal, De Haan & Hawley, 2002; McCubbin, McCubbin & Thompson, 2001). For the family to adapt effectively, they need to be aware of the often subtle influence that culture plays in shaping our behaviours and beliefs, for example our ideas about family roles and authority in the family, about marriage, or about our responses to when a family member is ill or disabled. A study conducted by Greeff and Aspeling (2004) found various discrepancies between the resilience factors that contributed to the adaptation of South African and Belgian single-parent families. The findings of this study contribute to the understanding that family traditions derived from our culture and heritage
have proved to be a stability factor within the adaptation process, but this also means that culture and ethnicity is ever present, real and alive. The family’s culture and ethnicity influences three levels of family appraisal: the family’s schema, the family coherence and the family’s paradigms. All three of these levels interact to assist the family in the process of deriving meaning from their situation and ultimately shape their responses, behaviour and problem-solving strategies and even add to the family’s cohesiveness (Bayat, 2007; McCubbin, McCubbin & Thompson, 2001).

The family’s schema (CCCCC) forms the fifth level of appraisal and involves their shared values and beliefs. Their schema is ultimately part of their identity, shapes their worldview, and guides the family’s behaviour. The family’s schema also serves as a framework against which decisions and strategies are evaluated and legitimised during the adaptation process. This is an important factor because a family needs to make meaning from a situation, which will transcend the stressor and the associated hardship and provide the family with a view of the greater scheme of things. This means that the family will often reframe their experience to fit their frame of reference, or schema (Whitman, 2004). Reframing can happen through the process of affirmation (seeing the positive which will come from their experience) or spiritualization (seeing their experience through the lens of their spiritual or religious beliefs) and often leads to a greater sense of mastery and control (or family coherence) (Bates et al., 2006).

Level four is concerned with the family’s sense of coherence (CCCC) and can be described as “a construct that explains the motivational and appraisal bases for transforming the family’s potential resources into actual resources, thereby facilitating changes in the family systems, coping, and promoting the health of family members and the well-being of the family unit” (McCubbin, McCubbin & Thompson, 2001, p. 42). This means that the family’s sense of coherence contributes to their perception that the world is manageable, explainable and predictable and that they, the family or its individual members, are active role players in this situation and can therefore contribute to the changes that will enhance the family’s ability to adapt (Antonovsky, 1987; Bates et al., 2006; Walsh, 2003).
The family’s paradigms (CCC), or level three, are the rules, boundaries and expectations which the family adopted and adhere to. It guides the family’s patterns of functioning and their choices of problem-solving and coping strategies concerning various aspects of the family’s life, such as work, recreation or spiritual/religious orientation (Bates et al., 2006; Whitman, 2004).

Level two, situational appraisal (CC), involves the family’s assessment of the relationship between the demand and their resources. A positive appraisal means that the family believes that they have the necessary resources to meet the demands of the stressor and that they will be able to cope and adapt to the situation. This positive appraisal serves as a motivation for the family to make the much needed changes in order to adapt and to persevere throughout the process.

Level one deals with the family’s appraisal of the stressor (C). This level of appraisal involves the family’s beliefs and definitions around the severity of the stressor they are faced with. As discussed before, stressor appraisal is part of the adjustment process of the Resiliency Model.

2.5.2.5 Family Adaptation (XX)

McCubbin, McCubbin and Thompson (2001, p. 51) defined family adaptation as “a process in which families engage in direct response to the excessive demands of a stressor and depleted resources and realise that systemic changes are needed to restore functional stability and improve family satisfaction”. This means that adaptation involves making changes to their pattern of functioning, their roles and responsibilities, to engage in collaborative problem solving and to manage resources in order to cope while the family meets the demands of a stressor. All changes and employed strategies are evaluated and legitimised against the family’s appraisal processes. Adaptation on an appraisal level brings the family to value, accept and affirm changes over time, to develop insights, to stimulate meaningful relationships and facilitate bonadaptation (Allen et al., 1997; McCubbin & Patterson, 1983; Walsh, 2003). Bonadaptation refers to an outcome where the family was able to resolve and manage a crisis using various resources, and changing, maintaining or
eliminating certain patterns of family functioning in order to restore harmony and balance within the family system.

On the other side of the continuum, families might get to that point where they are not satisfied with changes within the family system and experience incongruence toward the system. In such a case, maladaptation has taken place. The family will revert to a crisis state and re-enter the adaptation process, aiming towards harmony and stability within the family system (Hawley, 2000; McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001).

When a child is diagnosed with ASD, the child’s diagnosis, its implied hardships and lifestyle changes are considered to be the stressor and can result in a crisis situation. The extent of the diagnosis adds to the strain placed on the family and demands changes within the family’s patterns of functioning in an attempt to cope with the stressors and added responsibilities. Changes include finding appropriate day care, employing therapists, or making plans so that the child with ASD will be cared for in the future. The family needs to take stock of the resources available to them (such as a mother who works half-day or financial resources which opens the opportunity to various therapeutic interventions). The onus will rest on the family to acquire or develop those resources needed to meet its demands. These resources could range from experimenting with efficient stress management strategies to giving priority to established family traditions (such as birthday parties or games evenings) in order to bring about stability and help the family to cope. Collaborative problem-solving strategies, such as special schooling or employing a domestic worker can all contribute to the family’s attempts to cope with their situation. A big factor contributing to the family’s adaptation is their appraisal of the situation. The family might need to re-evaluate their priorities, their expectations, or their frame of reference in order to incorporate the uniqueness of each family member and to bring about the necessary changes that will facilitate positive appraisal and ultimately, bonadaptation.

2.6 Research Review on Family Resilience in Families Coping with Autism Spectrum Disorder

The family can serve as a buffer against hardship, seeing as the family fosters both protective and recovery factors to shield its members against hardship and to enable them to bounce back from
adversity. General resiliency factors include family problem-solving communication, family hardiness, family time and routines, equality, spirituality, flexibility, truthfulness, hope, social support, and health (Allen et al., 1997). Families with a child living with ASD face a myriad of challenges and it is useful to become aware of their unique problems and their coping mechanisms as this knowledge can provide valuable insight into a family’s adjustment and adaptation (Hawley, 2000; McCubbin, McCubbin & Thompson, 2001; Ryff & Singer, 2003; Walsh, 2003). Unfortunately, very little research has been conducted on the resilience of families coping with ASD. Although authors such as Drew and Norton (1994), Edelson (1999), Jones and Passey (2005), and Schall (2000) studied the impact of ASD on the family or its sub-systems and the stressors they face, very little is known about the predictors of good family outcomes when coping with ASD (Bayat, 2007). An overview of the family resiliency literature that has emerged, as well literature on coping with a child with ASD, follows.

In a study conducted by Morgan and Sanders (1997), the researchers made a comparison between the parents of autistic, Down syndrome and developmentally normal children and their perception of family stress and adjustment within the family. These researchers’ results indicated that parents of autistic children generally report more family stress and adjustment problems than parents of children with Down syndrome. Both disability groups reported more stress than families with developmentally normal children (Morgan & Sanders, 1997). Many resiliency factors are geared towards reducing family stressors and to generally decrease the levels of stress experienced by the family.

Whitman (2004) described three sets of protective factors based on the Resiliency Model (McCubbin, Thompson & McCubbin, 2001) which aids the family with a child living with ASD in adjusting to their situation and reducing stress. These three protective factors are historical factors, coping resources and the family’s social support. Whitman (2004) argued that these factors can form a buffer for the family and assist the family to become resilient. Whitman explained that the inclusion of historical factors does not suggest that the family’s functioning is predetermined by the past, but rather that individuals and families are in the process of continually reconstructing themselves, drawing on experience of prior familial and extra-familial relationships, personal traits and socio-
emotional characteristics. Coping resources, such as parenting knowledge and skills, emotional competence, problem-solving skills, values such as optimism and hope, organisational abilities, time management and religiosity and/or spirituality adds to the family’s repertoire for dealing with stressors and moving towards adjustment and adaptation. The family’s coping resources are all influenced and shaped by historical factors. Family coping resources and family social supports are reciprocal in their influence on each other. Families with more coping resources are most likely to develop an extensive social support group as their resources will most likely include teachers and therapists, medical professionals, support groups, families who deal with similar difficulties, volunteers and respite care or child care workers. A diverse social support group contributes to the resilience of the family by strengthening its resources.

Social support can be a valuable resource to the family of a child living with ASD. Connolly, Novak and Twoy (2007) used the F-COPES to indicate that parents of autistic children seek the support and encouragement of friends and other families who face similar difficulties as well as formal support from agencies, programmes and professionals. However, Jones and Passey (2005) warned that family, friends and professionals who are unsupportive or not accepting of the family and the member with ASD, could add to a family’s experience of stress. Social and formal support should be aimed at placing control back into the hands of the family and helping them to reframe their experience. By doing this, the family reaffirms their locus of control which results in lowering stress levels (Jones & Passey, 2005). Only once the family view themselves as active role players in their situation, will they be able to develop a sense of coherence and cope (Connolly, Novak & Twoy, 2007; Jones & Passey, 2005).

Bayat (2007) concluded that the establishment of a close family bond and finding spiritual strength are some of the strongest resources of emotional support for the family with a child living with ASD. Jones and Passey (2005) found that coping strategies which involves the maintenance of family integration, co-operation and optimism contributed significantly to reduced stress experienced by the family. Bayat’s (2007) study echoed the results of Jones and Passey (2005). These factors are closely linked to the family, and more specifically the parents’ locus of control. Haggan (2002)
encouraged family activity and togetherness. This researcher promoted involvement in sports as a means of involving the family as a team. This researcher viewed sports activities as an opportunity to develop a sense of coherence and to promote family relationships. However, Morgan & Sanders (1997) found that parents of children with ASD differ significantly from other families with regard to involvement in active recreational, intellectual and cultural activities, mostly due to a lack of energy, free time or involvement from all family members especially the autistic child.

Morgan & Sanders (1997) found that the parents of both autistic and Down syndrome children are pessimistic about their child’s future, specifically about difficulties they might encounter during adulthood. Children diagnosed with developmental delays are not as independent as normal children are and will most probably need supervision. The parents felt their despair most when reflecting on their own mortality, and commented that future planning is usually a stressful activity and may potentially cause family conflict. Parents of autistic children in this study also held strong views that their child has negative characteristics – much more so than parents of Down syndrome children (Morgan & Sanders, 1997). Many parents struggled to let go of the dreams and expectations they had for their developmentally challenged child (Bates et al., 2006). The study of Bates et al. (2006) underlined the importance of hope as a contributing factor to the family's ability to remain positive and persevere from day to day. Jones and Passey (2005) emphasised the importance of how the family perceives their situation as this contributes greatly to the family’s sense of control.

Hope and the family’s perception of their situation are linked to another important protective factor which is the family’s belief system and appraisal processes. An investigation into the changes in the belief system of families of children with autism or Down syndrome found that raising a child with disabilities is life-changing for the whole family and urges the family to re-examine their priorities, expectations and beliefs (Bates et al., 2006). An altered perspective on disability and family functioning can lead to the realisation of the autistic child’s contribution to the family and his community, and contributes to the family’s sense of coherence and hardiness. Reframing is a particularly useful strategy and readjusts the family’s perspective of a situation from being a problem to being a challenge which can be overcome (Bates et al., 2006; Bayat, 2007; Whitman, 2004). Other
changes in belief systems include focusing on strengths rather than deficits, devaluing the importance of achievement and rather viewing limited progress as personal growth, celebrating small accomplishments, appreciating life and people, and re-evaluating the needs of individual family members (Bayat, 2007). These all contribute to the resiliency of families with a child living with ASD.

2.7 Conclusion

Chapter two introduced the theme of resilience in the field of positive psychology. In the past, studies focused on the personality traits which predicted resilience under adverse conditions. Authors such as Walsh and McCubbin developed resilience to a family construct level and focused on family strengths and potential based on a systems perspective. The systems perspective lends itself to a more holistic view of family resilience, and recognizes the role that the individual, community and environment play within the adjustment and adaptation of the family to crises.

This chapter gave a detailed description of McCubbin and McCubbin’s Resiliency Model of Family Stress, Adjustment and Adaptation which depicts the family’s response to stress and crises. This model views adjustment and adaptation as two distinct but related processes and aids our understanding of the family’s experience of living with a child diagnosed with ASD. The model also contributes to the identification of various resilience factors and their promotion. The identification of resilience factors contributes to our knowledge base and enables support of families from vulnerable populations, such as families that include a child diagnosed with ASD.

From the limited literature available, it is apparent that families with a child living with ASD are facing life changing stressors and several hardships that put the family within a crisis. However, these families do develop and acquire a diverse range of resilience resources to help the family cope as a unit and as individuals and ultimately facilitate adaptation. Chapter three provides more insight into the impact of ASD on the family.
Chapter 3: Autism Spectrum Disorder in Children

3.1 Introduction

In the previous chapter, an overview of the development of the construct of resilience was provided. A detailed discussion focused on the Resiliency Model of Family Stress, Adjustment, and Adaptation. The value of this model in the conceptualization of the adjustment and adaptation process during crises was discussed. Chapter three focuses on one such a crisis that some families face, namely adjusting and adapting to living with a child that has been diagnosed with autism spectrum disorder (ASD).

The terms autism spectrum disorders (ASDs) and pervasive developmental disorders (PDDs) are used interchangeably to refer to a wide range of neurodevelopmental disorders that have three core features: impaired social interaction, impaired verbal and nonverbal communication, and restricted or repetitive patterns of behaviour (American Psychiatric Association [APA], 1994). Disorders which are included within the broader term of ASDs are: Asperger’s disorder, childhood integrative disorder, Rett’s disorder, and autism disorder.

For many families, coping with ASD includes a total lifestyle change as they need to accommodate the needs of the child with ASD in all family activities and routines and the family often struggles to maintain balance in their lives. Just as the effects of ASD are pervasive, so is the impact of such a diagnosis on the family (Buschbacher, Dunlap & Fox, 2000; Cutler, Domingue & McTarnaghan, 2000). Families are confronted with various challenges such as schooling, therapy, challenging behaviour, child care, family activities, travel arrangements, respite care and future care to name a few (Buschbacher, Dunlap & Fox, 2000).

Chapter three provides a brief historical overview of ASD. This is followed by a discussion of the etiology, prognosis and treatment of ASD, and specifically autism disorder. The researcher also presents a literature overview which explores the psychosocial impact that living with a member with ASD has on the rest of the family, and the coping strategies employed by the family system.
3.2 Historical Overview of Autism Spectrum Disorder

In 1867 Henry Maudsley, a psychiatrist, attended to a serious condition in children characterised by deviation, delay and distortion in developmental processes, previously thought to be psychoses (Kaplan & Sadock, 1998). In 1943 Dr Leo Kanner, a child psychiatrist at John Hopkins University, wrote the first paper, *Autistic Disturbances of Affective Contact*, describing children which he/she termed “infantile autistic” (Kaplan & Sadock, 1998, p. 1182) due to their self-absorbed nature and severe social, communication and behavioural delays (Edelson, 1999; Kanner, 1943), or as Dr Kanner said – children with an “inability to relate themselves in the ordinary way to people and situations from the beginning of life” (Kanner, 1943, p. 242). Dr Kanner recognised the complexity of this developmental disability which makes it extremely difficult to diagnose and suggested that some children might have been mistakenly classified as mentally retarded or schizophrenic in the past. In 1944 the Austrian Paediatrician, Hans Asperger, also described socially withdrawn children, but these children developed bizarre obsessions and were highly verbal (Nash, 2002). However, their speech was unusual and stereotyped and non-verbal communication was odd (Whitman, 2004). A combination of these symptoms were called Asperger’s syndrome.

In the 1960s, Kanner and Bruno Bettleheim, both psychiatrist, viewed the development of autism to be the product of environmental trauma, that is maternal neglect and emotional aloofness from mothers (Whitman, 2004). During that same time, Bernard Rimland stated that he found evidence of a biological theory for autism and linked autistic-like symptoms to that of organic brain dysfunction (Rimland, 1967). Rimland had an autistic son and played an instrumental role in forming the Autism Society of America. He also disproved Kanner and Bettleheim’s stereotyped characterisation of the parents of autistic children (Whitman, 2004).

Since the late 1970s, the description of autism has become increasingly refined, but has also been extended to be included as a spectrum disorder (Gillberg, 1990; Lord & Risi, 2000). The term ASDs or PDDs was adopted to highlight the pervasiveness of autism and to provide individuals who share critical deficits associated with autism with a formal diagnosis. These terms also help to differentiate ASDs from general cognitive disabilities such as mental retardation. The idea of a
spectrum suggests that autism can be seen as a prototype of the disorder and the other ASDs as an extension of the prototype in decreasing severity and decreasing number of domains affected (Lord & Risi, 2000). Since the 1980s, major advances have been made in understanding the social and communication deficits of children with ASD. This has lead to advancements with regard to diagnoses, specifically that of autism disorder, and therapeutic interventions (Lord & Risi, 2000). Behaviour modification techniques became increasingly popular. Ivar Lovaas (1977) developed a form of behaviour modification called discrete trial training – a therapy which is known today as Applied Behaviour Analysis (ABA). In addition to Lovaas, many other scholars made contributions to the field of ASD, such as Robert Koegel and Micheal Rutter (researchers), and Eric Schopler and Gary Mesibov (editors of the Journal of Autism and Developmental Disorders) (Whitman, 2004). Many individuals with autism also contributed to an improved understanding of the inner world of autism. Temple Grandin and Donna Williams are well known for providing insights into the nature of autism (Sicile-Kira, 2003; Whitman, 2004).

Today, ASD is believed to be of neurogenic origin (Prizant & Wetherby, 2000). The next section gives an overview of the diagnostic criteria for ASD and discusses the characteristics of ASD with special reference to autism.

3.3 Diagnostic Criteria and Characteristics of Autism Spectrum Disorder

Although researchers are lead to believe that autism is a neurobiological disorder with a genetic component, a biological component that can assist with diagnoses has not yet been found (Drew & Norton, 1994; Lord & Risi, 2000). Consequently, the syndrome must be defined on the basis of behavioural observations as depicted in the formal diagnostic systems of the APA (APA, 1994) and the World Health Organisation (WHO, 1993). As mentioned earlier, making a diagnosis presents a challenge to medical professionals. Autistic symptom patterns, characteristics and range of abilities vary in combination and severity, which makes every autistic child unique (Deverell & Ross, 2004; Freeman, 1993; Mash & Wolve, 2002). Although a diagnosis made on the spectrum implies core characteristics and impairments, it is often difficult to differentiate between the various ASDs
Edelson (1999) described the complexity of the autism diagnosis by making the following comment:

There is no adjective which can be used to describe every type of person with autism because there are many forms of this disorder. For example, some individuals are anti-social, some are asocial, and others are social. Some are aggressive toward themselves and/or aggressive toward others. Approximately half have little or no language, some repeat (or echo) words and/or phrases, and others may have normal language skills.

Lord and Risi (2000) echoed Edelson’s (1999) statements regarding the complexities of diagnoses, but also commented on the difficulties associated with diagnosing very young children, mostly due to the limited array of skills acquired through normal development and the variability in typical young children of that age (Whitman, 2004). A diagnosis of autism (or any other disorder on the spectrum) is often postponed (Cutler, Domingue & McTarnaghan, 2000; Drew & Norton, 1994) or sidestepped. In the researcher’s conversations with parents of children with an ASD, many parents commented on professionals’ lack of commitment to a diagnosis, often rationalising delayed development as a gender related issue, confusion due to exposure to different languages and even a reaction to performance driven parents. Lord and Risi (2000) explained that this is often the case with children younger than 2 years who do not show the full pattern of behaviour yet. The diagnosis of autism should be a rational process and a collaborative effort involving various professionals and experts, including speed-language therapists, paediatricians and psychologists (Lord & Risi, 2000).

A diagnosis yields important information about the course, development and response to treatment (Whitman, 2004). For families, being diagnosed often means access to specialised services and being undiagnosed leaves children excluded from specialised education when early intervention is highly desirable (Cutler, Domingue & McTarnaghan, 2000; Drew & Norton, 1994; Lord & Risi, 2000). This section gives an overview of the diagnostic criteria for autistic disorder and attempts to
differentiate between the various disorders on the autistic spectrum, namely, childhood disintegrative
disorder, Asperger’s disorder, atypical autism and Rett’s disorder.

3.3.1 Diagnoses on the Autistic Spectrum

A diagnosis on the autism spectrum necessarily implies impairments on any number of the
following domains: social interaction, communication and imaginative behaviour and play — also
referred to as the triad of impairment. The onset of the disorder is prior to 36 months of age (APA,
1994; WHO, 1993). Autism is defined by the whole triad of deficits in social reciprocity,
communication, and repetitive behaviours or interests, which can occur at various levels (APA, 1994;
WHO, 1993). Some individuals that are not autistic might display similar difficulties in social
reciprocity and either communication or restricted behaviour. These individuals often need the same
services and often follow the same course as those with autism. Even when impairment in all three
areas is noticeable, these individuals can still vary significantly in the degree to which they are affected
by the behaviours associated with autistic disorder (Deverell & Ross, 2004; Mash & Wolve, 2002;
Whitman, 2004). Some might show incomplete manifestations of the syndrome, but these individuals
still show marked deficits which may cause significant and lifelong impairment, even though they do
not meet the three-domain definition of autism (Deverell & Ross, 2004; Lord & Risi, 2000). Other
criteria which distinguish autism from other ASDs are age of onset, the presence of language or
cognitive delay, presence of co-morbid factors, and specific neurological features (Lord & Risi, 2000).

3.3.1.1 Autism Diagnosis

According to formal diagnostic guidelines, autism presents with impairment in social interaction
for example a lack of social or emotional reciprocity, or marked impairment in the use of multiple non-
verbal behaviours such as eye contact, facial expression, body postures and gestures to regulate
social interaction (APA, 1994; WHO, 1993). Impairments in communication are also clear and include
a delay in, or total lack of the development of spoken language or significant impairment in the ability
to initiate or sustain a conversation with others (APA, 1994; Kaplan & Sadock, 1998). Autistic children
also present with restricted repetitive and stereotyped patterns of behaviour, interests or activities and
often engage in repetitive motor mannerisms such as hand or finger flapping or twisting or complex
whole-body movements. Delays or abnormal functioning will manifest in at least one of the following
areas, with onset prior to age 3 years: social interaction, language as used in social communication,
or symbolic or imaginative play (APA, 1994; Kaplan & Sadock, 1998; Lord & Risi, 2000; WHO, 1993).

3.3.1.2 Atypical Autism/Pervasive Developmental Disorder Not Otherwise Specified

This diagnosis implies severe, pervasive impairment in social interaction or communication skills
or the presence of stereotyped behaviour, interests and activities (APA, 1994). These impairments
manifest as a lack of social or emotional reciprocity, or an apparently inflexible adherence to specific,
non-functional routines or rituals. The ICD-10 (WHO, 1993) specifies that the impaired development
should be evident at or after the age of 3 years. Generally, pervasive developmental disorder shows a
better outcome, better language skills and more self-awareness than autism (Kaplan & Sadock, 1998).

3.3.1.3 Childhood Disintegrative Disorder

A child diagnosed with childhood disintegrative disorder will have had typical development up to
the age of 2 years, followed by a significant loss of previously acquired skills at the onset of the
disorder. The DSM IV (APA, 1994) specifies that this loss should be before the age of 10 years. The
regression should include at least two of the following: expressive or receptive language, play, social
skills or adaptive behaviour, bowel or bladder control and motor skills. A loss of social functioning will
manifest in ways such as abnormalities in communication (such as with autism) or restricted, repetitive
and stereotyped patterns of behaviour, interests and activities, which includes motor stereotypes and
mannerisms (WHO, 1993). After the regression this disorder will closely resemble that of autism
(Kaplan & Sadock, 1998).
3.3.1.4 Asperger’s Disorder

A child with Asperger’s disorder exhibits no clinically significant general delay in cognition or language development. Single words can be spoken by the age of 2 years and communicative phrases are used by 3 years of age or earlier. During the first three years the child’s self-help skills, adaptive behaviour and curiosity about the environment are regarded to be at a level consistent with normal intellectual development. However, motor milestones may be somewhat delayed which is usually accompanied by motor clumsiness (WHO, 1993). Abnormalities in reciprocal social interaction (as with autism) are apparent such as impairment in non-verbal communication and a lack of spontaneous seeking to share in enjoyment (APA, 1994). The child also manifests restricted, repetitive and stereotyped patterns of behaviour, interests and activities (as with autism, although motor mannerisms are less common) (WHO, 1993).

3.3.1.5 Rett’s Disorder

Rett’s disorder can be described as the development of several specific deficits following a five to six month period of normal functioning after birth. Rett’s disorder manifests as normal psychomotor development through the first five months and normal head circumference at birth. A deceleration of head growth occurs between 5 months and 4 years. A loss of acquired hand skills occurs from 5 to 30 months of age and is associated with concurrent communication dysfunction and impaired social interaction. The appearance of poorly coordinated gait and/or trunk movements now manifests. The result is severe impairment of expressive and receptive language, psychomotor retardation and stereotyped midline hand movements (so-called hand-washing) with an onset at the time when purposeful hand movements are lost (APA, 1994; WHO, 1993). The long term physical effects are scoliosis, resulting in muscular spasticity and rigidity and many individuals with Rett’s disorder become wheelchair bound. Rett’s disorder has only been reported in females and there is speculation about a genetic basis for the disorder (Kaplan & Sadock, 1998). This disorder is typically associated with severe or profound mental retardation (Whitman, 2004).
3.3.2 Characteristics of and Challenges Presented by Autism Spectrum Disorder

ASD is a combination of several developmental delays, its main features characterised by a triad of impairments which can vary from mild to severe. The triad of impairments relates to social interaction, behaviour and imagination, and language and communication (APA, 1994; Autism South Africa, 2006; WHO, 1993). However, each child’s experience of autism is unique (Deverell & Ross, 2004) and can include other challenges. This section highlights the main characteristics of ASDs.

3.3.2.1 Impairment of Social Interaction

The autistic child has poor social skills and an air of aloofness, generally failing to show interest, empathy or relatedness to their parents and other people or to make appropriate social contact with others (Deverall & Ross, 2004; Kaplan & Sadock, 1999; Whitman, 2004). This can be due to their limited responsiveness to social cues such as eye contact, nodding or smiles. Lord and Risi (2000) commented specifically on the lack of eye contact and the “sharing” of experiences with others when the child is of a young age (Whitman, 2004). Most of the children prefer to engage in individual play, are indifferent to having friends, and may even dislike loving physical contact (Grandin, 1995; Paris, 2000). Autistic children’s social development lacks attachment (although it is not always absent) and fails in early person-specific bonding (Donellan & Moreno, 1991; Huebner & Kraemer, 2001; Kaplan & Sadock, 1999).

3.3.2.2 Impairment in Behaviour, Play and Imagination

Children with ASDs often find the world of play to be confusing and over-stimulating. This often leads to stereotyped patterns of play as an attempt to make their world more controllable (Kolberg & Whitman, 2004). In the first few years, exploratory play is limited or absent and play is characterised by its monotonous, repetitive and rigid nature (Kaplan & Sadock, 1999).

A common characteristic with ASD is perseverance. Signs of perseveration can be seen in their language (echolalia or repetitive speech), play (arranging objects in lines) and behaviour (rocking, spinning, finger-flicking, continual fiddling with objects, spinning objects, tapping and scratching on

The child’s ability for imaginative play may be limited or poor. The child also has a tendency to focus on minor or trivial aspects of things in the environment, instead of an imaginative understanding of the meaning of the whole scene (Huebner & Kraemer, 2001).

3.3.2.3 Impairment of Verbal and Non-Verbal Communication

Development of speech and language may be abnormal, delayed or absent with minimal reaction to verbal input and, as commented on by Deverall and Ross (2004), inappropriate to the child’s intellectual level. Some children communicate with gestures rather than words or their language can be restricted to a few words (Schall, 2000). Lord and Risi (2000) stated that the use of gestures is a significant indicator of the possibility of autism at a very young age. Often autistic children will use their parents’ hands as a tool in communication, for example, placing the parents’ hand on a door knob to indicate their desire to go outside. The ability to comprehend is often lacking with autistic children. The repetition of words, questions, phrases and/or sentences (both immediate and delayed echolalia) is common, but this does not imply that the child comprehends what he/she is saying (Paris, 2000; Twachtman-Cullen, 2000; Whitman, 2004). Autistic children make little use of meaning in their memory and would therefore verbalise words (and some might even read astonishingly well) without knowing the meaning of their utterances (Kaplan & Sadock, 1999).

It has been noted that some children are far advanced in reading and often appear not to have any difficulty to converse with others. However, the use of metaphorical language will prove to be confusing as the child’s interpretation hereof will be literal (Twachtman-Cullen, 2000; Whitman, 2004). Higher functioning autistic children who are conversant mostly lack shared social understanding of communication (Twachtman-Cullen, 2000). In such cases, the child lacks social competence and their conversations are characterised by non-reactive responsiveness (Kaplan & Sadock, 1999; Paris, 2000), for example, some autistic individuals could engage in endless monologues about their special interest, without adapting to the needs of the listener. Twachtman-Cullen (2000) explained that even
the most able autistic child will have difficulty with sarcasm and recognizing subtle social cues in messages as both require complex social understandings and understanding of paralinguistic features such as facial expression and tone of voice to derive meaning from these utterances. Most autistic children have difficulty in initiating and/or participating in conversation, especially in understanding and responding to affect or articulating their feelings or ideas (Huebner & Kraemer, 2001; Whitman, 2004).

### 3.3.2.4 Sensory Disturbances

Recently, many researchers postulate that a fourth dimension can be added: impairment of perceptual processes (Anzalone & Williamson, 2000; Deverell & Ross, 2004; Huebner & Kraemer, 2001; Kaplan & Sadock, 1999), which includes insensitivity to pain, hyper- and/or hypo-activity and attention deficits (Sicile-Kira, 2003; Whitman, 2004). Many children experience difficulties in modulating their response to sensory input (that is over- and undersensitivity) and maintaining optimal arousal and focused attention (Anzalone & Williamson, 2000; Paris, 2000). Some first-person accounts also give detailed descriptions of hypersensitivity to light, sounds, textures, smells and tastes (Anzalone & Williamson, 2000; Grandin, 1995; Sicile-Kira, 2003). These individuals also describe how they often tune out to auditory stimuli, one reason why many children with ASD are considered to be hearing impaired at first (Huebner & Kraemer, 2001). It has also been reported that autistic children might complain of the ‘sting’ of wool, the pressure of a hug from a parent or they might become overly emotional if surrounded by loud sounds (Grandin, 1995; Sicile-Kira, 2003). Three clinical profiles are distinguishable in children with autism: hyperreactive and hyporeactive patterns (both involving problems in sensory modulation), and dyspraxia (Anzalone & Williamson, 2000; Whitman, 2004).

Hyperreactivity refers to a low sensory threshold and a bias towards sympathetic nervous system reactions, such as heart rate, blood pressure and respiration. This means that the child has a high level of arousal as measured by his/her physiological response, but often displays flat affect and seems to be under-aroused (Anzalone & Williamson, 2000; Dunn, 1997; Whitman, 2004). However, the child could experience such sensory overload that it will cause an involuntary behaviour and physiological shutdown (Huebner & Kraemer, 2001). These children often develop rigid routines,
compulsions and stereotypic patterns to keep themselves in control (Paris, 2000). They often experience everyday sensory input like school bells, the slamming of doors or the texture of a new shirt as painful and will make attempts to limit such input, such as avoiding certain foods and only wearing certain clothing.

Hyporeactive children have a high sensory threshold and require a lot of sensory input before the stimuli has been registered (Anzalone & Williamson, 2000; Dunn, 1997). These children do not learn from the environment, because they do not notice it and appear to be wandering aimlessly (Huebner & Kraemer, 2001). Spinning motions (rotary vestibular activity) have been noted to be the most arousing stimulation to hyporeactive children and their expression of emotion is often brightening with vestibular stimulation (Whitman, 2004).

Praxis can be explained as consisting of three steps: ideation of the action, motor planning and execution (Anzalone & Williamson, 2000; Huebner & Kraemer, 2001). Children who display dyspraxia most often have difficulties with these three components. Many children with autism have difficulty with ideation. These children will have difficulty in thinking of different play possibilities in relation to toys and will often perseverate the same familiar play routines despite the play potential of the toy (Dunn, 1997), for example, spinning all his/her toys, or creating order by horizontally lining up all his/her toys against the wall. Problems in motor planning involve difficulty to construe the movements of their bodies to perform the action he/she has set out to do due to distorted or inadequate body awareness (Dunn, 1997; Paris, 2000). This often leads to difficulties in the execution of the task they have set out to do. Execution is influenced by the child’s motor development, skill, and coordination (Paris, 2000). These difficulties in sensorimotor explorations interfere with the child’s general ability to explore his/her environment, thereby potentially impacting his/her overall cognitive development and contribute to the greater clinical picture of ASDs (Anzalone & Williamson, 2000; Dunn, 1997; Huebner & Kraemer, 2001).
3.3.2.5 Impairment in Regulation of Emotion

Many authors also comment on the autistic child’s experience of emotion. Anzalone and Williamson (2000) commented that over- or underreactivity or distorted sensory perception often contributes to affective unavailability and fear reactions. The emotional expression of children with ASD tends to be flat and restricted (Freeman, 1993) with the exception when these children are engaged in high-intensity vestibular activities, where in this instance, they will appear happy and excited (Anzalone & Williamson, 2000; Whitman, 2004).

An inability to interpret and articulate emotion can lead to a response which might seem inappropriate. Emotional outbursts seem to be quite common and it may be difficult for the child to regain control (Whitman, 2004). A delay in emotional reaction is also possible and is probably due to perception and sensory difficulties and can seem as if the child’s emotional display is quite inappropriate. A change in routine and environment will also lead to major distress (Paris, 2000).

3.3.2.6 Other Characteristics and Challenges

Many autistic infants demonstrate autistic characteristics from birth and can be described as either unresponsive or overly agitated babies (Edelson, 1999) - behaviour that will carry over into childhood. These deficits include the acquisition of dysfunctional behaviour such as self-stimulatory behaviours, self-injury, difficulties in sleeping and eating patterns and enuresis (Edelson, 1999; Kaplan & Sadock, 1999; Whitman, 2004). Cognitive deficiencies include attention difficulties, difficulty in concrete thinking, impaired executive processes and impaired cognitive intelligence (Whitman, 2004). About 40% of autistic children have an IQ of below 50 to 55, 30% have an IQ between 55 and 70 and 30% have an IQ of above 70 (Kaplan & Sadock, 1999; Whitman, 2004). These IQ scores underline deficits with verbal sequencing and abstraction skills. Although mental retardation is a common characteristic, some autistic children do display savant skills in various fields such as music, art, exceptional memory and calculations (Paris, 2000; Treffert & Wallace, 2002).
3.4 Etiology and Pathogenesis of Autism Spectrum Disorder

Through the years, researchers offered various etiologies to explain the development and progression of ASDs. Social environmental theories such as parenting influences (Kanner, 1943) and institutionalisation effects (Hunt, 1961); psychological theories, including theories of mind (Baron-Cohen, Tager-Flusberg & Cohen, 2000; Russell, 1997); and biological theories, including brain development and dysfunction, genetic analysis and structural theories have seen the light (Huebner & Lane, 2001; Lord & Risi, 2000; Whitman 2004). This section discusses some of the most popular and most researched etiologies that came about through the decades to explain ASD. These include: psychodynamic and family factors, neurological and biological factors and genetic factors.

3.4.1 Psychodynamic and Family Factors

Studies by Dr Kanner revealed that parents of autistic children were devoid of emotional warmth and often treated their children impersonally (Deverell & Ross, 2004); a response in which the child withdraws from the unpleasant social reality and into their own world (Whitman, 2004). Recent studies do not confirm these findings, but rather conclude that there is little difference between the childrearing practices of parents rearing autistic or non-autistic children. Although psychosocial stressors and family discord can exacerbate symptoms in autistic children, there is no satisfactory evidence that deviant family functioning or psychodynamic constellation factors lead to the development of autistic disorder (Huebner & Lane, 2001; Kaplan & Sadock, 1999; Whitman, 2004).

3.4.2 Neurological and Biological Factors

Lord and Risi (2000) stated that although numerous reasons lead us to believe that autism is a neurobiological disorder with a strong genetic component, a biological marker has not yet been found. Studies with autistic children show more perinatal complications than any control group of normal children or those with other disorders, ranging from premature birth and bleeding in pregnancy to viral infections and toxaemia (blood poisoning) (Kaplan & Sadock, 1999; Mash & Wolve, 2002; Russell, 1997). Studies also show ventricular enlargement in 20 to 25% of cases using computed tomography
(CT) scans, and various electroencephalogram (EEG) abnormalities in 10 to 83% of autistic children (Kaplan & Sadock, 1999). Neuropsychological impairments across domains, including verbal intelligence, orienting and selective attention, memory, pragmatic language, and executive functions, indicate multiple regions of the brain to be affected by autism (Akshoornof, 2000; Huebner & Lane, 2001; Mash & Wolve, 2002; Russell, 1997; Whitman, 2004). Although no EEG is specific to autistic disorder, there are indications of failed cerebral lateralization and consistent localised brain lesions associated with autism symptoms and impairments (Huebner & Lane, 2001; Whitman, 2004). Abnormalities in the cerebellum of autistic children (the area of the brain largely responsible for motor movement as well as learning, language, emotion, thought and attention) are believed to explain autistic children’s difficulty to quickly shift their attention from one stimulus to another (Howieson, Lezak & Loring, 2004). Akshoornoff (2000) explained that maldevelopment of the cerebellum will result in additional structural abnormality of later-developing brain systems such as the cerebral cortex. Deficits with regard to social interaction, emotion regulation and expression and the relation between social behaviour and meaning are linked to abnormalities in the medial temporal lobe and connected limbic system structures such as the amygdala (Howieson, Lezak & Loring, 2004). Neuroimaging also suggests poorer blood flow to the frontal lobe of the brain in pre-school children causing a possible delay in the maturation of the frontal lobes (Huebner & Lane, 2001). These findings are consistent with deficits related to executive functions in children with autism (Huebner & Lane, 2001; Mash & Wolve, 2002; Russell, 1997).

3.4.3 Genetic Factors

Both Kanner and Asperger commented on the tendency of autistic features to run in the family. Unfortunately the up rise of the Freudian paradigm caused these studies to be overrun (Nash, 2002; Whitman, 2004). In 1981 Dr. Lorna Wing, a British psychiatrist, published an influential paper commenting on Kanner and Asperger’s work. She regarded Asperger’s disorder to be a variant of what Kanner described as “autism” and that both have their origin in the scope of traits encoded in the human genome (Nash, 2002; Whitman, 2004). Since then research on chromosomal and gene
disorders, and molecular genetics as well as family and twin studies indicate that genetics play a substantive role in the etiology of autism (Andres, 2002; Huebner & Lane, 2001; Jones & Szatmari, 2002; Kaplan & Sadock, 1999; Mash & Wolve, 2002). The identification of specific genes in autism will to a large extent add to our understanding of the disorder. Studies also found neuropsychological disorders such as depression, bipolar disorder, obsessive compulsive disorder, alcoholism, substance abuse, social phobia, anxiety disorders and motor tics to cluster in families with an individual diagnosed with autism (Arndt, Childress, Jacobi, Palmer & Piven, 1997; Bolton, Murphy, Pickles & Rutt, 1998; Bristol, Cohen & Costello, 1996; Haber, Hadden, Miles & Takahashi, 2003; McCracken, Smalley & Tanguay, 1995; NIMH Genetics Workgroup, 1998). The following section provides an indication of the predictors of prognosis in ASDs.

3.5 Prognosis of Autism Spectrum Disorder

The two strongest predictors of adult outcomes in an autistic child are language development and IQ. A child with an IQ above 50 and language development by the age of 5 shows better long-term outcomes than autistic children with lower IQ levels and poorer language development (Mash & Wolve, 2002). The next section discusses the various treatment and management options for ASDs.

3.6 Treatment and Management of Autism Spectrum Disorder

Many studies are concerned with educational interventions to improve autistic children’s social communication and behaviour (Bimbela, Koegel & Schreibman, 1996; Chan, Iacono & Waring, 1998; McConachie & Diggle, 2007; McEachin, Smith & Lovaas, 1993; Symon, 2005) with their aim to introduce prosocial and socially acceptable behaviour, to decrease odd behaviour, and to assist in the development of verbal and non-verbal communication. The main therapies used are behavioural interventions and biomedical interventions (Autismlink, 2007). There seems to be a lack of consensus about the appropriate treatments for autism (Autismlink, 2007; Kolberg & Whitman, 2004), however behavioural therapies have proven to be some of the most successful therapies for behaviour modification and is the therapy of choice within education systems, with helping professionals and
home-based training (Reddihough, Rickards, Simpson, Walstab & Wright-Rossi, 2007). The parents’ buy-in to the behaviour modification structure is imperative for maximum results and requires careful training of parents in concepts of behavioural methods. Parents also experience a decrease in stress levels if they actively participate in the construction of goals and a management plan for their child’s therapy (Cutler, Domingue & McTarnagahan, 2000). These programs are quite rigorous and demands much of parents’ time (Kaplan & Sadock, 1999). Just as each child differs in his/her manifestation of ASD symptoms, so does his/her response to early intervention programmes (Cutler, Domingue & McTarnagahan, 2000; Whitman, 2004). This section provides a brief overview of the most popular therapies available to families and children with ASD.

3.6.1 Applied Behaviour Analysis

Applied Behaviour Analysis (ABA) is based on the theory of B.F. Skinner and the philosophies of Dr Lovaas and is also referred to as Lovaas therapy (Autismlink, 2007). ABA has demonstrated efficacy in promoting social and language development and in reducing behaviours that interfere with learning and cognitive functioning (Delmolino & Harris, 2002; Diggle & McConachie, 2007; Graupner & Sallows, 2005). This approach can be used to teach social, motor, and verbal behaviours and reasoning skills. ABA involves extensive time spent in one-on-one therapy (approximately 20 to 40 hours per week) and the skills should be generalised to the child’s natural environment (Delmolino & Harris, 2002; Graupner & Sallows, 2005). For this reason, it is important that there is a good working relationship among the team that addresses the child’s educational and behavioural needs. Caregivers and parents should be kept abreast of the child’s progress and how they can contribute to the child’s progress in an attempt to generalise and shape his/her behaviour (Autismlink, 2007; Delmolino & Harris, 2002; Kolberg & Whitman, 2004).

The key aspects of ABA are firstly to observe the current behaviour, its frequency and consequences. The desired skill is then broken down into several steps and taught through the repeated presentation of discrete trials. The child’s performance is also tracked to monitor changes that occur over time (Autismlink, 2007; Delmolino & Harris, 2002; Diggle & McConachie, 2007;
Graupner & Sallows, 2005). The crux of ABA is the provision of immediate and positive consequences to reward positive and desirable behaviour (Autismlink, 2007; Delmolino & Harris, 2002; Diggle & McConachie, 2007; Graupner & Sallows, 2005).

3.6.2 Sensory Integration Therapy

Anzalone and Williamson (2000) described sensory integration as “a process that involves organizing sensation from the body and the environment for adaptive purposes” (p. 144), which includes posture and movement, balance and gravity, and visual, tactile and auditory modalities (Anzalone & Williamson, 2000). Sensory integration therapy looks holistically at the child with ASD, including the senses and motor system (Kolberg & Whitman, 2004). The ultimate goal for hyposensitive children is an increased level of alertness and activation as they confront specific stimulus inputs. With hypersensitive children, the therapist gradually introduces the stimuli to facilitate habituation (gradual introduction of materials that produce unpleasant sensations) (Kolberg & Whitman, 2004). The four key aspects of behaviour that are focused on are arousal, attention, affect and action. Each of these behaviour processes has a mutual regulatory influence on the other processes and are also vital components in understanding and participating in social transactions, responsive communication and managing emotions (Anzalone & Williamson, 2000; Schneck, 2001).

Sensory integration therapists emphasise exercises that promote motor development through affecting three systems: the tactile system, the proprioceptive system (a system which provides information on the body’s placement in space), and the vestibular system (a system that influences body movement and balance, which is mostly based in the inner ear) (Kolberg & Whitman, 2004). Such exercises include handling different textured materials, deep pressure massage, being moved around on a scooter board or jumping on a trampoline (Kolberg & Whitman, 2004). Typically, an occupational therapist or physical therapist will be involved with sensory integration (Schneck, 2001), however, just as in all other therapies, the parents are actively involved in generalising the principles of therapy to other environments (Kolberg & Whitman, 2004; Schneck, 2001).
3.6.3 **Speech Therapy**

Speech therapy will benefit both verbal and non-verbal children with ASD. Speech therapy is not just concerned with learning how to speak but also how to communicate. Most children with ASD have social deficits which impact on their speech patterns and articulation and often lead to misunderstanding the message. A focus of speech therapy is on the paralinguistics and pragmatics of speech, or understanding the speaker’s intent and knowing how to use language appropriately in social settings (Autismlink, 2007; Kolberg & Whitman, 2004). Discrete trial training is a popular method of teaching children with ASD how to communicate and is directed at the child’s natural responses and interests. Parents, peers and teachers are trained and skilled to use this approach in the child’s natural environment as well (Kolberg & Whitman, 2004; Prizant & Wetherby, 2000). Another type of speech therapy is the Picture Exchange Communication System (PECS), which makes use of visual cues (pictures, objects, printed words or a combination thereof) to teach the child to communicate (Autismlink, 2007; Sicile-Kira, 2003).

Prizant and Wetherby (2000) pointed out that speech and communication programmes should be both developmental and functional, so that the child can be more functional within his/her social interactions. These authors also recommended that parents and family members be taught how to interact more effectively with the child with ASD, seeing that communication is a transactional event between two or more people who must be able to understand each other.

3.6.4 **Play Therapy**

Play is a fundamental activity through which a child learns how his/her environment operates, how to interact with it and he/she also develops abilities such as planning, organising and transforming reality into imaginary play actions (Kolberg & Whitman, 2004; Schuermann & Webber, 2002; Schuler & Wolfberg, 2000). The rationale behind play therapy is to enter the child’s world via play and to expand the base of play to include new ideas and to focus on certain learning areas which is lacking from the child’s repertoire (Autismlink, 2007). For example, if the child is fascinated by the spinning wheels of a car, the therapist or parent will engage in this type of activity with him, and slowly expand
the behaviour to include driving the car around on the floor as a neurotypical child will do. This is an attempt to expand the child’s repertoire of play and to interact with the child thereby forming some kind of attachment.

A variety of therapeutic strategies are employed when constructing a play programme. On the one end of the spectrum, the approach can be flexible and child-based, in the sense that the therapy is built on the child’s interactions (Scheuermann & Webber, 2002; Schuler & Wolfberg, 2000). In contrast, structured approaches provide children with a choice of activities, but direct them toward activities designed to build specific skills (Scheuermann & Webber, 2002; Schuler & Wolfberg, 2000). A motivational environment is created through the use of incentives and reinforcers (Kolberg & Whitman, 2004).

3.6.5 Psychopharmacotherapy

Pharmacotherapy, a biomedical treatment, is not used for autism per se, but is valuable to decrease severity and occurrence of autism associated symptoms such as hyperactivity, aggression, seizures, self-injurious behaviour and obsessive-compulsive symptomatology (Autismlink, 2007, Kolberg & Whitman, 2004). Medication associated with the treatment of autism symptoms are psychototropic medications such as haloperidol (Haldol), risperidone (Risperdal), fluoxetine (Prozac), anti-convulsants and methylphenidate (Ritalin) (Kaplan & Sadock, 1998; Kolberg & Whitman, 2004). The American Academy of Pediatrics (AAP) (2000) noted that psychotropic medications are seldom administered to children under the age of three years, due to the potential for adverse side effects. The AAP also stated that pharmacotherapy should be used in conjunction with, and not as a substitute, for developmental, educational and behavioural therapies (AAP, 2000).

3.6.6 Other Therapies

Relationship Development Intervention (Gutstein method) is a relatively new therapy focusing on teaching children non-verbal cues and general awareness in a gradual, systematic way. The goal of the therapy is to systematically teach the motivation for and skills of experience sharing interaction.
An example of such an exercise will be for the ASD child and a parent or therapist to hold a tray with a glass of water between them while walking the distance of the room – a task that can only be achieved should the participants react to the fluctuations in movement and other social cues (Autismlink, 2007).

Homeopathic remedies are a popular alternative to pharmacotherapies. A meta-analysis performed by Boissel, Cucherat, Gooch and Haugh (2000) revealed that hardly any studies on homeopathic therapies can be judged as of high scientific quality. In addition, no significant difference has been found between the homeopathic remedies and a placebo treatment (Boissel, Cucherat, Gooch & Haugh, 2000).

Vitamin therapy has also been researched, especially the combined use of vitamin B₆ and magnesium. Although the combined use has been reported to reduce symptoms of schoolchildren with ASDs, no consensus has been reached with regard to the replication of the results (Brice & Nye, 2003; Kolberg & Whitman, 2004).

Several diet therapies involve the elimination of dairy (casein-free diets) and wheat (wheat-free diets) products from the child’s diet (Christison & Ivany, 2006). It has been suggested that the autistic symptoms are due to food allergies from food products that may cause an excess of morphine-like chemicals in the child’s digestive system, causing autism-like symptoms (Autismlink, 2007; Christison & Ivany, 2006). Kolberg and Whitman (2004) reported that there are no known advantages to the elimination of certain food items, and neither is there evidence of adverse effects when adhering to such a diet. However, the importance of a balanced diet is stressed (Christison & Ivany, 2006).

Other food supplements and additives which have been promoted to reduce the symptoms of ASDs are dimethylglycine and colloidal silver (Kolberg & Whitman, 2004). However, a study by Cauller, Dodd, Kendall, Kern and Mehta (2001) has found no significant difference in autistic symptomatology between placebo and dimethylglycine treatment groups. A risk factor to colloidal silver is agyria – a permanent greyish discoloration of the skin and organs due to silver deposits in the tissue. In fact, the United States Food and Drug Administration (FDA) declared in 1999 that no non-prescription drug containing colloidal silver may be marketed for the prevention or treatment of a disease, and further, the use of colloidal silver is strongly discouraged by the FDA (1999). This
section examined the most popular treatment and management options available to families with a member diagnosed with ASD. The following sections focus on the challenges that these families face, and the family’s attempts to adjust and adapt to their reality.

3.7 Psycho-Social Effects of Autism Spectrum Disorder on the Family

Families who live with a child who has been diagnosed with ASD are confronted with challenges that are unique to these families. These challenges and adaptations are life-long and impact on various other aspects of family life, such as vocational, personal, and financial aspects (Cutler, Domingue & McTarnaghan, 2000; Dunlap & Fox, 1999; Lounds & Whitman, 2004; Schall, 2000). The ways in which the family is affected differs considerably (Cutler, Domingue & McTarnaghan, 2000; Guralnick, 2000). How to cope with ASDs should be regarded as a family problem and not only that of the individual diagnosed with ASD, or their parents or care-givers (Schall, 2000). The whole family is faced with daily matters regarding child care, education, and future planning, with which they, as a family, need to cope. Families are also seen as a dynamic system of interdependent members and difficulties experienced by one member, will necessarily cascade to the rest of the members (Lounds & Whitman, 2004). The family context is therefore of critical importance (Walsh, 2003). A systems approach is justified because the child transacts with the family, and the family transacts with the child and both are embedded in, and transact with, the community (Buschbacher, Dunlap & Fox, 2000). This section will explore the experiences of families when confronted with a diagnosis of ASD. Special attention will be given to the impact that the diagnosis has on the family, followed by the challenges the family and its various sub-systems face.

3.7.1 Impact of an Autism Spectrum Disorder Diagnosis on the Family System

The process of diagnosis is an emotionally trying period for the family, characterised by uncertainty and emotional turmoil (Bates et al., 2006; Guralnick, 2000; Tommasone & Tommasone, 2000). Often their feelings of loss and grief are repressed to be fully experienced and managed only after their persistent requests for assistance and assessment toward a diagnosis and intervention
have been responded to (Lounds & Whitman, 2004). Living through the experience of grief usually orientates the family toward developing and implementing coping strategies to cope with and adjust to their situation (Guralnick, 2000; Drew & Norton, 1994; Tommasone & Tommasone, 2000).

Elisabeth Kübler-Ross described the five stages of grief as denial and isolation, anger, guilt and bargaining, depression and finally acceptance (Kessler & Kübler-Ross, 2005). Parents of a child diagnosed with ASD also experience similar stages, but instead of moving through it they face a continual cycle (Cutler, Domingue & McTarnaghan, 2000; Lounds & Whitman, 2004; Sicile-Kira, 2003; Tommasone & Tommasone, 2000). These parents mourn the loss of the child they expected and the child they will never have (Bates et al., 2006; Sicile-Kira, 2003; Tommasone & Tommasone, 2000). Many parents who have children with regressive autism or who has been diagnosed with Rett’s syndrome have to witness how their child develops normally and then starts to developmentally regress at the age of 5 to 18 months. These parents grieve for the loss of the child they had and who now slips away into the ASD (Sicile-Kira, 2003).

Sicile-Kira (2003) commented that although the parents never leave the cycle of grief, they do learn to spend more time in the acceptance phase as they learn to adjust to their situation. Kübler-Ross (2005) described the grief cycle as “…tools to help us frame and identify what we may be feeling” (p. 7). It is important for the family to acknowledge their emotions and feelings of grief as these emotions are normal and necessary and can often be the catalyst for positive action towards coping (Bates et al., 2006; Tommasone & Tommasone, 2000). Parents can use their emotions, such as anger and fear for the unknown, to fuel their role as advocate toward care and school placement or to gain knowledge about their situation and empower themselves for the future (Sicile-Kira, 2003). After the initial grief period following diagnosis of the child, parents and family can start to face the challenges that the diagnosis presents (Cutler, Domingue & McTarnaghan, 2000; Drew & Norton, 1994; Tommasone & Tommasone, 2000).
3.7.2 Challenges Faced by the Family Unit

Previous research suggests that families who are coping with a child with developmental disabilities are generally more vulnerable to stressors and experiences more stressors than other parents (Jones & Passey, 2005). Researchers proposed that the biggest stressors facing a family with a member manifesting ASD symptomology are: searching for and confronting the diagnosis, seeking and making sense out of the information available on ASDs, searching for services, financial and time burdens, social stigmatisation, changes in family roles, child-specific challenges, and amongst all these challenges, to still maintain a sense of control (Guralnick, 2000; Lounds & Whitman, 2004; Tommasone & Tommasone, 2000). Ultimately, how the family copes and adjusts to these challenges will influence the development of the child with ASD (Dunlap & Fox, 1999; Lounds & Whitman, 2004).

Much of the healing process is facilitated by the family’s search for knowledge. During the researcher’s interaction with various parents of children diagnosed with ASD, it was apparent that the parents are well informed with regard to resources, therapies and symptomology. For these parents, the role of the professional is to validate and test their ideas about ASD and not so much for expert advice (Lounds & Whitman, 2004). Literature seems to be inconclusive about how professional support and resources contribute to family and parental stress (Jones & Passy, 2005). Although some sources conclude as to the benefit of professional support to families (Sicile-Kira, 2003), other researchers have found that dealing with professionals could add to the stress experienced by the family (Minnes & Nashchen, 1997). This could be attributed to the myriad of therapies available for children with ASD, which means that most professionals will have experience with a limited amount of therapies (Lounds & Whitman, 2004). The effectiveness of these therapies varies from child to child (Whitman, 2004). However, the success of many therapies and remedies in reducing symptoms of ASD are yet to be proven scientifically (Autismlink, 2007; Boissel, Cucherat, Gooch & Haugh, 2000; Brice & Nye, 2003; Cauller, Dodd, Kendall, Kern & Mehta, 2001; Christison & Ivany, 2006; Kolberg & Whitman, 2004; Tommasone & Tommasone, 2000). Choosing a service provider, and especially an educational system, places huge stress on the family (Guralnick, 2000).
A major problem families are faced with is the financial burden that is implied when a child needs specialised services (Cutler, Domingue & McTarnaghan, 2000). Guralnick (2000) pointed out that many families make changes to their family structure and roles, the result being that one of the parents feels compelled to stay at home and become a full-time care-giver and assist with therapy. Such a change creates an even bigger financial burden and considerable sacrifices need to be made by all members of the household to lessen their expenses. Another limited resource is time. Meeting the needs of the child with ASD demands much more time from the parents (Cutler, Domingue & McTarnaghan, 2000; Morgan & Sanders, 1997). Other parental responsibilities, such as caring for the rest of the children, one’s spouse and managing a household, places extreme demands on the parents’ time (Guralnick, 2000; Lounds & Whitman, 2004). The family is faced with the challenge to find optimum solutions to take care of household chores, to take part in activities which contribute to the individual’s development and to still find time to spend with each other and with their support systems. Balancing time, energy, attention and finances within the family is a constant struggle (Cutler, Domingue & McTarnaghan, 2000).

Social support systems are important resources to assist the family in times of crises (Allen, Han, McCubbin, McCubbin, & Thompson, 1997). Many families find themselves embarrassed by their child’s behaviour and often tend to isolate themselves (Sicile-Kira, 2003). Families stop participating in social activities and stop family activities they previously enjoyed. Adverse reactions from the broader community to the child’s behaviour often lead to active avoidance by the family (Cutler, Domingue & McTarnaghan, 2000; Lounds & Whitman, 2004).

As mentioned previously in this section, the demands placed on the family by the needs of the child diagnosed with ASD, most often require a change in the family’s structure and their roles. One of the parents might stay at home to assume the role of therapy and child-care coordinator (Lounds & Whitman, 2004). Older female siblings often take on additional childcare, household and supervision responsibilities (Darling & Seligman, 1997; Drew & Norton, 1994). Generally older siblings tend to assume more power and authority seeing that the parents are focused on the needs of the child with disabilities (Drew, Egan, Hardman & Wolf, 1993; Drew & Norton, 1994; Sicile-Kira, 2003). A family’s
established patterns of functioning are some of the most difficult behaviours to change, even if new patterns of functioning might be very necessary. They are often in conflict with established patterns that provided stability and harmony at some stage in the family's functioning (McCubbin, McCubbin & Thompson, 2001). One of the family's major concerns is maintaining the roles they play in the life of the child with ASD (Schall, 2000). A realistic concern is the caretaking of the child when the parents are no longer able to. The family is confronted with the challenge of finding a way to perpetuate the care of the child throughout his/her lifetime.

The family is also faced with child-specific challenges, such as self-injurious behaviour, aggression, irregular sleeping patterns, enuresis, seizures, mental retardation, immune deficiency, hypersensitivity or certain food intolerances (Edelson, 1999; Lounds & Whitman, 2004). Depending on the child’s symptomology, many families face major challenges when they are to travel on holiday or even to the supermarket, when the child needs a haircut or a dental examination or when the family needs respite and requires a child sitter (Sicile-Kira, 2003). Although problem behaviour contributes to the stress experienced by the family, Jones and Passey (2005) found that this is not a significant predictor of the family’s adaptation to their situation. McCubbin and Patterson (1983b) confirmed that families of children with disabilities face several challenges such as strained relationships, changed priorities, increased financial expenses, social isolation, medical problems, special schooling or remedial teaching, and grief for the limited opportunities of the impaired child. Ultimately the complexities with regard to the family's internal experience of stressors should be considered when developing coping strategies and mechanisms of coping.

3.7.3 Challenges Faced by the Parents and Care-Takers

Literature does not agree on the effects that an ASD diagnosis has on the parents’ marriage. Although some studies suggest higher divorce and separation rates, no conclusions have been made as yet (Lounds & Whitman, 2004). Featherstone (1980) described the autistic child as “a symbol of shared failure” (p. 72) and stated that the situation evokes strong emotions from both partners resulting in extreme marital conflict. Drew and Norton (1994) added that the reshaping of family roles
can be a very stressful process and will add pressure to the already stressed marital relationship. On the other hand, Cobb (1987) claimed that the diagnosis of a disability can draw couples closer. According to Darling and Seligman (1997), it is not the marital relationship as such that suffers under the adjustment to their newly acquired lifestyle, but rather specific incidences that increase the stress on the couple as individuals. One of the major predictors of divorce is the strength and stability of the marital relationship prior to the onset of the major stressor (Drew & Norton, 1994). In other words, the stronger the relationship between the parents before the birth of their child and being diagnosed with ASD, the more likely they are to endure this challenge.

Parenting becomes complex when parents need to deal with their child diagnosed with ASD and their neurotypical children (Lounds & Whitman, 2004). Stress experienced by parents is often related to socialisation difficulties amongst the siblings. However, addressing this issue could promote adjustment for the whole family (Doppelt et al., 2004). Most parents have difficulty bonding with their autistic child (Donellan & Moreno, 1991; Huebner & Kraemer, 2001) which could lead to relationship problems.

The psychological well-being of the caretakers of an autistic child is also taken into consideration within the literature (Gordon, Gowar & Ramcharan, 2003). While some researchers indicate that primary caretakers of children with disabilities do not suffer from serious emotional problems (Carr, 1988), others have found caretakers, mostly mothers, to be more vulnerable to serious emotional problems such as sensitivity to stress, guilt and criticism (Drew & Norton, 1994; Featherstone, 1980) and depression (Hwang & Olsson, 2001). Lounds and Whitman (2004) suggested that fathers’ source of stress is mostly related to financial concerns. A study performed by Behr, Summers, and Turnbull (1989) indicated that although parents are at greater risk for stress-related disorders, they also report various positive outcomes from living with a child with ASD, such as increased happiness, personal growth, stronger family ties, greater tolerance for diversity and appreciation of life’s gifts.
### 3.7.4 Challenges Faced by Siblings

Support for the genetic contribution to the etiology of autism is accumulating which means that siblings share some genetic loading, possibly expressed as a lesser form of autism (Doppelt, 2004). Current research indicated that language impairment cannot as yet be seen as a behavioural marker for the genetic liability of autism, which shifted attention to the social-emotional disability (Doppelt et al., 2004). Doppelt, Gross-Tsur, Pilowsky, Shalev & Yirmiya (2004) reported that siblings of autistic children show remarkable social and emotional adjustment, despite the challenges they face. Several factors are believed to contribute to the siblings’ adjustment such as family size, the severity of the autistic sibling’s impairment, the age of the siblings at the time of diagnosis, the gender and age of the sibling, and their birth order (Sicile-Kira, 2003). In a recent study, a correlation was found between larger families and a delay in socialisation skills. The study also found that birth order or gender of the siblings did not contribute to the social-emotional adjustment of siblings (Doppelt et al., 2004). However, the parents’ attitude towards the autistic child and the siblings, as well as the parents’ expectations of the siblings, largely influenced the siblings’ adjustment (Sicile-Kira, 2003).

In a study by Siegal (1996), it was suggested that there are three prototypical ways in which siblings adjusted: becoming parentified, becoming a super-achiever, or withdrawing. The parentified child takes on parent-like responsibilities, to the extent that their self-worth is tied in with their responsibilities. Although it is normal for older, female siblings to take on additional childcare responsibilities (Darling & Seligman, 1997; Drew & Norton, 1994), and for older siblings to assume more power and authority than they had before (Drew, Egan, Hardman & Wolf, 1993; Drew & Norton, 1994; Sicile-Kira, 2003) due to changes in the family structure, maladjustment may occur when it is their predominant way of acting. The super-achievers are trying to compensate for the deficiencies of their sibling with ASD and strives to be exceptional in certain areas (Siegal 1996). This could also be an attempt to get attention from their parents, and in some cases, these children might even turn out to be the family clown or may become oppositional defiant (Lounds & Whitman, 2004; Siegal, 1996). Once again, this adjustment mechanism becomes problematic when the whole identity of the siblings is built on their achievements (Siegal, 1996). The coping mechanism, withdrawal, puts siblings at risk,
especially since withdrawal is a sign of expressing helplessness and often leads to depression (Siegal, 1996). Lounds and Whitman (2004) urged parents to be responsive to their other children’s needs and to create opportunities for enjoyable activities. In situations where positive adaptation took place, the siblings appeared to benefit from the experience as they displayed increased awareness and tolerance of individual differences in others (Darling & Seligman, 1997; Drew & Norton, 1994) and a sense of maturity and greater responsibility towards themselves and their family (Sicile-Kira, 2003).

3.8 Coping and Adjustment in the Family System

The previous section explored the unique challenges that families face when they are confronted with a member who has been diagnosed with ASD. Effective coping strategies are necessary for the maintenance of the family as a unit and the individual members’ quality of life to remain intact (Drew & Norton, 1994; Schall, 2000). Although these families are confronted with a myriad of stressors, many employ effective coping strategies and adjust well to their circumstances, in other words, the family demonstrates considerable resilience. Although several sources claim the importance of specific resilience factors in facilitating adjustment (Lounds & Whitman, 2004; Cutler, Domingue, & McTarnaghan, 2000), little evidence is available to justify such suggestions and very little is known about the predictors of good family outcomes when coping with autism (Bayat, 2007). The following section highlights several resiliency factors that proved to facilitate bonadjustment and bonadaptation in families who are living with a member that has been diagnosed with ASD.

3.8.1 Parenting Knowledge and Skills

The world of ASDs can be very confusing and parents need to deal daily with medical jargon, therapeutic interventions and so-called cures. Parents find it necessary to be knowledgeable about available treatments, the child’s management plan and symptomology in order to meet the demands of the child with ASD (Connolly, Novak & Twoy, 2007) and to be an active role player in their therapy (Cutler, Domingue & McTarnaghan, 2000). Parents who are competent and cognitively prepared to deal with their child, empower themselves and seem to experience less stress than other parents
The initial search for knowledge also seems to facilitate the healing process after the initial diagnosis of ASD (Lounds & Whitman, 2004).

### 3.8.2 A Sense of Hope

Hope is one of the general resiliency factors that have been identified by Allen, Han, McCubbin, McCubbin and Thompson (1997). A sense of hope is regarded as an important factor with regards to the family’s adjustment and adaptation processes (Bates et al., 2006), as it guides the family toward the cognitive context within which they interpret their circumstances. Having a belief system which speaks of hope, optimism and encouragement from which the family can draw strength (Walsh, 1998; 2003), enables the family to reframe their circumstances, to remain committed to each other, to persevere and to be optimistic about the future and what it holds (Bates et al., 2006; Bayat, 2007). This is especially important when research has suggested that families living with ASD are vulnerable to stressors which could ultimately lead to social isolation and depression (Bayat, 2007; Hastings & Johnson, 2001; Jones & Passey, 2005).

### 3.8.3 Religion and Spirituality

Spiritual, emotional and physical health is imperative for a family who are meeting a myriad of challenges on a daily basis (McCubbin, McCubbin & Thompson, 2001). Religion and spirituality are powerful resources which impacts on the family in various ways. Many families seek comfort and spiritual support from their God and from others who join them in prayer. An important aspect of religious and spiritual coping is how this context impacts on the family’s perception of their child’s illness (Pargament & Tarakeshwar, 2001). This process is called reframing. Reframing can happen through the process of affirmation (seeing the positive which will come from their experience) or spiritualization (Interpretations of illness as spiritual growth) and often leads to a greater sense of mastery and control (or family coherence) (Bates et al., 2006). Shared faith is also a powerful tool to strengthen relationships between spouses and family members and add to intra-familial emotional support (Bayat, 2007; Pargament & Tarakeshwar, 2001).
3.8.4 Family Hardiness

Hardiness can be described as a family’s internal strengths, their ability to work together and to depend on each other (Greeff & Human, 2004), and is considered to be a buffer against stress and a vital resource in the facilitation of family resilience (Hawley, 2000; McCubbin, 1995; McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001; Whitman, 2004). Hardiness is linked to the family’s sense of control over their challenges and a commitment to their family (McCubbin, McCubbin & Thompson, 2001). Decreased stress levels are associated with families where the parents maintain internal control and perceive their circumstances as manageable (Hastings & Brown, 2002; Jones & Passey, 2005). These families also illustrate active commitment to the development of its members and the management of their challenges (Schall, 2000).

3.8.5 Support Networks

Emotional, social and instrumental support leads the family to feel loved, respected and nurtured and contributes greatly to their ability to adjust and adapt to their circumstances (Connolly, Novak & Twoy, 2007; Jones & Passey, 2005; McCubbin, McCubbin & Thompson, 2001). The families are dependent on their support teams to cope, and the value of the support is not dependant on the team’s expertise, but rather the relationship that exists between the team and the family (Blakemore-Brown, 2002; Schall, 2000; Wing, 1992). Families living with a child with ASD seek support and encouragement from various sources, such as friends, extended family, formal support from agencies, programmes and professionals and from other families who face similar difficulties (Connolly, Novak and Twoy (2007). Grandparents have also proved to be a source of social and instrumental support (Croom, Le Couteur & Margetts, 2006). The establishment of a close family bond adds to the emotional support for the family living with ASD (Bayat, 2007).

The extended family and friends have been reported to be one of the best sources of support (McDonald, Scorgie & Wilgosh, 1998). This holds true for siblings of the child with ASD as well. The siblings who experience greater social support from peers report less loneliness and better academic achievement (Dewey & Kaminsky, 2002). Many families also benefit from support from their medical
support team (Sicile-Kira, 2003), although some sources conclude that dealing with medical professionals, and a lack of understanding from family and friends could add to the stress experienced by the family (Minnes & Nashchen, 1997).

Parents should not disregard the value of support groups and respite care to the family (Jones & Passey, 2005). Families, and especially mothers (Crittenden & Shin, 2003), who report having adequate social support resources, were found to be less stressed, which aids in adjustment (Lounds & Whitman, 2004). The use of respite care also correlates with families being less stressed and having a better quality of life than those parents who do not arrange such services (Chan and Sigafoos, 2001). Supportive family and friends can lend respite care to families who need to cope with ASDs on a daily basis (Lounds & Whitman, 2004).

3.8.6 Sense of Coherence

A sense of coherence links to the family's appraisal processes (CCCC). To develop a sense of coherence or togetherness, the family needs to be able to normalise and contextualise their experience and to construct meaning from it (Walsh, 1998; 2003). This promotes a pro-active attitude from the family (Antonovsky, 1987; Bates et al., 2006; Walsh, 2003), and facilitates changes in the family system to encourage adjustment and the well-being of the family (McCubbin, McCubbin & Thompson, 2001). Three processes with regards to the family's appraisal processes are covered in the literature: altering one's world view about disability, success and happiness; reframing one's circumstances; and the family's attitude towards the child with ASD. An altered perspective leads to the realisation that the child with ASD can contribute to the family and his/her community (Bates et al., 2006; Bayat, 2007; Whitman, 2004). Reframing adds to positive adaptation as families re-interpret a situation from being a problem to being a challenge that can be conquered (Bates et al., 2006; Bayat, 2007; Whitman, 2004). Acceptance of their situation is an important step for parents toward adjustment. The siblings’ adjustment is largely influenced by the parents’ expectations of the siblings as well as the parents’ attitude towards the autistic child and the siblings (Blakemore-Brown, 2002; Wing, 1992). Acceptance leads to more realistic expectations of the child with ASD than before
diagnosis, as well as for their other children. In addition, the family tends to become focused on personal development rather than that of a social norm (Blakemore-Brown, 2002; Wing, 1992).

3.8.7 Family Problem-Solving and Communication

Open, affirmative communication patterns within the family are of utmost importance and create an environment in which family members feel secure and respected and in which effective problem solving can happen (Walsh, 1998; 2003). Socialisation difficulties amongst the siblings could add to the family’s stressors (Doppelt et al., 2004). Regular communication between parents and their neurotypical children are necessary and keeps the parent involved in the siblings' process of adjustment where feelings of guilt, resentment, anxiety and embarrassment may come to the fore (Sicile-Kira, 2003). Parents can provide the necessary support, insight and understanding during this process and engage the siblings in problem-solving strategies to cope with their sibling with ASD (Doppelt et al., 2004). Engaging in collaborative problem-solving also leads to constructive conflict resolution and joint decision-making (Blakemore-Brown, 2002; Wing, 1992).

3.8.8 Other Family Protective Factors

An additional family protective factor that plays a role in the adjustment of families living with a child with ASD is family recreation. Family activities create unity within the family and thought must be given to the type of activities the family enjoy. Families should consider activities that will include the whole family (Sicile-Kira, 2003).

Another protective factor is changes in the family structure. These changes come about mostly due to a shared responsibility towards managing the household and caring for siblings. Family members assume new roles in order to cope with the challenge. Older siblings tend to assume a supervisor role toward younger siblings (Drew, Egan, Hardman & Wolf, 1993; Drew & Norton, 1994; Sicile-Kira, 2003) and many parents dedicate themselves to becoming full-time parents and assisting with therapy and managing the household (Guralnick, 2000; Lounds & Whitman, 2004; Tommasone & Tommasone, 2000). Although these structural changes were not anticipated, the changes most often
contribute to the family’s adjustment and adaptation, because it contributes to optimum family organisation and functioning.

3.9 Conclusion

Chapter three provided an overview of ASDs. The developments of ASDs have a rich history within which much confusion is apparent due to the spectrum-quality of such diagnoses. The chapter differentiated between the various disorders on the autism spectrum and its symptomology. A diagnosis of ASD impacts on the whole family and not just the diagnosed individual. ASD is a pervasive developmental disorder and impacts on nearly all aspects of the child’s development. This implies that the family will face a myriad of challenges and stressors in their daily interactions with the child and each other. However, despite the family’s vulnerability towards stressors, many families do seem to adjust well to their circumstances. It is generally believed that these families possess protective factors which make them resilient. The latter part of this chapter provided a literature overview of the most researched protective factors that facilitate bonadjustment and adaptation in families living with ASD. The following chapter will cover the research methodology and procedures used in this study.
Chapter 4: Research Design and Methodology

4.1 Introduction

Chapter four describes the research design and method used to obtain the data for this study. The chapter gives an outline of the research aim and the motivation for using both exploratory and descriptive research designs. It continues to describe how participants were identified to participate in the study. Both qualitative and quantitative methods of data collection were used and this chapter discusses the various instruments employed to obtain the necessary data in order to satisfy the research aims, followed by an explanation of how the data was analysed. This chapter concludes with the ethical issues that were considered in this study.

4.2 Research Aim

The aim of this study was to explore and describe the resiliency factors that facilitate adjustment and adaptation in families with a child with Autism Spectrum Disorder (ASD).

4.3 Research Design

The following section deals with the various aspects which concern the design of the research. The purpose of this research is both exploratory and descriptive in nature. An explanation of and motivation for each design follows.

4.3.1 Exploratory Research

An exploratory research design is useful when a topic is unstudied or the extent of the phenomenon is unclear (Neuman, 2006; Routio, 2006). The concept of individual resilience, especially with children, has been thoroughly researched through the years. However, research with regard to resilience in the family as a primary unit is a relatively recent trend and therefore lacking. In South Africa, research on family resiliency is limited. Existing South African published studies on resilience

aimed at identifying and describing resilience factors in families in which a parent accepted a voluntary retrenchment package (Der Kinderen & Greeff, 2003), families in which a parent has died (Greeff & Human, 2004), divorced families (Greeff & Van der Merwe, 2004) and South African and Belgian single-parent families (Greeff & Aspeling, 2004). This left wide scope for further exploration.

4.3.2 Descriptive Research

Descriptive research presents us with a picture of the subject being studied (Coolican, 1999), and is especially useful when an attempt is made for initial investigations into an area of interest (Coolican, 1999; Neuman, 2006), making use of low-constraint research methods (Graziano & Raulin, 2000). Descriptive research reports on and describes scores of variables without the intention of motivating the grounds for this phenomenon (Cozby, 2004; Harris, 1998). In this research, the researcher aimed to explore and describe resilience in families with a child with ASD.

Various descriptive methods are available within low-constraint field research (Goodwin, 2005; Graziano & Raulin, 2000). The researcher could make use of observational research, in which case the researcher or appointed observer will observe specific behaviour or people and report on the frequency of events as it occurs in the participants’ natural environment (Coolican, 2001; Graziano & Raulin, 2000). Archival research, and the more recent method of meta-analysis, involves the study of information from existing records (Coolican, 2001; Graziano & Raulin, 2000). Another descriptive method is case study research. With this method, the researcher focuses its attention on a single group or person and reports on extensive observations made concerning the selected cases (Coolican, 2001; Cozby, 2004). Lastly, survey research can be used to ask specific questions about people’s behaviour and attitudes within their natural setting (Cherulnik, 2001; Cozby, 2004; Graziano & Raulin, 2000). Being a descriptive method, a goal of survey research is to learn more about the attitudes, beliefs, opinions and self-reported behaviour of an identified population (Graziano & Raulin, 2000). For this reason, a cross-sectional survey research design was used in the present study to obtain information from participants with the help of a biographical questionnaire, an open-ended
question and seven standardised instruments. The survey method is discussed in more detail in the following section.

4.3.2.1 Survey Research

A survey is a set of structured questions that is administered to a group to gain information about their demographics, attitudes, beliefs, behaviour or tendency to act (Cozby, 2004; Goodwin, 2005). The participants' responses provided information about the relationship between various variables and their family's ability to adjust and adapt to life with a child diagnosed with ASD (Graziano & Raulin, 2000; Harris, 1998; Neuman, 2006).

Survey data can be collected in three ways: face-to-face interviews, telephonic interviews, electronic surveys and written questionnaires (Cozby, 2004; Goodwin, 2005; Graziano & Raulin, 2000). This research requested the research participants to complete various written questionnaires to obtain data in an attempt to explore and describe the resiliency factors of a family with a child diagnosed with ASD.

There are various advantages to using survey data. According to Cozby (2004), the survey method is more cost effective than interviewing and can also save time as data can be gathered in one sitting. The survey method also lends itself to greater privacy for the participants (Cozby, 2004). The validity of survey data is relatively easy to establish, should the sample be well specified (Graziano & Raulin, 2000; Salkind, 2003). Neuman (2003) commented that the research results can also be generalised to the larger population should the confidence interval be high, in other words, if the sample population closely represents that of the general population (Cherulnik, 2001; Graziano & Raulin, 2000).

Survey research also has its disadvantages. The most significant is probably sample bias – when the sample does not represent the attributes of the target population as a whole (Goodwin, 2005), but over-represent a specific characteristic within a chosen group (Coolican, 1999). Various factors could contribute to sampling bias such as the sampling procedure used by the researcher (Cozby, 2004; Goodwin, 2005), and low response rates (Shaughnessy, Zechmeister & Zechmeister,
Potential participants who did not respond to the survey could represent a subgroup with different characteristics from those who did respond (Salkind, 2003). The implication of sampling bias is that the results from the sample group will differ from that of the entire group and will threaten the external validity of the study (Cherulnik, 2001; Coolican, 1999; Salkind, 2003; Whitley, 2004). A common challenge concerning survey research is low response rates, which inadvertently produce a smaller sample than the researcher intended. The response rate is influenced by the participants who are not motivated to complete and return the questionnaires or who are distracted by the demands of their lifestyle and a demanding schedule (Cozby, 2004; Goodwin, 2005). Literacy problems, low educational background, mental retardation and vision problems also add to low response rates (Cozby, 2004).

Other disadvantages concerning survey research are the likelihood that the participants will misunderstand items and submit incomplete responses (Cozby, 2004; Neuman, 2006; Whitley, 2002). Finding research participants also presents a challenge which acquires considerable time and effort from the researcher (Cozby, 2004; Whitley, 2002). Often the researcher needs to deal with uncooperative participants and extraneous sources of variance such as socially acceptable responses or omitted items, also resulting in an insufficient response rate (Cozby, 2004; Neuman, 2003; Whitley, 2002).

It is clear that the unpredictability of response rates is a major factor that the researcher needs to take into account and necessary steps to counter this difficulty should be considered. To manage possible low response rates, the researcher identified more families than were intended for the study. In an attempt to motivate the potential research participants, the researcher entered into a brief telephone or face-to-face conversation with the family and explained the aim of the study as well as the benefits that the family can reap from the results. The families were also ensured that their efforts were highly appreciated and valued. Dealing with a family and a child with ASD is very demanding on the care-givers and during the personal conversation, the researcher negotiated a time limit of approximately two weeks for completion of the questionnaires. The researcher made regular follow-
up attempts via cellular phone messages and telephone calls in an attempt to keep the family motivated to complete and return the questionnaires.

Each participant was given sufficient information about the rationale for the study, the instructions for completing and returning the questionnaires, their ethical rights as research participants as well as the contact details of the researcher should they have had any further questions or concerns related to the study. An inclusion criterion of the study was that the research participant should have an Afrikaans or English language proficiency at a Grade 8 level, at least. This was done in an effort to avoid any difficulties related to literacy and low educational background. Furthermore, all questionnaires were available in Afrikaans and English and the participants received the questionnaires and instructional letter in the language of their choice.

To circumvent any difficulties that might result from postal deliveries, the researcher offered to deliver and collect the questionnaires. If this arrangement was not possible, a self-addressed pre-paid envelope was included for the participants to return the questionnaires to the researcher. Other participants returned the questionnaires to the school that their child living with ASD attended, where it was collected by the researcher.

This section highlighted the importance of guarding against the potential pitfalls of survey research. Necessary steps were taken in an attempt to control sample bias and the possibility of low response rates. The sampling procedure and issues related to the research participants are discussed in the following section.

4.4 Participants and Sampling

The sampling procedure is often the cause of sampling bias within the research population (Cozby, 2004; Goodwin, 2005), and is therefore critical when identifying the research sample. The following section indicates how the sample for the study was obtained.
4.4.1 Sampling Procedure

This study used a non-probability purposive sampling method to gather participants. Non-probability sampling implies that the researcher is not familiar with the size or members of the specific population being studied (Graziano & Raulin, 2000; Neuman, 2003), therefore the probability of a person being chosen as a research participant is unknown. Non-probability sampling is less expensive than other methods and the cluster of the population included is easily accessible to the researcher (Cozby, 2004). However, a limitation of non-probability sampling is that the results cannot be generalised beyond the extent of the research sample, because the participants are not randomly selected (Cozby, 2004). Non-probability sampling could also contribute to a sample bias (Cozby, 2004; Graziano & Raulin, 2000). In light of the exploratory descriptive nature of this study, the limitations to this type of sampling were considered not to be significant to the study (Cozby, 2004).

Purposive sampling allowed for the researcher to use his/her judgment in the selection of participants (Sudman, 1976; Whitley, 2002), weighed up against the specific goals of the research and the inclusion criteria of the sample (Shaughnessy, Zechmeister & Zechmeister, 2000). This means that participants are chosen on the grounds of certain characteristics of knowledge, related to the purpose of the study. Purposive sampling could impede the generalisability of the results as researcher bias comes into play (Graziano & Raulin, 2000), but advantages of this method include the researcher’s control over the applicability of the participants to the research population and the researcher does not require a sampling frame to sample from (Cozby, 2004; Shaughnessy, Zechmeister & Zechmeister, 2000).

To counter the possibility of an inadequate sample, snowball sampling was also used to contact additional research participants. Snowball sampling makes use of already selected participants to identify possible other research participants who will fit the inclusion criteria of the study (Whitley, 2002). The researcher approached the research participants to assist in identifying other possible participants within the ASD community by including referral slips to the set of questionnaires. This process assists in nominating more potential participants, which continues the snowball effect until a satisfactory number of participants are identified (Cozby, 2004).
The abovementioned sampling methods were used to identify families who met the inclusion criteria for this study. For the purposes of this study, a family was defined as a group of people who are bound together by a set of rules and boundaries and who have gained access to the group via birth, marriage, adoption or a committed relationship. The goal of the study was to obtain 56 families as research participants. The inclusion criteria stated that the family should include a child younger than 18 years of age who has been diagnosed by a recognised professional with ASD, as set out in the criteria for the various ASDs by the American Psychological Association (APA) (APA, 2000). The time passed since diagnosis must have been between six months and three years to curb possible confounding of the results as the time-period since diagnosis could contribute to the level of the family's adaptation response to the diagnosis of ASD. Baxter (in Darling & Seligman, 1997) has found smaller families to experience more stress in care and management of the child with ASD than larger families do and single-parent families are specifically vulnerable to stress. It was decided that for the purpose of this study, participating families must constitute at least three members (including two adult parents and/or guardians), to counter the effects of single parent families. Two parents and/or guardians of the child living with ASD were asked to complete the instruments. Only participants with a grade-efficiency equal to a grade 8 qualification were included to ensure sufficient understanding and completion of the instrument items. Even though grade 10 language proficiency is required, previous studies have proved successful with adolescents having a grade 8 language proficiency level (Der Kinderen & Greeff, 2003; Greeff & Human, 2004; Greeff & van der Merwe, 2004).

Two Eastern Cape schools for learners with ASD and developmental disorders were identified and assisted the researcher to identify learners whose family fitted the inclusion criteria of the sample. The first school, a small private school, has eight learners who are autistic, or are diagnosed with Retts Disorder or Aspergers Disorder. The head of the school provided the researcher with the opportunity to interact with the parents one afternoon when the parents came to fetch their children, and to inform them of the study and its aim. Those parents who were not available on that day were contacted by the head of the school, who provided the researcher with a list of contact details of parents who were willing to participate in the study. Questionnaires were delivered in person to the
eight families that were willing to participate. Regular follow-ups and reminders were made to keep
the participants motivated and to maximise the return rate of the questionnaires. Two families mailed
their questionnaires to the researcher and the researcher collected the other questionnaires in person
from the remaining six families.

The second school was a larger school within the Eastern Cape. The school educates 62
learners of which 15 are residing in the hostel. The researcher introduced the Eastern Cape
Department of Education – Education Support Programmes to the proposed study. Permission was
granted on condition that the researcher was only to send an informative letter with a return slip (see
Appendix B) to the parents via the child. The researcher was only allowed to contact the family once
the return slip was received, clearly stating the family’s interest in the study and consent to be
contacted by the researcher. Due to time constraints it was agreed that letters be forwarded to the 47
learners whose families reside in Port Elizabeth. Seven families indicated their interest in the study
and where provided with the questionnaires which they had to return to the school on the day they
collected their child’s progress report. These families were also regularly reminded to complete and
return the questionnaires. Three of the questionnaires were delivered to the school as agreed, one
was returned via email and three were collected in person by the researcher.

During conversations with families, they were asked if they knew of any other families who fit the
description of the inclusion criteria and who might be interested in participating in the study. Four
families were identified using “snowballing”. Three of these families reside in Johannesburg and the
other family resides in Cape Town. These families were contacted and they agreed to participate.
The questionnaires were sent back-and-forth making use of postal mail.

A total of 60 families were contacted via telephone or informative letters in an attempt to reach
as many research participants as possible. Nineteen families completed and returned their sets of
questionnaires with the following distribution: 10 families where a mother and father each completed a
set of questionnaires, one family where a mother and grandmother each completed a set of
questionnaires, one family where a mother and her adult daughter each completed a set of
questionnaires and seven families where only the mother completed the questionnaires. It was
proposed that two caregivers per family complete the questionnaires, but after the data collection it was decided that for statistical and validity purposes, only the questionnaires completed by the mothers within the family will be analysed. This means that the sample group represents a homogenous group of mothers, who are part of a family with at least two adult care-givers and a child that was diagnosed with ASD. The biographic characteristics of these families are discussed in the next section.

4.4.2 Research Participants

Nineteen families participated in the study and these families reside in the Eastern Cape, Gauteng and the Western Cape. The majority of the participating families were from Port Elizabeth (15 families), three families were from Johannesburg and one family was from Cape Town. The researcher included families from other areas in South Africa to allow for a bigger sample of research participants. However, this contributes to research bias as the majority of participants are from the Eastern Cape and are therefore not representative of the autism spectrum community of South Africa, nor the Eastern Cape.

Seeing that only the questionnaires of the female caregiver/guardian/parent were used, all 19 participants were female and the mother of the child with ASD. The majority of the participants were married (n=17, 89.47%), while two of the participants were in a co-habitant relationship with the father of their child diagnosed with ASD. The number of years the participants had been living with their partners ranged from 5 to 28 years with a mean of 13.53 years. The youngest participant was aged 25 and the oldest was aged 48. The mean age of all the participants is 38.32 years. The ages of the spouses ranged from 28 to 57 years of age with a mean age of 40.95 years.

Four of the participants had one child, whereas the majority (n = 12, 63.16%) of participants had two children and three participating families had three children. The mean age of the firstborn children were 10.68 years and ranged from 4 to 26 years with a median age of 11 years. Ten of the firstborn children were male. The age of their second child ranged from 1 to 24 years with a mean age of 10.67 years and a median age of 7 years. The majority (n = 9, 60.0%) of the second born children were
male. The age of the third born children ranged from 4 to 13 years of age with a mean age of 9.67 years. Two of the third born children were male and one was female. The age of the children living with ASD ranged from 4 to 13 years where the average age of the child is 8.05 years with a median age of 7 years. The majority of these children are male \((n = 15, 79.5\%)\)

Most of the participants \((n = 15, 79.5\%)\) indicated that no additional people lived with them in their home. Four participants indicated that they do have somebody staying with them, which included a domestic worker, a child-care worker, siblings and their parents.

The sample indicated a relatively even distribution of English and Afrikaans-speaking research participants. Nine participants indicated that their home language is English, eight indicated Afrikaans and two families indicated that Xhosa is their home language. The questionnaires were distributed in English and Afrikaans, and both Xhosa-speaking families indicated that they are fully conversant in English.

The majority of the participants \((n = 17, 89.47\%)\) indicated that they completed further education on a tertiary level. Nine participants obtained a diploma and eight participants obtained a degree. Two of the participants completed their high school education.

The inclusion criteria of this study stated that the child should have been diagnosed with ASD between six months and three years ago. However, resilience research suggests that adaptation is a life-long process (McCubbin, McCubbin & Thompson, 2001; Walsh, 1993, 2003). This finding concurs with literature stating that each stage of child development presents the family with new challenges in terms of the ASD child, proving that the family is in a continuous process of flux to which they need to adjust and adapt (Edelson, 1999; Sicile-Kira, 2003). It was therefore decided that diagnoses made longer than three years ago be included in the study. The average years since a diagnosis was made are 47.74 months (3.98 years). The years since diagnoses ranged between 7 and 120 months (0.58 to 10 years) with a median of 36 months (3 years).

Various structured instruments and questionnaires were used to obtain the data from the research participants. These instruments and questionnaires are discussed in the following section.
4.5 Research Method and Measures

4.5.1 Triangulation of Method

Smith (1996) explained that essentially the rationale behind triangulation is to strengthen the findings of the research. Triangulation literally means that two perspectives about the same thing are considered (Coolican, 1999; Neuman, 2006). There are four different approaches to triangulation. Triangulation of observers means that different observers are used to obtain information about the same thing. When different observers are employed, the researcher gains data from various perspectives which contributes to a more inclusive view of the subject of study (Coolican, 1999; Struwig & Stead, 2001). Different measures can be used to obtain data. Even using more than one theory can contribute to developing multiple viewpoints on the same subject. Fourthly, triangulation of method entails using more than one data collection method to obtain data on the same subject to ensure comprehensiveness of the findings (Coolican, 1999; Hammersley, 1996; Mays & Pope, 2000; Smith, 1996; Struwig & Stead, 2001). Hammersley (1996) explained that triangulation of method is an example of methodological eclecticism and that the combination of more than one method can cancel out its respective weaknesses.

In this study, triangulation of method was employed. This means that both qualitative and quantitative methods of data collection were used to enrich the data that has been obtained (Neuman, 2006) and to withstand possible threats to validity, should the methods have been used on its own (Hammersley, 1996). Qualitative data were obtained from the open-ended question on the biographical questionnaire, which asked the participants to comment on the strengths that helped the family to cope with a family member who has ASD. Walsh (1993) commented that qualitative research methods such as using open-ended questions lends itself to exploring meanings, perceptions and ideas of the studied families, which tied in with the exploratory descriptive aim of this study. Other researchers have also called for more qualitative research in order to complement empirically based studies (Futrell, McCubbin, Thompson & Thompson, 1997).

The following seven structured paper-and-pencil questionnaires were used to gather the quantitative data for the purposes of this study:
- Family Attachment and Changeability Index 8 (FACI8)
- Family Crisis-oriented Personal Evaluation Scales (F-COPES)
- Family Hardiness Index (FHI)
- Family Problem-solving Communication (FPSC)
- Family Time and Routine Index (FTRI)
- Relative and Friend Support (RFS)
- Social Support Index (SSI)

These measures were accompanied by a biographical questionnaire which assisted the researcher to contextualise the research findings. The biographical questionnaire also contained the qualitative question put to the research participants. Although seven questionnaires were used, they could be completed within an hour. The FACI8 was used as the measure of adaptation of the family, i.e. the dependent variable. The other instruments gave an indication of the independent variables which influenced the extent to which the family adapted.

These measures, which were available in English and Afrikaans, have not yet been standardised for the South African population. However, previous studies conducted with the South African population using these instruments have been accepted for publication (Der Kinderen & Greeff, 2003; Greeff & Human, 2004; Greeff & van der Merwe, 2004). These studies considered a Grade 8 language proficiency in English or Afrikaans as sufficient for the understanding and completion of the questionnaires (Der Kinderen & Greeff, 2003; Greeff & Human, 2004; Greeff & van der Merwe, 2004). Following is a brief discussion on the questionnaire and instruments.

4.5.2 Biographical Questionnaire

The biographical questionnaire (see Appendix D) was compiled to acquire necessary demographic and background information concerning the participants' family composition, marital status of the parental figures, age and gender of the children, educational level of family members, home language and particulars with regard to when their child was diagnosed with ASD. Even though
the biographical questionnaire only provided descriptive data, it was essential to include as it contextualised the findings of the qualitative and quantitative data.

The biographical questionnaire posed an open-ended question which appealed to the participants’ opinion on the family’s coping skills and adaptation. This question was formulated as follows: “In your own words, what are the most important factors, or strengths, which have helped you as a family with an autistic child?” This question provided the family with an opportunity to reflect on their strengths as a family and to comment on any additional strengths and factors which contribute to their adaptation that were not covered by the other instruments distributed to the participants.

The other instruments attempted to measure the various components of the Resiliency Model of Family Stress, Adjustment and Adaptation as discussed in Chapter Two. Following is an overview of the seven questionnaires.

4.5.3 Family Attachment and Changeability Index 8 (FACI8)

H. McCubbin, A. Thompson and Elver (1995) adapted the FACI8 from the Family Adaptability and Cohesion Evaluation Scales (Bell, Olson & Portner, 1989). This instrument was used to identify and measure family functioning (McCubbin, McCubbin & Thompson, 2001).

The FACI8 is a 16-item instrument which uses a 5-point Likert scale (never, sometimes, half of the time, more than half, always) to measure the family’s level of attachment (cohesion) and changeability (flexibility). These constructs are represented in two subscales – eight items measure the strength of the family’s attachment and eight items measure the flexibility within the family’s relationships with one another. Examples of items from the Family Attachment and Changeability Index 8 include: “Family members discuss problems and feel good about the solutions” and “When problems arise, we compromise”.

The internal reliability (Cronbach’s alpha) for the subscales varies between .73 and .80. The internal reliability (Cronbach’s alpha) for the subscales in this study is .62 (attachment) and .79 (changeability). Chi-square analysis was utilised to determine the FACI8’s validity and determined the correlation of the scores to successful outcomes (McCubbin, McCubbin & Thompson, 2001).
4.5.4 Family Crisis-oriented Personal Evaluation Scales (F-COPES)

The F-COPES was developed by H. McCubbin, Larsen and Olson (1981) to identify problem-solving and behaviour strategies that families could apply when faced with stressors (AA) and/or crises (X). The F-COPES draws upon the various coping dimensions as set out in the Resiliency Model of Family Stress, Adjustment and Adaptation which integrates family resources (BB), meaning perception factors (CCC) and the family’s coping strategies (PSC) when faced with a pile-up of stressors (AA).

The F-COPES consists of 30 items on a 5-point Likert-type scale (strongly disagree, moderately disagree, neither agree nor disagree, moderately agree, strongly agree). High scores indicate effective positive coping behaviour. The scale consists of five subscales divided into two dimensions, as depicted in the Resiliency Model of Family Stress, Adjustment and Adaptation, namely: (a) internal family coping strategies (coping among its members), and (b) external family coping strategies (coping with regard to their social environment). The five subscales are: (1) acquiring social support, (2) reframing, (3) seeking spiritual support, (4) mobilising family to acquire and accept help, and (5) passive appraisal. The subscales are divided into internal and external coping strategies. The following are possibilities of how the family could respond to problems and difficulties, as taken from the F-COPES: “Seeking encouragement and support from friends”, “Watching television” and “Having faith in God”.

The F-COPES has a test-retest reliability of .71 and an internal reliability coefficient (Cronbach’s alpha) of .77 for the total scale (McCubbin, McCubbin & Thompson, 2001). In this study, the internal reliability for the five subscales was as follows: (a) acquiring social support equalled an internal reliability of .84 (Cronbach’s alpha), (b) reframing was .82 (Cronbach’s alpha), (c) seeking spiritual support was .89 (Cronbach’s alpha), (d) mobilising family to acquire and accept help was .52 (Cronbach’s alpha), and (e) passive appraisal had an internal reliability of .56 (Cronbach’s alpha).
4.5.5 Family Hardiness Index (FHI)

The FHI was developed by McCubbin, McCubbin and Thompson (1986) to measure the characteristics of hardiness (the family’s perceived internal strength and durability) as a stress resistor and adaptation resource within the family as the unit of analysis. Hardiness serves as a buffer against stressors and demands and will assist the family to adapt positively to their situation, to alleviate the strain of stressors over time and thus, to become more resilient (McCubbin, McCubbin & Thompson, 2001).

The instrument tapped into the commitment and control the family displayed and the challenges they were able to withstand and are closely linked to the family’s schemas (CCCCC). These three factors comprise the various subscales of the 20-item instrument. The FHI required of participants to assess the degree to which statements described their current family situation on a 5-point Likert scale (false, mostly false, mostly true, true, not applicable). The following are examples of items on the Family Hardiness Index: “We have a sense of being strong even when we face big problems”, “Being active and learning new things are encouraged” and “We realise our lives are controlled by accidents and luck”.

The internal reliability (Cronbach’s alpha) of the FHI is .82. In this study the internal reliabilities (Cronbach’s alpha) of the subscales are .75 (commitment), .73 (challenge) and .67 (control). In this study the overall internal reliability of this instrument is .49 (Cronbach’s alpha). Investigations conducted by McCubbin, McCubbin, Thompson and Pirner (1988) revealed that the FHI correlated positively with criteria indices such as Family Time and Routines (FTR), Family Flexibility, Family Satisfaction, Marital Satisfaction and Community Satisfaction (McCubbin, McCubbin & Thompson, 2001), validating the instrument.

4.5.6 Family Problem-Solving Communication (FPSC)

The FPSC, developed by McCubbin, McCubbin & Thompson (1988), assessed two dominant patterns of communication in families during times of stress and crisis. It is understood that the quality of communication is an indication of the families' functioning, adjustment and adaption.
The FPSC is a 10-item instrument with two subscales: incendiary and affirming communication. Incendiary communication describes communication styles which intensify stressful situations, whilst the latter refers to communication which conveys support and care. The participants were requested to comment on their family’s typical behaviour during family struggles and problems, using a 4-point Likert scale (false, mostly false, mostly true, true). Examples of items on the Family Problem Solving Communication instrument are: “We talk things through till we reach a resolution” and “We make matters more difficult by fighting and bring up old matters”.

The alpha reliability for the total scale is .89. The overall internal reliability for the instrument in this study is .95 (Cronbach’s alpha) and for the incendiary and affirming subscales are .81 (Cronbach’s alpha) and .82 (Cronbach’s alpha) respectively. The validity of the FPSC is supported by several family studies, including ethnic studies (McCubbin, McCubbin & Thompson, 2001).

4.5.7 Family Time and Routine Index (FTRI)

The FTRI, developed by McCubbin, McCubbin and Thompson (2001), assessed the type of activities and routines families use and maintain and the value they place on these activities. These activities and routines contribute to the family’s range of new and existing resources (BB). The specific activities and routines that the family engages in, offer relatively reliable indices of family integration and stability, which contribute to family resiliency. This instrument taps into the family type (T) component of the Resiliency Model of Family Stress, Adjustment and Adaptation.

The FTRI which consists of 32 statements can be subdivided into eight subscales: parent-child togetherness, couple togetherness, child routines, meals together, family time together, family chores routines, relative connection routines and family management routines. The participant assessed on a 4-point Likert scale (false, mostly false, mostly true, true) the degree to which the statement was a true statement of the family’s behaviour. In addition to this scale, the family had to assess how important this routine was in keeping the family together and united. The response is indicated by marking one of the following options: NI = Not Important, SI = Somewhat Important, VI = Very Important and NA = Not Applicable. Examples of items on the Family Time and Routine Index include the following:
“Family has a certain family time each week when they do things together at home”, “Parents have a certain hobby or sport they do together regularly” and “Whole family eats one meal together daily”.

The FTRI has an internal reliability of .88 (Cronbach’s alpha). In this study the overall internal reliability of this instrument is .70 (Cronbach’s alpha). The FTRI’s validity is supported through significant correlations with multiple criteria indices of family strengths (McCubbin, McCubbin & Thompson, 2001).

4.5.8 Relative and Friend Support Index (RFS)

The Relative and Friend Support Index was developed by McCubbin, Olsen and Larsen (1981) to assess the degree to which the families engaged relative and friend support as a coping mechanism during times of hardship and stress. The instrument attempts to measure the family resources (BB) component of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin, McCubbin & Thompson, 2001).

The RFS which is an 8-item instrument relates to behaviours such as “seeking advice from relatives” and “asking relatives how they feel about the problems we face”. Responses require a rating on a 5-point Likert scale (strongly disagree, disagree, neutral, agree, strongly agree).

The RFS has an internal reliability of .82 (Cronbach’s alpha) and the overall internal reliability for this study is .78 (Cronbach’s alpha). The validity coefficient (correlated with the Family Crisis Oriented Personal Evaluation Scales [F-COPES]) is .99 (McCubbin, McCubbin & Thompson, 2001).

4.5.9 Social Support Index (SSI)

McCubbin, Patterson and Glynn (1982) developed the Social Support Index (SSI) (McCubbin, McCubbin & Thompson, 2001) to determine the extent to which families were integrated in the community and the degree to which the family receives support from their community (BB). Social support (BBB) is viewed as a vital component of family resilience and is often viewed as promoting family recovery and as a mediator to family distress (McCubbin, McCubbin & Thompson, 2001).
Social support includes emotional (such as recognition and affirmation), esteem (such as affection) and network (relationships with relatives) support.

The SSI consists of 17 statements. The family was requested to rate the statements as they apply to their family based on a 5-point Likert scale (strongly disagree, disagree, neutral, agree, strongly agree). The following questions are taken from the SSI: “I feel good about myself when I sacrifice and give time and energy to members of my family” and “I feel secure that I am as important to my friends as they are to me”.

This instrument has an internal reliability of .82 (Cronbach’s alpha) and a test-retest reliability of .83. For this study, the internal reliability (Cronbach’s alpha) for the SSI was .73. The validity coefficient (correlation with the criterion of family well-being) for the SSI is .40 (McCubbin, McCubbin & Thompson, 2001).

4.6 Research Procedure

Cozby (2004) stated that ethical concerns are “paramount when planning, conducting, and evaluating research” (p. 35). Throughout this study, the researcher was vigilant about her scientific, professional and social responsibility as a psychological researcher (Cherulnik, 2001). The subsequent section describes the research procedure that was followed in the execution of this study and how it was attempted to uphold the responsibilities in the capacity of a researcher.

In view of ethical research procedures, a copy of the research proposal of this study was submitted to the Ethics Committee (Human) of the Nelson Mandela Metropolitan University (NMMU) for its perusal and to request permission to implement the research project. This request was successful. The researcher planned to use an Eastern Cape school for learners with autism and other ASDs as a referral source. Access was guarded by the Eastern Cape Department of Education – Education Support Programmes. The researcher introduced the Department and the school to the research project and submitted the letters requesting access to the head of the Eastern Cape Department of Education and the head of the school in question. The original research proposal, a letter of authorisation from the Ethics Committee (Human) of the NMMU, and the proposed letter to be
sent to the parents of the school were also presented to these parties. The Department granted the researcher permission to use the school as a referral base to families who have a child with ASD.

An informative letter with a return slip (see Appendix B) was distributed to the parents via the learners. Due to time constraints, it was decided to involve only those parents who reside in Port Elizabeth. The parents indicated on the slip whether they were interested in the study. If they expressed their interest, the parents were requested to provide their contact details. Interested families were thoroughly briefed as to the aim, procedure, outcomes and the significance of the study using a letter of introduction (see Appendix A) included in the “participant pack”. This “pack” also included: a “roadmap” which explained the contents of the pack and instructions for the completion and return of the questionnaires, a pre-designed consent form (see Appendix C), two biographical questionnaires and sets of questionnaires (one for each care-giver/guardian or parent), a referral slip, should the family know any other families who meet the inclusion criteria and who might be interested in participating in this study, and a self-addressed envelope. The researcher contacted the interested families to verbally explain the aim of the study, their rights as a research participant which included their right to refuse further participation at any time, without recourse. Other issues of concern that were discussed were anonymity, confidentiality and informed consent and the researcher attended to any questions the family had prior to their agreement to participate in the proposed study. The families gave verbal and written consent (see Appendix C) before the researcher commenced with data collection. Participant packs in the participants’ preferred language (English or Afrikaans) were distributed by the class teachers to the participating families via the learners. The participating families returned the questionnaires to the school in a sealed self-addressed envelope on the day they collected their child’s report card. Three families requested time extensions and the researcher collected the questionnaires in person. One participant required the questionnaires in electronic form and submitted it electronically as well.

An Eastern Cape private school for learners with ASD and developmental disorders, was also approached to assist with the identification of families who fit the inclusion criteria of the study. The head of the school granted the researcher the opportunity to approach the parents one afternoon
when they fetched their children from school. Those families who were not reached in this way were contacted by the head of the school and their contact details were forwarded to the researcher. An initial telephone call was made to the interested families. During this conversation the researcher explained the aim of the study, their role as potential participants, their rights as participants, voluntary participation, voluntary consent and confidentiality. The participant packs were delivered in person to all the families from this school who were interested to participate in the study. Two of the families agreed to return their questionnaires by postal mail. A self-addressed, pre-paid envelope was included for this purpose. The researcher collected all the remaining envelopes in person.

Four other families were identified via referral from existing research participants. These families were contacted by telephone and informed about the study. When they conveyed their interest in the study, the aim of the study, their role as potential participants, their rights as participants, voluntary participation, voluntary consent and confidentiality were discussed. All four families gave verbal consent to participate in the study and the participant packs were mailed to them in their chosen languages. These questionnaires were returned via mail in a self-addressed, pre-paid envelope that was included for this purpose.

Regular follow-ups were done and reminders were sent via cellular messages to all the participating families. This was done primarily to provide the participants with an opportunity to withdraw from the study, should they want to, to ask questions related to this study and to request more information, should anything be unclear. The follow-ups also served as a reminder and motivation to complete and return the questionnaires - an attempt to maximise the response rate.

A total of 60 families were contacted or received an informative letter to introduce them to the study. A total of 19 families showed interest in the study and each family received a participant pack. All of these families returned their sets of questionnaires, which added up to a total of 31 questionnaires (two care-givers/guardians or parents from 12 families each completed a questionnaire). However, it was decided that for statistical and validity purposes, only the questionnaires completed by the mothers within the family were analysed. This allowed for a
homogenous sample of mothers who are part of a family with at least two adult care-givers and a child that was diagnosed with ASD.

4.7 Data Analysis

The researcher employed triangulation of method, which means that two types of data had to be analysed: qualitative data and quantitative data. The qualitative data from the open-ended question in the biographical questionnaire were coded and content analysis was used to analyse this data. Regression analysis, a correlation data analysis technique, was used to analyse quantitative data obtained from the structured questionnaires. This section describes how the qualitative and quantitative data was analysed respectively in terms of the aim of the study.

4.7.1 Qualitative Data

Content analysis was used to analyse the qualitative data from the open-ended question systematically and in a rule-based way (Schilling, 2006; Weber, 1990). Content analysis refers to the process by which themes and categories are generated as they emerge from the data through analytical categorising (Henwood & Pedgeon, 1997; Mays & Pope, 2000) in an effort to reduce the qualitative data into more manageable portions (Weber, 1990). Tesch (1990) proposed an eight-step model for a schema to categorise the data meaningfully. The researcher followed Tesch’s (1990) Model of Content Analysis in the following manner:

1. After collection, the researcher read through all the data gathered to get a general idea of what was being presented and to start formulating ideas around recurrent themes. To uncomplicate further analyses, all the documents were coded alphabetically.

2. Secondly, documents were analysed individually to identify topics from the material in an effort to capture the essence and underlying meaning of the data. All identified topics were documented with the corresponding document code.
3. All the identified topics were listed and categorised within themes, or more specifically, main themes, exclusive themes and miscellaneous. This was done in such a way that the individual themes could still be tracked to its document source.

4. All themes were now coded and the codes were documented within the relevant sections of the document text it was obtained from. During this process the researcher explored the possibility of any new themes and codes which could be integrated into the text or possible revisions within the classification scheme.

5. The list of themes in each category was now grouped in relation to one another in an effort to reduce the number of themes to the crux. The cluster of themes (categories) were described and named appropriately.

6. Categories were alphabetised once the abbreviations for each category had been agreed on.

7. All the categories and their related data were accumulated for the initial analysis. The contents were summarised and screened to identify information that was pertinent to the study.

8. Finally, after extensive analysis, it was decided that the categories were sufficient and recoding was not necessary.

The researcher employed Guba’s model of trustworthiness (Guba & Lincoln, 1985) to ensure objectivity and to counter researcher bias throughout the qualitative data analysis process. The model looks at credibility, transferability, dependability and conformability of the results of the qualitative data (Guba & Lincoln, 1985). These constructs are better known for their more conventional terms within the positivist paradigm i.e. internal and external validity, reliability and objectivity. These constructs are briefly discussed.

Credibility refers to the validity of inferences made about the data, i.e. the relationships amongst variables and the communication of procedure and findings (Coolican, 1999; Guba & Lincoln, 1985). The researcher always remained vigilant to communicate data accurately. Attention was given to the accurate description of the research participant as this formed the context within which the results are interpreted.
Transferability is viewed as being similar to external validity refers to the extent to which the research findings of this study can be generalised to the larger population (Coolican, 1999). However, this study is exploratory and descriptive in nature and its aim was not to generalise the findings to the larger population.

Dependability refers to the possibility of the study being replicated and the possibility of similar results being achieved. However, qualitative researchers reject the positivist notion of reliability, as we are living in a changing society with ever-changing conditions. To replicate a study within a dynamic society is problematic. However, it is necessary to be meticulous when describing the setting and conditions within which qualitative research was conducted, as well as that of the participants, the research design and procedure (Coolican, 1999).

Lastly, conformability describes the issue of remaining objective throughout the execution of the research study and remaining focused on the data at hand. In this study, the researcher adhered to conformability by employing an independent coder to recheck the thematic analysis and to counter the possible effects of potential research bias.

4.7.2 Quantitative Data

Descriptive statistics were employed to analyse the biographical information. Correlation analyses were employed to assess the strength and significance of the relationship between the variables. In this study, the FACI8 is representative of the dependent variable. The FACI8 is used as an indication of the family’s resilience by measuring the extent of their adaptation after a time of hardship and crisis. Regression data analysis methods were employed, seeing as a single independent variable may not correlate significantly with the dependent variable, but a combination of independent variables might, which in turn gives an indication of which variables influence the family’s adaptation significantly. Regression data analysis methods were employed and correlated the FACI8 (dependent variable) against all the other questionnaires and the biographical information, which were viewed as the independent variables.
The Pearson product-moment correlation coefficient ($r$) was calculated to assist in determining the strength and the direction of the correlation between the dependent and independent variables (Coolican, 1999; Ezekiel & Fox, 1963; Harris, 1998), i.e. the level of the participating families’ adaptation and potential resiliency variables. The value of Pearson $r$ can range between $+1.00$ and $-1.00$, where $0.0$ will indicate non-existence of any relationship between the variables. A bigger numerical value of Pearson $r$ (regardless of the positive or negative sign), indicates a stronger relationship between the correlated variables. The sign preceding the numerical value of Pearson $r$, indicates the direction of the relationship – a positive correlation means that as the value of the independent variable increases, so does the value of the independent variable. On the other hand, a negative correlation means that as the value of the independent variable increases, the value of the dependent variable decreases (Coolican, 1999; Cozby, 2004; Graziano & Raulin, 2000). Pearson product-moment correlations are limited to establishing the strength of the relationship between two variables which enabled us to make predictions of one score (dependent variable), based on another (independent variable), but not to make inferences about the causality of the relationship (Coolican, 1999; Cozby, 2004; Graziano & Raulin, 2000; Harris, 1998). The strength of the relationship was interpreted using the well-established guidelines set forth by Guilford (1946). Guilford’s guidelines are as follow:

- Less than .20 Slight – almost negligible relationship
- .20 – .40 Low correlation – definite but small relationship
- .40 – .70 Moderate correlation – substantial relationship
- .70 – .90 High correlation – marked relationship
- .90 – 1.00 Very high correlation – very dependable relationship

The level of significance for correlated relationships between the variables were set at a 5% ($p = .05$) level. Coolican (1999) commented that .05 is considered to be the conventional level for a $p$-value.

Correlation and regression analysis are closely linked (Harris, 1998), as regression analysis cannot be performed unless there is a significant correlation between two variables (Coolican, 1999).
Regression analysis was used to determine which combination of independent variables, as opposed to a single independent variable, predicted the value of the dependent variable. Stated in terms of this study, the motivation for employing regression analysis was to establish which resiliency factors are related to the family’s level of adaptation.

The abovementioned data analysis and the research procedure as a whole were executed whilst being vigilant of ethical guidelines. In the last section of this chapter, the researcher gives a brief overview of the ethical considerations as it pertains to this study.

4.8 Ethical Considerations

Research plans should carefully consider the well-being of the participants and ensure humane and sensitive treatment at all times (Davidshofer & Murphy, 2001; Graziano & Raulin, 2000). A copy of the research proposal was submitted to the Ethics Committee (Human) of the Nelson Mandela Metropolitan University to obtain permission to continue with the proposed study. The researcher should respect the participants’ basic rights to privacy, provide participants with sufficient information to make an informed decision as to their participation in the proposed research study and protect participants from psychological harm. These considerations are briefly discussed.

4.8.1 Informed Consent and Voluntary Participation

The Ethics Code of the APA (2002) provides very clear guidelines about informing the potential research participant about their rights as a research participant. In this study, the researcher honored those rights and provided the potential research participants with extensive explanations about their right to refuse or discontinue the study at any time without any recourse, the possible advantages and disadvantages of participating in the study, the research procedure and the duration for completion of the questionnaires. Information on the abovementioned topics, the aim of the study, instructions for completion of the questionnaires and contact details of the researcher were given to the participants verbally, during telephone and person-to-person conversations, and in writing in the form of an introductory letter and informational letter included in the participants’ packs. During every
conversation, the research participants were given the opportunity to ask questions pertaining to the study. Prior to commencing with data collection, participants were requested to complete and sign a pre-designed consent form, authorized by the Ethics Committee (Human) of the NMMU, which confirms in writing the agreement to voluntarily participate in the study. The researcher values the Belmont Report’s principle of respect for persons (Cozby, 2004) and regarded each participant and role player during this research study as an autonomous person.

4.8.2 Privacy and Confidentiality

The privacy of learners and their families is of vital concern to the Eastern Cape Department of Education, and for this reason, permission had to be granted by the director of the District Office of Education Support Programmes for the researcher to gain access to an identified school. In the letter received from this department, it also clearly stated that the school, principal and educators should not be identifiable within the research results and that all information from the school should be treated as highly confidential. In keeping with these regulations, the APA Ethical Code (2002) and my responsibility as a researcher and a professional (Cherulnik, 2001), all identifiable data were treated as highly confidential and was only available to the researcher for the purposes of this study. Identifiable data have also been destroyed in an appropriate manner, to make future identification impossible. The privacy of the research participants and their families were a priority on which the researcher did not want to impose. The researcher gave participants a choice of whether they wanted to make use of a postal mail agreement, or whether they would agree for the researcher to distribute and collect the questionnaires in person. The heads of the schools and the participants were also contacted telephonically to make arrangements for visits and collection of the questionnaires so as not to inconvenience the normal flow of the school proceedings or impose on their privacy.

4.8.3 Minimising Psychological Risk and Harm

Coolican (1999) stated that everything possible should be done to protect research participants from harm or discomfort. This study was considered to be of minimal risk as the study is embedded
within positive psychology and focuses on resiliency factors which assist the family in adaptation to their unique circumstances. However, safeguards and psychological resources have been put in place, should participants experience discomfort or have the need for debriefing or additional psychological counseling due to their participation in this study. One such a resource is the University Psychology Clinic (UCLIN) at the Nelson Mandela Metropolitan University. Participants could also be referred to the Eastern Cape branch of Autism SA who will refer them to their nearest support group within South Africa. The research participants were also given the researcher’s contact details should they experience discomfort while completing any of the measures. Throughout the study, research participants were treated with respect and the researcher was courteous and punctual at all times. The researcher wanted this experience to be a positive one for the participants and wanted to gain some perspective on the concept of resilience and how they, as a family have been resilient.

4.8.4 Dissemination of Results

Participants were given the opportunity to respond on the biographical questionnaire as to whether they wanted to receive feedback in the form of a brief general report, outlining the findings of the study. The District Office, Educational Support Programmes also requested that a copy of this treatise be handed to their offices as part of sharing the knowledge gained through this research study. Copies of this treatise will also be catalogued in the Nelson Mandela Metropolitan University Library.

4.9 Conclusion

Chapter four discussed the methodology and research procedure pertaining to this study. This study was exploratory and descriptive, which ties in with the aim of the study. Several standardised measures and an open-ended question were used to gather the qualitative and quantitative data. The sample was identified using non-probability purposive and snowball sampling. Despite active attempts, the response rate was considered to be low. Contact was made with sixty families and only nineteen sets of questionnaires were completed and used for analysis. The qualitative data was
analysed using Tesch’s thematic content analysis. Correlation and regression analysis were used to manipulate the quantitative data.

Throughout this study, the researcher was vigilant of the ethical principles guiding scientific research and ensured the well-being of the research participants. The results from this study are discussed in the following chapter.
Chapter 5: Results and Discussion

5.1 Introduction

Chapter five describes the results of the study as obtained from the data gathered by using qualitative and various quantitative measures. The description of the results is in line with the aim of the present study: to explore and describe the resiliency factors that facilitate adjustment and adaptation in families with a child with Autism Spectrum Disorder (ASD).

Seven structured questionnaires were employed to gather data for the purposes of this study. These questionnaires were the Family Attachment and Changeability Index 8 (FACI8), the Family Crisis-Oriented Personal Evaluation Scales (F-COPES), the Family Hardiness Index (FHI), the Family Problem-Solving Communication (FPSC), the Family Time and Routine Index (FTRI), the Relative and Friend Support (RFS) and the Social Support Index (SSI). For the purpose of this study, the FACI8 was the dependent variable and was used as an indication of the family’s resilience by measuring the extent of their adaptation after a time of hardship and crisis. The FACI-8 (dependent variable) was correlated against all the other questionnaires (the independent variables). An open-ended question was used to gather the qualitative data.

This chapter describes the results from the various measures and the open-ended questionnaire. This is achieved by referring to the relationship between the dependent and the independent variables.

5.2 Results from the Quantitative Analysis

Correlation and regression data analysis techniques were employed to analyse the quantitative data. In the following section, the results of these analyses are discussed.

5.2.1 Correlation Analysis

The Pearson product-moment correlation coefficient ($r$) was calculated to assist in determining the strength and the direction of the correlation between the dependent (the FACI8) and independent
variables (Coolican, 1999; Ezekiel & Fox, 1963; Harris, 1998). The Pearson product-moment correlation indicates whether a relationship exists between the variables, as well as the direction of the relationship (positive or negative).

The significance of the correlations was indicated by the $p$ values. The level of significance was set at a 5% ($p = .05$) level, as convention dictates (Coolican, 1999). Guildford’s (1946) guidelines were used to interpret and describe the strength of the relationship ($p$-value) among the variables. These guidelines are as follows:

- Less than .20 Slight – almost negligible relationship
- .20 – .40 Low correlation – definite but small relationship
- .40 – .70 Moderate correlation – substantial relationship
- .70 – .90 High correlation – marked relationship
- .90 – 1.00 Very high correlation – very dependable relationship

The results of the correlation analysis are presented in Table 1. The Pearson product-moment correlation coefficient (Pearson $r$) and the $p$-values are also indicated in this table.
Table 1: Pearson product-moment correlations between adaptation (FACI8) and potential resilience variables (*p < .05)

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>r</th>
<th>p</th>
</tr>
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<tbody>
<tr>
<td><strong>Family Time and Routine Index (FTRI)</strong></td>
<td></td>
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</tr>
<tr>
<td>Behaviour Total Score</td>
<td>0.54</td>
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<tr>
<td>Value Total Score</td>
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<td>Child Routines</td>
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<td>Couple Togetherness</td>
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<td>0.04*</td>
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<td>Eating Meals Together</td>
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<td>Parent-Child Togetherness</td>
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<td>Family Togetherness</td>
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<td>Relatives Connection Routines</td>
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<td>0.96</td>
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<tr>
<td>Family Management</td>
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<td>0.00*</td>
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<td><strong>Family Hardiness Index (FHI)</strong></td>
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<tr>
<td>Total FHI Score</td>
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<td>0.00*</td>
</tr>
<tr>
<td>Commitment</td>
<td>0.37</td>
<td>0.12</td>
</tr>
<tr>
<td>Challenge</td>
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<td>0.03*</td>
</tr>
<tr>
<td>Control</td>
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<td>0.00*</td>
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<td>Total RFS Score</td>
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<td><strong>Family Crisis-Oriented Personal Evaluation Scales (F-COPES)</strong></td>
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<td>Social Support</td>
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<td>0.21</td>
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<td>Mobilisation</td>
<td>-0.14</td>
<td>0.57</td>
</tr>
<tr>
<td>Passive appraisal</td>
<td>0.03</td>
<td>0.89</td>
</tr>
<tr>
<td><strong>Family Problem-Solving Communication (FPSC)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total FPSC Score</td>
<td>0.70</td>
<td>0.00*</td>
</tr>
<tr>
<td>Affirming Communication</td>
<td>0.75</td>
<td>0.00*</td>
</tr>
<tr>
<td>Incendiary Communication</td>
<td>-0.61</td>
<td>0.01*</td>
</tr>
</tbody>
</table>
The results from the correlation analysis indicate that several resilience factors can be described as predictors of adaptation (as indicated by the total scores on the FACI8) for families living with a child with ASD. These resilience factors were represented by the various measures used in this study. The following section describes and discusses these significant resilience factors in the context of the literature presented in chapters two (Family Resilience) and three (Autism Spectrum Disorders and the Family).

5.2.1.1 Family Time and Routines (Family Time and Routine Index)

The FTRI, developed by McCubbin, McCubbin and Thompson (2001), assessed the type of activities and routines families used and maintained. The routines that families adopt, the time spent together and the activities they participate in are good indicators of family integration and stability, including how they handle problems and how they deal with major crises. The instrument is divided into eight subscales, namely parent-child togetherness, couple togetherness, child routines, meals together, family time together, family chores routines, relative connection routines and family management routines.

A moderate correlation is suggested between the FACI8 and the Behaviour total score of the FTRI (\( r = .54 \)), which indicates a substantial relationship between family adaptation and the family’s time and routines. Another moderate correlation is suggested between the FACI8 and the couple togetherness subscale (\( r = .47 \)) and the FACI8 and the family management routines subscale (\( r = .64 \)). These correlations indicate a substantial relationship between the family’s adaptation and the parents’ routines and time spent together, as well as the family’s efforts to predict routines and organise the household in such a manner that family order is maintained within the home (McCubbin, McCubbin, & Thompson, 2001). In this study, family time and routines have a significant influence on the family’s ability to adapt to their unique circumstances.

Many changes are made in the family structure in an attempt to cope and be resilient, such as siblings who assume new child care and household responsibilities (Drew, Egan, Hardman & Wolf,
1993; Drew & Norton, 1994; Sicile-Kira, 2003) and parents who make career changes in order to adapt to the new demands placed on the family and who aim to meet the needs of the individual members, as well as the child with ASD (Guralnick, 2000; Lounds & Whitman, 2004; Tommasone & Tommasone, 2000). The family adopts new patterns of functioning and enhances existing patterns that will contribute to effectively managing the family (McCubbin, McCubbin & Thompson, 2001). However, continued demands place stress on the family, and recreational activities for the family and its sub-systems are necessary to enhance the wellness of the family (Sicile-Kira, 2003). The abovementioned literature on families adapting to the demands of ASD confirms the Behavioural total score of the FTRI.

In this study, the participants agreed that the family places emphasis on establishing predictable routines, specifically to promote communication and interaction between parents, as indicated by the couples togetherness subscale. The maintenance of a strong and stable marital relationship is a significant predictor of divorce (Drew & Norton, 1994), which underlines the importance of communication and interaction between the couple. A diagnosis of ASD has been found to draw couples closer (Cobb, 1987), however, substantial evidence on this matter has not yet been established (Lounds & Whitman, 2004).

The research participants in this study indicated that family management routines are a significant resilience factor. Amidst the ongoing changes within the family structure, a sense of continuation and stability is needed and the family’s routines are an important resilience factor in this regard (Allen, Han, McCubbin, McCubbin & Thompson, 1997; Hawley, 2000). Employing routine adds to effectively managing and coordinating the family and all its activities which contributes to a well-functioning family (Allen et al., 1997; Jones & Passey, 2005). In addition, the implementation of routines is imperative in many families with a child with ASD, seeing that children with ASD seem to cope better with predictability (Deverall & Ross, 2004; Paris, 2000). The busy schedule of most parents who manage a career, household, extra-mural activities, and various therapeutic interventions, demands sufficient organisational processes. Organisational processes have been
identified as a resilience factor (Guralnick, 2000; Jones & Passey, 2005; Lounds & Whitman, 2004; McCubbin, McCubbin & Thompson, 2001; Walsh, 1998; 2003; Whitman, 2004).

The family’s time and routines are significant factors which contribute to the family’s adaptation. The participants from this study confirmed that routines which contribute to communication and interaction between the couple and the family’s management routines are especially important in adapting to living with a child with ASD.

5.2.1.2 Family Hardiness (Family Hardiness Index)

The FHI was developed by McCubbin, McCubbin and Thompson (1986) to measure the family’s ability to withstand stress, to have a sense of control over outcomes, and to play an active role in adjusting and adapting to crises (the family’s perceived internal strength and durability) (McCubbin, McCubbin & Thompson, 2001). The instrument has three subscales, namely control, challenge and commitment, and are closely linked to the family’s schemas (CCCCC) and existing resources (BB).

The results of the correlation analysis suggest a moderate positive correlation between the FACI8 and the global score on the FHI ($r = .64$), indicating a substantial relationship between family adaptation and family hardiness. The results also suggest a significant relationship between the FACI8 and two subscales of the FHI, namely challenge ($r = .49$) and control ($r = .69$), indicating a moderate relationship with both subscales. This means that in this study family hardiness is a factor associated with positive adaptation in families living with a child diagnosed with ASD.

Family hardiness is one of the general significant resiliency factors (Allen, Han, McCubbin, McCubbin & Thompson, 1997; Hawley, 2000; McCubbin, 1995; McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001; Whitman, 2004) and literature on resilience describes hardiness as the steeling quality of a family (Allen et al., 1997). Literature on ASDs indicates that hardy families report decreased stress levels as a result of parents’ ability to maintain internal control and to perceive their circumstances as manageable (Hastings & Brown, 2002; Jones & Passey, 2005), a subscale which, in this study, correlated moderately well with family adaptation. Ultimately, how the
family copes and adjusts to the challenge to maintain control will influence the development of the child with ASD (Dunlap & Fox, 1999; Lounds & Whitman, 2004).

The outcome of the challenges subscale reflects results from studies which indicate that families who live with a child with ASD and who are committed to the development of its members and the management of their challenges show positive adaptation (Schall, 2000). The positive appraisal of their circumstances from being a problem to a challenge is an important step towards acceptance of, and adaption to their child’s diagnosis and the impact it has on the family (Bates, Baxter, King, King, Rosenbaum, & Zwaigenbaum, 2006; Bayat, 2007; Blakemore-Brown, 2002; Whitman, 2004; Wing, 1992).

5.2.1.3 Communication (Family Problem-Solving Communication)

The FPSC, developed by McCubbin, McCubbin and Thompson (1988), assessed positive and negative patterns of communication used in the family, seeing as both are important factors in communication and resilience. The instrument has two subscales, namely incendiary and affirming communication.

In this study, there is a high positive correlation between the FACI8 and the global score \( r = .70 \) of the FPSC as well as with the affirming communication subscale \( r = .75 \). This correlation indicates a marked relationship between adaptation and affirming communication patterns. There is a moderate negative correlation between the FACI8 and the incendiary communication subscale \( r = -.61 \), indicating a substantial negative relationship between adaptation and incendiary communication. These relationships imply that communication is an important factor in the adaptation of the families who participated in this study.

Open and constructive communication enables collaborative problem-solving (McCubbin, McCubbin & Thompson, 2001; Walsh, 1998; 2003) – a general resilience factor which is important for the family to adjust and adapt adequately (Allen et al., 1997). Literature on ASDs indicates that honest, open and affirming communication provides an opportunity for parents and children to share
their experiences, thoughts and feelings about their situation with each other (Sicile-Kira, 2003). This builds trust among the family members and promotes conflict resolution, collaborative problem-solving, and joint decision-making (Wing, 1992; Blakemore-Brown, 2002). Affirming communication patterns provide the family members with an opportunity which could facilitate growth especially when conducted within a supportive environment in which family members feel secure and respected (Hawley, 2000; McCubbin, McCubbin & Thompson, 2001; Walsh, 1998; 2003).

The participants from this study indicated that incendiary communication does not contribute to problem-solving and exacerbates stressful situations. Literature substantiates this finding and indicates that siblings often experience difficulty in socialising with their sibling living with ASD (Doppelt, Gross-Tsur, Pilowsky, Shalev & Yirmiya, 2004). Socialisation difficulties amongst siblings often add to frustration and stressors experienced by the family and could result in destructive and incendiary communication patterns (Doppelt et al., 2004) within the family. Parents can engage siblings in problem-solving strategies to cope with their sibling with ASD (Doppelt et al., 2004).

In conclusion, affirmative communication promotes conflict resolution, collaborative problem-solving and joint decision-making in families living with a child with ASD. Incendiary communication exacerbates stressful situations and contributes to destructive patterns of communication. The following section focuses on the results from the regression analysis.

5.2.2 Regression Analysis

Regression analysis was used to determine which combination of independent variables, as opposed to a single independent variable, predicted the value of the dependent variable (FACI8). The results of the regression analysis are shown in Table 2.
Table 2: Regression analysis for family adaptation (FACI8) as dependent variable versus potential resiliency variables

<table>
<thead>
<tr>
<th>VARIABLES</th>
<th>n = 19</th>
<th>B</th>
<th>p-level</th>
</tr>
</thead>
<tbody>
<tr>
<td>FHI: Control</td>
<td>0.750</td>
<td>0.001</td>
<td></td>
</tr>
<tr>
<td>FHI: Total</td>
<td>0.223</td>
<td>0.011</td>
<td></td>
</tr>
<tr>
<td>F-COPES: Spiritual and Religious Support</td>
<td>0.302</td>
<td>0.004</td>
<td></td>
</tr>
<tr>
<td>F-COPES: Mobilisation</td>
<td>-0.518</td>
<td>0.003</td>
<td></td>
</tr>
</tbody>
</table>

The results of the regression analysis indicated that 81.8% ($R^2 = .818$) of the variance of the FACI8 scores can be explained by the identified variables. The following variables are the best combined predictors for family adaptation, as measured by the FACI8 and completed by the research participants:

- The encompassing belief that the family can influence the course of events, creating a sense of containment i.e. an internal locus of control (FHI: control).
- The family's ability to withstand stress, to have a sense of control over outcomes, and to play an active role in adjusting and adapting to crises (FHI: total score).
- The family's ability to acquire spiritual and religious support and resources when needed (F-COPES: spiritual and religious support).
- The family's ability to identify and acquire family and community resources and to accept help from others (F-COPES: mobilisation).

5.2.3 Summary of the Quantitative Results

From the correlation analysis, it can be concluded that three measures correlated significantly with the FACI8, as indicated by the research participants. These measures were the Family Time and Routine Index (FTRI), the Family Hardiness Index, and the Family Problem-Solving Communication (FPSC). These results suggest that the family’s hardiness, their time spent together and adopted
routines and the use of more affirmative and less incendiary communication are resilience factors which predicts the family’s bonadaptation. From the regression analysis, it can be concluded that a combination of the following resilience factors could predict bonadaptation: The family’s sense of control together with their hardiness, their spiritual and religious support and the ability to mobilise familial and community resources.

The results indicate that the Family Crisis-Oriented Personal Evaluation Scales (F-COPES), the Relative and Friend Support (RFS) and the Social Support Index (SSI) did not correlate significantly with the FACI8, as indicated by the research participants. This is in contrast with literature on family resilience and families living with a child with ASD which emphasised the importance of a social support network for the family (Connolly, Novak & Twoy, 2007; Jones & Passey, 2005; McCubbin, McCubbin & Thompson, 2001). This could be attributed to the questionnaires’ emphasis on emotional, network and esteem support, when literature on families coping with a child with ASD states that instrumental support (Croom, Le Couteur & Margetts, 2006; Sicile-Kira, 2003) and a sense of acceptance experienced by these families from their extended family, friends and the community (Minnes & Nashchen, 1997; Sicile-Kira, 2003) are valued. It could also be suggested that the participants interpreted the construct community in terms of their geographical community, rather than the various other social communities they belong to, such as the school community, or the community of families affected by ASD. The correlation results do not indicate a significant correlation between the FACI8 and the Family Crisis-Oriented Personal Evaluation Scales (F-COPES) or its subscales. However, literature highlights the importance of reframing in the adjustment and adaptation of families living with a child with ASD (Bates et al., 2006; Bayat, 2007; Whitman, 2004). Reframing could happen within a religious or spiritual frame of reference. This factor, which contributes to the family’s resilience, has been identified with the use of regression analysis, but not from the correlation analysis. Religious and spiritual coping impacts on the family’s perception that they hold of the child with ASD (Pargament & Tarakeshwar, 2001). The following section discusses the results from the qualitative analysis.
5.3 Results from the Qualitative Analysis

From the total of nineteen research participants (n = 19), all nineteen responded to the open-ended question on the biographical questionnaire. The participants were asked to comment on the most important factors and strengths which contributed to the family’s adjustment and adaptation to a family member with ASD. The qualitative data were analysed using Tesch’s model of content analysis. The themes and strengths that were identified are presented in Table 3. The following section describes and discusses the results from the qualitative analysis.
Table 3:  Themes that emerged from the content analysis (n = 19)

<table>
<thead>
<tr>
<th>THEMES</th>
<th>FREQUENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Support</strong></td>
<td>33</td>
</tr>
<tr>
<td>Extended family and friends</td>
<td>(10)</td>
</tr>
<tr>
<td>Religious and spiritual</td>
<td>(7)</td>
</tr>
<tr>
<td>School</td>
<td>(5)</td>
</tr>
<tr>
<td>Families in the same situation</td>
<td>(4)</td>
</tr>
<tr>
<td>Grandparents</td>
<td>(4)</td>
</tr>
<tr>
<td>Professionals</td>
<td>(3)</td>
</tr>
<tr>
<td><strong>Spousal Relationship</strong></td>
<td>10</td>
</tr>
<tr>
<td>Strength of the relationship</td>
<td>(4)</td>
</tr>
<tr>
<td>Mutuality</td>
<td>(2)</td>
</tr>
<tr>
<td>Support</td>
<td>(2)</td>
</tr>
<tr>
<td>Time alone</td>
<td>(2)</td>
</tr>
<tr>
<td><strong>Family Activities, Togetherness and Routines</strong></td>
<td>9</td>
</tr>
<tr>
<td><strong>Gaining Knowledge and Skills</strong></td>
<td>7</td>
</tr>
<tr>
<td><strong>Acceptance</strong></td>
<td>6</td>
</tr>
<tr>
<td><strong>Hope, Optimism and Perseverence</strong></td>
<td>6</td>
</tr>
<tr>
<td><strong>Family Structure</strong></td>
<td>5</td>
</tr>
<tr>
<td><strong>Health and Well-being</strong></td>
<td>4</td>
</tr>
<tr>
<td><strong>Individual Needs of Family Members</strong></td>
<td>4</td>
</tr>
<tr>
<td><strong>Reframing</strong></td>
<td>4</td>
</tr>
<tr>
<td><strong>Other identified factors and strengths</strong></td>
<td></td>
</tr>
<tr>
<td>Respite Care</td>
<td>3</td>
</tr>
<tr>
<td>Adequate resources</td>
<td>2</td>
</tr>
<tr>
<td>Open and Constructive Communication</td>
<td>2</td>
</tr>
<tr>
<td>Personality traits</td>
<td>1</td>
</tr>
<tr>
<td>Proactiveness</td>
<td>1</td>
</tr>
</tbody>
</table>

5.3.1  Social Support

Six main sources of social, emotional, instrumental and network support were identified from the participants’ responses. These are: their extended family and friends (n = 10), religious and spiritual
sources (n = 7), the school which the child with ASD attends (n = 5), other families who share similar circumstances (n = 4), grandparents (n = 4), and medical and therapeutic professionals (n=3). These sources of support are illustrated by the following quotes taken from the participants’ responses to the open-ended question:

- “Finding good support networks in family (extended) … is important.”
- “I always try to remember (during tough times) God will never give you a load that is too heavy for you.”
- “Godsdiens, kerk en homecell-lede” [Religion, church and members of our home cell group.]
- “[The headmaster of our child’s school] – a tower of strength to us.”
- “I have also been very encouraged by the new group of friends I have made through my sons school.”
- “other families who have autistic children”
- “We have a very supportive family … and he spends a lot of time with his grandparents and great grandparents he doesn’t mind going to them.”
- “I personally have gone to therapy coz I felt that I needed to speak to someone who was not my family.”

Most participants did not refer to specific types of support, such as emotions, social, instrumental or network support, but rather to support in general. Therefore the researcher was not able to differentiate accurately which type of support added most significantly to the family’s adaptation. However, one apt response was: “I think to be successful in dealing with a child on the spectrum, one does need many different types of support”.

Literature on ASD confirmed that parents seek support from diverse sources such as friends, grandparents, church groups, other families who face similar difficulties, teachers and therapists, support groups, volunteers and respite care or child care workers and professionals (Connolly, Novak and Twoy, 2007; Croom, Le Couteur & Margetts, 2006; Pargament & Tarakeshwar, 2001; Whitman, 2004). The presence of social support groups are associated with fewer reports of depression and loneliness and lower levels of stress in families with a child with ASD (Crittenden & Shin, 2003; Dewey
& Kaminsky, 2002; Lounds & Whitman, 2004; Schall, 2000). Some families are comforted by social support groups which are evident in the following response: “All the mothers [of the school] get together regularly to chat, support, give advice etc. I have probably got the most out of this relationship because you know that you aren’t alone and every obstacle you face has been faced by everyone in the group”. Instrumental support is also prominent. A participant commented that “extra help for example our domestic worker” is very helpful in assisting the family with household tasks and caring for the needs of the other siblings.

Spiritual, emotional and physical health is important to withstand stress, to cope, and to be resilient (McCubbin, McCubbin & Thompson, 2001). Social Support (BBB) is of particular value to the family affected by ASD, as the presence of social support impacts on all three these domains. Emotional, esteem and network support leads the family to feel loved, respected and nurtured and includes them in a network involving mutual support and understanding (Connolly, Novak & Twoy, 2007; Jones & Passey, 2005). When communities are uneducated, unruly behaviour from the child with ASD can attract critical remarks and stares from the community, causing many families to rather withdraw and isolate themselves from such embarrassing situations (Cutler, Domingue & McTarnaghan, 2000; Lounds & Whitman, 2004; Sicile-Kira, 2003). However one mother made the following remark: “[What helped us] is sharing [the knowledge] with others in trying to cope with various difficulties. Talking about autism openly and not hiding the autistic child from the public and so trying to educate the public and create more awareness of autism. The look of understanding when people are told about autism and then start treating your child differently is worth it.”

5.3.2 Spousal Relationship

Participants regard their relationship with their spouse to be of significant value in their adjustment and adaptation (n = 10). Participants referred to specific aspects of the spousal relationship which include: the strength of the relationship (n = 4), mutuality (n = 2), support from the spouse (n = 2), and alone time with their spouse (n = 2). The spousal relationship as a protective
factor is illustrated by the following quotes taken from the participants’ responses to the open-ended question:

- “The husband and wife team take turns watching the autistic child.”
- “…Lastly but most importantly, my husband gives me strength …and generally supports me in any way he can.”
- “Having a solid marital relationship.”
- “My husband’s commitment and the bond that my husband and I share.”
- “Setting aside time alone with my husband.”

Literature on ASD and resilience commented on the family members being a source of support and strength for each other, however, despite efforts, the researcher could not find any references focusing on the spousal relationship as a protective factor. Literature does not concur as to the impact that an ASD diagnosis has on the marital relationship (Lounds & Whitman, 2004), however, previous studies have found that such a diagnosis could draw couples closer together (Cobb, 1987).

5.3.3 Family Activities, Togetherness and Routines

Various participants indicated the importance of family activities, togetherness and routines as a factor that contributed to the family’s bonadaptation (n = 9). Family togetherness contributes to their sense of coherence (CCC) which contributes to the family’s well-being (McCubbin, McCubbin & Thompson, 2001; Sicile-Kira, 2003), whilst routines assist in creating a predictive, stable environment within which change can take place (Hawley, 2000; McCubbin, McCubbin & Thompson, 2001). The participants made the following responses:

- “He is included in everything we do.”
- “Doing normal things like holidays or going out for meals etc. as a family where we accept him just as he is.”
- “To pursue activities that we all enjoy rather than marginalising one child for example going for walks, picnics etc. not hanging around shops/malls.”
“The understanding of all members of the family to follow a routine at home so that the autistic child can know what to expect next.”

“To be consistent with routines but flexible in our approach.”

Literature on families adjusting to a lifestyle affected by ASD indicated that family activities and togetherness creates a bond between the family members within which they can find support (Bayat, 2007) and leads to a significant reduction in the stress experienced by the family (Bayat, 2007; Jones & Passey, 2005). Not only are routines important in maintaining stability within the family, but also in creating a predictable environment for the child with ASD who is opposed to change and novel situations (Deverall & Ross, 2004; Paris, 2000).

5.3.4 Gaining Knowledge and Skills

Participants also acknowledged the contribution that the obtainment of knowledge and skills related to ASD made to their bonadaptation (n = 7). Families made use of several sources of information to empower themselves. Examples of statements included:

- “To learn about normal child development and behaviour so that we understand not all behaviour is autistic.”
- “Other strength I get is from doing research in books, on the net and also by attending workshops and seminars. With information comes power.”
- “Technology helps – being able to access information from all over the world and to know current world-wide trends.”

Three participants commented that their teaching background provided insight into normal child development and alerted them to the needs of their child with ASD. Literature indicated the importance of knowledge, skills and prior experience to master one’s situation (McCubbin, McCubbin & Thomson, 1997). In this case, families acquire the necessary information and skills to assist with their child with ASD’s therapy and development (Connolly, Novak & Twoy, 2007). Knowledgeable families tend to cope better with stressors (Lounds & Whitman, 2004) and are more competent in dealing with ASD related problems (Dunlap & Fox, 1999).
5.3.5 Acceptance

Research participants indicated that accepting their child’s diagnosis contributed to their resilience (n = 6). Many participants linked the concept of unconditional love to acceptance. Examples of such statements included:

- “I had to accept my child as he is.”
- “Ons is almal baie lief vir hom en die hele familie … aanvaar hom nes hy is.” [We all love him and the whole family accepts him the way he is.]
- “Ek het aanvaar dat hy die res van sy lewe met outisme sal moet saamleef.” [I have accepted that he will have to live with autism for the rest of his life.]

Acceptance is regarded as the final stage within the process of grieving (Kübler-Ross, 2005) and orientates the family toward facing the challenges that ASDs present (Cutler, Domingue & McTarnaghan, 2000; Drew & Norton, 1994; Tommasone & Tommasone, 2000). Should there be acceptance, the family’s expectations for and attitudes towards the child with ASD and their other children will become more realistic (Blakemore-Brown, 2002; Wing, 1992), which will largely influence the siblings’ adjustment. Acceptance sets the path to normalising and contextualising the family’s experience and to constructing meaning from it (Walsh, 1998; 2003). Constructing meaning from a situation adds to a family’s sense of coherence (CCCC) or perception that the situation is bearable, manageable and acceptable (Antonovsky, 1987; Bates et al., 2006; Walsh, 2003). A positive situational appraisal (CC) means that the family believes that they have the necessary resources to meet the demands of ASDs and that they will be able to cope with and adapt to the situation (McCubbin, McCubbin & Thompson, 2001).

5.3.6 Hope, Optimism and Perseverance

Hope is a general resiliency factor (Allen et al., 1997). It is also a contributing factor to the family’s ability to remain positive and persevere from day to day (Bates et al., 2006). This was illustrated in the following statements from the participants (n = 6):
“The determination of every member of the family to never give up on the autistic child and doing the same thing over and over hoping he will give a suitable response.”

“Being positive… has helped a lot.”

“Hoping, that my child will improve as the time goes, gave me strength and positive attitude about his disorder.”

“We are very positive individuals.”

5.3.7 Family Structure

Changes in the family structure were identified as a factor associated with the bonadaptation of the participants and their families (n = 5). The family’s organisational processes are regarded as a resiliency factor (Jones & Passey, 2005; McCubbin, McCubbin & Thompson, 2001; Walsh, 1998; 2003; Whitman, 2004) and changes made to the family structure and roles can be viewed as an effort to facilitate optimal functioning. Examples included:

- “Sharing the load, [which allows] time out for the parents so they can fill their tanks again.”

- “As a working mother I struggled coping with my children. I resigned in Dec 2005. I cope much better with them when I started working from my house.”

Due to the excessive demands placed on the family affected by ASD, changes in the family structure and the previous roles played by the family members are necessary to cope with these demands. Such changes include supervisory roles appointed to older siblings, sharing of household tasks, becoming a full-time parent, fulfilling the role of an assistant therapist and being an activist for the rights of the ASD community (Bayat, 2007; Jones & Passey, 2005; Schall, 2000). Literature on family resilience substantiates these findings (McCubbin, McCubbin & Thompson, 2001). However, newly instituted patterns of functioning could be clashing with the family’s schemas and paradigms causing further distress which adds to their stressors (Walsh, 2003). Although such changes might be met with initial resistance and discord, necessary changes could provide for harmony and balance within the family in the long run (McCubbin, McCubbin & Thompson, 2001).
5.3.8 Health and Well-being

The participants indicated that their health and well-being were protective factors that contributed to adaptation (n = 4). Health is a general resiliency factor (Allen et al., 1997). Examples of statements were:

- “I personally have gone to therapy coz I felt that I needed to speak to someone who was not my family.”
- “Having sporting as a hobby.”
- “Physical exercise for myself.”
- “Ek ly aan depressie en het ‘n kliniese sielkundige wat ek tyd tot tyd mee kontak maak.” [I suffer from depression and make contact with my clinical psychologist from time to time].
- “Diet, vitamins and supplements.”

Sense of coherence plays an important role in the acquisition and application of resources within the family system. The family’s sense of coherence allows the family to transform their potential resources into actual resources, and thereby facilitates changes in the family system to promote coping and the health of its members and the well-being of the family unit (McCubbin, McCubbin & Thompson, 2001). Emotional, physical and spiritual health is necessary for families to draw energy and reserves from (McCubbin, McCubbin & Thompson, 2001), and many coping mechanisms are oriented toward reducing stress and promoting mental health. Literature on family resilience discusses the value of personal resources such as healthy self-esteem (Whitman, 2004) and a sense of mastery (Bayat, 2007), and resources from the family system and the community, such as professionals, to contribute to the overall health and well-being of the family. Literature on families affected by ASD found that these families, especially mothers, are vulnerable to stressors and emotional problems (Drew & Norton, 1994; Featherstone, 1980; Hwang & Olsson, 2001). Interventions oriented towards reducing stress and enhancing general wellness of the family unit are vital and contribute to efficient functioning of the family unit and its individual members (Hwang & Olsson, 2001).
5.3.9 Individual Needs of Family Members

The participants indicated that tending to the individual needs of family members are important in remaining integrated and motivated as a family, and contributed to their bonadjustment and bonadaptation \(n = 4\). Refocusing on the needs of other family members brings balance to the family system and validates each member as an integral part of the family system (Bates et al., 2006). Examples of such statements included:

- “Spending quality time with our neurotypical child.”
- “Having a sporting hobby.”

5.3.10 Reframing

The participants indicated that reframing of their situation contributed to the family being resilient \(n = 4\). The process of positive appraisal and changing one’s belief systems adds to a sense of coherence, which is an important factor in adjustment and adaptation (Bates et al., 2006; McCubbin, McCubbin & Thompson, 2001). An example of such a statement included:

- “Everyone in this lifetime has challenges but we just differ in degrees and reactions to those.”

The family’s schema (CCCCC) is the fifth fundamental level within the family’s appraisal processes (C). The family schema involves the family’s shared values, beliefs and their identity and forms the framework within which their worldview, behaviour, decisions and strategies are shaped (reframed) and measured against (McCubbin, McCubbin & Thompson, 2001). Reframing can happen through the process of affirmation or spiritualization (Bates et al., 2006). The family schema of many participating families is embedded within religion or spirituality and this context impacts on the family’s perception of their child’s illness (Pargament & Tarakeshwar, 2001). Such statements included:

- “I believe God allows certain things to happen to us so that we can stay close to God.”
- “I believe that God gives certain families certain or special children for a purpose.”

Literature on ASD underlined the role of social and formal support in helping the family to reframe their experience which reaffirms their locus of control, and results in lowered stress levels (Jones & Passey, 2005). A positive, affirming belief system enables the family to reframe their
circumstances, to remain committed to each other, to persevere, and to be optimistic about the future and what it holds (Bates et al., 2006; Bayat, 2007; Walsh, 1998; 2003).

5.3.11 Other Identified Factors and Strengths

Other factors and strengths that were less prominent from the participants’ responses to the open-ended question included the following:

- **Respite care:** One participant responded by saying that making use of respite care “allows us to occasionally go out alone or to functions”. The only source of respite care that was indicated by the participants was the extended family. Another participant stated that “we have a very supportive family who understands our son and assists us with baby sitting”. The use of respite care results in lower stress levels and a higher quality of life for the family affected by ASD (Chan & Sigafoos, 2001).

- **Adequate resources:** The participants mentioned two resources namely financial resources (“being financially sound”) and human resources (“having qualified [especially autism specific] therapists” and “we employed tutors”). A positive appraisal means that the family believes that they have the necessary resources to meet the demands of the stressor and that they will be able to cope and adapt to the situation (Allen et al., 1997).

- **Open and constructive communication:** Problem-solving communication has been identified as a general protective resource (Allen et al., 1997) and the use of affirmative communication contributes to an environment which fosters trust and enables family members to be affirmed (Walsh, 1998; 2003). A participant stated that “openness, and willingness to talk about the condition” contributed to their family’s adjustment and adaptation.

- **Personality traits:** Participants identified certain personality traits as a strength which assisted the family’s adjustment and adaptation processes. Statements which identified these traits were: “patience, patience, patience” and “a sense of humour”. Literature indicated that some personality traits can help families to cope with the daily struggle of their situation (Whitman, 2004).
• Proactiveness: The last factor that participants identified was that of getting actively involved in an attempt to assist the family and the child with ASD to cope, adjust and adapt. One participant explained that she “felt that I should rather do something to help my child rather than crying about it, and this has been what we have been doing since the diagnosis. This has made me so much stronger.” Families who live with a child with ASD and who view themselves as active role players in their situation will be able to develop a sense of coherence and cope with better with their circumstances (Jones & Passey, 2005).

5.4 Summary of the Qualitative Results

The open-ended question presented the participants with an opportunity to report verbatim what the strengths of the family are and which factors contributed to their adjustment and adaptation to living with a child diagnosed with ASD. Various themes emerged from the qualitative analysis. The theme which was commented on most was the importance of social support from various sources. This was followed by the importance of the marital relationship, family time and routines, gaining knowledge and skills, and accepting the child with ASD unconditionally. The results from the qualitative analysis compares well with literature on the most prominent resilience factors associated with the adjustment and adaptation of families living with a child with ASD. One exception relates to problem-solving communication. Although identified within the qualitative results, it does not feature as prominently as suggested in research (Walsh, 1998; 2003). The following section discusses the integrated qualitative and quantitative results.

5.5 Integrating the Qualitative and Quantitative Results

When integrating the quantitative and qualitative results, interesting differences can be noted. Themes that emerged from the quantitative results were replicated in the qualitative results to a lesser degree (such as communication). Selected themes that emerged from the qualitative results were not replicated in the quantitative results (such as reframing of their situation). Literature presented themes that facilitate adjustment and adaptation that were not reflected in the quantitative results.
despite measures tapping into these constructs (such as social support). Lastly, literature confirmed the themes which emerged from the qualitative analysis. The following section briefly outlines the significant discrepancies and similarities noted across the qualitative and quantitative results.

- The positive correlation between a subscale of the FTRI, the couple togetherness subscale, and the FACI8 is confirmed in the spousal relationship theme from the qualitative results. This indicates that couples from families living with a child with ASD attribute significant value to the marital relationship and support from their spouses.

- The results from the regression analysis concluded that the combination of an internal locus of control (FHI, control subscale), playing an active role in adjusting and adapting to crises (FHI, global scale), the family’s ability to acquire spiritual and religious support (F-COPES, spiritual and religious support subscale), and the family’s ability to identify and acquire social resources (F-COPES, mobilisation subscale) contribute to the family’s ability to adjust and adapt. All four these themes were identified within the qualitative results as significant factors which contributed to the family’s adaptation.

- The following themes emerged from the qualitative results, but were not confirmed by the results of the correlation analysis: seeking spiritual support, reframing, seeking and acquiring social support, and mobilising the family to acquire and accept help. These themes were all tapped into by the F-COPES. However, regression analysis identified two of these subscales on the F-COPES (seeking spiritual support and mobilising the family to acquire and accept help) as variables which contribute to a combined set of predictors for family adaptation, as measured by the FACI8. It is speculated that the F-COPES places emphasis on emotional, network and esteem support, whilst literature on families coping with a child with ASD states that instrumental support is valued.

- Both the qualitative and quantitative results indicated the importance of family time and routines.
5.6 Conclusion

This chapter discussed the results of the study. Both qualitative and quantitative data analysis methods were employed. The sample size of this study was small and the results should be interpreted with caution. The quantitative results indicated that the family’s time and routines, their hardiness, and their problem-solving communication were the protective factors in the process of adjustment and adaptation. These results were confirmed by the qualitative results. However, from the qualitative results, several themes emerged that were not echoed in the quantitative results. From the results obtained, references were made to literature on ASD and family resilience. The following chapter discusses the conclusions drawn from the results, limitations of the study and recommendations for future research.
Chapter 6: Conclusion, Limitations and Recommendations

6.1 Introduction

Chapter five presented and discussed the findings of this study. In this chapter a summary is provided of the conclusions that can be drawn from the research findings. This is followed by an overview of the value and limitations of this study. Chapter six concludes with recommendations for further research.

6.2 Conclusions of the Study

The aim of this study was to explore and describe the resiliency factors that facilitate adjustment and adaptation in families with a child with Autism Spectrum Disorder (ASD). The following section is concerned with the conclusions that were drawn from the study as it pertains to the research aim.

Research on family resilience has proved that some at-risk families have the ability to cultivate strengths that enable them to meet the challenges of life and return to previous levels of functioning following a challenge or crisis (Allen, Han, McCubbin, McCubbin & Thompson, 1997). The Resiliency Model of Family Stress, Adjustment and Adaptation studies family strengths, resources and coping in an effort to understand the process of resilience which illustrates problem-solving skills, a directedness towards goals and life satisfaction and being more flexible and able to adjust to conditions of flux (Deal, De Haan & Hawley, 2002; McCubbin & McCubbin, 1996; McCubbin, McCubbin & Thompson, 2001; Walsh, 1993, 2003). This study aimed to explore and describe the resilience factors associated with an at-risk population namely families who are living with a child that has been diagnosed with ASD. It is concluded from the results of this study that the research population were able to adjust and adapt to living with their child after being diagnosed with ASD.

Structured measures were employed to gather quantitative data. Various resilience factors that contribute to the family’s bonadaptation were identified from the quantitative data. The following resilience factors proved to be the most important in the families’ adjustment and adaptation: the family’s ability to withstand stress, to have a sense of control over outcomes, and to play an active role
in adjusting and adapting to crises; the family’s ability to challenge crises with novel ideas and a positive attitude; activities and routines that provide stability to their lifestyle and an opportunity for togetherness which contributes to their family bond; activities and routines that specifically offer explicit opportunity for the parental unit (couple) to bond; and lastly, patterns of communication that speak of support, concern and love (affirmative communication), rather than incendiary communication which results in the break-down of communication and trust.

The qualitative data were gathered by making use of an open-ended question on the biographical questionnaire. The participants were asked to comment on the factors and strengths that they believed contributed to their adjustment and adaptation. The qualitative data were used to validate the results obtained from the structured questionnaires, but also to enrich the findings of the study. The qualitative data thus provided a prioritised list of family strengths and/or resilience factors as perceived by the participants. Fifteen themes emerged from the qualitative data and social support was identified as the most important protective factor. The participants identified various sources of support which ranged from formal to informal support structures and family networks. The second most important theme was the relationship between the spouses. Following emerging themes were family activities, togetherness, and routines, gaining knowledge and skills, acceptance and hope, optimism and perseverance. Changes in the family structure, health and wellbeing, being cognisant of the needs of the individual family members, and the process of reframing were also included. The last few resiliency factors that did not feature as strong were the use of respite care, having adequate resources, open and constructive communication, certain personality traits, and being pro-active. A family’s resources can be sourced from three systems, namely the individual member, the family system and the community (McCubbin, McCubbin & Thompson, 2001). The identified resiliency factors in families living with a child with ASD are distributed across these three systems. Personality characteristics and personal well-being are examples of personal resources, family time, routines and togetherness and affirmative communication are examples of family resources and social support stems from the community system.
An overview of the significant discrepancies and similarities within the results must be highlighted as this is important to the conclusions of this study. Both the qualitative and the quantitative results indicated the importance of the marital relationship in the process of adjustment and adaptation, which is supported by literature on families living with children diagnosed with ASD (Cobb, 1987). It can be concluded that the relationship between the spouses are an important resource and factor that contributes to the adjustment and adaptation of the family. The participants commented on the value of the emotional, social and instrumental support from their spouses as well as the strength they gain from the bond shared between them. The relationship within the parental sub-system will necessarily influence the well-being of the rest of the family system (Lounds & Whitman, 2004). The strength and stability of the marital relationship also impacts the family’s ability to endure throughout life’s challenges (Drew & Norton, 1994).

Both the qualitative and quantitative results indicated the importance of family time and routines and this finding is supported by literature on family resilience (McCubbin, McCubbin & Thompson, 2001) and on families living with a child that has been diagnosed with ASD (Deverall & Ross, 2004; Paris, 2000; Sicile-Kira, 2003). Not only does family time and routines add to the stability and continuation of the family system, it also contributes to the functioning of the child living with ASD, as novel experiences and the lack of routine can cause them emotional upsets.

Themes emerged from the qualitative results and were supported by literature, but were not represented in the quantitative results, despite measures such as the RFS and the F-COPES tapping into these themes. These themes were seeking spiritual support, reframing, seeking and acquiring social support, and mobilising the family to acquire and accept help. It was speculated that the structured questionnaires tapped into emotional support and not as much into instrumental support which was indicated in the participants’ responses to the open-ended question. The participants indicated that they value extended family members and friends who are accepting of their situation and their child with ASD, who interacts with them socially and who assists with providing instrumental support. Various items on the questionnaires also refer to whether the family asks others for advice. From the literature and from the researcher’s interaction with these families, it is clear that ASD and
ASD behaviour are often misunderstood and requires particular knowledge and skills to be managed and to provide insights into the needs of the child with ASD (Connolly, Novak & Twoy, 2007; Lounds & Whitman, 2004; Sicile-Kira, 2003). Asking other individuals who do not share the same situation, or who do not have knowledge or skills with regard to ASD or managing ASD, is thus unjustifiable. Furthermore, the use of the word “community” could have been confusing and participants could have interpreted this construct to refer to their neighbours and neighbourhood, rather than other communities they find themselves in, such as the community of families coping with ASD, a church community and so on. The following section discusses the value of this research.

6.3 Value of the Research

This study adds to the body of knowledge within the positive psychology paradigm which view families as challenged rather than damaged (Csikszentmihalyi & Seligman, 2000; Walsh, 2003). This study made use of a family framework and identified the strengths (that is resilience factors) of families with a child living with ASD which helped them to cope with life's demands. The value of a family framework is that it acknowledges the uniqueness of these families, the collaborative effort of the family to adjust and adapt to their circumstances, and the family's strengths (Walsh, 2003).

Literature suggests that a focus on what makes families strong in the face of adversity could be beneficial to the family (Hawley, 2000; McCubbin, McCubbin & Thompson, 2001; Ryff & Singer, 2003; Walsh, 2003). In accordance with this statement the aim of this study was to explore and describe the resilience factors that facilitate adjustment and adaptation in a family with a child that has been diagnosed with ASD. Walsh (1993) commented that qualitative research methods such as using open-ended questions lend itself to exploring meanings, perceptions and ideas of the studied families, which tied in with the exploratory descriptive aim of this study. Other researchers have also called for more qualitative research in order to complement empirically based studies (Futrell, McCubbin, Thompson & Thompson, 1997). As a result, the findings of this study lend itself to an improved understanding and an in-depth exploration of the factors which contribute to the resiliency of these families and could assist in guiding specialised institutions toward providing more comprehensive
information and support to these families than was available before. In addition, the study contributes to the limited previous research on family coping strategies associated with ASD (Cutler, Domingue & McTarnaghan, 2000; Jones & Passey, 2005) and research concerning the process of resilience within families with a child living with ASD, using the Resiliency Model of Family Stress, Adjustment and Adaptation. As noted in chapter three, parents find it necessary to be knowledgeable about ASDs, its management and possible therapies (Connolly, Novak & Twoy, 2007). Increased knowledge and associated skills contribute to a decrease in the family’s levels of stress (Connolly, Novak & Twoy, 2007). The findings from this study contribute to the knowledge base of the family raising a child with ASD, as they can now provide for the needs of the family unit to assist with their process of adjustment and adaptation, whilst meeting the needs of the ASD individual. The following section outlines the limitations of the study.

6.4 Limitations of the Study

Although a vast amount of previous research has been conducted to identify the stressors faced by families raising a child with ASD, little research is available on the resiliency factors that contribute to their adjustment and adaptation (Cutler, Domingue & McTarnaghan, 2000; Jones & Passey, 2005), specifically within the South African context. This means that the researcher did not have an extensive literature base to access. This limitation of literature resources contributed to the study’s aim of being exploratory in nature.

Another limitation pertains to whether the findings could be generalised to the whole population of families raising a child with ASD. Although the use of a non-probability sampling procedure is convenient for the researcher, it does not allow for a sample that is representative of the whole population of families with a child living with ASD. The participants comprised a homogenous group of mothers of children with ASD that are part of a family which consists of at least three people of which two of them are parents, guardians/care-takers. The participant acted as the representative of the whole family. Kyzar, Lee, Summers and Turnbull (2007) stated that too many researchers use the female parent/guardian/care-taker as the representative of the family, further contributing to the
unrepresentativeness of the studied samples. The low response rate is also regarded as a limitation of the study. The researcher contacted 59 families via personal contact (n = 12) or an informational letter (n = 47). A total of 19 families participated in the study, of which seven participants came from the latter group. Due to the stipulations stated by the Eastern Cape Department of Education, the researcher only had access to this group once they stated their interest in the study and provided the researcher with their contact information. The contact details of this group would have allowed the researcher to extend a personal invitation to these families, which could have persuaded them to assist in the research study, and would most likely have increased the response rate.

Another limitation of this study pertains to the questionnaires that were used. The Family Time and Routines Index (FTRI) makes reference to activities involving adolescents. Such questionnaire items were not applicable to most of the families in this sample, seeing as their children have not reached adolescence yet. The Social Support Index (SSI) and the Relative and Friend Support (RFS) does not tap into instrumental support, which is an important source of support to many families raising a child with ASD (Connolly, Novak & Twoy, 2007; Croom, Le Couteur & Margetts, 2006). Some questionnaire items make reference to whether the family seeks advice from family and friends. ASDs is a specialised field and parents will rather ask the advice of others who share the same situation, such as families who are also raising a child with ASD, or that of medical or therapeutic professionals, which again, refers to instrumental support (Connolly, Novak & Twoy, 2007; Whitman, 2004). Questionnaire items which refer to family and friends as a general source of advice is thus irrelevant for these families. The following section discusses various recommendations for further research.

6.5 Recommendations

Further research on the topic of resilience in families living with a child with ASD within the South African context is recommended. Such research will contribute to the growing body of literature on family resilience in South Africa as well as to limited literature on resiliency factors in families raising a child with ASD. Further research will not only assist specialised institutions and care-givers but also
parents of children with ASD. The researcher observed that these parents are well educated with regard to autism. They are familiar with literature on the topic and are frequently in conversation with helping professionals and other families with a child with ASD to learn and share their skills. This community serves as a valuable resource for future research as they are up to date with the current issues and difficulties in this field of study. From this researcher’s conversation with parents, most of them are not in need of theoretical information on ASDs, but rather practical advice to deal with everyday difficulties regarding nutritional options, schooling options, parenting and improving their quality of life. These parents are pro-active and want to contribute to initiatives which will contribute to their child’s progress and future. Findings of studies on resilience in families raising a child with ASD could provide these families with information to improve their quality of family life and to strengthen their resilience which would then contribute to their adjustment and adaptation.

To address the issue of findings that can be generalised to the whole population of families raising children with ASD, it is recommended that future studies strive to use a representative sample of the studied population. The inclusion of siblings as research participants in family resiliency studies can provide valuable insight into how the siblings adjust and adapt to living with a sibling with ASD.

To counter low response rates, it is recommended that the researcher makes contact with potential research participants on a personal level. Personal contact might prove to be more effective in the recruitment of participants than using an informative letter (Cozby, 2004). Personal contact could be established through an extended parent-teacher meeting which could provide an opportunity for the researcher to communicate face-to-face with the parents and to request their assistance with research projects.

Although the participants did not comment on the length of the questionnaires, they did comment on the number of questionnaires used and doubted that the estimated time of one hour was sufficient for the completion of the questionnaires. One might consider making use of fewer questionnaires in the future. With regard to questionnaire items which are not applicable to the studied population (see the limitations of this study), a questionnaire which addressed the specific needs of this population should be considered. The use of qualitative methods are also recommended, seeing as this provides
the studied population with an opportunity to comment on their behaviours and routines and appropriate questionnaires can be selected from the outcomes of such methods. The families who participated in this study were eager to provide insight into their frustrations, concerns and needs pertaining to raising a child with ASD. The following section discusses main issues raised by these families as well as observations for the attention of policy makers, institutions and professionals.

6.6 Observations for the Attention of Policy Makers, Institutions and Professionals

Many parents commented that literature suggests that potential autistic children should be assessed and diagnosed as soon as possible for the best prognosis – a fact they encountered when their children started therapy as well. However, their experiences with local doctors have left them thinking that ASD is a diagnosis medical professionals shy away from and are hesitant to make. This is in spite of the fact that many parents feel that once they know that it is autism or any other ASD they will be able to prepare better for the child and provide for the needs of the child. However, few doctors want to offer the diagnosis. Many parents are left with a diagnosis made after being assessed by a psychologist, but most psychologists refer the parents to medical professionals to rule out possible medical causes of the symptoms, leaving the parents with a provisional diagnosis only.

Observations lead the researcher to consider that younger parents, especially those who have only one child, are in need of parenting skills. Parenting presents a significant challenge to a first-time mother, but even more so if you have to deal with a child that does not follow the rules of normal child development (Buschbacher, Dunlap & Fox, 2000). It was noted that these parents jump from quick fix to quick fix in an attempt to please their child for that moment. Instant gratification and inconsistent parenting behaviour does not contribute to an environment which will gradually teach the child discipline, but rather one where the parents are exhausted from continuously pleasing their child in an attempt to gain some peace and quiet for themselves. It is evident that more mature parents keep their family life and routines, and adapt to accommodate the child with ASD within this environment.

The parents pointed out that the Eastern Cape lacks schooling facilities for children with ASD. One school in Port Elizabeth caters for the overflow from schools for specialised education and will
accept children with ASD should they have docile behaviour and be well adapted to the social scene. Most parents agreed that intensive therapy throughout the day should be a priority of schools for ASDs. Many mothers choose home schooling as the best option and employ primary school teachers, occupational therapists, physiotherapists and speech therapists to aid with the child’s therapy. These professionals are used on a rotational basis, meaning that the professional will see the children in pairs or individually on a specific day and time, and rotate among all the families clubbing together.

Parents also complain about limited day care facilities in Port Elizabeth which are suitable for children with ASD. Most mothers are not in the position to work in full-day posts because they need to take care of their child with ASD after school or therapy. Most children display behaviour that will not be tolerated at local day-care facilities and the child is asked to leave the school.

Parents are on the steering committee of the Autism SA branch of the Eastern Cape. The organisation lacks monetary funding to set up a centre where parents can go to receive information on ASDs, schooling options, and so on. Parents are also concerned as to the future of their child once the child leaves school. Many of these children are not equipped to enter tertiary education or to enter the world of work. Parents are in need of a sheltered-employment centre where their children are offered the opportunity to work and contribute to the community.

6.7 Conclusions

This study aimed to identify resilience factors which contribute to the adjustment and adaptation of families with a child living with ASD. Qualitative and quantitative research methods were employed and the data were interpreted within the framework of the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin, McCubbin & Thompson, 2001). This framework is embedded within positive psychology. The findings of this study proved that families raising a child with ASD are resilient and the significant resiliency factors have been discussed.

This study concluded with a discussion on the limitations of this research study, but also the value that this study holds for parents, organisations and professionals as well as for the existing body of knowledge on family resilience and the resilience of families raising a child with ASD within a South
African context. Recommendations were also made for future study and reference was made to the researcher’s observations which hold implications for policy makers, organisations and professionals.
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Appendix A:

Cover Letter
Dear Participant

As part of my course work for the Masters degree in Counselling Psychology, I am required to complete a research treatise. The title of my treatise is: “Resilience in families with an autistic child”. The proposed study aims to explore and describe the factors that facilitate adjustment and adaptation in families with a child with autism. With this goal in mind I wish to approach you for your help.

Should you agree to participate in this study you will be requested to complete a consent form and a biographical questionnaire in addition to seven other brief questionnaires with regard to adjustment and adaptation as a family with a child diagnosed with autism. The researcher will provide instructions for completing the questionnaires which will be available in Afrikaans and English. Completion of all the questionnaires should take approximately an hour. As all responses to the questionnaires will be regarded as confidential you are requested to answer the questions as honestly as possible. You will receive the questionnaires in a coded envelope. In addition, all the questionnaires will also be coded in order to keep track of the information. For the sake of record keeping, a list of the participants’ names with the code corresponding to their questionnaires will only be available to me.

It is essential that you complete all the questionnaires to provide extensive data analysis for the study. Once all the questionnaires are completed, you are requested to place the questionnaires in the envelope and hand them back to the researcher.
Should you wish it, the researcher will gladly provide general feedback. Please indicate if you would like to receive general feedback at the relevant section on the biographical questionnaire. If you do not want to continue with the study at any time, you may withdraw from the study without any recourse.

Your assistance will be truly appreciated. In the event that you should require any additional information, I can be contacted via the following number and e-mail address: [redacted], [redacted]@nmmu.ac.za.

Yours sincerely

Leché Hanekom
Researcher
Nelson Mandela Metropolitan University

Ottilia Brown-Baatjies
Supervisor
Nelson Mandela Metropolitan University

Prof Mark B. Watson
Head of Department
Nelson Mandela Metropolitan University
Appendix B:

Informative Letter With Return Slip
Dear Parent/Guardian

As part of my course work for the Masters degree in Counselling Psychology, I am required to complete a research treatise. The title of my treatise is: “Resilience in families with an autistic child”. The proposed study aims to explore and describe the factors that facilitate adjustment and adaptation in families with a child with autism spectrum disorder, or stated differently, I would like to determine what helps such a family to cope with daily life. With this goal in mind I wish to approach you for your help.

Should you agree to participate in this study you and another adult family member will be requested to complete a consent form and a biographical questionnaire in addition to seven other brief questionnaires with regard to adjustment and adaptation as a family with a child diagnosed with autism spectrum disorder. The researcher will provide instructions for completing the questionnaires which will be available in Afrikaans and English. Completion of all the questionnaires should take approximately an hour. All responses to the questionnaires will be regarded as confidential.

If you consider participating in this study, please complete the attached form and return the form to Quest School. I will contact you to discuss the questionnaires and any other questions you might have regarding the study. If you do not want to continue with the study at any time, you may withdraw from the study without any recourse.
Your assistance will be truly appreciated.

Warm regards

Leché Hanekom  Ottilia Brown-Baatjies
Researcher  Supervisor
Nelson Mandela Metropolitan University  Nelson Mandela Metropolitan University

Prof Mark Watson
Head of Department
Nelson Mandela Metropolitan University

I, ..............................................(name) is interested in the study on resilience in families with an autistic child and would like to receive more information.

Contact no:.............................................

Most convenient time to be contacted:.............................................

☐ I am not interested in the study.
Appendix C:

Consent Form
Title of the research project | “Resilience in families with a child living with Autism Spectrum Disorder”
---|---
Reference number | 
Principal investigator | Ms Leché Hanekom
Address and Postal Code | NMMU  
Department of Psychology  
PO Box 77000  
6031
Contact telephone number | 

| A. DECLARATION BY OR ON BEHALF OF PARTICIPANT | Initial |
| (Person legally competent to give consent on behalf of the participant) | |
| I, the participant and the undersigned | (full names) |
| I.D. number | 
| OR | |
| I, in my capacity as | (parent, guardian etc.) |
| of the participant | |
| I.D. number | |
| Address (of participant) | |

1. I, the participant, was invited to participate in the above-mentioned research project that is being undertaken by Ms Leché Hanekom of the Department of Psychology in the Faculty of Health Sciences of the Nelson Mandela Metropolitan University.
2. The following aspects have been explained to me, the participant:

2.1 **Aim:** The investigators are studying resilience in families with a child diagnosed with Autistic Disorder. The information will be used to gain an understanding of the factors that contribute to families’ bouncing back after a child in the family has been diagnosed with Autistic Disorder.

2.2 **Procedures:** I understand that I will be provided with questionnaires that will take approximately one hour to complete and I will receive general feedback regarding the results of the study after its completion.

2.3 **Risks:** I cannot remain anonymous; but I was assured that my identity and responses will be treated as confidential.

2.4 **Possible benefits:** As a result of my participation in this study more insight can be gained on the factors that contribute to the resiliency of families living with an autistic child. This information can be used in intervention programmes to offer families guidance, information and support.

2.5 **Confidentiality:** My identity and responses will **not** be revealed in any discussion, description or scientific publications by the investigators.

2.6 **Access to findings:** Any new information or benefit that develops during the course of the study will be shared as follows: The researcher will provide information in a general feedback session to the group of participants as well as with general written feedback in the form of a letter.

2.7 **Voluntary participation/refusal/discontinuation:** My participation is voluntary.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

My decision whether or not to participate will in no way affect my present or future care, employment or lifestyle.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>
3. The information above was explained to me, the participant, by Ms Leché Hanekom in:

<table>
<thead>
<tr>
<th>Afrikaans</th>
<th>English</th>
<th>Xhosa</th>
<th>Other</th>
</tr>
</thead>
</table>

I am in command of this language.  
Yes  No

I was given the opportunity to ask questions and all these questions were answered satisfactorily.  
Yes  No

4. No pressure was exerted on me to consent to participation and I understand that I may withdraw at any stage without penalisation.

5. Participation in this study will not result in any additional cost to myself.

A.2 I HEREBY VOLUNTARILY CONSENT TO PARTICIPATE IN THE ABOVE-MENTIONED PROJECT

Signed/confirmed at _____________________________(city/town) on _______________________________ 20____.

Signature or right thumb print of participant

Signature of witness

Full name of witness

B. STATEMENT BY OR ON BEHALF OF INVESTIGATOR(S)
I, Leché Hanekom, declare that:

• I have explained the information given in this document to the participant;

• he/she was encouraged and given ample time to ask me any questions;

• this conversation was conducted in ________________________________;

• I have attached Section D and given it to the participant.

  Yes  No

Signed/confirmed at Port Elizabeth on ______________________________ 20____.

Signature of witness

Signature or right thumb print of participant  Full name of witness

D. IMPORTANT MESSAGE TO PATIENT/REPRESENTATIVE OF PARTICIPANT

Dear Participant

Thank you for your participation in this study. Should, at any time during the study:

• an emergency arise as a result of the research; or
• you require any further information with regard to the study; or
• you are unsure about how to complete the questionnaires;

kindly contact Leché Hanekom at 076 476 7700.
Appendix D:

Biographical Questionnaire

(English Version)
Questionnaire nr:

BIOGRAPHICAL INFORMATION

Please complete the following by making a tick in the appropriate block or by filling in the blank spaces provided. You are encouraged to answer honestly as your responses will be kept confidential.

1. Residence

2. Current Marital Status (please tick the box which best describes your current status and fill in the number of years):

   Married  Co-Habiting  If other, please specify:

   How long have you been living with your partner?  ............ Completed Years

3. Family Composition – please indicate all members of your family and if they are currently residing with you (y for “yes”) or not (n for “no”).

<table>
<thead>
<tr>
<th>Member</th>
<th>Self</th>
<th>Age</th>
<th>Gender</th>
<th>Residing</th>
</tr>
</thead>
</table>

   Is there anyone else who lives permanently with you in your home?

   No  Yes Please provide details:

4. Education
4.1 What is your home language?

Afrikaans  [ ]  English  [ ]  isiXhosa  [ ]

If other please specify:  ........................................................................................................

4.2 What is your highest level of education completed?

Primary School  [ ]  High School  [ ]  Diploma  [ ]  Degree  [ ]

If other please specify:  ........................................................................................................

5. When was your child diagnosed with autistic disorder?

........................................................................................................................................

6. In your own words, what are the most important factors, or strengths, which have helped you as a family with an autistic child?

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7. Would you like to receive general feedback regarding the results of this study?

No

Yes Please provide contact number: Landline - (0 )

Cellphone -

Thank you again for your co-operation! It is highly appreciated.